

COMMISSIONED BY LEEDS SURVIVOR LED CRISIS SERVICE

S.H.E.P.

SELF-HARM EVALUATION PROJECT

A report by

Judy Beckett, Gerardo D'Angelo, Laura Pattison & Tamsin Walker

2011 - 2012



An evaluation of services for individuals who repeatedly self-harm focusing on A&E and Leeds Survivor Led Crisis Service (Dial House)

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1. Executive Summary

Introduction

- 1.1. This is a report covering an evaluation project undertaken between August 2011 and April 2012. The project considered the experiences of people who repeatedly self-harmed and attended Accident and Emergency (A&E). Its primary purpose was to evaluate services provided to them from within the NHS and at Leeds Survivor Led Crisis Service (LSLCS), also referred to as Dial House, a third sector mental health crisis service. The project was carried out by four people with direct experience of self-harm, or of caring for someone who has self-harmed. The team was led by Judy Beckett.
- 1.2. The project interviewed 20 people who had repeatedly attended A&E for self-harm. For the purposes of this project “repeatedly attending A&E” was defined as four or more times in a 12 month period. The project spoke to some people who had attended Dial House in the past and some who had not. Interviews were transcribed and analysed for themes. The information which was collected was then used to develop this report. This summary outlines the salient points.

Background

- 1.3. The project was commissioned by LSLCS with funding provided to them from NHS Leeds (formerly Leeds Primary Care Trust) as part of ongoing work in the city looking at services for self-harm. This work includes: monitoring attendances at the A&E departments in Leeds; reviewing current protocols for managing individuals who present with self-harm; looking at mental health from a public health perspective; and finally, beginning to understand **the experiences of those who repeatedly attended A&E having self-harmed**. This project was to address this final aspect of the work.
- 1.4. Since individuals who repeatedly self-harm fall within the population which LSLCS, Dial House seeks to support, the service wanted to find out their views. Dial House wanted to know how effectively, and if, they were providing for these individuals. Additional aims of the project were to provide feedback for funders (commissioners) and to provide information on the NHS services that are currently provided. The project was seeking to cover three key areas:
- a) What are the views and experiences of those who repeatedly attend A&E for self-harm?
 - b) What are the barriers and facilitators to these individuals accessing Dial House?
 - c) What did people find helpful/ unhelpful in their journey through A&E/NHS services and / or Dial House?
- 1.5. In order to gather this information the project planned to speak to two groups of individuals
- Those who visit Dial House and who have also frequently attended A&E for self-harm.
 - Those who have frequently attended A&E for self-harm in the preceding 12 months who have not attended Dial House

Methods

- 1.6. An interview team was established and trained in evaluation skills by Judy Beckett, freelance researcher and training consultant. A steering group was set up which included an NHS commissioner, the manager of LSLCS, a manager for the Self-Harm Team (NHS) and a visitor representative for LSLCS (Dial House). Judy Beckett attended these meetings.
- 1.7. Participants for the project were approached in writing. A&E participants were approached by identifying repeat referrals to the Self-Harm Team. Protocol indicates that A&E should refer all individuals who self-harm to the Self-Harm Team for assessment. Dial House participants were provided with information packs by Dial House staff. All participants opted-in to the project by sending a reply slip directly to the interview team. In this way confidentiality was protected. Participants were then chosen to represent a cross section of experience and age, gender and background. Participants were contacted by telephone to arrange interviews which took place at Dial House. Interviewers worked in pairs. Transport and a gift token were provided to individuals who were interviewed for the project. All interviews were fully transcribed and analysed using a Framework Approach (Richie & Spencer in Bryman and Burgess 1994), which sorts information into themes. This report was then compiled.

Results

- 1.8. Out of 159 people who were invited to take part, 47 individuals responded. This amounted to a response rate of approximately 30% overall. Of these 44 identified themselves as white British. Those who identified as non-white British were automatically invited for interview since they were so under-represented in the responses. The project interviewed 20 people. Five men and five women who had used A&E and who had never used Dial House (apart from one male participant recruited through A&E). From Dial House the project interviewed four men and six women all of whom had attended A&E repeatedly in the past as a result of self-harm.

Main findings related to Dial House

- Of the 20 people we interviewed 16 had heard of Dial House and 11 had used the service. Four people from A&E had never heard of Dial House.
- People tended to hear about Dial House from friends, or from other mental health services.
- Feeling overwhelmed and as though they might self-harm was a major reason given by this group for contacting the service.
- People commented that it could be difficult to get through on the phone to Dial House and some A&E participants said they could not afford to telephone the service.
- Most people arrived at Dial House by taxi. Several people who had never visited the service were unaware that Dial House could provide taxis.

- People liked the environment of Dial House, for the most part, describing it as homely and comfortable and as having a good atmosphere. People said they felt safe at Dial House.
- People felt a sense of belonging and part of a community at Dial House.
- Others felt like they wanted to keep themselves to themselves and one person who hadn't visited the service felt it might be a "clique".
- People valued contact with staff at Dial House. They liked the chance to talk one to one and the opportunity to spend time in the social areas of the house with staff, informally.
- One person felt confused about how one to one workers were allocated resulting in them stopping attending the service.
- Several people described the service at Dial House as non-intrusive, an approach which they particularly liked.
- People valued the opportunity for peer support at Dial House but sometimes felt that they could be upset by other visitors. Some A&E participants avoided the service because of links with people connected to Dial House (other visitors, people living near by etc)
- Information about other service was available at Dial House but the notice board was in need of updating.
- People liked the non-medical environment of Dial House and being able to have a bath and a meal there.
- People appreciated being treated with respect and kindness
- Visitors felt understood and benefited from the distraction of being at Dial House
- Two people overall were pleased that the service had an accepting policy towards self-harm although two people pointed to concerns about this impacting on them negatively.

Things which got in the way of visiting Dial House

- not being able to get through on the phone, not being able to afford the phone, or not being able to explain on the phone
- The location of the service is too out-of-the-way
- Feeling too unwell to contact the service, or feeling as though they didn't deserve the support, or having already self-harm ed
- Knowing someone connected with the service would stop them visiting.

Main findings related to NHS and A&E

This summary includes findings from all 20 interviews since a prerequisite for being interviewed for the project was that individuals had attended A&E for self-harm on several occasions.

- Participants had attended A&E frequently. The project team estimated that up to a quarter of participants were attending A&E at least once a week.

- When asked about their most recent admission to A&E, most people went to hospital via ambulance, three went into hospital with the police.
- People had many difficult life circumstances including ongoing mental health difficulties, issues with drug and alcohol use, domestic abuse, sexual assault, isolation and loneliness, anxiety and depression, physical illness or disability
- Many people spoke of loneliness and isolation as triggering self-harming episodes (or contributing to them)
- Most people waited in cubicles in the A&E department some found this better and more private than the waiting room, others struggled with being left alone.
- Ten of the 20 participants had negative experiences of staff attitudes in A&E, 4 had positive experiences and the remaining 6 had mixed experiences.
- Several people felt their mental health diagnosis negatively affected staff attitudes towards them
- 12 people said that staff in A&E recognised them. Four individuals viewed this positively and it appeared to help in their experience of A&E and they felt a sense of 'belonging'. Six others viewed it negatively saying it adversely affected staff attitudes. Overall individuals valued a kind and compassionate, or at the very least non-judgemental, approach from staff.
- People recognised the likely demands on A&E staff time and understood that they may have to wait.
- People did not always want to stay overnight for the self-harm team assessment and some people walked out before the assessment.
- Five people felt that the self-harm mental health assessment was too focussed on re-telling their life story which they found upsetting and in some cases, made them want to self-harm again.
- People wanted the Self-Harm Team staff to read the notes from the previous assessment
- People were not consistently being given advice, or guidance on other sources of support.
- Four people we interviewed had no additional mental health support despite frequent attendance at A&E for self-harm.
- The police were involved in admissions to hospital for 12 of the 20 participants. Aspects of this had clearly been upsetting for some people.

Helpful and Unhelpful Aspects

Helpful

- ± Being checked on whilst they were waiting in A&E
- ± Being recognised by staff was helpful to some
- ± Being able to talk about normal day to day things
- ± Being shown kindness
- ± Being able to talk about things with staff

Unhelpful

- Being recognised by staff and staff reacting negatively, or feeling embarrassed about being recognised
- A perceived lack of understanding of mental health amongst A&E staff
- Being made to talk about things when the person does not want to

- Overhearing staff talking about them in shared staff areas.
- Staff being patronising and not enquiring as to the knowledge that an individual might have
- Waiting a long time for a self-harm assessment
- Having to re-tell their life story at the self-harm assessment
- Lack of consistent follow up, or community support.

Recommendations

This section draws together all the recommendations which have been made as a result of the evaluation of services for repeat self-harm. The recommendations have been clustered together where they address similar issues.

Recommendations for good practice

- 1. For support for individuals who repeatedly self-harm to be holistic and tailored to their particular circumstances addressing social and medical needs.**
- 2. For individuals known to be managing serious injuries at home or overdoses to be actively encouraged to seek medical attention at these times.**
- 3. Opportunities for staff in A&E, the Self-Harm Team and Dial House to recognise their positive contribution to the management of individuals who repeatedly self-harm through feedback from service users/ visitors.**
- 4. For good practice in the area of care and compassion to be identified and acknowledged.**

Recommendations for A&E

- 5. For specialist mental health workers to be located in A&E.**
- 6. To have people with specialist mental health knowledge available on shift in A&E departments.**
- 7. For staff in A&E to be mindful of those waiting alone in cubicles, to check on them when practically possible.**

Recommendations about the Self-Harm Team

- 8. For the Self-Harm Team or mental health assessor to ensure that each individual receives a copy of a list of other place to contact in the event of crisis and to ensure that service users are clear that Dial House provides a taxi to and from the service.**

9. **To improve access to self-harm / mental health assessments so that individuals are not routinely waiting for many hours.**
10. **To employ a mental health worker who could undertake assessments within A&E.**
11. **For referrals on to other services to be properly checked-out to ensure that the referral is appropriate and for there to be follow up to check the progress of referrals.**
12. **For the structure of the self-harm mental health assessment to be reviewed in the light of the findings of this evaluation, particularly in relation to individuals who attend repeatedly.**
13. **For existing notes to be accessed where there are repeat episodes of self-harm to ensure there is minimal duplication of assessments.**

Recommendations for staff training

14. **That all A&E staff are made aware of the spirit and content of the NICE Guidelines for managing self-harm.**
15. **That all workers who have contact with individuals who self-harm have at least a rudimentary understanding of aspects of dissociation and its likely impact on the individual's presentation.**
16. **That all workers who have contact with individuals who self-harm have some level of understanding of the likely difficulties which those who have been labelled with a diagnosis of personality disorder may face. For all workers to be aware that these individuals are highly likely to have had a history of trauma *and* that workers are mindful of the likely impact of these difficulties on the individual's presentation.**
17. **To have ongoing mental health awareness training and support available to A&E staff.**

Recommendations related to the police

18. **Better liaison with the police in relation to mental health and individuals who repeatedly self-harm.**
19. **For routine monitoring to pick up on the extent of police involvement in the individual's journey through services.**
20. **For support and training to be offered to the police service in relation to mental health and self-harm.**

Recommendations related to improving out of hours provision

- 21. For there to be an increased recognition of the important role of social contact and the corrosive effects of loneliness and social isolation when planning for services for repeat self-harm.**
- 22. For interventions to address social isolation to take account of longer term needs by creating and identifying social opportunities which can 'grow with time.'**
- 23. For Dial House to review the kind of provision it could offer to individuals who repeatedly self-harm and the practicality of setting aside a limited number of places for these individuals within the service.**

Recommendations specific to Dial House

- 24. For Dial House to review its current methods of publicity and to target organisations which support disabled people.**
- 25. For Dial House to establish a phone number which is free from mobile phones and to update their advertising to accordingly stating explicitly that the number is free for mobile phones.**
- 26. For Dial House to look at systems of how workers are allocated to visitors for one to one support and to seek to make this as transparent as possible offering visitors the opportunity to say if they would prefer to work with someone else.**

2. Introduction

- 2.1. This document reports on a project undertaken from August 2011 to April 2012 aimed at capturing the views of those who repeatedly self-harm in relation to two service providers in the Leeds: NHS (Accident and Emergency and The Self-Harm Team), and Leeds Survivor Led Crisis Service (LSLCS Dial House) a third sector service which provides support to individuals experiencing mental health crisis. The project was seeking to understand the experiences of these individuals, the difficulties they face and to identify any suggestions they might have for service improvement in this area. Since individuals who repeatedly self-harm form a key group which Dial House wishes to attract to their service, where individuals were not accessing Dial House the project sought to understand any barriers. Participants were recruited through A&E referrals to The Self-Harm Team and through Dial House (LSLCS).
- 2.2. The following project was undertaken by a team of individuals with direct experience of self-harm, or of supporting close friends or family members who have self-harmed. It was led by Judy Beckett a freelance training consultant and researcher who provided training to the project team and who compiled this report.
- 2.3. Twenty interviews were undertaken, recorded, fully transcribed and analysed for content. The results are outlined here along with a discussion of the implications and recommendations for service development in this area. This report begins with a brief background to the project.

3. Background

- 3.1. It has been estimated according to recent monitoring figures provided by Leeds Teaching Hospitals Trust (LTHT) that around 200 people attended A&E as a result of self-harm four or more times over a 12 month period (2010-2011) in the city. Some of these individuals also visited Dial House (LSLCS). In summer 2011 Leeds was undertaking work looking at self-harm and the provision of services for this. This included: monitoring attendances at the Accident and Emergency (A&E) departments in Leeds; reviewing current protocols for managing individuals who present with self-harm; looking at mental health from a public health perspective; and finally, beginning to understand the experiences of those who **repeatedly** attended A&E with this presentation.
- 3.2. LTHT currently provides all A&E services in Leeds. In the event of attendance at A&E for self-harm current protocol requires that individuals be admitted to the Clinical Decisions Unit (an assessment area within A&E referred to as CDU) until their mental health can be assessed even if they are physically fit. The mental health assessments are usually carried out by the Self-Harm Team (a liaison psychiatry service), by the duty psychiatrist, or by the Crisis Resolution Home Treatment Team. All of these services are based within Leeds and York Partnership Foundation Trust (formerly Leeds Mental Health Trust).

3.3. Dial House is a third sector service which has been established since 1999. It has approximately 32 visits per week from individuals in mental health crisis. The percentage of Dial House visitors who have previously attended A&E following self-harm is not currently known although it is suspected that these individuals account for a significant percentage of the overall visitors to the house. From routine service monitoring data collected in 2010, self-harm was identified as a presenting issue for some 50% of visits. This figure was pretty much unchanged for 2011 (49%). It would seem reasonable to assume therefore, that some individuals who are Dial House visitors will also be among those who repeatedly attend A&E for self-harm (and anecdotally the service knows this to be the case).

3.4. In 2011 Dial House was asked to commission a piece of work to capture the views and experiences of those who repeatedly attended A&E for self-harm and those who also visited Dial House. Since these individuals arguably formed a core group which Dial House wished to provide for, the focus of the project was to be on how, and if, Dial House was providing for this group. It also wished to ascertain what kinds of experiences these individuals had whilst in A&E. Three areas for investigation in relation to those who repeatedly self-harm were established:

- a) What are the views and experiences of those who repeatedly attend A&E for self-harm?
- b) What are the barriers and facilitators to these individuals accessing Dial House?
- c) What did people find helpful /unhelpful in their journey through A&E and / or Dial House?

3.5. In order to ascertain any barriers to the service which Dial House provided, participants were to be recruited through A&E and Dial House. Individuals who had not used Dial House but who were attending A&E would be specifically approached to discover their views.

3.6. Both Dial House and LTHT collect routine monitoring data which identify patterns in attendance. Qualitative data has been collected in this area (Horrocks et al 2005; Bryant & Beckett 2006) but focussed qualitative work looking at people who attend repeatedly has been more limited in scope. The evaluation was intended therefore to extend current understanding of the experience of this particular group and to help inform future commissioning decisions to meet this need.

4. The Evaluation Team

4.1. The project was designed by Judy Beckett. The following section gives some brief background to those who worked on this evaluation which consisted of a team of four people (three interviewers and a project leader). Everyone on the team either had direct experience of self-harm, or of supporting someone who had self-harmed. The team trained together in interviewing skills. The training programme was developed and delivered by Judy Beckett to address the needs of the interviewers. It included consideration of the impact of the interview process on participants, managing risk in the interview situation and self care in the face of distressing disclosures. In addition, since the data collection was to be carried out by people with personal experience,

special attention was paid to the impact of shared experience on the interview process. It was hoped this would limit, to some extent, problematic aspects of the 'interviewer effect' (Denscombe 2007 p. 184) (in other words the impact of the self of the interviewer on the data collected) and promote interviewer curiosity. This was prompted by previous experience of the project leader of working with service user and carer evaluation groups. An ongoing process of reflection on interview transcripts and recordings was also built into the process as well as some training in analysing interview data.

4.2. Each team member has been asked to provide a brief introduction of themselves for the purposes of this report.

4.3. **Judy Beckett** is a freelance training consultant and researcher. Her freelance work has included a variety of service evaluations (including commissioning reviews for NHS Leeds and working with The Mental Health Foundation in London), designing and coordinating service user involvement processes for the modernisation of mental health day services in Leeds and a wide variety of training with service users, workers and health professionals in the area of mental health. During her late teens and early 20s she had direct experience of mental health services and self-harm. Judy is a trained counsellor and a trained, UKCP registered, Systemic Family Psychotherapist. She has worked in wide variety of settings over a ten year period, including 6 years as a researcher at the University of Leeds, working with Relate as a family counsellor, and in 2009/10 working as a school counsellor with young people aged between 3 and 19 years and their families. She worked as a crisis worker at Dial House between 2005 - 2007. Judy is currently working in the NHS as a psychotherapist. She is also working as a visiting lecturer at York St John University on their BA in Counselling.

4.4. **Gerardo D'Angelo** is an experienced, independent registered counsellor. He is currently studying for a further qualification in Cognitive Behavioural Therapy (CBT). Gerardo has had experience of self-harm both personally and amongst family members. He has a special interest in working with people whom experience, or have experienced psychological stress and he is passionate about ensuring men's mental health needs are addressed. Gerardo has volunteered for Cruse as a bereavement support worker since 2006, offering individual bereavement counselling and group work. In addition, Gerardo continues to support people with mental health difficulties.

4.5. **Laura Pattison** is currently studying for a Health and Social Care degree at Leeds Metropolitan University and is in the final stages of her second year. Laura's role as a mum is a very important part of her life and she juggles this with working part time at a hospice in Leeds. Laura has had an ongoing interest in issues related to mental health. She has direct experience of supporting close friends and family members with difficulties with substance abuse, alcoholism and self-harm and the accompanying mental health difficulties. During her late teens Laura made a film as part of a BTEC course which focussed on her mother's experience of mental health services. She interviewed a number of people for this project including mental health activists, family members and friends. The film was shown in Millennium Square in Leeds. In the coming

months Laura plans to begin volunteering with Home-Start, a project which supports families who are experiencing difficulties whilst bringing up young children. A significant part of this work involves supporting parents directly. She has previously worked with children whilst undertaking a Certificate of Higher Education in Early Years and Educational Studies. Laura plans to begin volunteering for Leeds Survivor Led Crisis Service (Dial House) in the very near future.

4.6. **Tamsin Walker** is currently returning to work after being a full time mother for the last two years. Previously, she worked for a number of years for Leeds Mind's Self Help Initiatives Project (SHIP). She ran workshops and delivered presentations about self-harm, mental health and self-help for a number of organisations including probation workers, housing workers, and nursing students. Tamsin was part of a multi-agency group which developed and delivered training about working with self-harm to professionals in Leeds. She was also involved in campaigning against the diagnosis of borderline personality disorder with "Women at the Margins". She contributed to their edition of Asylum magazine, as well as speaking at conferences and running workshops with other members. Tamsin had direct personal experience of mental health services and self-harm as a teenager and in her early twenties. Tamsin is a qualified Citizenship and PSE teacher. Immediately prior to becoming a mother she was working with pupils who had been excluded from mainstream school, many of whom self-harmed. Tamsin is currently illustrating and creating resources to go with a book for children who have parents who have self-harmed.

5. Methods

5.1. The project was developed jointly by LSLCS and the NHS. Judy Beckett, recruited in a freelance capacity to undertake the project, developed a protocol with the support of a steering group. The steering group comprised:

- A commissioner from NHS Leeds
- A member of the Self-Harm Team based at Leeds and York Partnership NHS Foundation Trust
- The manager of Leeds Survivor Led Crisis Service (LSLCS Dial House)
- A service user representative from LSLCS

The protocol was made available to NHS Research and Development departments in Leeds Teaching Hospitals Trust, NHS Leeds (formerly Leeds PCT) and advice was sought to confirm the project met the criteria for evaluation meaning it would not need to go through the NHS ethics committee.

5.2. Recruitment

The project hoped to collect information from two groups:

- Those who visited Dial House and who had also frequently attended A&E for self-harm.
- Those who had frequently attended A&E for self-harm in the preceding 12 months who had not attended Dial House

5.3. This was designed to give an overview of the experience of NHS services for repeat self-harm and to establish the role of Dial House in relation to this client group. It hoped to

identify areas for service improvement and to clarify any barriers which may exist to these individuals in accessing Dial House.

- 5.4. In order to reach both these groups it was decided to recruit to the project both through Dial House visitors¹ and through referrals to the Self-Harm Team who regularly see individuals who attend frequently. All individuals who attend A&E for self-harm should be referred to the Self-Harm Team for assessment. A&E participants were identified through repeated referral to the Self-Harm Team.
- 5.5. All participants were approached in writing. An “approach pack” containing: an information sheet, approach letter and opt-in form, along with a stamped addressed envelope was created.
- 5.6. Packs were provided to every visitor at Dial House over a period of several weeks until adequate responses had been received by the evaluation team, with enough of a cross-section for purposive sampling within the timescales available. Packs were distributed primarily by staff, by hand as visitors left after their visit to the service. The service recorded envelope numbers, and visitor numbers for those who had attended the house. Those who visited but for some reason were not in a position to take a letter (for instance if they were taken to hospital in an ambulance, or it was overlooked as they were leaving the service) were identified through this system and approach packs were sent out through the post by Dial House administrative staff. By recording in this way the service could identify any potential gaps in recruitment since records are kept of the visitor numbers for any particular night.
- 5.7. Participants from A&E were also approached in writing. A list was generated from routine monitoring systems of referrals to the Self-Harm Team. A cut-off date was identified October 2011 and those who had been referred four or more times in the preceding 12 month period were sent approach packs by post.
- 5.8. Letters and information sheets were tailored to the needs of the Dial House or the A&E group. Reply slips and envelopes addressed directly to the evaluation team enabled participants to opt into the project without the services knowing who had come forward to be interviewed. In this way confidentiality was protected. The project had a mobile phone number enabling potential participants to contact the project should they wish. Opt-in reply slips included some brief questions to enable the team to purposively sample (select according to pre-agreed criteria). This was designed to capture the views of people with wide range of experiences (copies of the contents of the approach pack can be found in appendix 1.).

5.9. Interviews

Once selected individuals were contacted by telephone to arrange interviews and sms text messages were sent to confirm interview times. Interviews were conducted at Dial House and taxis were provided to participants to and from the interviews.

¹ Dial House refers to individuals who attend their service in crisis as ‘visitors’

5.10. Interviewers worked in pairs ensuring good support in the interview situation. Consent was taken in writing from participants including explicit consent for the audio digital recording of their interview. The terms of confidentiality were re-explained (including the responsibility of interviewers to pass on information in the event of a disclosure of an imminent risk to self or another). Participants were offered the opportunity to ask any questions about the process and were provided with a £15 supermarket voucher as a token of appreciation for their time. Interviews followed a semi-structured format using a topic guide which had been developed with the interview team and approved by steering group members. Interviews were approximately one hour in duration. All audio digital recordings were transcribed and the use of names was avoided on the digital recording. In order to protect confidentiality all interviews were assigned a code number and every effort was made to anonymise data. Consent forms were kept separately from project data.

Analysis

5.11. The project generated a substantial amount of data (over 500 pages of transcript). Once collected and transcribed interviews were analysed using a framework approach (Richie & Spencer in Bryman and Burgess 1994). This is a kind of thematic analysis ideal for service evaluation as it seeks to answer pre-defined questions. The project team received some training in interview analysis providing further opportunity to expand research and evaluation skills. Once completed a written report was developed. The use of anonymous quotations from interviews was designed to 'bring alive' people's experience and explicit consent was taken from participants to do this. The results were reviewed by the project team and the steering group. Recommendations were developed and the final corrections to the report were made.

5.12. A launch event was planned for summer of 2012 and it was intended that the findings would be disseminated in a variety of ways including a summary report, presentations and full reports being made widely available, including through the Dial House website. The work of the project was also to be presented to the staff of Dial House for reflection and consideration at a learning event in summer 2012.

6. Results

Participants

6.1.1. The project interviewed a total of 20 people. Ten people (comprising five men and five women) were recruited through referrals to the Self-Harm Team and ten (comprising four men and six women) through Dial House. All participants were recruited because they had repeatedly self-harmed. So the results are focussed on **the experiences of both services from the perspective of individuals who repeatedly self-harm.**

6.1.2. The response rates for the project were surprisingly high. It had been anticipated that, based on previous work, they would be around 10% with only half of those

attending at interview. Instead, response rates were higher with an approximate 22% response rate amongst the A&E group (25 responses from a possible 116). The Dial House response rate was very high with a total of 22 responses received to 43 approach packs which were distributed (an almost 51% response rate). The overall response rate across both groups was approximately 30%.

- 6.1.3. Of the total responses across both groups (n=47), all but three individuals identified themselves as white British. Of these, one identified as “European”, one as “mixed” (respondent’s term) and one did not want to say. All three were interviewed. A total of 19 males came forward to be interviewed (eight from Dial House and 11 from A&E). A total of 27 females came forward (14 from Dial House and 13 from A&E). One person did not wish to disclose their gender. Respondents’ ages ranged between 18 and over 65 years. Of the 20 interviews four individuals reported themselves to be between 18 years and 24 years, ten were between 25 years and 45 years and five were between 45 years and 65 years. One person did not wish to disclose their age.
- 6.1.4. In total 26 individuals were contacted to be interviewed. Six individuals did not attend, or cancelled the interview on the day. Four of the six were A&E participants. The rate of non-attendance at interview was much lower than in a previous study which interviewed individuals who attended A&E for self-harm. In that study, 50% of all booked interviews did not attend on the day (Bryant et al 2006). For the current project the non-attendance and cancellation rate overall was 25%.
- 6.1.5. The higher than expected response rate may be because these individuals have an increased investment in, and sense of ownership of, the services they access (including A&E) because they use them frequently. This would be consistent with the findings of this report which identify a ‘sense of belonging’ as central to many participants’ experience of services. The higher than expected response rate may also be attributed to the project’s capacity to offer a gift of a supermarket voucher in return for participants’ time.
- 6.1.6. Most people, who did not attend for interview, cancelled the interview by text message, or by ringing the mobile phone. Reminders for interviews were sent via sms message which perhaps felt less formal than a letter and made it easier to respond in the event of cancellation. Interviews were also arranged at quite short notice for the most part, three or four days beforehand, typically. It may be that by giving less notice there was less possibility for difficult events to intervene such as repeat attendance at A&E.
- 6.1.7. For the purpose of clarity these results are divided between information related to Dial House and information related to A&E. Since both groups were asked about the other service where the information is combined this will be made explicit.

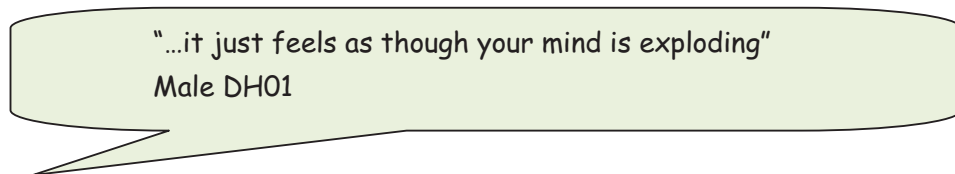
Results Dial House

Hearing about Dial House

- 6.1.8. Participants were asked about when and how they heard about LSLCS, if indeed they had heard of the service. Of those who were recruited through Dial House people had heard about the service between two and, up to a maximum, of five years before. One person was unable to remember when, or where they had heard about Dial House. One person had only recently made their first visit to the house. Over half (n=6) had heard through the NHS from a variety of sources including two from GPs, three from Mental Health Acute Care Services, and one from the Personality Disorder Network. One person had found out about the service when looking for a volunteering opportunity and subsequently used the house when in crisis. The remaining two had heard from third sector organisations.
- 6.1.9. Of those recruited through A&E six said they had previously heard of Dial House although one individual seemed to have confused the service with something of a similar name. Of these one was using the Connect Helpline² and one had used Dial House. Individuals who were not accessing the service but had heard of it tended to have heard via friends. One person who was recruited through A&E and who also attended Dial House was told about the service by the Self-Harm Team. Four people reported that they had never heard of the service.

Contacting Dial House

- 6.1.10. Interviewees were asked about the circumstances of their most recent decision to contact Dial House and their experiences in relation to this. All individuals described extreme states of stress, or of feeling overwhelmed. Several people described feeling suicidal, or feeling as though they would self-harm as reasons for approaching LSLCS. One individual described how Post Traumatic Stress Disorder (PTSD) caused them to experience flashbacks which prompted them to request a visit.



"...it just feels as though your mind is exploding"
Male DH01

- 6.1.11. Feelings of being dissociated or disorientated featured in some people's descriptions

² Connect Helpline is a telephone support service, which is part of LSLCS, and is located in the same building as the crisis service.

"I don't feel like my home is safe to be in at the moment. And um, I've been sleeping rough, but I've not been always aware of the weather and stuff. And um just know that I've got really cold and not able to think and um disorientated and stuff. And um, it's been like that for quite a few weeks now, it's that what brings me here." Female DH02

...as did feelings of being overwhelmed

"...But every now and then things just get on top of me completely and just I can't cope enough, you know, there's just not the strength left in me for me to carry on fighting it on my own side. So that's when I actually rang Dial House up and asked them if I could come" Female DH07

Barriers to contacting the service

- 6.1.12. All participants who had visited Dial House had called the service by telephone to request a visit. Several people spoke of difficulties with getting through on the phone and the importance of ringing early to request a visit.
- 6.1.13. For a couple of people in the A&E group not having access to phone credit presented a significant barrier to contacting Dial House. This had led them to call 999 simply because there was felt to be no alternative.

"... then the only thing you can do really is ring 999 then, but it's like... because before I did and it was like, do you want an ambulance and I was like, not really but I need obviously someone to calm me down or something. Well I'm going to send the ambulance and the police. So it's like, no I don't want that, you know" Female SH02

- 6.1.14. Several people spoke of being conscious of the possible demands on the service. Some people described themselves as feeling "unworthy" of the support. Concerns in this area led some individuals to try to manage without contacting LSLCS

"...a couple of times where I've really, really needed the visit and then rung them back and said, look, I'll try and deal with this on my own, you know. They've said to me, you can have a place, and I've said look, don't bother, give it to someone else, because sometimes I feel there's other people in more need." Male SH08

Getting there

- 6.1.15. Most people we spoke to who had visited Dial House had come to the service via taxi. For some individuals support was offered to get into the taxi. For instance one individual who struggled with disorientation reported that staff would support them over the phone to get into the taxi. This aspect of the service is clearly appreciated and communicated part of an overall caring attitude.

"They always make sure you get here safely and get home safely" Female DH10

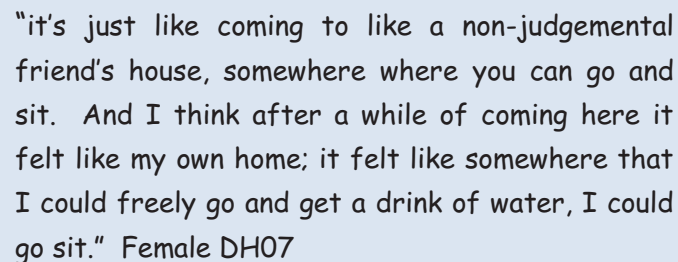
- 6.1.16. Interestingly, of those in the A&E group who had heard of the service few were aware that Dial House provided taxis. Furthermore, two individuals expressed concern about the distance that they lived from the service and the struggle they would face travelling there.
- 6.1.17. Another area which was raised repeatedly by Dial House interviewees was the wait for the call back to say whether a visit could be offered or not. People spoke of this as a particularly difficult aspect of the process. Some people described things they did to manage this including pacing up and down or putting on a DVD. Others stated that over time they had found the service to be reliable and that this made the waiting a little easier. One area of concern was that although a time was given when the service would ring back in practice this could take longer. Individuals understood this but felt it created additional pressure at a time of crisis.
- 6.1.18. One person spoke specifically of wishing for phone support from Connect whilst waiting for her allotted visiting time and taxi. She was upset that this was declined on the basis that she had been accepted for a visit to the house because she felt that she needed help to stay safe whilst waiting. Another individual pointed out that by the time someone rang Dial House at six o'clock they may well have already been in crisis for three hours. In this instance the additional two hour wait before a visit felt very difficult to bear.

The environment

- 6.1.19. The house itself generated almost unanimous appreciation. People used terms such as "cosy", "comfortable", "homely and warm" and "welcoming like a home". One

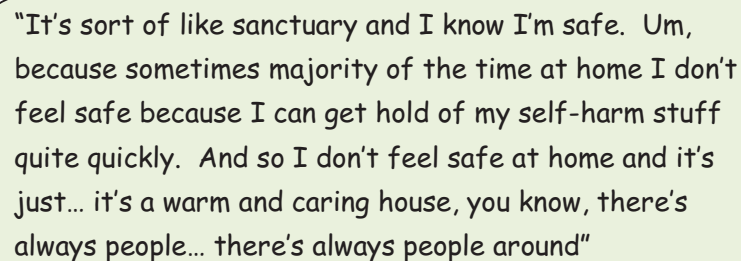
person commented on the paint colours saying they were “warm and friendly”. Three people said it was like going to someone’s house. On the other hand one person commented that the environment reminded him of other mental health services stating “they’re all the same”. One person, having been away from the service for several years, commented that she liked the external smoking area. She felt it made the house feel less crowded and that this had generally improved the atmosphere of the service.

6.1.20. The ambience of the house was a key area that people commented on.



“it’s just like coming to like a non-judgemental friend’s house, somewhere where you can go and sit. And I think after a while of coming here it felt like my own home; it felt like somewhere that I could freely go and get a drink of water, I could go sit.” Female DH07

6.1.21. Six of the 10 people we interviewed from Dial House spoke particularly about ‘feeling safe’ at Dial House, a caring atmosphere and a feeling of ‘home from home’. Some participants talked about the importance of getting away from a difficult home situation. One person spoke of the sense of safety in the house and being away from the means of self-harm.



“It’s sort of like sanctuary and I know I’m safe. Um, because sometimes majority of the time at home I don’t feel safe because I can get hold of my self-harm stuff quite quickly. And so I don’t feel safe at home and it’s just... it’s a warm and caring house, you know, there’s always people... there’s always people around”

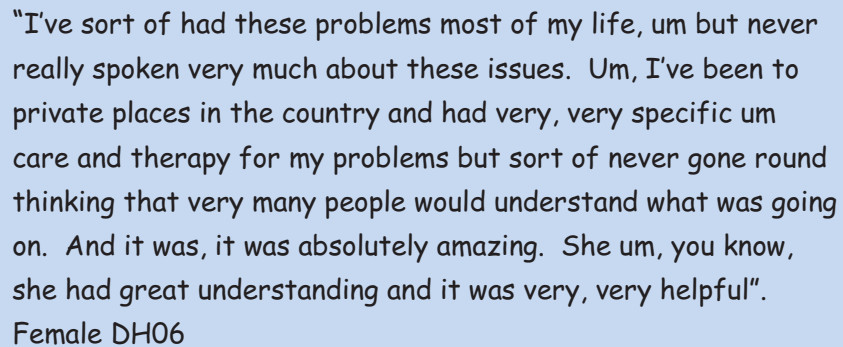
Female DH04

6.1.22. For some people a sense of belonging to the service also appeared to be very important. It should be recognised however that this sense of community and belonging may present a barrier to those who have not used LSLCS. One person who frequently attends A&E had not used the service, despite being aware of it, because she feared it would be a “clique” (SH07). Another individual felt he was unable to

access the service due to his former partner being a visitor to Dial House. Despite this, overall from those who were using Dial House the feedback was very positive.

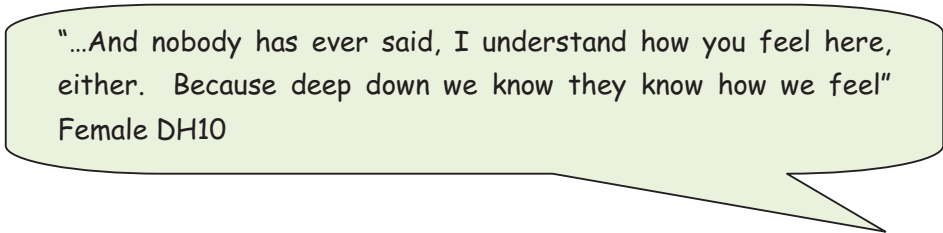
Staff at Dial House

- 6.1.23. Feedback about the staff at Dial House was generally very positive. A couple of people commented particularly on knowledge of staff in relation to certain types of difficulties for instance PTSD or dissociation.



"I've sort of had these problems most of my life, um but never really spoken very much about these issues. Um, I've been to private places in the country and had very, very specific um care and therapy for my problems but sort of never gone round thinking that very many people would understand what was going on. And it was, it was absolutely amazing. She um, you know, she had great understanding and it was very, very helpful".
Female DH06

- 6.1.24. Several people spoke positively about speaking with staff who have had experienced crisis themselves one person spoke specifically about a sense of 'increased empathy' from staff, whilst another stated:



"...And nobody has ever said, I understand how you feel here, either. Because deep down we know they know how we feel"
Female DH10

- 6.1.25. One person who was new to the service felt concerned that staff with personal experience would need to be 'well enough' themselves (psychologically) in order to undertake the work and support others. This interviewee saw the expertise of staff in certain types of difficulties as most important.

- 6.1.26. One person spoke of a sense in which staff were "united but different" in their approach to work in the service, offering a friendly and supportive environment. Staff being friendly, easy to talk to and non-judgemental emerged as a major theme. Individuals appreciated the chance to informally chat with staff in the social areas, to be able to have a cigarette together, or a cup of tea. This was seen as a 'human touch' which many people referred to in different ways. It appeared to help with normalising an otherwise difficult experience. One person stated they felt like they were treated "like an adult" at Dial House which was in contrast to their experience

in other services. This positive account of staff's approach was echoed in several interviews:

"One of the benefits here is that they don't intrude. If you want help they will give it but they don't stomp on you" Male DH05

"The seemed to understand and they didn't seem to judge you, so it was a lot better really. And you can trust them as well" Male DH09

"Where here if I don't want to say owt, you know, if there's something I want to keep to myself, I can do. Does that make sense, I feel more obliged to blurt my mouth out at hospital." Male SH08

6.1.27. Two of these quotes identify a sense of non-intrusiveness by staff and this was mentioned by three of the five male participants who had used the service (one of these individuals was recruited through A&E). A less medicalised approach was also appreciated by most people describing the service as "...not clinical... its just home from home" DH10

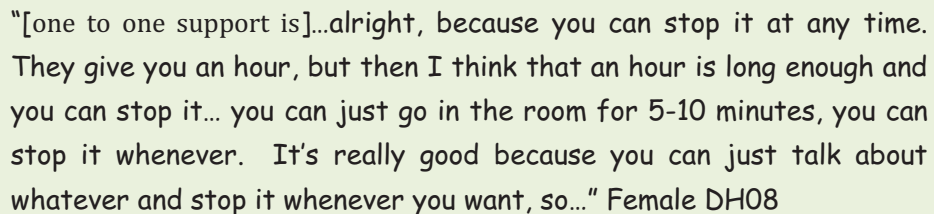
"...Tremendous to know somebody cares, genuinely cares about you as a person rather than um, you know, your illness" Female DH02

"I get psychotic and they let me be psychotic but with the support there. And um make sure that I don't get out of control. Um, because it's paranoid by nature, it's not... I'm not violent towards other people, but I get past myself with it." Male DH05

6.1.28. Although the opportunity to have social time with staff at Dial House appeared to be an important part of the overall experience of a visit, at least two individuals we spoke to explained that it could be difficult having time socialising in the house rather than being offered one to one support when they were in crisis. Other people mentioned the power of peer support within the service, however, explaining how this made social time a useful distraction from their difficulties in an environment where they felt 'safe' and understood.

One-to-One Support

6.1.29. Dial House currently offers 'one to one support' of up to an hour, to most crisis visitors to the service. This provides an opportunity for individuals to discuss difficulties and reflect, as well as enabling staff to 'sign-post' to other support services. We asked people who visited Dial House about the one to one support they received whilst visiting. The feedback was largely very positive. One person explained how staff focussed on their problems and not 'leading' them in the conversation which allowed them to work it out themselves. They felt this was helpful. Another person spoke of appreciating that Dial House staff were more likely to give feedback during the conversation (as oppose to listening passively). This individual was comparing the support at Dial House to the experience of speaking to the Samaritans. The phrases 'non-judgemental' and being 'able to trust staff' came up repeatedly in the interviews when one to one support was discussed. One person spoke of how they felt that staff didn't "analyse you" at Dial House. From the descriptions given during the interviews it also appeared that they did not feel under pressure in one to one support. One person spoke of using art materials during support which they enjoyed. Other people explained that they could talk about what they liked and use the time in the way that they preferred. They could have up to an hour but could have less time if that felt more manageable.



"[one to one support is]..alright, because you can stop it at any time. They give you an hour, but then I think that an hour is long enough and you can stop it... you can just go in the room for 5-10 minutes, you can stop it whenever. It's really good because you can just talk about whatever and stop it whenever you want, so..." Female DH08

6.1.30. Some people preferred to have one to one support with the same staff member. In practice this was not always possible.

"Well as it happens when I've had a one to one I've had the same person all the time. So it's been easier for me. Um, and I seem to get on with this person, um he seems to understand me. Oh no I tell a lie, there's been once when I've had a different person and I felt uncomfortable speaking to that different person" Female DH03

6.1.31. For others the system regarding which worker they were allocated to see seemed unclear. They didn't know if they could ask for the same person or not. One person spoke clearly about finding it difficult to ask for someone different for support, they didn't know if they could. This individual attended a few times previously (4 years ago), had one to one support with the same person and the experience felt unsatisfactory. From their perspective the one to one support became focussed around something which was not a priority for them (some physical health problems). Not knowing that they could request someone else, they went along with it and then stopped using the service. When they returned to the service recently they were allocated a different worker on their visit. On this occasion they felt they had a much better experience of the service and they felt more able to talk. This episode highlights the difficulties some visitors may face in making their needs known and understanding systems at Dial House. The implications of this will be considered further in the discussion section of this document.

Knowing the Staff

6.1.32. We wanted to ask people particularly about the impact of being familiar with staff at Dial House. This seemed to be an important aspect of the service for most of the people we spoke to (n=7). Knowing staff was seen to contribute to a homely environment

I mean the staff are here, the staff are here to help me, and help other people as well and it's like um home from home if you know what I mean." Male DH01

6.1.33. For several people being known to the staff meant they felt staff were holding their situation in mind which for one person meant staff were attentive to the difficulties they faced coming into the service and for another it led to a feeling of being understood.

"... feel like I don't have to explain things...I trust people here..." Male DH05

- 6.1.34. One person explained that *not knowing* all the staff felt difficult in social areas and that they would prefer to be more familiar with all the staff. One individual said that knowing staff at Dial House sometimes made them feel “paranoid” and particularly with one member of staff

I used to feel like she [staff member] didn't like me and stuff and I felt like she didn't want me here... I don't know if its my paranoia or its... she's not here anymore now" Female DH10

- 6.1.35. Having said that, this interviewee also spoke very positively about being known to staff at the service in other parts of the interview. One individual was pleased that a member of staff remembered her after several years of not visiting the service and that they remembered ‘something nice’ about her.
- 6.1.36. Two of the people wanted staff to use their knowledge of visitors more proactively. One person wanted staff to approach them as they arrived and ask them if they had brought anything into the service with which to harm themselves, the other individual suggested that the service could initiate contact with previous visitors if they hadn't been seen for a while. It is recognised, however, that the latter suggestion is inconsistent with the current Dial House approach.

Other visitors at Dial House

- 6.1.37. Most participants who had visited Dial House spoke about the presence of other visitors at Dial House. For some they were seen as a valuable source of peer support, yet for others being amongst other people in crisis felt difficult.
- 6.1.38. One of the positives which people identified was that other visitors could offer pointers to other services and support. During some interviews a strong sense of camaraderie came through. One person stated that the social contact was important to them as they were socially isolated, whilst several others referred to a sense of being understood by people with similar experiences (n=4).

"...And you're like counting yourself with other people, you know, because you realise you're in an environment where other people are suffering with the same type of disorders, etc, etc, and you feel more sort of at home if you know what I mean." Male DH01

- 6.1.39. One person explained how they could benefit from some peer support through having social time rather than a one to one support although she was clearly mindful

of the needs of others (one other person referred to being considerate of the needs of others in a similar way).

"...if I don't have a one to one it's not too bad because there's always someone to talk to anyway, but just not um in a room, you know, it's sort of in a social setting. But there's other people being like myself here, you are free to sort of talk quite openly without going into graphic details because you've got take into account the other people... .. but just being with people like myself I can be fully myself. When I'm with other people, and friends I've known, anybody on the outside there's that front that you have to put up, if you know what I mean. Sometimes you slip and you get worried over that, you don't have that here, you know, you can be exactly how you are on that day." Female DH02

- 6.1.40. Another individual spoke of staff intervening on conversations if visitors asked questions of her which she found intrusive (like why she was at the service). In this way she felt protected by staff.
- 6.1.41. Less positively, several people spoke of concerns about being amongst others in a state of crisis. These views ranged from feeling shy about interacting with others, or not wanting to interact, to feeling that contact with other visitors had been a negative experience. One person felt that there were visitors who were exploiting the service, by calling in when they were not in crisis. They feared that these individuals were not being recognised by staff and that some negative behaviour was not tackled directly enough. In direct contrast another person spoke of staff handling difficulties directly but with "tact and respect". One person suggested that visitors might need support to avoid being exploited by others and advice on how to keep themselves safe for instance, thinking carefully before establishing friendships /relationships with other visitors beyond the service. A male participant spoke of staff 'banning' a visitor who brought alcohol on to the premises which he was glad about as he felt having been alcoholic himself it would tempt him.
- 6.1.42. Another participant had been avoiding the service because of not wanting to reconnect with others from mental health and self-harm 'world' as they were trying to 'break away' from self-harm.

"...kind of sink into the fact that you're around other people that have got issues that don't quite fit into normal society and sometimes they're quite socially not well adapted. And seeing them sort of behave like that in social scenes, and you kind of sort of joined in and you're kind of like, that's fine, you know, mental health issues, I can act like this. And that was what I was trying to sort of... I was nervous about coming here and thought that I might fall back into sort of it [self-harm] being acceptable" Female DH07

Similarly a male participant feared he might be influenced by others to self-harm

"It depends how poorly you are. If I were poorly, yes. If someone's doing that, that would give me the idea to do it then, you know what I mean." Male DH09

6.1.43. One female visitor spoke of the negative effect of when one visitor's experience mirrored her own. This individual felt this may have precipitated further self-harm on her part.

"It linked with everything that's going on with me at the moment....I took it home" Female DH10

6.1.44. For one participant visiting Dial House for the first time she stated clearly she did not want to mix with other visitors to the service and saw one to one support as the most useful aspect of the service (DH06)

6.1.45. Finally one of the A&E participants had not been to Dial House because an ex-partner used the service. They were keen not to bump into that the person and so felt they could not use the service at all.

6.1.46. This section reveals that the context of peer relationships is a very important part of the service which Dial House provides and the volume of data generated on this subject suggests it is high on the visitor agenda both within the service and beyond.

Signposting

6.1.47. People were asked if they were given information about other services. Of the 10 participants recruited through Dial House five were given information about other services. One person was referred for advocacy but felt this was not really going to be of help to them. Another individual said they had received information via other visitors at the service. One person said they had struggled to find up to date information about groups and activities not connected to the service. This individual felt that staff were not always up to date with what groups are still running in Leeds and about services beyond Dial House. They had noticed that some information on the service notice board was a long way out of date. Dial House has a computer available for use by visitors, however. A different individual described how staff would use this computer with visitors, jointly searching on the internet for other sources of support.

Involvement from other services

6.1.48. Perhaps unsurprisingly, given the target group for recruitment to this project (repeated self-harm) and the methods of recruitment, most people we spoke to who

attended Dial House had involvement from other specialist mental health services including Acute Day Service, Inpatient services, Community Mental Health Teams, The Personality Disorder Network and some spoke of other third sector services. This was in contrast to the A&E participants half of whom appeared to have no additional support.

Things which helped

6.1.49. Throughout this results section there have been comments about what is particularly helpful about Leeds Survivor Led Crisis Service, Dial House. This section draws some of these together as people identified them in the interviews.

- **The service offers a non-medical or non-clinical environment.** Three people specifically mentioned this as a positive aspect of Dial House.

"...no pressures, nobody analysing you... You're totally looked after"
Female DH02

"being able to talk and be able to be whoever you want to be. Um, you don't have clinical words rammed down your neck." Female DH04

"...if you go to somewhere like ACS [NHS day treatment service] and you suffer psychosis they just want to stuff medication down you and shut you up and put you in a box somewhere. Here they don't."
Male DH05

- **The service offers a non-intrusive response** As detailed previously four people specifically referred to this as a positive aspect of the service.

"Oh no, they [Dial House Staff] don't rush you at all...I mean if you don't want to open up you don't have to open up. It's up to you, you can sit and cry your eyes out or whatever you want to do." Male DH01

- **The service treats people like adults and offers respect and kindness.** One person referred specifically to being treated like an adult at Dial House in contrast to their experience in some other services.

"They address you like an adult ... they don't judge"
Female DH10

...Whilst others reflected on a sense that staff show respect and kindness to visitors.

"...they just treat you with respect. Kind of I'd say with a little bit of TLC as well, give you a bit of TLC, you know. They give you warmth and respect..." Female DH04

- **The service provides social time with the staff.** This informal contact with staff was highly valued by visitors to the service and mentioned in many different ways throughout the interviews. It was seen to be a significant part of the overall experience of the service.
- **The service is non-judgemental of people** A number of people spoke of the non-judgemental approach of the staff and highlighted this as one of the most helpful aspects of the service. One individual explained how this attitude on the part of staff had enabled him to talk about a crime he had committed whilst unwell without fearing their response. This helped him to trust the staff at the service.
- **Visitors felt understood** This was an aspect of the service which was highlighted as particularly helpful. Some individuals referred to staff having had direct experience of crisis as underpinning an understanding attitude

"I think everybody has had some sort of crisis themselves, so the amount of empathy is increased...they don't push things on you...and they're up front about it, the staff as well, you know, that they've had their own issues. They don't detail them, but they've had their own issues. Um, that's a massive benefit over clinicians" Male DH05

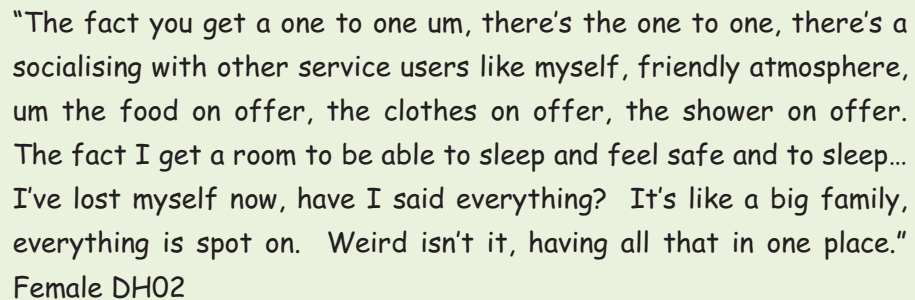
- **The service provides one to one support, space to talk and the opportunity for face to face contact.** Five people highlighted this as a particularly helpful aspect of the service. Having space to talk and to release feeling was seen by many as central to the support they received from Dial House.

"You see the one to one it's just like they ask me what's gone on, how I'm feeling, and then it just becomes a general chat and, yes, it's just a bit of a calming down..."
Male SH08

- **The service provides distraction and the opportunity to be around other people.** One person explicitly named this as a helpful aspect of the service, for many of the other interviews however, it was implied. This included people speaking about getting away from a difficult home situation, or having the chance to be around other people and gain some perspective on the difficulties they faced.
- **The service attitude to self-harm and that people can safely self-harm on the premises.** One individual highlighted this. For them, the staff attitude to self-harm felt positive and supportive. They also valued the service policy which is tolerant of self-harm. It should be noted however that during the interviews two individuals spoke less positively about the idea of people being able to self-harm on the premises. Most people saw the service as a way they could avoid self-harming.

"just knowing that they were okay and knowing they were okay with self-harm as well, that, well we're not going to judge you, if you need to self-harm while you're here that's fine, and it was just that like, well yes, we accept it. If people don't accept it they shouldn't be in your life type of attitude, and it was that that was really nice about them. They were like, we don't see you any different, we don't see it as a bad coping method, you know. It's not as if you're going cutting other people to cope, it's... you know, you do it and um... though I do it sort of very methodical anyway, and I don't... never put myself in danger in any way. So it was nice to have someone that understood that I wasn't wanting to end my life every time I self-harmed, you know, I knew what I was doing" Female DH07

- **Being able to have a bath, a meal, and even clean clothes if they are needed.** Three people spoke directly of these 'homely' aspects of Dial House as being of particular benefit. The quote below summarises many of the helpful aspects which were identified during the interviews.



"The fact you get a one to one um, there's the one to one, there's a socialising with other service users like myself, friendly atmosphere, um the food on offer, the clothes on offer, the shower on offer. The fact I get a room to be able to sleep and feel safe and to sleep... I've lost myself now, have I said everything? It's like a big family, everything is spot on. Weird isn't it, having all that in one place."
Female DH02

Unhelpful things.

- 6.1.50. We asked participants to identify any aspects of the service which were unhelpful. The process of getting into Dial House was stressful for several people we interviewed. One person spoke of his struggle waiting for the service to call back to let him know whether or not he had a visit. Several other people mentioned how difficult it was to be declined a visit if they felt they were in crisis.
- 6.1.51. Another area which came up related to the actual experience of visiting. One person had someone who they didn't get on with for one to one support which affected their experience considerably and they didn't know how or if they could ask for someone else (referred to in paragraph 6.25). Another person felt unhappy with the hour time limit on one to one support and felt that it should be more open ended as they felt their distress could not be limited in an hour 'box'.
- 6.1.52. Two individuals spoke about the service policy to confidentiality and their anxiety that the service had the power to contact other services if they were concerned. Both identified difficult relationships with NHS workers and felt concerned that Dial House may be in contact with them. One of these individuals was upset when the service had broken her confidence by contacting someone when she had self-harmed but she also understood why. She felt the process to be unhelpful however. One person spoke of "being banned" from using the service following an incident. This participant stated this had been unhelpful at the time.
- 6.1.53. Finally the limited opening hours were identified by several people as an unhelpful aspect of the service with some individuals calling for 24 hours/ 7 days a week opening and others feeling that the service would be improved if it was open for 7 nights a week.

Barriers to accessing Dial House

6.1.54. We asked people about what might get in the way of them coming to Leeds Survivor Led Crisis Service, Dial House. The A&E group were asked to imagine what might prevent them using this kind of service. This section includes information gleaned from Dial House and A&E interviews. Barriers to coming to Dial House fell broadly into four areas: location, difficulties related to the phone, issues related to mental health and other people who might be connected to the service

6.1.55. Three people mentioned the location of Dial House as being a potential barrier to visiting the service. One of these individuals was recruited through Dial House but felt that the location may be an off putting factor for those who live in more distant parts of the city. Of the individuals recruited through A&E two spoke of the location being 'out of the way' and said that they did not realise that the service provides taxis. One participant who had never used the service suggested that it might be good to have a second service in another area of the city, possibly a more central location.

6.1.56. When asked about barriers to accessing the service 10 participants referred to difficulties related to the telephone contact with the service. Four people spoke of not being able to get through on the phone and (for those who knew the service) the importance of ringing early for the best chance of a visit to the house.

"...but it's difficult to make a referral in the first place because you could be on the phone 20 minutes just redialling the number just to get through to talk to somebody, which is frustrating in itself"
Female DH03

6.1.57. Seven people spoke of the anxiety at the prospect of not being able to get in at the service and one person talked of how not being able to have one to one support would stop them using the service.

"I think that's the hardest bit is having to discuss why you want to come in here... A lot of people do hurt themselves while they're waiting because it's so horrible waiting for that call whether you get it in or not... if you hear the word declined, well not just me but everybody, it's like you've been let down, your safety as been took away. It's like somebody throwing a brick at your face and saying no, sorry, can't have you tonight. And you've got to find support quickly because you know that crisis is going to build up if you don't, and end up in something serious."
Female DH10

- 6.1.58. Five people stated that it could be very difficult to explain issues over the phone and make clear to staff answering calls the extent of their distress. Four of these individuals had visited Dial House. One participant who had never visited the service but who had contacted a telephone support service (which may have been Connect or the Samaritans he didn't know which) explained that severe speech difficulties due his disability rendered him difficult to understand over the phone. In one instance this had led to him being rejected by a service who suggested he had been drinking. He responded angrily and abandoned the attempt to get support by slamming down the phone. This was a barrier to him attempting to contact Dial House or Connect or any form of support by telephone as it had been his experience on more than one occasion.
- 6.1.59. Three people (two from A&E and one from Dial House) talked about not being able to afford to call the service. This was because the crisis house number is a landline number and they frequently didn't have credit on their pay-as-you-go mobile phone. As already identified this left 999 as the only free call they could make in times of difficulty.
- 6.1.60. Seven people explained that issues related to their mental health could inhibit them from contacting and visiting Dial House. The most frequent issue referred to in this context were issues related to self-esteem. Four individuals spoke about feeling bad about taking up a space which someone else could have, or of being not deserving of support. One A&E participant who had never visited the service spoke about the difficulties they imagined they would face trying something new (like Dial House) whilst they were feeling 'down' or in crisis. Another A&E participant suggested they would likely be too angry to contact a service like Dial House since their self-harm and crisis often involved alcohol and high levels of anger. Two individuals explained that they would not come to the service if they had already harmed themselves. Both had attended Dial House in the past.

"...if I'd just cut myself because other people don't need to see that do they? It's the last thing they need to see if I walk in and there's blood all down my sleeve and that. So no I won't... yes it does stop me coming here..."
Male SH08

- 6.1.61. As already stated one individual recruited through A&E felt concerned that Dial House might be a 'clique', so although they had used Connect Helpline they had not visited the house. One person recruited through A&E felt they would be unable to come to Dial House as a relative who they did not want to see was local to the service. Two others referred to not wanting to see other visitors at the service, who they knew. This included one individual (A&E participant) whose ex-partner used

the service and another (Dial House participant) who felt they preferred to avoid others who self-harmed who they knew from their past.

Results NHS and A&E experiences

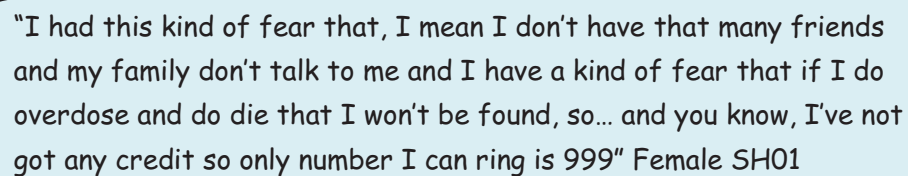
6.2.1. The following section considers the experiences of those who repeatedly attend A&E following an episode of self-harm. The information in this section is drawn from all 20 interviews since an inclusion criterion for the project was that all participants had attended A&E on more than one occasion.

Going to A&E

6.2.2. We asked participants to talk to us about their most recent trip to A&E as a result of self-harm. It was difficult for several participants to accurately recall the most recent trip to the department as some had attended more than once in recent weeks or days. Some people struggled to remember details as a consequence of an overdose they had taken, alcohol, or their mental health at the time. It is accepted therefore, that some of these accounts may represent aspects of several trips to A&E merged as one.

6.2.3. The participants had a range of experience in relation to self-harm. Three individuals spoke of cutting themselves, 11 people described overdoses and a further six individuals referred to switching between methods of self-harm: cutting, overdosing and other methods of self injury.

6.2.4. Of those recruited through A&E all but two said they were transported to hospital by ambulance. One of these individuals called the ambulance themselves as they were afraid of dying and not being found.



"I had this kind of fear that, I mean I don't have that many friends and my family don't talk to me and I have a kind of fear that if I do overdose and do die that I won't be found, so... and you know, I've not got any credit so only number I can ring is 999" Female SH01

6.2.5. One person pulled an emergency cord in their accommodation and was taken by the police to hospital (having first been arrested). One individual was taken in by police and ambulance after calling the Samaritans. She was threatened with arrest if she refused to go to hospital. Three participants were 'found' by a friend, or relative who called for help and one individual was sent by their GP.

6.2.6. One person explained that they often took public transport, or walked to hospital, self reporting to the department. He explained that he frequently dressed wounds at home but on this occasion he had taken an overdose because of hearing voices

and felt afraid of consequences. Overall three out of the ten participants recruited through A&E had police involved in their admission to the A&E department.

- 6.2.7. Of those recruited through Dial House, four people had been sent most recently to A&E by Dial House Staff and one person was taken by the police. Two individuals self-reported to A&E because they felt concerned. One person was recommended to go to the department by another service because *they felt like* harming themselves. They reported that in this instance staff at A&E were unsympathetic.

"...[Day Treatment Service] was the big one on selling that to me, you know, go to A&E if you feel like you're going to self-harm. And I went once and got treated like shit, basically turned round and told to go away." Female DH07

- 6.2.8. In contrast another individual, attending for a similar reason described how going to A&E helped to avoid self-harming whilst she was pregnant and that she was glad that she went. On the most recent occasion at A&E her current partner rang the ambulance. He was especially concerned about her because she was pregnant.
- 6.2.9. Of the Dial House participants only one person did not explain how they got to hospital but they did describe that their visits to A&E were in the context of psychotic episodes. It is assumed that this may have influenced their recall of specific aspects of the episode.

Context of Self-harm

- 6.2.10. This section considers the issues which participants faced in their lives and its impact on their self-harm. A fifth of participants overall (n=4) referred to alcohol as a significant part of the picture of self-harm for them (3 from A&E and 1 from Dial House). One person spoke of how alcohol and bad thoughts tended to work together to make them more likely to self-harm. Another participant explained that she became very angry when under the influence of alcohol and recognised that this made helping her more difficult. She also spoke of regretting her actions afterwards.

"...But when I think about that [own] behaviour now I think, oh god that was terrible." Female SH02

- 6.2.11. One male recruited through A&E, who described himself as alcoholic, explained that whilst he didn't consider himself a violent person, when he had been drinking he

could become angry and threatening towards police. This individual was broadly happy with his treatment in A&E. All of these individuals described the involvement of the police in numerous admissions to A&E. Two participants from this group felt that alcohol negatively affected staff attitudes towards them. One male suggested that staff may benefit from a better understanding of the link between alcohol and mental health difficulties and particularly psychosis.

6.2.12. Of the ten participants recruited through A&E half were physically disabled (n=5). This compared with those recruited through Dial House where there were no disabled participants. The findings for this group, however, were broadly similar to those represented across all participants and there were no apparent consistent factors which linked their disability with their experience of A&E.

6.2.13. Five people spoke specifically of the impact of loneliness and isolation. All but one of these individuals had attended A&E only (four had never visited Dial House). The following quote shows how one person benefited from the human contact at A&E, the second quote considers the increased stress a participant faced when they moved from communal living to living alone. They attributed, in part, the subsequent increase in their self-harm to this change of circumstances.

"Because I don't have much of a social life at the moment, um so I do spend I'd say 95% of my time on my own so I can't have conversations about day-to-day things. So when I do go to hospital and they do talk about things like that, it does help because like I say... I mean in the past I was one of the most sociable people you'd ever meet, and to go from being sort of life and soul of the party and talking to everyone, to not seeing anyone and not talking, it's very hard to cope with." Female SH01

"...it [supported living] did help, but... and that all went a bit wrong because like I say I just sort of got my own flat and they just left me, you know, to do my own thing right, with not much support or anything, you know. Obviously I hadn't lived by myself, ever, it was a massive, massive shock to the system. But as I say, I've been at hospital a lot more times, in fact quite often recently." Female SH02

6.2.14. The impact of isolation and loneliness on these individuals attending A&E could be seen as a mirror to the positive accounts of social contact revealed by Dial House participants. One individual from the A&E group spoke of her struggle when she was not able to talk to anyone in the supported living environment where she was housed. This individual described particularly self-harming at times when she felt low and where staff were not on duty.

"...well the staff [in supported living] won't listen to me it makes me feel, you know, bad and that" Female SH10

- 6.2.15. One individual talked about the impact of auditory hallucinations which made him want to self-harm, another individual cited a sexual assault as having triggered their self-harming episodes. Two women described the impact of domestic abuse on their feelings of wanting to self-harm (both these participants were from the Dial House group) and one of these referred to an insecure housing situation. One person spoke of their feelings of despair and sadness following a string of bereavements and that this made them feel they "want to die".
- 6.2.16. Three people referred to self-harm as a kind of 'coping strategy'. Each individual spoke specifically about cutting themselves. One person referred to the cutting as a kind of addiction, another spoke of using cutting to calm himself down. The third individual talked about cutting in the context of dissociation. This participant felt that after they had cut themselves the crisis was over so that by the time they were in A&E they would be feeling better. They felt this might be misunderstood in the A&E context and they called for a better understanding of dissociation overall amongst healthcare staff. This will be considered further below. All three of these participants had used Dial House in the past and each had cut themselves on previous occasions but dealt with wounds (cleaned and dressed) themselves at home.
- 6.2.17. Nine individuals referred to ongoing mental health difficulties when talking about self-harm. These included Personality Disorder, Dissociation, Psychosis, Post Traumatic Stress Disorder and Hearing Voices. It appeared that those recruited through A&E were less likely to speak about mental health problems as such and were more likely to refer to precipitating events. This may be simply a reflection of the referral routes for Dial House (secondary mental health services).

Frequency of visits to A&E

- 6.2.18. Participants on this project reported multiple visits to A&E for self-harm ranging between two and over 250 visits in a twelve month period. Six individuals spoke of trying to avoid going to A&E particularly for cutting themselves. They did this by either treating wounds themselves, or by trying to minimise their self-harm for instance cutting in 'safe' places, or avoiding making 'deep' cuts.

"I just wanted to be patched up because some of the time I got everything in my arms, bandages and things like that. I sometimes buy that just so I don't have the hassle to be there" Male SH03.

" I get my own bandages, I've stitched my own wounds up and stuff so I don't go in there..."
Female DH02

6.2.19. Two individuals described themselves as attending "very frequently", "all the time" but neither was able to be specific. Some people spoke of going regularly over a period of time, or attending on a weekly basis. One person said that they had been "60 odd times" in one year. Based on the people that were interviewed the project team estimates that around a quarter of the participants were attending A&E very frequently, possibly at least once a week.

Arriving and Waiting

6.2.20. Once they arrived in the A&E department seven individuals described being placed in a curtained cubicle, or a room. One person was left in the waiting room, one stated they were left in a corridor and a further two described being taken directly to a bed in the Clinical Decisions Unit (CDU). Nine individuals either were not specific or could not remember where they waited (or if they did wait³).

6.2.21. Some people preferred to be in a cubicle to the waiting room, stating being in the waiting room was anxiety provoking, whilst others described being left alone in a room as problematic leading to their thoughts and feelings becoming more intense.

"...And what they don't realise is that your thoughts and everything else are getting more intense because you're more... you're in distress even more, you're agitated so you just want to kick off or storm out"
Female DH04

" ...They're [voices] paranoid and they get intense when I'm psychotic. When I was in hospital they left me alone for too long on my own ...and as a consequence of that the psychosis got out of control and um I was trying to get out of a locked door in front of me when there was a wide open door to the left of me, but I was so focused on getting out that I was trying to kick the door down. And then some security guards came up and took me from behind. The nursing staff were telling them to leave me alone and to just talk me down, but they weren't having any of it. And because they'd taken me from behind and because I was in that state I just went lunar and eight of them in the end it took them to hold me down and sedate me" Male DH05

³ Some individuals would have needed such urgent medical care for their self-harm that they did not wait.

6.2.22. Two individuals spoke of trying to harm themselves whilst they were waiting for treatment. They felt this behaviour had negatively affected their subsequent experiences in the department.

6.2.23. One participant who was pregnant talked of waiting in a cubicle with the curtain open with staff checking on her frequently. She found this very reassuring and felt safe in A&E.

"I did and I didn't want to harm the baby or myself, but my head was all over at that time, so I thought before I do something stupid get help and see if I can stop that, so that's why I went to hospital..."

...I know that I can't do anything while I'm there [in A&E], so that's why I feel safer" Female DH08

...and later went on to say

A&E staff

6.2.24. A significant part of the interviews reflected on the interactions with A&E staff. Initially during thematic analysis these comments and experiences were grouped into: broadly positive, broadly negative and mixed (negative and positive comments and experiences). Overall four participants had a predominately positive experience in A&E in their interaction with staff, 10 individuals gave accounts of negative interactions with staff and six participants gave accounts of mixed experiences reflecting on positive and negative aspects of interactions with staff. The chart below shows the comments sorted by which service individuals were recruited from.

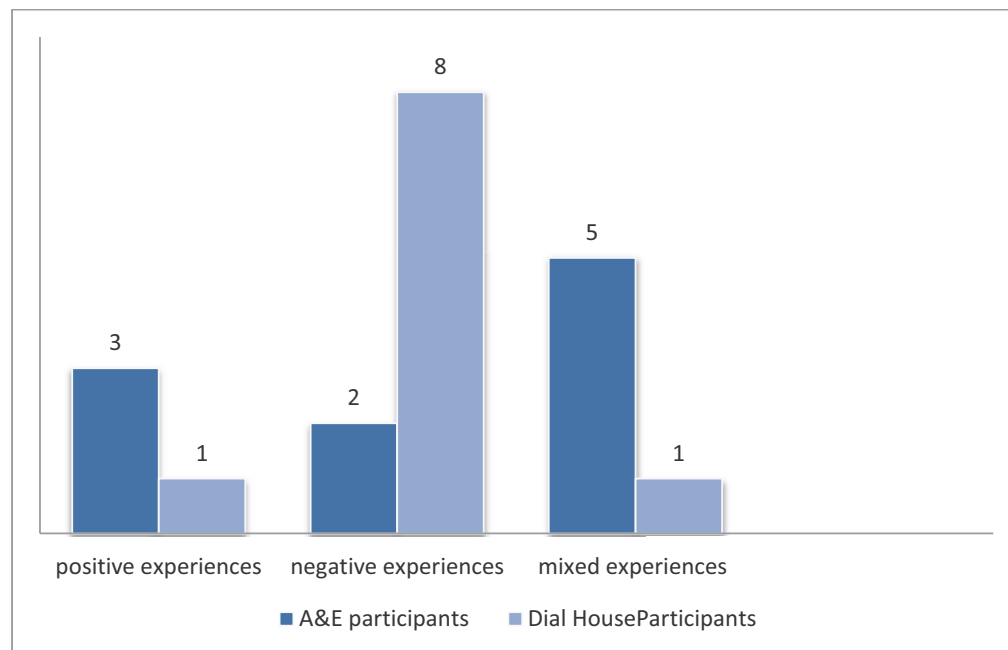
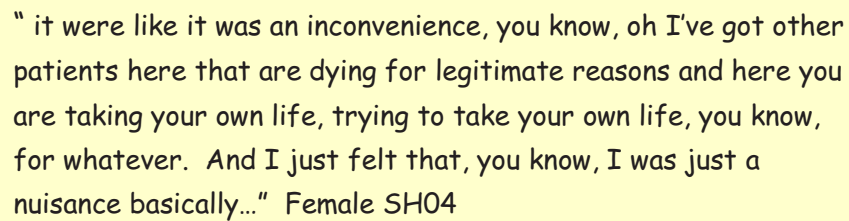


Figure 1 Experiences of interactions with A&E staff

6.2.25. The information suggested that those who were using A&E only tended to give more positive accounts (n=3) than those who attended Dial House (n=1). Dial House participants gave predominately negative accounts of A&E (n=8). Whilst mixed accounts were more strongly represented in the A&E participants (n=5).

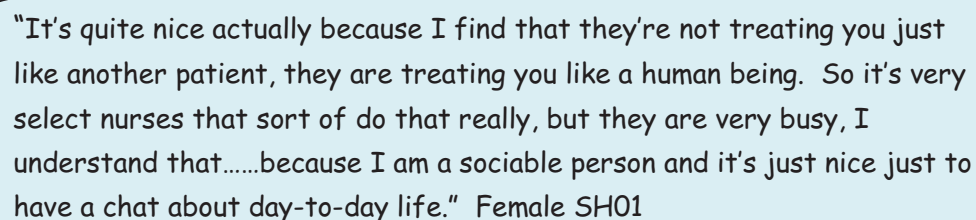
6.2.26. Four individuals referred to a sense that staff may have felt they were time-wasting. This included two from Dial House and two from A&E. Phrases such as “what are you doing here again?” were referred to. One individual described that whilst she felt the nurse was understanding she felt the doctor was much less so



“ it were like it was an inconvenience, you know, oh I've got other patients here that are dying for legitimate reasons and here you are taking your own life, trying to take your own life, you know, for whatever. And I just felt that, you know, I was just a nuisance basically...” Female SH04

6.2.27. One individual (A&E participant) said that a member of nursing staff had shouted at her after she had taken a further serious overdose whilst waiting in the department. She said she had done it there because she thought “they'd be used to life and death” and was surprised by the nurse's response. Another remarked on the importance of staff taking time to listen and whilst some did, others did not. One individual put negative attitudes from A&E staff down to them not having a good understanding of mental health issues generally. One participant recounted an episode where a doctor had told her she might die (the doctor had overheard her on the phone to her counsellor saying that she was going to be alright). She believed the doctor said this to her to frighten her.

6.2.28. Seven individuals referred to positive interactions with nursing staff. One person spoke of how reassuring staff were. Three male participants spoke of nursing staff giving them food which they experienced as kind and thoughtful. Two people particularly mentioned staff speaking 'normally' about normal 'day to day' things as being helpful to them.



“It's quite nice actually because I find that they're not treating you just like another patient, they are treating you like a human being. So it's very select nurses that sort of do that really, but they are very busy, I understand that.....because I am a sociable person and it's just nice just to have a chat about day-to-day life.” Female SH01

6.2.29. One individual spoke of how seeing a pleasant nurse in A&E, who genuinely seemed concerned about her, made her want to stop self-harming. Another woman who found staff very reassuring partly suspected this might be because she was pregnant. Another individual felt that staff trying to understand his situation and act "like a social worker" as he put it, was helpful to him and he appreciated it. One person described a conversation with nursing staff as one of the most helpful aspects.

"Two of the nurses were very helpful. They talked to me about taking an overdose and that, why I did it for. So I told them my legs are getting worse and nobody's doing nowt for me." Male SH05

6.2.30. In contrast, one person was very clear that they did not think that staff being understanding, or trying to offer emotional support was useful stating that they would go elsewhere if they required this. Rather, they wanted staff to treat them and to not judge their situation, or be patronising.

"...when you go to an A&E department or wherever you go, you know, they are only doing... they're not your psychiatrist, they're not your therapist, they are giving a service and it's a very specific service, you know, and really they are not in the place to make judgements, you know, they are there to offer a very specific service, they're not there to make further judgements about a person or a person's behaviour." Female DH06

6.2.31. Four participants referred to a patronising attitude from staff, or being talked down to in A&E. One individual pointed out that staff would not know if she was a medically trained herself. Another referred to the expertise she had developed in managing her own self-harm. One person felt that they were treated less favourably by staff because they were handcuffed by the Police when they arrived in the department (they had been handcuffed as they had refused to go to A&E following cutting themselves). Another individual described staff attitudes as dismissive when they assumed she had cut herself deliberately (due to previous scarring) when in fact she had been injured by someone else accidentally. Her account of this episode of care was very negative.

6.2.32. Five people (all Dial House participants) referred to the impact of their diagnosis on staff attitudes in A&E. One individual felt his diagnosis of psychosis made staff more likely to assume he would be violent, although he acknowledged he had been

violent in the past. He felt that staff did not offer any assistance with “calming down” and expected him to be able to do it himself

- 6.2.33. Two individuals referred specifically to the impact of having a diagnosis of personality disorder on staff attitudes. They felt this adversely affected their experience in A&E and also that the term was not well understood. One of these individuals stated that although they continued to self-harm they avoided A&E

“I don't go to A&E now, I avoid A&E like the plague. Um, I don't like their manner and the way they treat you - with like - your diagnosis and they find out that you've got a particular diagnosis and then they like treat you like shite” Female DH04

- 6.2.34. Interactions with nursing and medical staff clearly formed a central aspect of the experience of A&E for individuals who attend repeatedly for self-harm. This section has highlighted the positive and negative aspects of this from a service user perspective.

Being known by the staff

- 6.2.35. Given that the participants were all individuals who repeatedly attended A&E, familiarity to staff was an important context to consider. Five people did not think staff recognised them. Of these, one person said he recognised some of the staff and this made him feel more “at ease” whilst another person said that he would be upset if staff did recognise him.

- 6.2.36. The majority of interviewees confirmed that staff did recognise them (n=12). Two people made no comments except to say that staff recognised them. Half of this group (n=6) felt that being recognised was a negative thing from their perspective. One individual gave a mixture of positive and negative accounts of being recognised depending on who recognised him. Several of this group felt their treatment was adversely affected by having attended regularly. One individual reflected that their most positive experiences in the department had been when the person dealing with them did not know them (SH07). The information we gleaned suggested that individuals in this group felt a mixture of embarrassment and a sense of disapproval from staff. Comments from staff which indicated previous knowledge of them were experienced negatively. Several people referred to staff making comments like “back again?”

“I only have to walk through the door and they know me straight away, which is embarrassing” Female DH10.

"I think they think I am taking the piss out of the system" Male SH06

"...they start like going um... I don't know why you're doing this again, why don't you just get a life and stuff. And then like when they're talking to the doctors they always transfer over from the nurses and they talk and it's, oh she's got this problem and that, another regular. And so I've stopped going because I actually end up being classed as a... not a regular as such, but frequent user um because of my overdosing. So now I just don't go" Female DH04

6.2.37. Four individuals had positive feelings about being recognised however. Three of the four had never attended Dial House. One person appeared to particularly benefit from the social contact (SH01). The quotes below were both given in the context of describing helpful aspects to A&E.

"they all knew me because I've been there before" SH05

"...they know me, it's like my home that"
Female SH10

6.2.38. The only participant recruited through Dial House who gave a more positive account of A&E, appeared to suggest that it was an understanding of the difficulties she faced which was the most helpful aspect of knowing staff in the department.

"Sometimes I think they're sick of seeing me because I keep going in, but they know that I need help and they give me it. And the new staff what haven't seen me before feel weird, but some staff know what I go through..."
Female DH08

... Nevertheless, this participant felt that whilst it was good that staff understood her difficulties, mentioning previous attendances at A&E may awaken bad memories and make her feel worse...

"...the bad stuff is when you go in they say, oh I remember you, and you don't want them to remember you, but that's sometimes what they say and that upsets me when they say that. They say they remember you from last time I was in. And I don't think they should say that." Female DH08

6.2.39. Overall for four people there was a sense of 'belonging' (SH01, SH10, SH05, SH06). These individuals exclusively used A&E and had not contacted Dial House. All gave some positive aspects to being familiar with A&E staff (three were exclusively positive about being recognised)

6.2.40. Less positively, four different participants referred to overhearing staff talking about them with other staff in shared staff areas which they found distressing. Three of these participants were recruited through Dial House and one through A&E. One individual was upset by a nurse who repeatedly told colleagues that she had taken an overdose in the department previously. This made her feel guilty.

"They judge me because you know when I'm in that cubicle, this is what really gets to me, they talk about me at the nurses' desk, you know, while I'm waiting to be seen by the doctor. And I always hear my name... "She's here again, she's always here. That's all I ever hear. [NAME]... she was only here a couple days ago and look she's back again. And I don't like to hear that because obviously I'm there for a reason. I don't enjoy going to A&E, I mean does anybody want to go there and get abused verbally. No. But yes I always end up getting brought by the police anyway because I always refuse my ambulance" Female DH10

"...Just leaving me there [in cubicle] as if I was wasting NHS money that I was taking up time. You know, and you could hear, overhear what she was saying to her work colleagues, and her work colleagues were acting... how they reacted to what she said was, you know, they agreed with her." Female DH07

Perspectives on context of A&E

6.2.41. Contrary to what might be expected there was recognition from several participants that there were other pressures on staff at A&E. Four people referred to this. Each of these individuals either cut themselves, or combined cutting with an

overdose. Two were recruited from Dial House and two from A&E. Three out of four of these individuals had used Dial House in the past.

"But it's a cut, I'm not high priority because it's a cut; I understand that. I get that, do you know what I mean, I'm not going to moan about it, I'm not. Because people... there's people in worse states that need looking at before us, it's just a cut" Male SH08

"... To be fair I guess there is people that are there that need... that are there because they don't... they've chosen not to be, like people who are injured or ill or whatever, so you can see their point to an extent" Female SH02

"And it's right, because I mean you're self-harming and you're doing this that and the other and then, you know, the contrast is they've got somebody who is there who has had a heart attack or a stroke or whatever, you know what I mean, they've not done owt to harm themselves and stuff." Female DH02

"what are you doing here again, you know what I mean, it's that... I don't want to go but I'm being took there, so there could be some poor bastard dying of cancer that needs that bed, but I'm in it just for being in a state, drunk and cutting myself, you know what I mean?" Male SH06

Treatment and overnight stays

6.2.42. Several participants reported that they were kept in over night or asked to wait to see the self-harm team or crisis team. A number of people were unhappy with having to wait. One person explained that they felt their opinion was not respected when they said they did not want to talk to anyone.

"I didn't want to go for a long wait, 6 hours and then um... when I go there I don't want to talk with no one, with any crisis team, and they make me wait all that hours. I know it's for my safety too, but um I end up being a little bit pissed off. Sorry about my language. Because Um, it's so many hours I've been waiting for and then I get even more frustrated because I didn't want to talk with no one, they kind of... they forced me to and um I didn't want to..." Male SH03

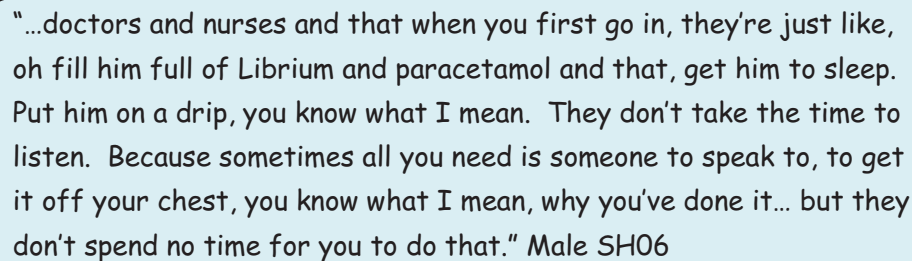
- 6.2.43. One individual explained that she felt under pressure to remain in hospital overnight but that this put additional stress on her as she had pets she wanted to get home to. She felt she would have preferred to contact her CPN who knew her, when she got home.

"I think I normally find it quite frustrating. Certainly the last time I went in I sort of... I said to the doctor, I said, look I said, I know it's sort of routine that you ask us to stay and see somebody, um, but once again for me I have a CPN and, you know, I would prefer to get straight in touch with [CPN name] rather than see somebody that I don't know and they don't know me." Female DH06

- 6.2.44. One individual reported leaving the hospital during the night as they couldn't settle on the ward. In this instance they were contacted by the hospital and asked to return to the ward for further treatment for an overdose. Another individual reported that on her most recent visit she had been cleaned up and discharged fairly quickly and had not been asked to stay to see the self-harm team.
- 6.2.45. One quarter of participants (n=5) suggested that A&E staff may lack necessary mental health skills to deal with those who attend with repeated self-harm. This group included participants from both streams of recruitment. One person of this group reported their mental health tended to deteriorate in A&E and that they frequently felt "petrified" and often became angry and aggressive.
- 6.2.46. One individual who had attended for an accidental cut described being treated with the cubicle curtain open and felt this was humiliating as she had to remove her top. She had dressed the wound herself but she felt it still needed medical attention. A&E staff assumed she had injured herself (she suspects this was due to previous scarring on her arm). The clinician involved used no anaesthetic to suture the wound despite the fact that this procedure was painful. They also broke off repeatedly from the task. The interviewee felt the staff member was "just leaving her like she was a waste of time and money"
- 6.2.47. Another individual was distressed by having to remove her top so that heart monitor stickers could be applied. This reminded her of the abuse she had suffered at the hands of a relative.
- 6.2.48. One participant (recruited through A&E) spoke of issues with the way that cuts were dealt with. He was brought in by the police as he had cut himself. NHS Direct had called the Police following the individual ringing for advice. The police had handcuffed him because he did not want to go to hospital. He felt that because he was handcuffed A&E staff responded differently to him (more negatively) and staff

insisted that the police stay with him whilst they stitched up his wounds. He felt this was unnecessary.

- 6.2.49. One participant explained that they sometimes settle him straight into a bed with some Librium and paracetamol due his alcohol problems but that sometimes he would like to be able to talk to A&E staff.



"...doctors and nurses and that when you first go in, they're just like, oh fill him full of Librium and paracetamol and that, get him to sleep. Put him on a drip, you know what I mean. They don't take the time to listen. Because sometimes all you need is someone to speak to, to get it off your chest, you know what I mean, why you've done it... but they don't spend no time for you to do that." Male SH06

Seeing the Self-Harm Team

- 6.2.50. Participants were asked about the self-harm assessment they received from mental health workers following the incident. For several people this was a worker from the self-harm team, for some it was an individual from the mental health crisis team and yet for others, it was unclear who they saw.
- 6.2.51. Numerous participants reported waiting to see the team and several had stayed over night. Some people did not want to wait for this assessment. It was also clear that not everyone had an assessment in some cases they either walked out, or they were discharged. One person mentioned that they preferred to see the self-harm team but that he had been discharged before seeing them in the past.
- 6.2.52. The form of the assessment was mentioned by eight interviewees. Two people described how previous advice had been helpful to her. She felt it would have been better though if it had been written down as she struggled to retain information when she was were upset. Another individual described how a subsequent psychiatry appointment had been arranged which had helped him but there seemed to be no follow up after this.
- 6.2.53. A quarter of participants (n=5) were unhappy about having to go over the details of their history (three A&E participants, two Dial House). Some suggested that the team might take more time to read existing notes and that going back over childhood experiences made them feel worse, and for some, as though they wanted to self-harm again. This issue would appear particularly pertinent for people who are attending repeatedly.

"I mean I understand you've got to see them once at least to give your life story, you know what I mean, I'll do, everybody will do it the first time, they will do it the second and third but eventually they're going to go, not again [laughs] you know" Male SH08

"it's like they're just like, we know your history, um start asking me loads of questions and I'm like, can you please stop asking me questions, it's wrote down in your stupid file, why are you asking me this when I don't think it's appropriate, do you know what I mean?" Female SH02

"I didn't like it [self-harm assessment] because they just want to... they just...want to repeat itself again, same things, since I've been born until now and what things have been happening, what's not happening, what did happen in the past. Some of the times it was really hard and bad for me, you know, when I've finished with them. Some of the time I harm myself even more and things like that" Male SH03

"don't know because obviously you're going to have to tell the hospital why you've gone in, then you're going to have to start and tell the self-harm team, but I didn't want to... because he didn't... I don't think he had any information about me because he kept... he said start from the beginning and tell me what's happened. And... but I think they should either give them some information about why I'm in, unless they do and they don't tell us, but I had to explain myself again and I found it quite hard and upsetting, but I got through it because I knew I was going to get help at the end of it". Female DH08

6.2.54. In contrast one individual was upset as she wanted to talk about how her past had impacted upon her situation and was told she shouldn't because talking about the past would make her worse. Three people wanted the assessor to "listen more" and felt that the conversation was driven by the assessor's agenda. One person had asked about access to therapy other than CBT but felt that the worker was not interested and pursued their questions regardless of her request.

"They need to listen more I think some of them just need to sit and listen to you because, I mean I've gone away from hospital just feeling just as bad as I did when I took the overdose, because they don't seem to listen to you. And I just think it's rude." Female SH01

"...And she kept asking me the same questions, it felt like an inquisition asking me the same questions over and over. And I don't easily lose my temper but I felt I did with her, and I kind of said, you don't have to ask me three times... and she wasn't interested, she said, I'm only here to do an assessment" Female SH07

- 6.2.55. Several people mentioned the link with other services. One person had not wanted information to be passed on to his worker but felt ultimately it had been in his best interest and had helped him.
- 6.2.56. One individual was frustrated by services not linking up. This participant underwent an assessment and then was left waiting in A&E whilst the worker apparently went back to the mental health unit. She would have preferred that he had taken her straight over to the mental health unit, or at least come back to take her across there. Instead, her experience was that she spent a long time explaining personal details of a situation to a mental health worker who she did not know, who left her in A&E, and who she never saw again despite being admitted to the mental health unit a couple of hours later.

Other services for A&E participants.

- 6.2.57. Those who were recruited through A&E, despite attending repeatedly, seemed generally less likely to have other services involved (apart from the self-harm team) with four appearing to have no additional support. Three people spoke about having CPNs involved. One person spoke of now having a good psychiatrist who they could work with but they had been rejected by all other referrals to services due to their history. One person spoke of involvement with Leeds Addiction Unit, and one person lived in a mental health supported housing situation. One individual was involved with the early intervention in psychosis service in Leeds. Two of those who lacked specialist support appeared to have had some brief follow up (crisis team or a single outpatients appointment) and nothing further. Of the other two, one was accessing counselling and the other was now awaiting a community mental health team assessment.
- 6.2.58. A&E participants were asked if they were given information about other services in A&E or during the self-harm assessment. The information we gleaned in this area seemed patchy despite the fact that these individuals had frequent episodes of self-harm. Three people confirmed they had received some written information, a list of numbers for support. Three individuals recruited through A&E said they had not had any written information. The remaining individuals did not refer to being given information about other sources of support. One person (SH03) suggested this would have been a waste of time anyway because he has been repeatedly rejected from services due to his history.

Leaving the department and follow-up

- 6.2.59. Twelve participants talked about how they left the department. Six individuals referred to walking out before the self-harm assessment either on their most recent visit to A&E or on previous visits. Three people referred to instances where they had gone on to be admitted to acute mental health beds. Of those who talked about 'walking out', three people referred to the police being sent to collect them when they had left the department. One person frequently signed themselves out from CDU the next day as he wanted to leave to go and get alcohol.
- 6.2.60. One person explained that staff usually got them a taxi or ambulance home the following day. This participant appeared, from their description, to be very well known to staff at A&E and the ambulance service. Another participant cited being able to stay for treatment in A&E as an improvement in their health as previously they tended to walk out straight away.
- 6.2.61. In terms of follow up, two people specifically mentioned difficulties with this. One individual explained that he had been referred on to other services but due to his history many services rejected him. This caused him a lot of frustration. At the time of the interview he was relieved to have found a psychiatrist who could work with him to deal with medication issues and his mental health was improved. The second person referred to her CPN not following up after she had been in hospital. When she attended for the interview her CPN had not made contact with her well over a week after her attendance at A&E. This individual spoke of acute social isolation.

Police

- 6.2.62. Contact with the police was mentioned repeatedly throughout the interview. It suggests that this might be an important part of the process to consider for this group of individuals. Out of the 20 interviews, 12 people referred to contact with the police in relation to admissions for self-harm. The contact with police fell broadly into three categories: Being taken to hospital by the police, police becoming (or remaining) involved during their time in A&E and finally being collected by the police having left the department before their treatment was complete.
- 6.2.63. Ten people spoke of occasions when they had been taken to hospital by the police. Six of these were individuals who had used Dial House in the past and four had not. Some reported being aggressive and violent, or under the influence of alcohol at the time of their self-harm, some simply did not want to attend the department. One female participant described the police as "brutal".
- 6.2.64. Six participants referred to police involvement whilst they were in the A&E department. It appears these situations tended to be where there were high levels of distress or where the individual did not want treatment.

6.2.65. Finally five people spoke of the police bringing them back to hospital when they left before their treatment was complete. Most individuals were upset by this. Three individuals had involvement at all three stages of their admission.

Things which helped and did not help

6.2.66. In summary, we asked people about the things which helped and did not help overall in the A&E environment.

6.2.67. **Helpful Aspects**

- **Being checked on in A&E.** Checking in with someone that they were okay helped them to keep calm, was seen as caring and appeared to be reassuring. Conversely those left alone for long periods seemed to struggle.

"It was quite hard because I was still thinking bad stuff but I knew I was in a safe place because of the hospital I was in so... At least she was caring and kept coming to see if I was alright and stuff so..." Female DH08

- **Being recognised by staff.** Some people spoke of liking being recognised by staff and this being helpful. This could mean that the staff member was familiar with the struggles a particular individual faced. Participants who identified this tended to give largely positive accounts of A&E.

"...because they sort of know your history... well a bit of your history and nurses come and... um, there were a nurse on there called [staff name] and she's lovely and we've met a few times, and we always seem to have a bit of a giggle. She always seems to put a smile on my face no matter how sort of down I'm feeling. So it is nice and they sort of know like how to talk to you and things like that, so it does help" Female SH01

- **Staff talking to people normally.** Several people spoke of the benefit they found from being distracted by talking about normal day to day things whilst they were being treated in A&E.

"...there was one nice nurse in LGI, she was really nice to me. Um, she was more or less talking to me and you don't often get that, they just leave you alone... She didn't judge me" Male SH09

- **The importance of kindness being shown towards people in A&E.** A kind or caring attitude from staff was identified as very helpful for several people attending A&E regularly.

"Yes, it takes all the nasty thoughts out of your head doesn't it, you know what I mean? Someone being nice to you..." Male SH06

- **Being able to talk about things with staff.** Several people spoke of the importance of being able to talk about things if they wished to. The quote below was from an individual who found it very difficult to give much specific information but they identified talking, a long with several other participants, as one of the most helpful things to them.

Interviewer: Does that help you?
Respondent: Yes, when they [A&E staff] talk to me.

6.2.68. Unhelpful Aspects.

- **Being recognised by staff.** This was also seen as unhelpful by some people who felt that they received less favourable treatment as a result of being known. It frequently brought up feelings of embarrassment, or as though they were a nuisance.
- **Staff not understanding mental health.** This was seen as unhelpful by several participants. Individuals came up with a range of solutions to this issue including having mental health nurses based in A&E or having a separate A&E for self-harm. It clearly was a central concern for several people.
- **Being made to talk about things.** In contrast to those that felt that talking was helpful some people felt that talking about difficulties was very unhelpful. These individuals appeared to want a respectful and kind approach but without having explain their situation.
- **Overhearing staff talking about them.** This was very unhelpful for several people leaving them feeling like they wanted to avoid the A&E department at all costs.
- **A patronising approach.** People wanted to be dealt with respectfully and some had experienced staff attitudes as patronising, or humiliating. Participants wished to remind

the A&E staff that they may themselves be medically trained or possess specialist knowledge.

- **Having to wait a long time for self-harm assessment.** Waiting for the self-harm assessment caused several people concern and upset and resulted in people leaving the department prematurely.
- **Having to go through life story with the self-harm assessment.** Several people found this upsetting and not useful especially when they were being seen repeatedly.
- **No follow-up.** Not all individuals received follow up and this was identified as unhelpful. Several individuals appeared to have attended numerous times before referrals were made on to other services.

6.3. Overall Themes for People Who Repeatedly Self-Harm

6.3.1. This section considers themes from across the 20 interviews in three areas: Whether any intervention or situation was impacting upon self-harming behaviour; what ideas individuals had about how services for repeated self-harm might be improved; What would individuals define as a good outcome in terms of services for repeated self-harm ?

Changes in self-harm over time

6.3.2. Information was collected about changes in self-harm over time for this particular group and anything which was seen to contribute to that change.

6.3.3. Four of the Dial House group stated that they were harming themselves less and three of the A&E group (total seven participants harming less). Most of these reported they were harming themselves less frequently but one person stated that they did not harm themselves as severely as she had got rid of sharp objects which she could easily hurt herself with, so for instance she had no sharp knives in the house. One other person (Dial House participant) told us that a family member had taken his tablets away from him. This had helped him to stop overdosing. Another individual explained that although she had reduced self-harming her mental health had suffered as a result as it was a coping strategy for her. Other reasons for reduced self-harm included:

- Attending Dial House
- Having a dog to care for
- Counselling or therapy
- Getting away from a violent partner
- Having to 'comply' with society which disapproves of self-harm
- Getting away from others who self-harm
- Medication (which reduced auditory hallucinations or 'psychotic symptoms')

- Having a good worker who has helped with practical things and has reduced isolation.
- Having a good psychiatrist who understood situation and took time to help with medication
- Improved coping strategies

6.3.4. Three of the Dial House participants stated things had got worse for them (self-harming more often) and two stated particularly so over the last two years. One of these individuals put this down to worsening domestic abuse. They felt that despite this, support from Dial House had enabled them to stay for treatment in A&E more often. They said in the past they would have walked out. This was identified as an improvement. The third person explained that although they are harming themselves more they go to hospital less because of how they've been treated in the past. Four people in the dial house group referred to avoiding A&E even when they had self-harmed. In the A&E group one person said things had got worse for them in terms of self-harm as a result of not being able to talk about difficulties from the past.

6.3.5. Nine individuals overall made no comment in relation to changes in their self-harm. Two people did comment however, on things which helped, or which they thought could help. One person thought that access to free telephone support from her mobile phone would help (A&E participant). Another explained that when he was able to visit Dial House he could avoid harming himself (A&E participant who had also visited Dial House).

Ideas for improvements of services in this area

6.3.6. Participants were asked if they could identify any ways in which services in this area could be improved.

- **Education:** Three people identified improvements which could be linked to education. One person called for less discrimination towards people who have a history of drug use, one called for a better understanding of dissociation and the third suggested people be educated in harm minimisation to avoid damaging themselves in ways which had long term consequences.
- **A&E environment:** Three people referred specifically to aspects of waiting in A&E. They suggested that it would be better if service users could wait in an area where the staff could keep an eye on them. One person mentioned that having a quiet area to wait was important. One person suggested that services could be improved if there was more support or supervision for individuals in the clinical decisions unit. One person suggested a separate A&E for self-harm or a different kind of environment.

- **More resources for Dial House:** Three people suggested that increased resources directed at Dial House would improve services in the area. One person felt increased opening hours, or a Dial House worker in A&E would be a positive step.
- **Access to services:** Six people commented in this area. One person spoke of providing services which were walk in, instant access and open 24 hours a day. They felt this could be a more responsive service. Several people mentioned increasing the opening hours for Dial House to allow more people to use the service. Three individuals spoke of the need for more responsive community services since all had waited for a considerable time for the community mental health support which they required. One person suggested this community support should be set up before the person leaves the hospital department.
- **Information:** Two people referred to the need for more information. One suggested more information cards freely available in the A&E waiting areas. The other individual felt that it would be helpful if the self-harm team went through the contact sheet which they gave out and identified any particularly relevant services. They also called for more specific information about the work of each organisation listed on the sheet.
- **Social contact:** Two people spoke of a need for improved opportunities for social contact for those who repeatedly self-harm.
- **Social workers in A&E:** Two individuals felt that the service could be improved if social workers were available in A&E and helping them to deal with difficulties in their living situations, or lack of support from other services.
- **Employing people with personal experience:** One person called for employing people who have been through self-harm to support others who are self-harming.
- **Talking to people:** Four people said that more space and time for talking to people (even if you're drunk) would be a way to improve services. One person called for access to therapies other than CBT.
- **Specialist mental health workers based in A&E:** Three people suggested employing specialist mental health staff in A&E. Two called for dual trained general and psychiatric nurses with specialist responsibility for self-harm and mental health issues to be based in the department. It was felt this would provide a more appropriate service for mental health issues and also a more responsive service so that people were not waiting for assessments from the self-harm team. The third person suggested this worker could be someone from Dial House but was keen to say that they would prefer to see Dial House staff in the environment of Dial House and that she was not sure how much a Dial House worker could influence the A&E environment. She was concerned that individuals would still be left waiting for self-harm assessments even if support was offered in the department by Dial House staff. It seemed that for these individuals the key issue was about more rapid access to self-harm assessments.

Service User Identified Outcomes

6.3.7. The project hoped to identify some indicators, from a service user perspective, of effective services for repeat self-harm. Participants were asked how they would know services in this area were working well. These were grouped into three broad areas.

i. Changes in Understanding

6.3.8. Four people made comments about changes in staff understanding affecting care and this being an indicator of improved standards.

- More personalised care in A&E which appeared to involve a kind approach which was tailored to the individual's mental health and physical needs. The participant felt that this would mean that individuals would be through the department more quickly.
- For staff to be better informed about personality disorder and for the prejudice which individuals experience in relation to it to be reduced.
- For staff to be more accepting of the role of alcohol in the self-harm
- For staff (A&E and mental health) to have a better understanding of the role of dissociation in self-harm and to work accordingly inasmuch as they would not be surprised to have someone who had self-injured who was calm in front of them.

ii. Personal Outcomes

6.3.9. These were areas where individuals felt that if services were working well for them personally they would be able to tell because they would be:

- 'Thinking less' as this caused the individual distress
- Individual felt they would be more outgoing and sociable

iii. Use of Services

6.3.10. Six people referred to this aspect when asked to identify indicators of effective service provision in this area.

- More people using services for self-harm and people who self-harm would be more visibly seeking advice (two participants)
- People attending or returning to a service indicated the service was working well (so repeat visitors to Dial House should be an indication of an effective service)
- Reduced number of deaths as a result of self-harm but not a reduction in the number people attending as a result of self-harm
- Reduced levels of self-harm (linked to effective support)
- Less severe self-harm when it happens.
- Fewer attendances at A&E (two people)

The next section of the report will consider the results which have been presented and identify areas for service development for people who repeatedly self-harm.

7. Discussion

- 7.1. This project has focussed on a group of individuals with the specific experience of attending A&E repeatedly for self-harm. It is *not* expected that their experience will be typical of all people who attend A&E for self-harm, nor of all those who visit Dial House. This project recognises these individuals as important stakeholders in both services and as such, their views and experiences were sought explicitly. This discussion is focussed on the findings from speaking with these individuals. It summarises areas which point to possible service improvements for those who repeatedly self-harm.

Isolation and Loneliness

- 7.2. Isolation and loneliness were important themes throughout the project. Many people spoke of the benefits of ordinary social contact at Dial House as well as in the A&E department. Some people directly attributed their self-harm partly to isolation, whilst others referred to this more implicitly. Individual accounts in this area suggested that even where support had previously been in place, consideration of the importance of social contact as a serious concern in subsequent support arrangements was lacking. The corrosive effects on mental health of loneliness and isolation were palpable in the accounts of many participants, which included those who lived in some level of apparent supported housing. This would appear to indicate that in these cases the level of support may need to be reviewed.
- 7.3. The issue of isolation and loneliness seemed to affect participants across the age range. The extent to which ongoing mental health difficulties and physical health problems contributed to this was unclear. Although self-harming episodes may be contributing to increased isolation, it is also important to recognise the vicious circle this may create from social isolation to self-harm, to further social isolation. Interventions which are focussed on addressing crisis needs, therefore, may further entrench this painful and difficult cycle where the only social contact happens at times of crisis. Nevertheless this should not be used as a way of avoiding offering support since isolation and loneliness clearly does escalate to crisis regularly for many of the people we interviewed. The information we gathered related to 'changes in self-harm over time' suggested that changes in support levels had the potential to influence self-harming. In some cases participants attributed reduced self-harming episodes to having more effective support and conversely, elsewhere, some individuals linked reduced amounts of support with increased levels of self-harm.
- 7.4. Themes around 'belonging' and 'community' emerged strongly during this evaluation. The importance of these themes was particularly noticeable in those who had attended Dial House. Nonetheless for some A&E participants being

known by A&E staff was also important, as well as having their difficulties recognised and acknowledged in that context.

- 7.5. Given the current pressures on community mental health resources, places where people can 'be', feel they 'belong' and where they feel 'safe' are arguably reducing in number. The trend towards short-term working and time-limited interventions may be out-of-step with the needs of some of the individuals we have identified. Many had previous experiences of time limited interventions and yet were still facing significant difficulties in their lives.

Recommendations

- **For there to be an increased recognition of the important role of social contact and the corrosive effects of loneliness and social isolation when planning for services for repeat self-harm.**
- **For interventions to address social isolation to take account of longer term needs by creating and identifying social opportunities which can 'grow with time.'**

Kindness and compassion

- 7.6. A compassionate attitude was valued by almost all participants and certainly, a non-judgemental approach was mentioned as important by the vast majority. At times when being known appeared to undermine staff's compassion towards them, individuals spoke negatively about being recognised. It is likely that it can feel frustrating for staff in all services when confronted with the same individual, apparently facing very similar difficulties, over and over again. It has the potential to make staff feel ineffective. The responses we received from service users/visitors suggest that above all else, a kind and compassionate approach in both the NHS and Dial House, are highly valued by these individuals and the capacity to adopt this kind of approach is something which staff should be aiming for. We heard an account which suggested that the kindness one participant had received at A&E had made her feel like she would like to stop self-harming. Being checked on whilst waiting in A&E was greatly appreciated and communicated a caring attitude although it is recognised that A&E is a busy environment and checking may not always be possible. Nonetheless staff should be mindful of the negative impact of leaving someone alone in a cubicle waiting for prolonged periods. This is consistent with the NICE Guidelines 2004 which suggest that staff should be mindful of the distress experienced by those who attend as a result of self-harm.

Recommendations

- **Opportunities for staff in A&E, the Self-harm Team and Dial House to recognise their positive contribution to the management of individuals who repeatedly self-harm through feedback from service users/visitors**

- **For good practice in the area of care and compassion to be identified and acknowledged.**
- **For staff in A&E to be mindful of those waiting alone in cubicles, to check on them when practically possible.**

People's life circumstances

- 7.7. The 'context of self-harm' section of this report suggests that high levels of social isolation, difficulties with drug and alcohol use, history of (or current) domestic abuse, or sexual assault, ongoing serious mental health difficulties (including hearing voices), anxiety and depression all appear to be contributory factors to repeated self-harm for these individuals. This is consistent with research evidence (NICE 2004). Interestingly, "relationship problems" as identified in NICE (2004 p.21) was not mentioned as a current precipitating factor, for the most recent episode of self-harm, by any of the participants in this evaluation. Given the small number of participants this project is unable to draw any general conclusions about reasons why individuals may repeatedly self-harm. Evidence in this area suggests, however, that motivation can change between episodes of self-harm anyway (Horrocks et al in NICE 2004 p.18). This is a vulnerable population and the reasons given for the cancellation of interviews by potential participants (these were people who the project never managed to interview) further illustrated the high risks which this population may be exposed to not least as a result of self-harm, but also in terms of physical health problems, being the victim of violence from others, or of ongoing acute mental health difficulties. All the findings here and the existing evidence reinforce the need for tailored, individualised support for people who repeatedly self-harm and perhaps some participants' calls for social workers in A&E gives an indication of the social problems several of them were facing. Support should be attentive to the individual's particular circumstance, and look beyond a single precipitating event or cause.

Recommendation

- **For support for individuals who repeatedly self-harm to be holistic and tailored to their particular circumstances addressing social and medical needs.**

Seeking Treatment

- 7.8. The results of this project suggest that those who repeatedly self-harm do not always seek treatment. This may be partly attributed to embarrassment but this also appears to be due to previous negative experiences in A&E departments. To avoid having to seek treatment some people appear to be using 'harm minimisation' techniques. Others, perhaps more worryingly, appear to be trying to manage overdoses or injuries at home which may leave them vulnerable to

serious health consequences and infection. It is interesting to note that in the outcomes identified by service users some individuals felt that returning to services, or seeking treatment was a measure of a good service. Contrary to what might be expected then, from this position it could be argued that more attendances at A&E or Dial House would mean the service was working well.

Recommendation

- **For individuals known to be managing serious injuries at home or overdoses to be actively encouraged to seek medical attention at these times.**

Ill-health and Disability

7.9. Consistent with research evidence, several of the A&E participants were suffering ill-health or disability.

"Many people who self-harm have a physical illness at the time and a substantial proportion of these report that this is the factor that precipitated the act (De Leo et al.1999)" (NICE 2004 p.21).

The finding that the majority of these individuals had not heard of Dial House was striking although given the small numbers involved may simply be coincidence. It may suggest, however, that Dial House is not effectively reaching out to these groups. Some of the findings of this project may also suggest that the needs of these individuals are not being effectively met by NHS or third sector services in general.

Recommendations

- **For Dial House to review its current methods of publicity and to target organisations which support disabled people.**
- **For The Self-Harm Team or mental health assessor to ensure that each individual receives a copy of a list of other place to contact in the event of crisis and to ensure that service users are clear that Dial House provides a taxi to and from the service.**

Alcohol and Self-harm

7.10. The role of alcohol was mentioned by several participants as relevant to their self-harm. The link between self-harm and alcohol use is well established (NICE 2004 p.22; NICE 2011 p.4). In these instances the police were frequently involved in admission to hospital and some individuals felt that staff in hospital reacted negatively to their intoxication. It is recognised that in these situations it can be difficult to manage the high levels of anger or distress exacerbated by the influence of drugs or alcohol. Several individuals called for a better understanding of the link between alcohol, drug use, mental health problems and self-harm. Several people spoke of wanting to have the opportunity to talk even though they

had been drinking. Dial House is not able to offer a service to individuals who are drunk although they will see individuals who have had a drink. The exclusion criteria is currently that they would not offer a visit to someone who was so drunk that they could not make use of one to one support or benefit from the service. Nonetheless this leaves a group of people who will tend to go to A&E since other services are not available to them. Ensuring adequate attention is paid to underlying issues will remain challenging where the initial presentation is vague due to intoxication. Locating a specialist mental health worker in A&E may provide reassurance to service users that their mental health needs are of importance and being recognised, whilst also ensuring the work was taking place in an environment where medical needs could be adequately managed.

Recommendation

- **For specialist mental health workers to be located in A&E.**

Contact with the Police

- 7.11. Contact with the police was mentioned in several interviews. Recognising the important role that police fulfil in relation to the care of individuals who repeatedly self-harm has been a significant finding of this project. Given the level of involvement in some cases including: staying with individuals through treatment, transporting them over to the acute mental health unit and collecting individuals who have left the department before treatment it would seem that the involvement of police is a crucial part of many individuals' journeys. Experience of the police clearly varied from positive experiences, to experiences which were described as "brutal". These findings may suggest that more recognition of the role which police currently play in acute mental health and self-harm is overdue. Better linking up with the police (by Dial House and NHS services), improved training and support for police personnel may benefit the whole pathway through services for repeat self-harm.

Recommendations

- **Better liaison with the police in relation to mental health and individuals who repeatedly self-harm.**
- **For routine monitoring to pick up on the extent of police involvement in the individual's journey through services.**
- **For support and training to be offered to the police service in relation to mental health and self-harm.**

Staff Attitudes

- 7.12. We found evidence of negative staff attitudes towards self-harm in A&E. One person described threatening comments from a doctor who she felt was using

scare tactics. The interview team were surprised to learn that even seven years after the NICE Guidelines were published, one person was describing being sutured without anaesthetic. This is out of step with the NICE Guidelines completely which calls for *“effective measures to minimise pain and discomfort”* (NICE 2004 p.29)

It goes on to say...

“In the treatment and management of injuries caused by self-cutting appropriate physical treatments should be provided without unnecessary delay, irrespective of the cause of the injury. (GPP)” (NICE 2004 p.63)

...and

“It is totally unacceptable to use scare tactics (e.g. refusal to use anaesthetic or threaten service users with sectioning) or to ‘talk over’ the service user to their friends/family members or advocate if the person is conscious and has capacity (GPP)” (NICE 2004 p.83)

- 7.13. Several participants described overhearing staff conversations about them. This suggested that A&E staff need to be sensitive to the distress which these individuals may be experiencing. This distress may or may not be obvious. It may be useful for staff to have better understanding of “dissociation” which can mean that the individual who has self-harmed can appear calm and settled. This may, in turn, be misinterpreted as a ‘not bothered’ attitude on the part of the service user leading to feelings of frustration for medical staff.

Recommendations

- **That all A&E staff are made aware of the spirit and content of the NICE Guidelines for managing self-harm.**
- **That all workers who have contact with individuals who self-harm have at least a rudimentary understanding of aspects of dissociation and its likely impact on the individual’s presentation.**

Specialist Mental Health Knowledge

- 7.14. Several people spoke of a lack of specialist mental health knowledge in A&E and this included a very poor understanding of the diagnosis of personality disorder. Individuals who are carrying this label spoke of extremely negative staff attitudes in relation to the diagnosis. This may point to a need for further information for staff about these issues and the prejudice which individuals can face. Additionally, benefit may be felt from having staff with specialist mental health training available in the department. Several of the descriptions which people gave during the interviews suggested that they may be being re-traumatised (replaying of traumatic past experiences) whilst in the A&E department. A&E staff need to be aware that some individuals may experience treatments in A&E as mirroring past

traumatic incidents such as assault, rape or sexual abuse. This can lead service users to respond in ways which to clinicians may seem out-of-step with the environment (fighting people off for instance, or experiencing routine nursing or medical interventions as “vicious” as it was described by one participant). In these situations it appeared to the evaluation team that things could quickly escalate in the A&E department to dreadful levels of distress. A gentle and kind approach is absolutely crucial in these situation and this is more likely to happen when professionals understand the process of what is happening, or why someone is responding in the way that they are.

- 7.15. Some people spoke of wishing for dual trained general and psychiatric nurses who could work alongside A&E staff but who also had specialist understanding of mental health. Others felt that having a member of staff from Dial House (a crisis support worker), or a psychiatric nurse available in the department would help them. One person thought that having someone with personal experience of self-harm supporting others would be helpful. It is suggested here that embedding staff within A&E, who also have mental health background, could be a positive step as long as there is adequate support. It should be considered that having an identified mental health worker in A&E may prevent A&E staff from being as actively involved with individuals who self-harm. This could de-skill existing staff, developing a culture where self-harm is seen as not part of their job, or where they are fearful that they lack the necessary skills. It should be remembered that primarily service users value kindness, respect and compassion. From the service user perspective, it might be argued that anything which would support staff to be more understanding would be seen as a positive step.

Recommendations

- **That all workers who have contact with individuals who self-harm have some level of understanding of the likely difficulties which those who have been labelled with a diagnosis of personality disorder may face. For all workers to be aware that these individuals are highly likely to have had a history of trauma *and* that workers are mindful of the likely impact of these difficulties on the individual’s presentation.**
- **To have people with specialist mental health knowledge available on shift in A&E departments.**
- **To have ongoing mental health awareness training and support available to A&E staff.**

Self-Harm Team Assessments

- 7.16. Comments about the Self-Harm Team mental health assessment suggested that, particularly for individuals who attend frequently, the process is not working as effectively as it could be.

- 7.17. It will be noted that several individuals spoke of frustration when waiting for an assessment, including those who said they frequently “walked out”. Some people spoke of the need for rapid access to an assessment in A&E. This could be helped by having staff based in A&E. People also called for continuity between services. It appeared that many of individuals we spoke to experienced services as rather disjointed. Some described follow up after the episode of self-harm as being slow, or it taking months for appropriate community support to be put in place, or being referred to organisations which they were unable to access due to aspects of their history. This led one person to suggest that the follow up should be in place before leaving hospital. This would present considerable logistical challenges but a process by which follow up could be confirmed might help to make sure individuals don't ‘slip through the net’ only receiving further help when they present at A&E again for self-harm .
- 7.18. In terms of “walking out” it may also be that individuals who attend repeatedly may be more likely to leave the department before the assessment because they perceive that the assessment is not appropriate to their needs. Individuals spoke of having to recount their life story over and over again to different clinicians at different assessments. For some this was exceptionally distressing, leading to further self-harm. This demonstrates that re-telling of traumatic events over and over again can be counterproductive and risks causing individuals more distress. There is a balance to be struck here between gathering enough detail to make an accurate assessment and putting service users through repeated, traumatic re-telling of distressing events. This particularly arises with individuals who attend and are referred to the self-harm team repeatedly, raising the question as to whether the standard assessment process is ‘fit for purpose’ for these individuals.

Recommendations

- **To improve access to self-harm / mental health assessments so that individuals are not routinely waiting for many hours.**
- **To employ a mental health worker who could undertake assessments within A&E**
- **For referrals on to other services to be properly checked-out to ensure that the referral is appropriate and for there to be follow up to check the progress of referrals.**
- **For the structure of the self-harm mental health assessment to be reviewed in the light of the findings of this evaluation, particularly in relation to individuals who attend repeatedly.**
- **For existing notes to be accessed where there are repeat episodes of self-harm to ensure there is minimal duplication of assessments.**

Dial House

- 7.19. Finally issues arose during the project which suggest that Dial House may not be reaching out as effectively as it could be to those who repeatedly self-harm. It appears that for some people having no access to phone credit left them no alternative but to call 999. Given that most people have access to mobile phones but not necessarily to landlines it would be better if Dial House were able to establish a phone number which was free to mobiles.
- 7.20. Another area which was identified was that people who had not used the service but had heard of it lacked good quality information. More than one person was unaware that the service provided taxis and had assumed they would not be able to get to the service because it was too far from home. This indicates that the information about travel arrangements to and from Dial House needs to be much more visible in their publicity.
- 7.21. Preferences for certain workers for one to one support at Dial House came up in some interviews with some visitors preferring to see the same worker each time they visited and others, feeling that they were unclear how visitors were allocated to workers. The results section details an experience where someone only saw one worker who they did not get on with over several visits leading them to stop coming to Dial House. When they returned the worker had left and they had a much improved experience. This raises the issue of how transparent the allocation of a one to one worker is for visitors. The individual concerned was unsure if they had a choice and since they did not know who they would be speaking to until they arrived at the service they felt unable to ask. It may be useful for Dial House to develop a way of letting people know in advance who their support is with which would enable individuals to let staff know if they were not happy with this. Obviously this will be affected by resources and availability of staff on any given night but moving towards a more transparent system can help to attract new visitors to the service and make them feel it is a place which they can return to.
- 7.22. There is no doubt that Dial House is currently providing a service to individuals who repeatedly self-harm and some people felt that it had reduced their self-harming episodes, not least by providing distraction and social contact when they attended the service (increase social contact was identified as a way in which services could be improved by two participants). Nonetheless if attending Dial House is the active ingredient which prevents the self-harm then without it the suggestion is that individuals are continuing to self-harm. For these individuals then their need, and therefore requests for visits to Dial House, may well be ongoing possibly until other social factors can be addressed. In this instance the service may choose to define its role as 'preventing things from getting worse' at that particular time with this particular visitor group. It may be that the service wish to formally identify places for people who are likely to make contact who otherwise would find themselves in A&E. Some visitors of Dial House called for

increased opening hours to the service and one A&E participant identified a 24 hours walk-in, instance access service as her ideal.

Recommendations

- **For Dial House to establish a phone number which is free from mobile phones and to update their advertising to accordingly stating explicitly that the number is free for mobile phones.**
- **For Dial House to look at systems of how workers are allocated to visitors for one to one support and to seek to make this as transparent as possible offering visitors the opportunity to say if they would prefer to work with someone else.**
- **For Dial House to review the kind of provision it could offer to individuals who repeatedly self-harm and the practicality of setting aside a limited number of places for these individuals within the service.**

In Summary

- 7.23. Most people value a consistent and accessible service, where they are known, cared for, valued and treated with respect and this report demonstrates these are also important priorities for individuals who repeatedly self-harm. Whilst services address the immediate crisis which people who repeatedly self-harm face, it seems that the provision of more consistent follow up is still patchy. These individuals are recognised as a very high risk group. Our findings suggest that where underlying issues are not addressed such as isolation, loneliness and serious mental health problems individuals continue to go from one form of crisis service to another, possibly failing to get adequate follow up because the services they engage with do not routinely provide that to any degree. Dial House clearly has a role to play but given the long term nature of some of the challenges people who repeatedly self-harm face, this project has highlighted above all else the need for, individually tailored, longer-term, consistent services with rapid access to appropriately skilled workers for these individuals.

8. Summary of Recommendations

- 8.1. This section draws together all the recommendations which have been made as a result of the evaluation of services for repeat self-harm. The recommendations have been clustered together where they address similar issues.

Recommendations for good practice

1. **For support for individuals who repeatedly self-harm to be holistic and tailored to their particular circumstances addressing social and medical needs.**

2. **For individuals known to be managing serious injuries at home or overdoses to be actively encouraged to seek medical attention at these times.**
3. **Opportunities for staff in A&E, the Self-Harm Team and Dial House to recognise their positive contribution to the management of individuals who repeatedly self-harm through feedback from service users/ visitors.**
4. **For good practice in the area of care and compassion to be identified and acknowledged.**

Recommendations for A&E

5. **For specialist mental health workers to be located in A&E.**
6. **To have people with specialist mental health knowledge available on shift in A&E departments.**
7. **For staff in A&E to be mindful of those waiting alone in cubicles, to check on them when practically possible.**

Recommendations about the Self-Harm Team

8. **For the Self-Harm Team or mental health assessor to ensure that each individual receives a copy of a list of other place to contact in the event of crisis and to ensure that service users are clear that Dial House provides a taxi to and from the service.**
9. **To improve access to self-harm / mental health assessments so that individuals are not routinely waiting for many hours.**
10. **To employ a mental health worker who could undertake assessments within A&E.**
11. **For referrals on to other services to be properly checked-out to ensure that the referral is appropriate and for there to be follow up to check the progress of referrals.**
12. **For the structure of the self-harm mental health assessment to be reviewed in the light of the findings of this evaluation, particularly in relation to individuals who attend repeatedly.**
13. **For existing notes to be accessed where there are repeat episodes of self-harm to ensure there is minimal duplication of assessments.**

Recommendations for staff training

- 14. That all A&E staff are made aware of the spirit and content of the NICE Guidelines for managing self-harm.**
- 15. That all workers who have contact with individuals who self-harm have at least a rudimentary understanding of aspects of dissociation and its likely impact on the individual's presentation.**
- 16. That all workers who have contact with individuals who self-harm have some level of understanding of the likely difficulties which those who have been labelled with a diagnosis of personality disorder may face. For all workers to be aware that these individuals are highly likely to have had a history of trauma *and* that workers are mindful of the likely impact of these difficulties on the individual's presentation.**
- 17. To have ongoing mental health awareness training and support available to A&E staff.**

Recommendations related to the police

- 18. Better liaison with the police in relation to mental health and individuals who repeatedly self-harm.**
- 19. For routine monitoring to pick up on the extent of police involvement in the individual's journey through services.**
- 20. For support and training to be offered to the police service in relation to mental health and self-harm.**

Recommendations related to improving out of hours provision

- 21. For there to be an increased recognition of the important role of social contact and the corrosive effects of loneliness and social isolation when planning for services for repeat self-harm.**
- 22. For interventions to address social isolation to take account of longer term needs by creating and identifying social opportunities which can 'grow with time.'**
- 23. For Dial House to review the kind of provision it could offer to individuals who repeatedly self-harm and the practicality of setting aside a limited number of places for these individuals within the service.**

Recommendations specific to Dial House

- 24. For Dial House to review its current methods of publicity and to target organisations which support disabled people.**
- 25. For Dial House to establish a phone number which is free from mobile phones and to update their advertising to accordingly stating explicitly that the number is free for mobile phones.**
- 26. For Dial House to look at systems of how workers are allocated to visitors for one to one support and to seek to make this as transparent as possible offering visitors the opportunity to say if they would prefer to work with someone else.**

9. Limitations of This Evaluation

- 9.1. This section considers the limitations of this evaluation. This project has focussed on a specific group of individuals namely those who *repeatedly* attend A&E as a result of self-harm. This means that their experience is unlikely to be typical of all individuals who attend A&E departments for self-harm. We identified these individuals through self report (Dial House group) and through A&E referrals for Self-Harm Team assessments (A&E group).
- 9.2. In the A&E group, for simplicity, the project chose to recruit by using a list which identified people as having been referred to the Self-Harm Team (after attending A&E) four or more times, retrospectively. This meant that in the A&E group, for some people it could have been up to 11 months since the last self-harming episode. It is recognised that this may have affected their recall of events. The alternative recruitment strategy to this would have been to recruit on a 'rolling' basis: once someone was referred for the fourth time they would be contacted. This was not used due to time constraints and the anticipated response rate for the A&E group. It was felt that we would not be able to recruit enough participants in the timescales of the project at a response rate of 10%. The benefit of recruiting in the way that we did was that where individuals' self-harm had changed over time people were able to reflect on this potentially offering some indication of possible service improvements in this area. Of course, recruiting in this way would fail to pick up those who were beginning a journey of attending repeatedly and meant the project could not always gather such immediate experience.
- 9.3. Since individuals were contacted through referrals to the Self-Harm Team for assessment, those who were not referred by A&E may not have been picked up by this project. In addition, those who were in prison or homeless at the time of recruitment were excluded from the evaluation. So this project is unable to comment on the experience of these groups.

- 9.4. The method of recruitment for Dial House included staff giving visitors approach packs at the end of the evening and recording visitor numbers. Whilst this was time efficient and ensured the participant experience of Dial House was recent, it meant that there was the potential for staff to filter, or gate-keep, giving out approach packs. Systems were implemented to offset this risk but nonetheless the limitations of this method of recruitment are acknowledged here. It also means that the individuals who responded would have been more likely to have had more recent crisis experiences than perhaps some A&E participants. This could have created variation in the data collected between the two groups.
- 9.5. All the information which was provided in the approach packs was written in English. This may have meant that those who struggle with literacy may have been less likely to come forward. Due to translation costs we were unable to provide the information in different formats and this may have affected the response rates of those where English is not a first language. The project failed to reach significantly into black and minority ethnic groups. Priority was given to interviewing individuals who identified as non-white British to try to capture the views of this group. In practice we had only one respondent who fell into this category. On this basis the project cannot claim to represent the views and experiences of all sections of the community in Leeds where repeated self-harm is a concern.

10. References

1. Bryant, L. Beckett, J. (2006) *The Practicality and Acceptability of an Advocacy Service in the Emergency Department for People Attending Following Self-Harm*. University of Leeds: Leeds
2. Denscombe, M. (2007) *The Good Research Guide: for small scale social research projects 3rd ed*. Maidenhead : Open University Press
3. Horrocks, J. et al (2005) *Patient Experiences of Hospital Care Following Self-Harm: A Qualitative Study*. University of Leeds in collaboration with Leeds MIND: Leeds.
4. NICE Guideline Number 133 (2011) *Self-Harm: Longer-term management*. National Institute for Clinical Excellence: London.
5. NICE Guideline Number 16 (2004) *Self-Harm: The short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care*. National Institute for Clinical Excellence: London
6. Richie, J. Spencer, L. (1994) *Qualitative Data Analysis for Applied Policy Research* in *Analyzing Qualitative Data*. Bryman, A, Burgess, R. Eds (1994) Routledge:London.

11. Appendix

Documents included here:

- Invitation letter A&E participants
- Information sheet A&E participants
- Topic guide A&E participants

- Invitation Dial House / LSLCS Participants
- Information Sheet Dial House/LSLCS Participants
- Topic Guide Dial House/ LSLCS Participants

- Consent Form for interviews
- Useful contact sheet provided to interviewees

INVITATION TO PARTICIPATE

Leeds Survivor Led Crisis Service (who run Dial House and the Connect Helpline) and NHS Leeds have asked an independent evaluation team to talk to people about the services they receive for self-harm. I am contacting you on behalf of that team.

We would like to speak to people who have attended A&E four or more times in the last 12 months because of self-harm. The evaluation team can offer you a £15 shopping voucher, plus travel expenses (including taxis), if you take part in a short face-to-face interview with us. We will be asking you about your experience of A&E services for self-harm – you will not be asked to share personal information unless you wish to.

More details about this evaluation are included with this letter. If you are interested in taking part, please return the reply slip attached to this letter in the envelope provided. If you respond, you will then be contacted by a member of our team to arrange a mutually convenient time when we can speak. We are only able to talk to a limited number of people, so people will be contacted on a “first come, first served” basis.

Copies of this letter are being sent to all the people who have been referred to the Self-Harm Team four or more times in the last 12 months. The Self-Harm Team has sent these letters out on the evaluation team’s behalf. **The evaluation team have not had any access to your personal details.** If you choose to take part in this exercise, neither the Self-Harm Team nor the staff at Dial House will know you have made contact with us.

If you do not want to take part in the evaluation, or you have been contacted in error please ignore this letter.

Many thanks

Judy Beckett

Self-Harm Evaluation Project (SHEP) Team Leader

A&E/ Self-Harm Team Reply Slip

Please use this reply slip to tell us you would be happy to be interviewed.

Name.....

Address.....

.....

YOUR CONTACT TELEPHONE NUMBER (If you do not include it here we will not be able to contact you)

What is the best time of day to contact?.....

Some More Information About You

It would help us if you could provide a little more information about yourself.

1. Have you ever attended Dial House, Leeds Survivor Led Crisis Service in the past? (please circle)

YES go to question 1.a.

NO go to question 2.

NOT SURE

a. If yes, how long is it since you last visited Dial House?

0 - 8 weeks ago

2 - 6 months ago

6 -12 months ago

1-2 years ago

2- 4 years ago

4-6 years ago

More than 6 years ago.

2. Are you?

MALE

FEMALE

DO NOT WANT TO SAY

3. Which of these age groups do you fall into?

18-24

25-45

45-65

65 +

DO NOT WANT TO SAY

4. How would you describe your ethnicity/background?.....

Thank you

Please return this in the envelope provided

Self-Harm Evaluation Project

Information Sheet (A&E)

(Information for you to keep)

You are being invited to take part in an independent evaluation of the experiences of people who have attended A&E as a result of self-harm on several occasions. This project will focus on the experiences of those who have attended A&E and those who visited Dial House, which is part of Leeds Survivor Led Crisis Service (LSLCS). The information below may help you decide whether or not you wish to take part.

What is the evaluation about?

Judy Beckett and a small team of independent researchers have been asked to undertake an evaluation of two services who work with people who repeatedly self-harm (Dial House and A&E). We've been asked to find out people's views on the services they received. We're interested in hearing about your experience of accessing services for self-harm. All of our team have direct personal experience of self-harm or of supporting someone who has self-harmed.

Who has asked for this evaluation, and who is paying for it?

The charity, Leeds Survivor Led Crisis Service who run Dial House, and the funders of the service (NHS Leeds) have asked for the evaluation, and they are paying for it to be done.

Why have I been contacted?

Everyone who has attended A&E four, or more times in the last 12 months and who has been referred to the Self-Harm Team is being contacted. The Self-Harm Team at Leeds Partnerships Foundation Trust has sent letters out on the evaluation team's behalf – we have not had any access to your personal details. If you choose to take part in this exercise, we do not need to know about the reasons why you harmed yourself. We would like to ask you about your experiences in A&E services, what you found helpful and any ideas you may have about how services in this area might be improved. The Self-Harm Team will not know you have made contact with the evaluation team and taking part will not affect any future service that might be offered to you by the NHS or Dial House.

Do I have to take part in the evaluation?

No, it is completely up to you. If you do not want to take part you can ignore this letter and you will not be contacted again. You can agree to talk to us face-to-face now but you can change your mind at any time before December 2011 and withdraw from the evaluation.

What will happen if I say I want to take part?

If you decide you would like to be interviewed face-to-face, a member of our team will contact you to arrange a time convenient to you when you could speak with us. The interviews will take place at Dial House and a taxi will be provided for you to transport you to and from the interview, or you can make your own way there and we will pay travel expenses. You will be given a £15 shopping voucher as a 'thank you' for taking part. We would like to make an audio recording of your interview so that we accurately record your views and experiences but we will ask your permission to do this. If more people come forward than we are able to interview, then we may not be able to speak to everyone. If we cannot interview you we will write to let you know.

Will the personal information I share be kept confidential/ private?

Yes. Your name will not be included in any recording or any final report and the evaluation team will remove all information which may identify you. Staff at Dial House, A&E and the Self-Harm Team will not know you have spoken to us unless you tell them. The only time we might not be able to keep things confidential is if there is a risk to you or someone else, but we will always try to discuss this with you first before speaking to anyone else.

What are the possible good things about taking part?

You get to have your say about the services you received and it may help to improve services for self-harm. You will receive a £15 shopping voucher and travel expenses (including taxis) if you are interviewed face to face. Some people like talking about their experiences and you may be helping others by helping to improve services for self-harm.

What are the possible bad things about taking part?

Occasionally, people find talking about their experiences upsetting. Sometimes the results of this sort of process can take time to have an effect on services, so you may not see an immediate change and this can be frustrating. Talking to us is likely to take a bit of time (probably about an hour) so make sure you are happy to do this.

What will happen to the results of the evaluation?

We will bring together the things that people tell us about the services for self-harm. A report will be written about how the services for self-harm are currently working, which may include ideas and recommendations for how these services could be improved. This will be sent to Dial House, NHS Leeds and the Self-Harm Team. We will also send you a copy of the report.

What if I am unhappy with the process?

If you have a concern about the evaluation process then you could contact Fiona Venner Service Manager at Dial House, at the address at the end of this information sheet.

What should I do now?

If you wish to take part, please send back the reply slip (attached to our letter) to express your interest in being interviewed face-to-face. We look forward to hearing from you.

Many thanks

Judy Beckett and the Evaluation Team.

If you have further questions please contact Judy Beckett on **07534 976 811**

**Leeds Survivor Led Crisis Service
Dial House
12 Chapel Street
Leeds
LS15 7RW
Tel: 0113 260 9328
www.lslcs.org.uk/dialhouse.html**

Topic Guide Self-Harm Evaluation [A&E Participants]

- Welcome and introductions. Re-explain terms of confidentiality. Sign Consent form and organise money. Switch on digital recorder – record date, time, interview code and name of interviewers

Most recent trip to A&E

I would like to ask you about your most recent trip to A&E following self-harm [if person struggling to remember move on to the most recent episode they can remember]

1. Can you tell me when you were last in A&E?
2. How did you get there (ambulance, taxi, took yourself in, taken by friend/relative)?
3. How did you make the decision to go to A&E (if you did)?
4. Can you tell me about what happened when you got there?

Prompts

- Who did you speak to?
 - Did you have to wait? – if yes, how was this?
 - What treatment did you receive?
 - Were you kept in over night?
 - Were you seen by a member of the self-harm team?
 - Can you tell us about this?
 - Were you given any information about other services?
 - Can you tell us how you left the department?
 - Have you received any follow up?
5. Are you familiar with the staff at A&E? YES/NO
 - What impact does this have?
 6. Looking back over your visits to A&E can you identify anything that has been particularly **unhelpful**?
 - How was it unhelpful?
 7. Looking back over your visits to A&E can you identify anything that has been particularly **helpful**?

- How did you know it helped/ what tells you it has been helpful to you?

Service outcomes

8. Has the support you have received had any impact on the self-harming?
 - If yes, what?
9. If you were in charge of designing support for people who repeatedly self-harm what would you say were the most important things to include?
10. How would we know if services for self-harm were really good/ better?

Dial House

We have been asked to conduct this evaluation by Leeds Survivor Led Crisis Service/ Dial House/ Connect.

11. Have you heard of the service?
12. Do you know anything about the service
 - If yes, what do you know?
 - How did you hear about it?
13. What would make it easier for you to come to a place like Dial House if you were in a crisis?
14. What might get in the way?
15. Is there anything else from your own experience that you think it is important for us to know about services for self-harm?
16. Any other comments?

End recording.

Thank the person and explain what will happen now.

Dear Dial House Visitor

Leeds Survivor Led Crisis Service (who run Dial House and the Connect Helpline) and NHS Leeds have asked an independent evaluation team to talk to people about the services they receive for self-harm. I am contacting you on behalf of that team.

We would like to speak to people who have attended Dial House and who have at other times attended A&E because of self-harm. The evaluation team can offer you a £15 shopping voucher as a 'thank you' if you take part in a short face-to-face interview with us. We will also cover travel expenses (including taxis). We will be asking you about your experience of A&E services for self-harm as well as your experiences of Dial House – you will not be asked to share personal information unless you wish to.

More details about this evaluation are included with this letter. If you have experience of attending A&E for self-harm and you are interested in taking part in this evaluation, please return the reply slip attached to this letter in the envelope provided. If you respond you will then be contacted by a member of our team to arrange a mutually convenient time when we can speak. We are only able to talk to a limited number of people, so people will be contacted on a "first come, first served" basis.

Copies of this letter are being given to anyone who attends Dial House over a three month period. The staff at Dial House are distributing these letters on the evaluation team's behalf. **The evaluation team have not had any access to your personal details.** If you choose to take part, neither the staff at A&E, or in the Self-Harm Team, nor the staff at Dial House will know you have made contact with us.

If you do not want to take part in the evaluation please ignore this letter.

Many thanks

Judy Beckett

Self-Harm Evaluation Project (SHEP) Team Leader

A&E/ Dial House Reply Slip

Please use this reply slip to tell us you would be happy to be interviewed.

Name.....

Address.....

.....

YOUR CONTACT TELEPHONE NUMBER (If you do not include it here we will not be able to contact you)

What is the best time of day to contact?.....

Some More Information About You

It would help us if you could provide a little more information about yourself.

5. Have you attended A&E for self-harm in the past?

YES go to question 1a & 1b

NO go to question 2

NOT SURE

a. When was the last time you were in A&E following self-harm approximately?

0 - 8 weeks ago

2 – 6 months ago

6 -12 months ago

1-2 years ago

2- 4 years ago

4-6 years ago

More than 6 years ago.

b. In the last two years how many times approximately have you attended A&E?

Between 0 and 2 times

Between 2 and 4 times

Between 4 and 8 times

More than 8 times

6. Are you?

MALE

FEMALE

DO NOT WANT TO SAY

7. Which of these age groups do you fall into?

18-24

25-45

45-65

65 +

DO NOT WANT TO SAY

8. How would you describe your ethnicity/ background?.....

Thank you

Please return this in the envelope provided

Self-Harm Evaluation Project

Information Sheet (Dial House)

(Information for you to keep)

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What is the evaluation about?

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The charity, Leeds Survivor Led Crisis Service, who run Dial House, and the funders of the service (NHS Leeds) have asked for the evaluation, and they are paying for it to be done.

Why have I been contacted?

Everyone who attends Dial House over a three month period is being contacted to see if they have also had contact with A&E for self-harm in the past. Letters at Dial House are being distributed by staff on the evaluation team's behalf – so we have not had any access to your personal details. If you choose to take part in this process, we do not need to know about the reasons why you contacted Dial House. We would like to ask you about your experiences in Dial House and in A&E services, what you found helpful and any ideas you may have about how services in this area might be improved. The staff at Dial House or A&E will not know you have made contact with the evaluation team and taking part will not affect any future service that might be offered to you by the NHS or Dial House.

Do I have to take part in the evaluation?

No, it is completely up to you. If you do not want to take part you can ignore this letter and you will not be contacted again. You can agree to talk to us face-to-face now but you can change your mind at any time before December 2011 and withdraw from the evaluation.

What will happen if I say I want to take part?

If you decide you would like to be interviewed face-to-face, a member of our team will contact you to arrange a time convenient to you when you could speak with us. The interviews will take place at Dial House and a taxi will be provided for you to transport you to and from the interview, or you can make your own way there and we will pay travel expenses. You will be given a £15 shopping voucher as a 'thank you' for taking part. We would like to make an audio recording of your interview so that we can

accurately record your views and experiences but we will ask your permission to do this. If more people come forward than we are able to interview, then we may not be able to speak to everyone. If we cannot interview you we will write to let you know.

Will the personal information I share be kept confidential/ private?

Yes. Your name will not be included in any recording or any final report and the evaluation team will remove all information which may identify you. Staff at Dial House, A&E and the Self-Harm Team will not know you have spoken to us unless you tell them. The only time we might not be able to keep things confidential is if there is a risk to you or someone else, but we will always try to discuss this with you first before speaking to anyone else.

What are the possible good things about taking part?

You get to have your say about the services you received and it may help to improve services for self-harm. You will receive a £15 shopping voucher and travel expenses (including taxis) if you are interviewed face to face. Some people like talking about their experiences and you may be helping others by helping to improve services for self-harm.

What are the possible bad things about taking part?

Occasionally, people find talking about their experiences upsetting. Sometimes the results of this sort of process can take time to have an effect on services, so you may not see an immediate change and this can be frustrating. Talking to us is likely to take a bit of time (probably about an hour) so make sure you are happy to do this.

What will happen to the results of the evaluation?

We will bring together the things that people tell us about the services for self-harm and Dial House. A report will be written about the how the services for self-harm are currently working, which may include ideas and recommendations for how these services could be improved. This will be sent to Dial House, NHS Leeds and the Self-Harm Team. We will also send you a copy of the report.

What if I am unhappy with the process?

If you have a concern about the evaluation process then you could contact Fiona Venner, Service Manager at Dial House, at the address at the end of this information sheet.

What should I do now?

If you wish to take part, please send back the reply slip (attached to our letter) to express your interest in being interviewed face-to-face. We look forward to hearing from you.

Many thanks

Judy Beckett and The Evaluation Team.

If you have further questions please contact Judy Beckett on **07534 976 811**

Leeds Survivor Led Crisis Service
Dial House
12 Chapel Street
Leeds
LS15 7RW
Tel: 0113 260 9328
www.lslcs.org.uk/dialhouse.html

Topic Guide Self-Harm Evaluation [LSLCS Participants]

- Welcome and introductions. Re-explain terms of confidentiality. Sign Consent form and organise money. Switch on digital recorder – record date, time, interview code and name of interviewers

Most recent trip to Dial House – Leeds Survivor Led Crisis Service

I would like to ask you about your most recent experience of Dial House as well as your experiences of attending A&E for self-harm.

17. Can you tell me when you were last at Dial House?
18. How did you hear about the service?
19. How did you make the decision to go to Dial House? – had you been there before?
20. Can you tell me about when you first contacted the service to ask to visit?
21. Can you tell me about your visit?
Prompts
 - How did you get to the house?
 - What happened when you arrived?
 - Who did you speak to?
 - Did you have to wait? – if yes, how was this?
 - How did you find the physical environment?
 - Were you given any information about other services?
 - Can you tell us how you left Dial House?
 - What happened next?
22. Are you familiar with the staff at Dial House? YES/NO
 - What impact does this have?
23. Looking back over your visits to Dial House can you identify anything that has been particularly **unhelpful**?
 - How was it unhelpful?
24. Looking back over your visits to Dial House can you identify anything that has been particularly **helpful**?

- How did you know it helped/ what tells you it has been helpful to you?

25. What would make it easier for you to come to a place like Dial House if you were in a crisis?

26. What might get in the way?

A&E Services

We would like to ask you about your experience of attending A&E for self-harm.

27. When was the last time you were at A&E as a result of self-harm?

28. How did you get there?

29. Can you tell us more about that visit?

30. How frequently have you been in A&E as a result of self-harm in the last twelve months?

31. Has this frequency changed over time?

Service Outcomes

32. Has any of the support you have received had any impact on the self-harming?

- If yes, what?

33. If you were in charge of designing support for people who repeatedly self-harm what would you say were the most important things to include?

34. How would we know if services for self-harm were really good/ better?

35. Is there anything else from your own experience that you think it is important for us to know about services for self-harm?

End recording.

Thank the person and explain what will happen now.

Self-Harm Evaluation Project

Consent Form

Interview code-----

I agree to being interviewed for the evaluation of services for self-harm. I have received a copy of the information sheet. I understand that the information I give will be used to develop a written report but that no information will be included which could identify me (for instance my name)

I agree to the use of anonymous 'word for word' quotes from my interview

I understand I can stop the interview at any point or withdraw from the evaluation and it will not affect any future service I might receive from Dial House or the NHS.

I agree to an audio recording being made of my interview.

Signed -----

Date -----

Interviewer Initials.....

Date.....

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Useful Numbers

Crisis Numbers

- Dial House – Leeds Survivor Led Crisis Service.
Open Friday, Saturday, Sunday, Monday 6pm – 2am
Tel: 0113 260 9328
- Connect Helpline – Leeds Survivor Led Crisis Service.
Open 6pm -10.30pm 7 days per week.
Tel: 0808 800 1212
- NHS Direct – Open 24/7
Tel: 0845 4647
- Leeds Women’s Aid – for women experiencing domestic violence and abuse.
Open 8am – midnight.
Tel: 0113 246 04 01
- Samaritans (Leeds) – Open 24/7
Tel: 0113 2456 789

Further Information

- Information for mental health directory
<http://www.mentalhealthleeds.info>
- FRANK- friendly, confidential drugs advice.
Tel: 0800 77 66 00 - Open 24/7
Website: <http://www.talktofrank.com>

Organisations Specific For Self-harm

- National Self-harm Network – Provides support and information and campaigns on issues related to self-harm
Website: <http://www.nshn.co.uk/>
Email: nshncg@hotmail.co.uk
[Tel: 0800 622 6000](tel:08006226000)
- Bristol Crisis Service for Women: 0117 925 1119
www.selfinjurysupport.org.uk - National helpline supporting girls and women in emotional distress, particularly those who self-harm.

