



An Evaluation of the Rachel House at Home Service for the Children's Hospice Association Scotland

Summary Public Report

December 2007



**UNIVERSITY OF
STIRLING**

DEPARTMENT OF
NURSING AND MIDWIFERY

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EXECUTIVE SUMMARY

- I. The Children's Hospice Association Scotland (CHAS) was established in 1992 and is known across the country as a charity committed to specialist caring, support and respite for children and young people with palliative care needs and their families. The primary objective of CHAS is to offer hospice services, free of charge to every child and family who needs and wants them (CHAS, 2005). CHAS has two hospices, Rachel House in Kinross and Robin House in Balloch, and offers a home care service in the Central Belt area, a 24 hour telephone support and advice service and a small home care service called Rachel House at Home (RHAH) in the north of Scotland based at Highland Hospice, Inverness.
- II. The Rachel House at Home service was set up by CHAS in 2004 to provide a home support service in the north of Scotland. The service provides non-nursing support to families in their own homes on an individual basis, and also offers support to families on a group basis through the social events they call 'ceilidhs' which take place on a quarterly basis at Highland Hospice.
- III. The Rachel House at Home service currently has one full-time worker and a team leader who works approximately 0.6 FTE, which is approximately 20 hours a week. Since the service began in January 2004 it has been used by 20 families. There are currently nine families actively using the service, with an additional five families receiving bereavement support.
- IV. CHAS currently have the same referral process for all their services so the families who wish to use the RHAH service, regardless of whether they wish to use either of the hospices, must meet the standard CHAS referral criteria. Referrals are welcome from any source on the understanding that it has been discussed with the family. The main criteria of the referral process are that children needed to be between 0-18 years at first referral and have a progressive life-limiting condition.
- V. The evaluation of the RHAH service was conducted in order to gain objective views of the services currently provided by RHAH and identify possible areas for development. Full ethical approval was received from the University of Stirling's Nursing and Midwifery Departmental Research Ethics Committee.
- VI. Data collection took place via interviews and focus groups between February and April 2007. Invitations to be interviewed were sent out to all of the 20 families who have had contact with the service and 19 professionals from health, social and education services. In addition the nine volunteers who work with the RHAH team were invited to take part in a focus group. Interviews were conducted with nine families and 15 professionals, and three volunteers took part in a focus group, resulting in 36 participants taking part in 27 interviews/focus groups.
- VII. Families and professionals praised the Rachel House at Home service for the support it provides to families and the unique flexibility of the service. Particular recognition was given to the RHAH team members who are dedicated, enthusiastic and motivated

their efforts to provide the best possible service to the families who require their support.

- VIII. The multi-level approach to supporting the whole family, sibling support, bereavement support and bringing families together through the ceilidh social events are highly regarded by families and professionals.
- IX. It is evident from the research findings that although the service offers excellent support to the families who currently use it, there appear to be some gaps in the service at this time and there is the potential for future service development if the service is to further meet the needs of children with life-limiting conditions in the Highland area.
- X. The current RHAH service provides social, emotional, befriending, bereavement and daytime respite support to families in the Highlands area and despite the value that families place on this support it is not known whether or not this is the only level of need that families have.
- XI. A key element for consideration is to review whether the RHAH service is fully meeting the need of young people and adolescents with life-limiting conditions, and to ensure that all the activities organised by the RHAH service are age appropriate, for all young people and adolescents.
- XII. There is a lack of epidemiological data on the incidence and prevalence of children with life-limiting conditions in the Highlands. Although the development of a standard recording mechanism for use throughout the Highlands is out with the control of CHAS the benefit of such data recording to the wider organisations in the Highlands such as NHS Highland could be promoted by CHAS.
- XIII. The team leader has worked hard to promote the service over the last three years but the research findings suggest that there is still a need for further promotion of the service amongst the wide range of people who may come into contact with families to ensure they are aware of the service and able to promote it accurately to appropriate families. It is important that all potential referrers have a good understanding of the referral criteria and are able to explain to the families clearly the type and level of support that is available through the team in order to avoid any misunderstanding or building of unrealistic expectations before families come into the service.
- XIV. One of the most significant gaps in the service noted in the research findings was the lack of service capacity due to the small size of the team. Perceived capacity of the team influenced some professionals when they considered making a referral to the RHAH service and has the potential to limit the time that staff can provide to current and potential new families.
- XV. For some participants the lack of any nursing care services to families who use the service was a significant gap in provision, however, there was a high level of indecision about whether nursing care services are needed within the current remit of the service.

- XVI. Volunteers are highly regarded within the RHAH service; however a number of key issues emerged from the research findings in relation to the development of the volunteer role and their potential contribution to the RHAH service.
- XVII. The RHAH service has successfully integrated with a number of other services, particularly within the immediate Inverness radius. However, the research findings suggest that there are various services where integration could be improved, including the children's ward, Highland Hospice, local bereavement services and with services that support children with a cancer diagnosis, particularly in terms of bereavement support for the family.
- XVIII. For CHAS to consider successful developments of the future Rachel House at Home service for children with life-limiting conditions in the Highlands a number of recommendations have emerged that warrant consideration:

Recommendation 1: Consider conducting a review of the number of staff and volunteers required in order to increase the number of care hours provided in the short-term whilst a thorough needs assessment is conducted (see recommendations 3 and 4).

Recommendation 2: Consider training and support for staff and volunteers in the provision of basic nurse orientated tasks to increase the respite time that can be offered to families with children who have specialist nursing needs.

Recommendation 3: Consider conducting a Needs Assessment to identify the level of need for the service across the Highland with recommendations for service organisation and delivery.

Recommendation 4: Consider conducting a Needs Assessment to identify the particular needs of 16-25 year olds in the Highlands and issues of transition from children to adult services.

Recommendation 5: Consider how CHAS may support further awareness raising of the RHAH service, providing a clear mission statement and referral criteria to all key stakeholders to promote referrals to the RHAH service and ensure that consistent information is provided to all families who may use the service.

Recommendation 6: Consider conducting a feasibility study looking at models of providing a support service in vast but sparsely populated remote areas, drawing on experiences from other services and approaches used elsewhere in countries with challenging geography. This would also include a review of the support structures that would be needed for the implementation of any chosen model.

Recommendation 7: Consider exploring the potential for the development of the role of volunteers within the current RHAH service and any future developments of the service, including support and potential training.

ACKNOWLEDGEMENTS

The Research Team from the Cancer Care Research Centre would like to thank all the participants of the study who gave their time so willingly and enthusiastically.

We would also like to extend a special thank you to all the families who welcomed the researcher into their home and spoke so honestly about their experiences with the Rachel House at Home Service. This provided valuable insight into their experiences of using the service.

We would also like to thank members of the Project Steering Group for their expert guidance during the research project; their time, contributions and comments were appreciated by the Research Team.

Finally, thank you to the Rachel House at Home staff for their help, support and continued communication throughout the research project.

NOTE TO READERS

This is a public summary version of the full report which the Cancer Care Research Centre submitted to CHAS for the evaluation of the Rachel House at Home service. The CHAS Board approved the full version of the report in August 2007 and approved this public summary version in November 2007.

The full report is a confidential internal document to CHAS. This public version of the report summarises the key contents and results from the full report. All quotes from participants have been removed from the results section for this public report as requested by CHAS in order to protect their anonymity. Therefore, the results and discussion sections descriptively summarise the key findings that emerged. The recommendations are presented in full as they were in the full report.

If readers would like any further information about the evaluation project please contact CHAS directly with the details below.

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1 INTRODUCTION

The Children's Hospice Association Scotland (CHAS) was established in 1992 and is known across the country as a charity committed to specialist caring, support and respite for children and young people with palliative care needs and their families. CHAS's primary objective is to offer hospice services, free of charge to every child and family who needs and wants them (CHAS, 2005). In Scotland it was estimated that there were some 1200 children with a life-limiting/life threatening condition and over half will require active palliative care (CHAS, 2005). Collectively Rachel House in Kinross, and the more recently opened, Robin House in Balloch have the capacity to provide 300 children and their families with 17 hospice nights per year. In addition, CHAS also offer a home care service in the Central Belt area, a 24 hour telephone support and advice service, and a small home care service called Rachel House At Home (RHAH) in the north of Scotland to offer support to families in more remote areas. The RHAH service has been running for nearly three years and it is timely that an evaluation of the service be carried out to assess the current service and make recommendations for its future.

Therefore, after a successful proposal bid, the CHAS Board commissioned the Cancer Care Research Centre, University of Stirling to undertake an evaluation of the RHAH service in order to gain objective views of the services currently provided by RHAH and identify possible areas for development. The research project was overseen by a Project Steering Group; details of the members of this group can be found in Appendix A.

2 THE RHAH SERVICE

The Rachel House At Home service was established in 2004 after a successful bid to the New Opportunities Fund (NOF) and was granted funding for three years. This funding came to an end in February 2007, with CHAS now funding this service.

The Rachel House at Home service is a small home care service in the north of Scotland, which offers home based care to families. Some of the families may also use Rachel or Robin House. Unlike the Rachel House Home Care Service, the Rachel House at Home service currently does not provide nursing or medical based interventions to families; it does, however, provide social, emotional, befriending, bereavement and daytime respite support to families in the Highlands area. The RHAH service offers support to families in their own homes on an individual family basis, but also offers support to families on a group basis through the quarterly ceilidhs held at the Highland Hospice in Inverness. The ceilidhs are social support gatherings, with a range of entertainment and support provided for the whole family at one time. Activities provided at the ceilidhs include hairdressing, massage, and quizzes for the children and young people, computer consoles and games and art and craft activities.

The RHAH service currently has one full-time worker and a team leader who works approximately 0.6 FTE. The service covers the Highland area and received its first family referral on 24th February 2004. Since the service began in

January 2004 it has been used by 20 families in the Highlands. There are currently nine families actively using the service, along with five bereaved families. In addition four other bereaved families have infrequent contact with RHAH and two families no longer have any contact with the service.

3 REFERRAL PROCESS TO CHAS

Referrals to CHAS can come from any source, provided the family have given their permission for the referral to be made. Families can also self-refer. Children/young people must be aged between 0-18 at the time of the first referral and must have a progressive life-limiting condition. With parental permission, medical information is requested about the child's/young person's illness and prognosis. Referrals are discussed at Rachel House by the GPs, Heads of Care, Deputy Heads of Care and other senior members of the team and if the referral is accepted, the level of support offered is dependent on the family's needs and stage of their child's illness (http://www.chas.org.uk/hospice_services/our_services/referral_procedure.html).

4 REFERRAL PROCESS TO RHAH

The referral process for the RHAH service is the same as the referral process to CHAS in general; families must meet the CHAS referral criteria before referrals will be made to the RHAH service. If the family live in the Highland area they are then provided with information about the RHAH service. If accepted to the RHAH service, the family receives a home visit from the RHAH staff team to discuss their needs and gather information about the child and the family. A care plan is then constructed over a 2-3 week period and families then begin to use the service.

5 METHODS

Within this qualitative evaluation interviews and a focus group were the methods used to collect data. Interview and focus group schedules were developed by the research team, who are experienced in evaluative research. These schedules were then discussed and refined with the Project's Steering Group. The study received full ethical approval from the University of Stirling's Nursing and Midwifery Departmental Research Ethics Committee.

5.1 Participants

To ensure a range of views were obtained, a number of families who had used the RHAH service, a cross section of professionals who had contact with RHAH and RHAH volunteers were invited to take part in the study. Invitations were sent out to 48 potential participants and 36 participants took part in 27 interviews and focus groups between February and April 2007. The participants who took part in the study were:

- ❖ 4 Families currently using the RHAH service
- ❖ 2 Families currently using the service and receiving bereavement support
- ❖ 1 family currently using the service for bereavement support only
- ❖ 2 Families who have withdrawn from the service
- ❖ 15 professionals with a relationship to the RHAH service
- ❖ 3 Volunteers from the RHAH service

5.1.1 Family interviews

All 20 families who have had contact with the RHAH service since its inception were invited to participate anonymously in the study, with the RHAH staff team addressing the study invitation packs to the families on behalf of the research team. Families were asked to return a participation form to the research team, indicating their preferred choice for involvement by ranking three options:

1. I would like my family to participate in an interview with the researcher
2. I would like to join the Project Steering Group as a Service User Representative
3. I wish to have no involvement / participation with this evaluation

Responses were received from 13 families. Based on first choice rankings, 9 families indicated they would like to participate in an interview with the researcher, 2 families indicated they would like to join the Project Steering Group and 3 families indicated that they wished to have no involvement with the evaluation at all.

Semi-structured interviews were conducted with 9 families who currently use or have previously used the RHAH service utilising the interview schedule in Appendix B. Three of these interviews were with one parent present, six interviews were conducted with the parent(s) and child and/or sibling(s) present. With participants' permission, all interviews were tape recorded and transcribed verbatim. The family interviews lasted between 25 – 90 minutes.

5.1.2 Professional interviews

The steering group identified 19 professionals from health, social and education services to be invited to participate in an interview as part of the evaluation. Responses were received from 17, with 13 of these accepting the invitation to participate in an interview. The other four professionals felt that they were not the most appropriate person to interview, with three of these suggesting alternative colleagues to invite instead.

In total 15 professionals participated in the evaluation. Individual semi-structured interviews were conducted with fourteen professionals and one professional provided their responses via email. With participants' permission, all interviews were tape recorded and transcribed verbatim. The interviews lasted between 25-70 minutes. The interview schedule can be found in Appendix C.

5.1.3 Focus group

The RHAH service currently has 9 volunteers and all were invited to participate in the study, with the RHAH staff team addressing the study invitation packs to the volunteers on behalf of the research team.

Responses were received from 5 of the volunteers; 4 indicated they would like to participate in a focus group and 1 indicated they would not. On the day the focus group was scheduled to take place, one volunteer advised they were no longer able to attend; therefore the focus group was conducted with 3 of the 4 consenting volunteers in order to gain an overview of their involvement, experiences and perspectives on the RHAH service. This group discussion utilised a standard format which can be found in Appendix D and was facilitated by a member of the research team. The focus group lasted 80 minutes and all participants agreed to the tape recording of the discussion.

6 ANALYSIS

All data collection activities were recorded and transcribed verbatim. Themed categories were identified by two researchers based on the research aims and questions. A computer software analysis package called NVivo was used to aid the organisation of the data and analysis. Analysis of the data was thematic and also explored whether participants agreed or disagreed about each issue. Thematic content analysis is a useful approach for answering questions about the salient issues for a particular group of respondents or for identifying typical responses (Hill & Weinert, 2004). For reliability and validity purposes, two researchers coded three interviews from a professional and two families separately, and then cross checked them together.

Subsequent transcripts were then coded individually by one researcher. The themes and sub-themes were then further interrogated by two researchers, which involved refining and condensing themes and sub-themes until the researchers arrived at a final list of sub-themes and categories.

7 KEY FINDINGS

As this is a public version of the full report, which is internal to CHAS, the key findings have been summarised for this report. All quotes from participants have been removed so the following section presents a general overview of each section based on the main themes identified in Table 1. For reference purposes, Table 1 lists the themes, and where appropriate, sub-themes that emerged.

Table 1 – Themes and Sub-themes

| Themes | Sub-Themes |
|-------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Initial overview of contact with RHAH service | Where people first heard about the RHAH service; First contact with RHAH service |
| Referrals | Understanding of referral process; Experience of the referral process; Difficulties within the current referrals system for the RHAH service; Factors influencing referrals – awareness of RHAH service; Factors influencing referrals – perception of service capacity; Issues for future development of referrals to the RHAH service |
| Level of contact with RHAH service | |
| Perception of RHAH service pre- and post-involvement | |
| The current RHAH service | |
| What makes the RHAH service special? | Flexibility; The RHAH staff team; Supporting families in their own homes; Impact of the RHAH service on families lives |
| Integration of the RHAH service with other services | Children’s Community Nurses; Drummond School & The Orchard; The Highland Hospice; The voluntary sector, Issues for future development of integration of the RHAH service |
| Meeting the needs of the local population | Equitable service provision; Meeting the needs of adolescents; Meeting the needs of children with an oncology diagnosis; Identifying the number of children with palliative care needs |
| Nursing element | |
| Volunteers | Support for volunteers; Developments for volunteer roles |
| The current remit of the RHAH service | Family satisfaction with the current service remit; families suggested improvements for the current service remit; Professionals suggested improvements for the current service remit |
| Future developments of the RHAH service | Increasing capacity and resources; Nursing element; RHAH premises; Overnight respite provision; Transport; Fundraising; Awareness raising |

7.1 Initial overview of contact with RHAH service

- In order to gather background factual information on the service all participants were asked a number of questions in the interviews about the contact they have with the RHAH service.
- When families were asked about how they first heard about the RHAH service, many said they heard about it through their community nurse or through their pre-existing contact with Rachel House.
- Families were also asked about their first contact with the RHAH service, both in terms of who and how they were first approached and contacted. The most common first contact was a visit from the RHAH staff to the family home.

7.2 Referrals

- All participants were asked about their understanding of the referral process and their experience of the referral system. Those participants who were aware of the referral process reported that CHAS has the same referral process for all of its services and uses the same referral form which requires a considerable amount of information and has strict criteria.
- It was generally understood that referrals the Rachel House at Home service receives are reviewed at Rachel House in Kinross. One professional felt that it may be an advantage that the referrals are decided upon at Rachel House rather than by the team based in Inverness.
- It did appear that participants interviewed demonstrated varying levels of understanding about the referral criteria and process, as some participants were very knowledgeable, whereas the knowledge of some participants was more limited.
- It emerged that families have been referred to the Rachel House at Home service through a variety of people including community nurses and the Rachel House team in Kinross. Other professionals mentioned as possible referrers included social workers, GPs and nurses.
- All the professionals interviewed were asked if they had made referrals to the Rachel House at Home service and about their experience of the referral process. Some professionals shared their experiences of having a family successfully referred to the service.
- Two difficulties were highlighted by participants about the current referral system. These were the strict criteria which families need to meet for the support service offered by RHAH, and how families may view being referred to a hospice as part of the referral process.

- The current referral system requires that families meet a strict referral criteria based on medical grounds and this has sometimes caused a problem in gaining support from the Rachel House at Home service for families.
- It was questioned whether this strict criteria is appropriate for the support service provided by the Rachel House at Home service.
- Some families reported that they were unaware of the Rachel House at Home service prior to their referral. Professionals also commented on the need to further promote the service.
- Two professionals who were interviewed spoke about the lack of referrals from oncology to CHAS generally.

7.3 Level of contact with RHAH service

- When families were asked about how much contact they have with the RHAH service, this appeared to vary between families, based on their circumstances.
- Families' reports of the levels of contact with the RHAH staff and service ranged between weekly, fortnightly or quarterly at the ceilidh events.

7.4 Perception of RHAH service pre- and post-involvement

- Families, professionals and volunteers were asked about their perceptions and knowledge of the RHAH service pre- and post-involvement. It emerged that many families' knowledge and understanding of the RHAH service was limited prior to their involvement with the service.
- For one family who were involved with the RHAH service in the early days the information they report being given and their understanding of the new service led them to expect a very different service to that provided by the team. This family believed the service would mirror the care that was offered in Rachel House. They reported having a negative experience of the service as their expectations about the level of care that would be provided were not met.
- Although some families' knowledge of the service and what it could offer was limited initially, this did change for many families after they became involved and began to have more contact with the service and the staff.
- Some professionals and volunteers also appeared to have varying levels of knowledge and understanding of the RHAH service before and after their involvement. Similar to many of the families, there were positive shifts in perceptions as their knowledge of the service increased.

7.5 The current RHAH service

- All participants were asked a series of questions about the current RHAH service in order to gain some insight into their experiences with the service.
- Participants spoke of the range of activities from play therapy to practical support provided to families, outings for siblings, bereavement support, and the ceilidhs which provide the families with the opportunity to get together on a quarterly basis.
- There was particular recognition of how the service supports the whole family including specific support for siblings which is highly regarded by both the families and professionals.
- Participants spoke of the bereavement support that the RHAH service offers to families. This was considered to be different to formalised bereavement counselling, which is provided by Rachel House staff in Kinross. The RHAH staff team were considered to provide the bereavement support in a sensitive manner, respecting the needs of the families.
- Although sibling support and bereavement support were discussed as two specific forms of support provided, participants also often commented on the general support provided by the service, which can make a difference to the whole family.
- One of the core ways support is provided to families and the families provide support to each other is through the ceilidhs organised and run by the RHAH staff team. The ceilidhs are held in the Highland Hospice on a quarterly basis. The ceilidhs were often viewed positively by both families and professionals. However, some families reported that they did not enjoy the ceilidhs.

7.6 What makes the RHAH service special?

- When participants were asked whether they thought there was anything special about the Rachel House at Home service, a number of elements of the service were discussed by families, professionals and volunteers.
- The flexibility of the RHAH service was considered to be one of the core things that make the RHAH service special by both families and professionals.
- The personal and professional qualities of the RHAH staff team were frequently discussed by families and professionals. The importance of the families' relationships with staff were often emphasised, as they frequently referred to the staff team as friends.

- Professionals and volunteers often commented on the personal qualities the staff members bring to the service.
- Families and professionals consistently discussed the benefits of the RHAH service providing care and support to families in their own homes. It was acknowledged that families behave more naturally in their own surroundings and are provided with opportunities to build and establish more natural relationships with staff because the support is provided in their home.
- The emotional nature of the care and support the RHAH staff team provide was recognised by families and professionals. Concerns over the support that is available to the staff team were raised, particularly as they are such a small team and are isolated from their colleagues in Rachel and Robin House.
- However, it was noted that the RHAH staff team have clinical supervision arrangements in place with a qualified counsellor in Inverness and have regular contact with staff from Rachel House. The importance of this support was recognised by the RHAH staff team.

7.7 Integration of the RHAH service with other services

- When professionals were asked if the RHAH service currently integrates with other services in the Highlands, this was considered largely to be the case.
- Professionals felt that the RHAH service integrates well with the local Children's Community Nurses.
- Families and professionals also felt that the RHAH service integrates with Drummond School and The Orchard. Drummond School is located in Inverness and is a school for children with additional support needs. The school caters for pre-fives through a nursery group, pupils up to the age of twelve in the primary department and pupils up to the age of nineteen in the secondary department. The Orchard is a residential respite unit managed by the Highland Council Social Services Department for children and adolescents with Learning Disabilities. Trained Nurses are provided at this facility.
- The Highland Hospice provides an adult service but there have been occasions when some of the adolescents from the RHAH service have utilised services and staff from this organisation.
- Some professionals did feel there are still services and areas where the RHAH service could strengthen its integration in the future. Services discussed included the children's ward, paediatricians, community nurses, Highland Hospice, local bereavement services, and bereavement support for families of children who had a cancer diagnosis.

- One professional spoke about the possibility of the RHAH service providing bereavement support for families of children with a cancer diagnosis due to the lack of support or grief services available locally.
- The issue about the timing of when children with cancer come into the RHAH service was also raised, as parents may not want to begin developing new relationships during the last few weeks of their child's life.

7.8 Meeting the palliative care needs of the local population

- When professionals and volunteers were asked whether the current RHAH service is meeting the needs of local children with palliative care needs participants' opinions were split.
- Some professionals and volunteers felt that the local need was being met within the current remit while others felt their knowledge of the service and number of families with needs in the area was insufficient to answer this question.
- The geographic spread of the Highlands was often discussed by professionals and contributed to concerns about the current RHAH service possibly not offering as equitable a service as would be ideal. Most families who use the current RHAH service are within the Inverness radius, so there were questions over whether there are other families further out in the Highlands who would be eligible to use the service.
- Professionals suggested some approaches the service could adopt in order to ensure the service is offered as equitably as possible across the Highlands, including training bank staff in different areas, increasing the size of the RHAH staff team and considering whether families who live further away from Inverness can be accommodated in Inverness to help facilitate attendance at the ceilidhs.
- CHAS accepts referrals for children and young people up to the age of 18 at the time of referral. This means that some young people can still be accessing and using the services of a children's hospice into their late teens or early twenties, so participants also discussed whether the current RHAH service, and wider CHAS service, is meeting the needs of their adolescent users.
- Many of the families who are referred to CHAS are affected by life-limiting illnesses that are not cancer related. Participants raised a concern that families affected by a paediatric oncology diagnosis do not use the RHAH service due to other services such as the oncology team meeting their needs.
- However, it was suggested that the current RHAH service, and CHAS as a wider organisation, could be more involved in meeting the needs of these families, particularly in providing bereavement support.

- There appeared to be inconsistencies in the knowledge of participants about the numbers of families in the area with palliative care needs and no participants were aware of any structured recording mechanism for this type of information.

7.9 Nursing element

- The current RHAH service is not a nursing based palliative care service. This issue was often discussed by participants who demonstrated a range of views on the matter from it not being important to it being an issue which is impacting on the level of service that can be provided.
- Some participants felt that the lack of the nursing element does impact on the service, particularly in terms of meeting the needs of the very ill children and young people. Some participants also suggested that it was initially something that families who use Rachel House at Kinross may have expected to be offered as part of the RHAH service.
- Some participants demonstrated that there is still some confusion around the RHAH staff and their remit as they assumed that the staff had nursing backgrounds.

7.10 Volunteers

- The RHAH service currently has nine volunteers, all of whom are highly regarded by the families and professionals.
- The volunteers are currently involved in a range of activities with the service, including office administration, the ironing service, helping out at the ceilidhs, and taking children and siblings to the cinema or park.
- During the volunteer focus group, participants discussed the various sources of support available for the volunteers. The most frequently mentioned sources of support were the RHAH staff team and various staff from Rachel House.
- CHAS run an annual volunteer conference, where volunteers from all the different CHAS services have the opportunity to come together for the day. This conference facilitates contact between volunteers from the different services and also promotes the value of the volunteers' inclusion in CHAS as a wider organisation.
- Volunteers are an integral part of the RHAH service and it is important to ensure that their skills, experiences and interests are fully utilised and that there are opportunities to develop their roles and strengthen the input they have to the service. Various ways of approaching this were suggested by participants including establishing a volunteer forum, providing some training on basic nursing orientated tasks to volunteers who were

interested in developing those skills, and introducing teenage volunteers to the service to support adolescents.

7.11 The current remit of the RHAH service

- Following the discussions about the current RHAH service, participants were asked to feedback any potential improvements to the service within its current remit.
- Families were asked to rate the quality of the support they have received from the service on a scale of 1-10, where 10 was the best, and were then asked what would need to change for them to give a score one more above their previous rating in the context of the current remit of the service.
- Many families rated the service highly and one family did not rate the service very highly.
- However, there were families who felt that they couldn't put a numerical value on the support they have received, and one family who had been involved in the early days of the service being developed did not rate the service very highly as their expectations had not been met by the service.
- Based on the initial score families provided, they were then asked what would need to happen for them to give a score one more above their previous rating in the context of the current remit of the service. The majority of families could not suggest anything that they thought would make a difference to their score as it was already 10 out of 10.
- However, there were a couple of families who did think their score could be improved by activities being tailored to suit a young person and by providing longer support visits to a family.
- When professionals were asked if there was anything that could be done to improve the service within its current remit, the prominent recurrent issues included the need to increase the resources available and meeting the nursing needs of the young people.

7.12 Future developments of the RHAH service

- Following discussions around improvements to the service in its current remit, families, professionals and volunteers were all asked about the future development of the service in general.
- The suggested developments included increasing the staff numbers, exploring the additional of a nursing element to the service, RHAH service having their own premises and transport, being able to provide overnight

respite for families, local fund raising, and continuing to promote the service and increase awareness throughout the Highlands.

- The issue of increasing the resources available was strongly emphasised across participant groups with the introduction of bank staff to the service considered one way of increasing staffing and resource levels, particularly at peak times during the year or in locations out with the immediate Inverness radius.
- The discussions surrounding the introduction of bank staff to the service transferred into the idea for some participants into the development of a satellite model for care across the Highland region. This would be completely reliant and dependent upon an increase in resources available as this would be in addition to the central hub where care is co-ordinated, but it was clear participants felt there is scope to involve volunteers in this model of care by training volunteers in various locations across the region.
- Increasing resource levels was often discussed in terms of increasing the sibling support that the RHAH service provides. Providing support to siblings in the current remit is highly valued, but participants often thought that increasing the resources available would allow this support to expand further.
- The nursing element of the needs of the children and families were consistently discussed in relation to future developments of the service. This issue was mainly raised by professionals, although some families and volunteers also considered this an important area for future development.
- However, some participants were unsure whether the RHAH service should encompass a nursing role, acknowledging the competence of the service as it currently stands and whether it should provide services which are offered by others.
- Other participants suggested that instead of providing a nurse there was the potential of providing training on specific issues to staff that were comfortable with providing that level of care.
- The RHAH service operates out of an office in the Highland Hospice in Inverness, with limited space and facilities available. Whilst appreciative of this support from the Highland Hospice, it was recognised that the RHAH service could be further developed if they had a building of their own.
- Many participants felt that the provision of overnight respite services would be beneficial as part of the future development of the service. Suggestions for providing this respite support varied from care for one night to care for a weekend.
- It was recognised that travelling to Kinross for overnight respite is difficult due to the distance involved, but there is still a need to provide overnight respite for the whole family, away from their home, but within practical travelling distances.

- The availability of specific RHAH transport was consistently discussed by participants, with many feeling that a fully adapted minibus that belonged to RHAH would allow for the service to develop, particularly in terms of the activities available to families.
- The RHAH service was funded by New Opportunities Fund for its first three years. As this period of funding has now come to an end, RHAH is funded fully by CHAS. It was recognised that CHAS is heavily reliant on public donations and fundraising to contribute to the cost of running all its services. Some participants felt there could be fundraising initiatives progressed on a local level, so that money raised by the Highland population for CHAS services stays in the Highlands, specifically for the RHAH service.
- As part of the future development of the service, many participants felt there was still a need for the RHAH service to be promoted more widely in the Highland area, particularly in terms of raising awareness of what the service offers.

8 DISCUSSION AND RECOMMENDATIONS

- Families and professionals praised the Rachel House at Home service for the support it provides to families and the unique flexibility of the service.
- Particular recognition was given to the RHAH team members who are dedicated, enthusiastic and motivated in their efforts to provide the best possible service to the families who require their support in the Highland areas within their service remit.
- The current RHAH service was often viewed positively by the families and professionals who were interviewed.
- Several aspects of the support provided were identified by the families and professionals for particular recognition and praise; these included the multi-level approach to supporting the whole family, sibling support, bereavement support, and bringing families together through the ceilidhs.
- The support offered by the RHAH team encompasses the whole family, not just the child with palliative care needs. The RHAH staff team and volunteers support children and young people, siblings, parents, grandparents and extended family both on individual and group levels.
- The bereavement support the RHAH staff team offer is not formalised counselling, as this is provided through staff at Rachel House if required. However, the importance of providing longitudinal bereavement support on a social or befriending basis was consistently recognised. Sharing experiences and building friendships amongst families is also seen as an important element of the support available through the current RHAH service. This is facilitated by the ceilidhs which the RHAH team organise

on a quarterly basis. These ceilidh events provide an opportunity for all families who have contact with the service to come together with the staff and volunteers for an afternoon at the Highland Hospice.

- It is evident from the research findings that although the service offers excellent support to the families who currently use it, there does, however, appear to be some gaps in the service at this time and that future service development is required if the service is to meet the needs of children with palliative care needs in the Highland area.
- For CHAS to consider successful developments of the future Rachel House at Home service for children with life-limiting conditions in the Highlands there are a number of issues which have emerged that warrant consideration.
- The key recommendations are not exhaustive of the data but are believed to be those that would have the most impact on the future support for families with children with a life-limiting condition from the Rachel House at Home service.

8.1 Development of the current remit - service capacity and resources

- One of the most significant gaps in the service noted in the research findings was the lack of service capacity due to the small size of the team.
- Perceived capacity of the team influenced some professionals when they considered making a referral to the RHAH service. This was primarily spoken about in terms of concern of whether or not the family would receive the level of support that the professional felt was necessary.
- The decision not to make referrals on this basis could also be masking the level of referrals that would be made to the service if it was perceived to have more capacity.
- Generally the families have not criticised the level of support they received, although some would appreciate more time if it were available.
- One of the most significant gaps in the current service for some participants was the lack of any nursing care services to families who use the service.
- Although this was a common issue in the research findings, there was a high level of indecision about whether nursing care services are needed within the current remit of the service.
- The current service is unable to support the nursing needs of some young people, for example, the administration of medication, moving and handling, and toileting regimes of those families receiving support from the service, which consequently impacts on how long parents can leave their child with the RHAH team.

- Some of these tasks do not require nursing qualifications as parents currently undertake these, but they do require training. It is maybe worth considering whether RHAH staff and volunteers could be trained in such tasks to an acceptable level to ensure staff and volunteers are comfortable in providing this potentially specialised care.

Recommendation 1: Consider conducting a review of the number of staff and volunteers required in order to increase the number of care hours provided in the short-term whilst a thorough needs assessment is conducted (see recommendations 3 and 4).

Recommendation 2: Consider training and support for staff and volunteers in the provision of basic nurse orientated tasks to increase the respite time that can be offered to families with children who have specialist nursing needs.

8.2 Defining and identifying the needs of families with children with a life-limiting condition in the Highlands

- An important factor which has been highlighted during this study is the lack of epidemiological data on the incidence and prevalence of children with life-limiting conditions in the Highlands.
- It appears that there is no clear method for identifying the number of children with life-limiting conditions living in the Highlands and their needs in order to know who could benefit from the support of a service like Rachel House at Home.
- Conducting a needs assessment to identify the level of need for the service and any geographic areas of need would be beneficial to the planning of future services.
- The needs assessment would identify what the needs are of families with children with a life-limiting condition, the support they require, the type and level of resource needed to meet the identified need and make recommendations about the capacity required to meet that need. This could be done in partnership with NHS Highland.
- It was envisaged in the original proposal for funding to the New Opportunities Fund that the RHAH service would conduct a needs assessment of the palliative care needs of 16-25 year olds in the Highlands during the first three years of the service.
- However, it is unclear whether this has been fully completed, but comments from professionals would suggest this is still outstanding as it appears there is a lack of knowledge in terms of numbers and level of potential need.

Recommendation 3: Consider conducting a Needs Assessment to identify the level of need for the service across the Highland with recommendations for service organisation and delivery.

Recommendation 4: Consider conducting a Needs Assessment to identify the particular needs of 16-25 year olds in the Highlands and issues of transition from children to adult services.

8.3 Promotion of the RHAH service

- The team leader has worked hard to promote the service over the last three years.
- However, it would appear that there is a need for further promotion of the RHAH service particularly amongst those who may have limited awareness of what the service offers and how to make referrals such as GPs, professionals working out with the Inverness area, those working in paediatric oncology, and managers and staff working in relevant organisations that support families.
- It is important that all potential referrers have a good understanding of the referral criteria and are able to explain to the families clearly the type and level of support that is available through the team in order to avoid any misunderstanding or building of unrealistic expectations before families come into the service.

Recommendation 5: Consider how CHAS may support further awareness raising of the RHAH service, providing a clear mission statement and referral criteria to all key stakeholders to promote referrals to the RHAH service and ensure that consistent information is provided to all families who may use the service.

8.4 Management and future development of the team

- Generally the families have not criticised the level of support they received, although some would appreciate more time if it were available.
- The travelling distances for families who live out with the Inverness area to attend the ceilidhs was mentioned by families and there is a real impact on the level of support that can be offered to families who live further away due to the travelling time for RHAH staff from the Inverness area.
- Concerns about the equity of service provision due to the geographic spread highlights the need to look at other models of providing a service to more remote areas such as satellite workers throughout the Highlands based within other services or through volunteers.
- Concern around this issue was frequently discussed throughout the study, which suggests that service capacity is a matter which warrants consideration as a priority to ensure that the necessary service capacity is

in place to meet the needs of the population and respond to appropriate referrals.

- Volunteers are highly regarded within the RHAH service; some families referred to receiving help with their ironing, transport arrangements and support at the ceilidhs from the volunteers in general.
- Issues around support available for the volunteers were discussed by participants.
- It was suggested that a volunteer forum could be established for volunteers to come together on a quarterly basis to share ideas and support each other.
- It was felt that the introduction of teenage volunteers to the RHAH service would be beneficial, to provide support to young people of a similar aged peer group.

Recommendation 6: Consider conducting a feasibility study looking at models of providing a support service in vast but sparsely populated remote areas, drawing on experiences from other services and approaches used elsewhere in Countries with challenging geography. This would also include a review of the support structures that would be needed for the implementation of any chosen model.

Recommendation 7: Consider exploring the potential for the development of the role of volunteers within the current RHAH service and any future developments of the service, including support and potential training.

9 CONCLUSION

The recommendations detailed in section 8 address the key issues from the data that CHAS may wish to consider. Having commissioned this work, CHAS have identified the need to assess the current RHAH service in order to determine the potential for the development of service provision across the Highland community for families with children with life-limiting conditions pre- and post-bereavement. It is anticipated that action on these recommendations will assist in these development processes, however, it is acknowledged that change can be challenging particularly when the service is so competently run by a small dedicated team. It is suggested that the CHAS board give some consideration to how they will engage, consult and support the current RHAH team during any discussions and implementation of any developments based on the recommendation contained in this report.

It is further anticipated that the study has identified pertinent issues which are relevant to effective partnership working, and may lead to developments in the current communication processes and integration between the RHAH service and various service providers. It is hoped that these findings will be a useful basis on which to develop existing and future partnership working whilst ensuring that the RHAH service remains central to the delivery of support to families with the appropriate needs.

10 APPENDICES

Appendix A - Names and Job Titles of the Project Steering Group

| Name | Job Title | Organisation |
|---------------------------|-----------------------------------------------|-----------------------------------------------------|
| Alison Stephen | RHAH Team Leader | CHAS |
| Yvonne Robbins | RHAH Support Worker | CHAS |
| Maria McGill | Chief Executive | Highland Hospice |
| Pat Rankine | Team Leader, Children's Community Services | NHS Highland |
| Fiona Shevill | Social Worker, Child Health Social Work Team, | Highland Council |
| Margaret MacSween | RHAH Volunteer | CHAS |
| Iain James | Occupational Therapist | Highland Hospice |
| Sally Amor | Child Health Commissioner | NHS Highland |
| Bernadette & Emily Cairns | Users of the RHAH service | |
| Katherine Knighting | Research Fellow | Cancer Care Research Centre, University of Stirling |
| Lisa McCann | Research Assistant | Cancer Care Research Centre, University of Stirling |

Appendix B – Family Interview Schedule

An Evaluation of the Rachel House at Home Service for the Children's Hospice Association of Scotland

Family Interview Schedule

1. Can you tell me how you first heard about the Rachel House at Home service?
2. What did you know about the service before you became involved?
3. When was your first contact with the RHAH service?
4. Who have you seen from the Rachel House at Home Team since then?
5. Can you tell me about the support you have received from [Alison / Yvonne / Volunteers] since your contact first started?
6. How often do you see [Alison / Yvonne / Volunteers]?
7. What do you think are the best things about the support you receive from Alison / Yvonne / Volunteers?
8. Do you think there is anything special about the type of support that Alison / Yvonne / Volunteers provide in their current roles?
9. Has there been a time when you have asked for support and it wasn't available?
10. On a scale of 1-10 [10 is the best], how would you rate the quality of the support you have received from the Rachel House at Home service?
11. What would need to happen for you to give the Rachel House at Home service X out of 10 (X would be 1 point above previous rating) within its current remit?
12. Finally, if the service could be anything that you wanted it to be (and a 10 out of 10), how would you like to see it develop?

Appendix C – Professional Interview Schedule

An Evaluation of the Rachel House at Home Service for the Children's Hospice Association of Scotland

Professional Interview Schedule

1. What is your current role / relationship with CHAS?
2. What is your understanding of the RHAH service and what it offers to families in the area?
3. Have you, or anyone within your organisation, referred any families to the Rachel House at Home service?
4. Do you receive any feedback from the families about their experiences with the service?
5. Do you think there is anything special about the Rachel House at Home service?
6. Do you think the Rachel House at Home Service integrates with other services?
7. Do you feel that the current RHAH service is meeting the needs of local children with palliative care needs?
8. Do you think there is anything that could be done to improve RHAH within its current remit?
9. Finally, if the service could be anything that you wanted it to be, how would you like to see it develop?

Appendix D – Volunteer Focus Group Schedule

An Evaluation of the Rachel House at Home Service for the Children’s Hospice Association of Scotland

Volunteer Focus Group Schedule

1. What was your understanding of the RHAH service and what it offered families before you became involved as a volunteer?
2. Has your understanding of the service changed since you began volunteering?
3. How did you become involved with the service, and what do you do in your volunteer role?
4. Do you ever receive feedback from the families about their experiences with the service?
5. What support is available to you as a volunteer?
6. How do you see the role of volunteers developing in the Rachel House at Home service?
7. Do you think there is anything special about the Rachel House at Home service?
8. Do you feel that the current RHAH service is meeting the needs of local children with palliative care needs?
9. Do you think there is anything that could improve the service within its current remit?
10. Finally, if the service could be anything that you wanted it to be, how would you like to see it develop?