RESpite care needs for families of children with life-limiting conditions

Janet Bowman, Ruth Butcher and Sue Dolby discuss how a children's charity has developed a resource allocation tool to use in partnership with service users.

Summary

The Framework for Respite in Partnership with Parents (FRiPP), developed by the Jessie May Trust is a tool to enable a standardised and equitable allocation of a limited resource. FRiPP reduces the opportunity for subjective allocation of respite-based care stemming from the professional-led model of telling families what they need. The tool is aimed at engaging families in identifying and articulating the support they require. After a successful pilot and evaluation, FRiPP is now used for all families on the Jessie May Trust's caseload. The authors reflect on the tool's development and implementation process in the context of promoting and protecting partnership working.

Keywords

Family-centred care, life-limiting conditions, palliative care, respite

Background

The Jessie May Trust is a registered charity, established in 1996 as a palliative care service for families of children and young people with life-limiting conditions. It aims to enhance the quality of life for the child and family through the provision of respite, palliative, end of life care and bereavement support before and after the child's death. Support and care is provided in the family's home by members of the care team which comprises registered children's nurses, qualified nursery nurses and a bereavement support worker.

Central to the philosophy of the trust is the provision of needs-led services and recognition that the parents, carers and young people who use the service are the experts in realising these needs. The level of support requested by each family varies. It can change at short notice and is influenced by the child's physical care requirements and the social and emotional needs of the family.

In 2001, families on the caseload were given the opportunity to indicate how satisfied they were with the service and to suggest improvements. The families were interviewed by an independent researcher who reported back to the trust. The results indicated that overall, families were very satisfied and valued the services provided. However, one of the themes that emerged was a request from parents to have more information on how respite visits were allocated. It became evident that to achieve genuine partnership working the service needed to develop a process of assessing needs that directly related to the allocation of respite visits.

This process aimed to:
- Enable an equitable, consistent and fair allocation of resources.
- Promote transparency and objectivity.
- Promote the use of listening and reflection to enable families to articulate their needs (Heimann 2000).
Palliative care

It also aimed to promote the principles of partnership working in relation to:

- Active participation of families and recognition of their expertise to lead on identifying their needs.
- Openness, honesty, mutual respect and trust.
- Negotiation and agreement.

**Assessment and allocation tool**

A review of the literature in 2001 revealed few assessment tools focused on respite allocation appropriate for use in a children's palliative care service. Most of the tools were symptom orientated and based on an 'expert' medical model. The team aimed to develop a tool based on a biopsychosocial model, enabling a holistic and systemic approach to understanding, identifying and assessing the child's and family's needs with the latter's participation.

The most valuable sources of information influencing the development of an appropriate tool came from sharing experiences and working collaboratively with other professionals and respite services. Personal communication with three teams in particular influenced the development of the tool. These were the Gwent, Chase Hospice and the Oxford respite teams. The Jessie May Trust team hoped to mirror Chase Hospice's dependency scoring system, which looked at the child's care needs and those of the whole family. It also hoped to reflect the simplicity and clarity of the headings in the Oxford respite team's tool.

Formats for the tool were explored. The team said the most pragmatic approach was to use a matrix-based table. This was influenced by the framework for assessment of children in need and their families being implemented at the time by the Bristol Area Child Protection Committee. This framework enabled children to be assigned a 'need' code and a 'response' level. The framework also enabled children to move from a low priority to a rapid response category, without the need for a detailed reassessment (Area Child Protection Committee 2002).

The combination of a matrix approach and the Oxford team's dependency tool provided the foundation for the Jessie May Trust framework, which became known as the Framework for Respite in Partnership with Parents (FRiPP). The matrix consisted of the following needs: nursing care; supervision; family support and emergency care rated across low, medium and high categories with an initial points scoring system of zero to five. A draft version of the assessment tool was shared with three families on the caseload to review the criteria and scoring mechanism for accessibility, relevance and accuracy. Their feedback led to increased 'care need' examples under the category headings and a wider range of scoring (zero to eight) to enable greater sensitivity to individual variability in need.

The families welcomed FRiPP as a move to enable them to articulate their requirements and clarify their expectations of the service. This was important in achieving the service's aspirations to establish a model of working in partnership. The team was mindful of preventing discrimination against families who under-report their needs. The reasons families give for this may be because:

- They believe they have not been fully informed about the service.
- Personal, subjective assumptions are made about what it is reasonable to ask for and the family then compare their requirements with those of other, possibly 'needier', families.
- They were inexperienced at articulating their needs, possibly because the families are at an early stage of their child's journey.
- Difficulties occur when asking for support which may feel incongruent with their family culture or expectations of their role as a parent (McGrath and Grant 1993).

**Survey**

To test the face validity and pragmatic applicability of the assessment tool, ten families (20 per cent of the caseload at that time) were recruited to use it as part of the annual care review process in place at the trust. The families were also asked to fill in a questionnaire at baseline and at three months follow up. This survey used five-point Likert scales for parents to rate the following:

- Whether or not FRiPP was a good idea.
- Whether or not the aims of FRiPP and how it worked were understood.
- The clarity and comprehensibility of the information booklet.
- Whether or not the FRiPP process felt fair, equitable and transparent.
- Whether or not the families felt as involved as they wanted to be in the allocation of their respite provision.

Nine families completed baseline questionnaires and eight families responded at follow up. The data at follow up indicated that the families approved of FRiPP, finding it understandable with clear advice on how to use it. These families also rated the process as fair and equitable, with their involvement being as much as they wanted. Additional comments indicated that families welcomed the transparency and improved information sharing that the tool enabled (Bowman et al 2004).
It was agreed to undertake a gradual implementation of the framework to the remainder of the existing caseload and to introduce it from the beginning for new referrals. Three core standards were identified for future audit and evaluation once the framework had been fully implemented (Box 1). It was recognised that the scoring system would need regular review to ensure equity whatever the overall resources available. Table 1 is an example of the FRiPP criteria and scores. Since the FRiPP review, the data have been amended to include four columns to help the scoring process.

**Negotiating allocation**

The team wanted to make use of the tool standard in a process of assessing, negotiating and agreeing allocation of respite hours in partnership with parents. The process of initial service-led assessment leading to a care agreement and regular reviews was adapted to integrate the new tool to form an overall framework for the allocation of the respite resources. This is summarised in Figure 1, page 18 (adapted from Dale 1996).

**Reflections on the process**

The FRiPP is now used for all families on the Jessie May Trust caseload and has been subject to an independent evaluation by the University of the West of England incorporating the above standards. This evaluation prompted the authors to reflect on the process of developing and implementing the FRiPP with a focus on the promotion and protection of partnership working described by Davis and Meltzer (2007). They describe the characteristics of an effective partnership as:

- Working closely together with active participation and involvement.
- Sharing power, with parents leading.
- Complementary expertise.
- Agreeing aims and process.
- Negotiation.
- Mutual trust and respect.
- Openness and honesty.
- Clear communication.

In this context the following reflective points have arisen:

**Listening to families** An important aspect of the FRiPP has been to enable families to use this tool to take the lead in conversations, tell their stories and to help contextualise their needs when considering the scoring ratings on the framework. In clinical supervision, staff have reflected on the impact of actively listening to families when they share their experiences and understanding of their situation.

| Table 1 Example of the Framework for Respite in Partnership with Parents’ criteria and scores |
|---|---|---|
| *Six to eight* | *Three to five* | *Zero to two* |
| Nursing care needs | High level of nursing required, for example ventilation, total parenteral nutrition. | Additional needs, for example medications, hoisting, gastrostomy, tracheostomy. | Usual care for a child of this age. |
| Supervision required | Constant supervision required because of age, health or behaviour. | Requires supervision on a regular basis. | Can be left in a safe place for short periods or is able to ask for help if needed. |

*Range of score (Eaton and Goodenough 2009) families can allocate themselves if they feel they meet the criteria in each column.*

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<th>Box 1 Core standards for future audit and evaluation</th>
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**Standard 1** 100 per cent of service users will rate their understanding of Framework for Respite in Partnership with Parents as four or more on a five-point scale (zero = not at all, five = fully).  

**Standard 2** 100 per cent of service users will rate their perception of fairness and equity as four or more on a five-point scale (zero = unfair, five = fair).  

**Standard 3** 100 per cent of service users will rate their level of involvement in as much as they wish it to be at four or more on a five-point scale (zero = poorly, five = fully).  

This has included adopting a negotiating position which respects the parents’ expertise and is sensitive to the emotional content of the discussion. Ongoing communication skills training and reflective practice support staff through this process.

**Reduced opportunity for subjective allocation of respite care** The framework has reduced the opportunity for subjective allocation of respite care based on the professional-led model of telling families what they need and allocating care on that basis. The authors argue FRiPP engages the family in identifying support required and how these needs might best be met. They believe by having a transparent, standardised framework and a negotiating process, staff are less likely to find themselves telling families what they need.
**Palliative care**

**Equitable allocation of resources** The authors maintain that the allocation of a limited resource is more standardised and equitable and will ensure that all families have the same opportunity to understand how the service works and what they can expect. However, promoting a respite service has sometimes caused families to believe that respite care is an entitlement. Skilled and clear communication at the negotiating stage has been required to explain what the Jessie May Trust hopes to provide. While the process of using the framework encourages families to score themselves and test their likely allocation before the meeting, this has sometimes encouraged families to expect a level of service that the charity is unable to fulfil. This is when it has been helpful to ensure families understand that it is a partnership rather than a consumer-led model that is being used.

Staff have developed clear communication skills to explain the available resources and how these are prioritised, such as cancelling visits because staff need to provide end of life care for another family. The authors say families have a better understanding of what the service can bring the partnership which has helped to manage families' expectations.

**Families can under-report needs** In some situations staff have continued to feel that families are under-reporting their needs. In these circumstances it may be appropriate to respectfully and non-judgementally challenge a family's self-assessment score. But staff must continue to value the family's culture and their perception of their need using sensitive and respectful communication skills. Some staff believe this can be easier when they already have a relationship with the family because they provide respite and support in their home. But, through reflective practice, the authors have also become aware that this familiarity can help create a more subjective and expert-led position. Challenging this in clinical supervision has helped staff to develop their skills and recognise the characteristics of an effective partnership.

**Need for staff training and parent support** The tool was designed to be used more flexibly by staff and parents in recognition of ongoing changes in requirements. The FRiPP score has sometimes remained unaltered despite changes in care because reassessment of need often only takes place alongside the annual care review. On reflection, an area for future development is staff training and parent support to enable more proactive, regular use of the FRiPP between the annual care reviews.

**Conclusion**

The process of developing and implementing the FRiPP has increased the active participation and involvement of service users. This involvement has development of mutual trust and respect at its core. The framework's outcome can only be achieved by negotiation. It encourages the expert position of carers and young people, and values the reality of their experiences and perception of their needs. Families can lead the discussion on what the Jessie May Trust may be able to offer towards meeting their needs. Partnership working for the service has moved from a theoretical concept to an operational reality which continues to develop with the FRiPP at its core.

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**Figure 1** 

Process to negotiate respite allocation in partnership based on the Framework for Respite in Partnership with Parents (FRiPP)

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