

Respite – the preferred ambulance at the top of the cliff: a Christchurch, New Zealand study¹

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Background

The overall aim of this research was to evaluate the effectiveness of the Stepping Stone Trust short-term respite care service for mental health service clients in Christchurch, New Zealand.

Stepping Stone Trust, a Christian organisation which establishes and oversees rehabilitation and accommodation for people with mental illness, has been operating respite care for almost four years. The Trust offers three forms of short-term, supportive accommodation:

- planned respite, where clients plan ahead and book respite (up to a maximum of 28 days);
- emergency respite, where clients require immediate 24-hour intensive supervision and care (up to a maximum of six days); and
- carer support, where the client's carers need the time out.

The service is staffed, on a 24-hour basis, by mental health professionals from predominantly social work and nursing backgrounds. The Trust provides this level of professional staffing to meet the needs of clients, although this is not a mandated or funded requirement. The service has grown in popularity and often cannot meet the demand for respite beds now that referral agents appreciate its value and ability to keep their clients out of hospital.

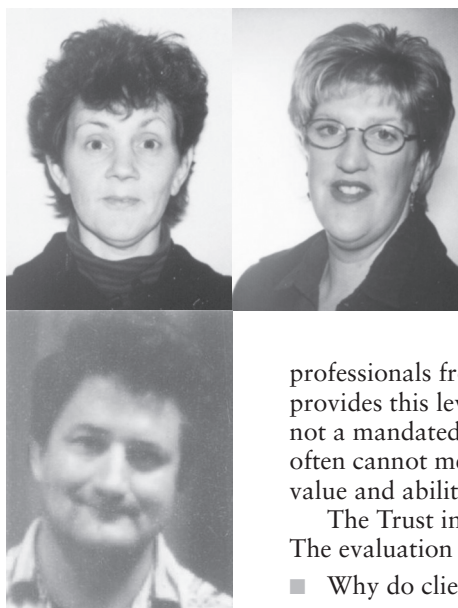
The Trust initiated this study to evaluate the effectiveness of the respite service. The evaluation sought to establish:

- Why do clients come to respite?
- What difference does it make for clients?
- What are some of the key strategies that work and why?
- Does the respite service keep people out of hospital?
- What comparisons can we make with other respite services?
- What gaps are there in respite services in Christchurch?

The intention was to provide a clear and systematic picture of the service. A seventh question also emerged during the evaluation: What is the value of respite over a hospital admission for clients?

The respite program

Respite care programs, originally established to relieve carers of their daily responsibilities by providing regular alternative care, have become more common in mental health service delivery. Respite provision comes as a direct result of



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deinstitutionalisation and the need to provide the 'least restrictive care'.

The term 'respite care' is used to describe a number of distinct forms of service delivery to differing client groups. Planned and emergency residential respite, such as that provided by the Stepping Stone Trust, is the 'attempt to therapeutically intervene to interrupt the complex cycle of instability, family stress, patient symptomatology and return to hospital' (Geiser, Hoche & King 1988, p. 292). Most of the current literature on respite care concentrates on carer burden (Lawton, Brody & Saperstein 1989; Caradoc-Davies & Harvey 1995; Jones & Peter 1992) and very little is dedicated to the respite needs of clients or consumers.

The aims of respite care are to:

- moderate the exacerbation of symptoms (Geiser, Hoche & King 1988);
- decrease the duration of hospital stay (Geiser, Hoche & King 1988);
- create and sustain positive perceptions of the reason for admission or referral (Nolan & Grant 1993);
- provide for an active and purposeful stay (Nolan & Grant 1993); and
- ensure medication compliance (Geiser, Hoche & King 1988).

These aims are to be achieved in a non-judgmental and non-adversarial manner (Geiser, Hoche & King 1988).

With the emphasis on deinstitutionalisation there is widespread demand, 'rooted in personal experience of the barren, ordered chaos of the acute ward' (Campbell 1996, p. 181), for alternative approaches and different supported accommodation options for people in mental health crisis. Consumers or clients want alternative options, other than medical services, to self manage and understand their crisis, as well as supportive and

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experienced staff who listen and are comfortable with the clients' distress (Campbell 1996).

Studies have found that some of the most important factors in maintaining people with mental health problems in the community are access to effective crisis support and sympathetic intervention for unpredictable behaviour (Warner et al. 1997). However, much of the literature on respite care relates to programs developed for the carers of the frail and elderly, notably dementia and Alzheimer's sufferers (Tepper & Toner 1993; Theis, Moss & Pearson 1994; and Shantz 1995). There are few

systematic surveys, research-based studies, or reports specifically on planned or emergency care providing residential respite for adults with mental health problems. In particular, notwithstanding Wadsworth's facilitated 'empowerment evaluation' by groups of psychiatric patients (McGuinness & Wadsworth 1991), little is known about respite provision, for this population group, in Britain (Cotterill et al. 1997), or Australia (Lofgren 1998) or New Zealand.

In addition, the issue as to whether mental health respite services are utilised to their fullest economic and social benefit remains open (Shantz 1995). However, in seeking to answer this question, it is important to note that other factors may impact on the benefit of respite use such as the severity of illness, medication and other outpatient treatments.

Methodology

The evaluation project, which was subject to the oversight of a Steering Group and which ran from October 2000 to mid 2001, involved a number of component approaches including:

- profiling the clients of the respite service;
- triangulating the clients, referral agents, and staff's perceptions of the respite service;
- auditing client hospital admissions over a two-year period; and
- tracking clients turned away from the service.

Clients

A complete database was established, recording details of all clients who used the respite service, including gender, age, length of stay, numbers of visits, and type of respite, diagnosis and referral agency.

Thirty clients (10% of the then total respite clients) were then interviewed at the Mental Health Resource Centre, Christchurch during March and April 2001. A matched sample technique was used to represent the overall profile of respite clients². The questionnaire used to explore clients' views was first piloted on respite clients not selected for interview. Initially there was difficulty getting clients to come for interview and a number of refusals. Through the use of follow-up letters, phone calls and five arranged home visits, responses were obtained from all 30 clients. Research participants were paid \$15 for their interview and asked to sign a consent form stating they understood that the information was for research purposes only.

The interviews of clients were conducted by a female and a male mental health consumer who were trained to do the interviews. The use of a 'consumer or client as interviewer' approach is based on a community development model. Nettle (1996) believes that consumers make better interviewers because they are less likely to 'coerce' the interviewee and are more likely to be told what

consumers really think about their situation than 'professional' researchers. Consumer interviewers help clients to explain their problems and use of services and treatments (Rogers, Pilgrim & Lacey 1993).

In addition, all respite clients were given a brief satisfaction questionnaire to complete when they had finished their time at the respite service. These completed questionnaires were summarised and analysed and included in the evaluation.

Referral agents

A cross-section of referral agents from community mental health teams, psychiatric emergency services, and acute in-patient staff were contacted. Using a snowballing technique we interviewed first the agents recommended by respite staff and then asked these respondents to nominate other interested team members including those not referring to the respite service. This process resulted in a total of 27 referral agents being interviewed between October and December 2000. We asked questions from three broad categories: the quality of care, outcome of care and aspects of the service that require change (Locker & Dunt 1978). The questionnaire used to explore the views of the referral agents was first piloted on staff and some amendments made. The mostly qualitative data were then analysed and summarised.

Respite care staff

At the time of the research there were five nurses and six social workers working either full- or part-time at the respite service. These staff were interviewed to establish their perceptions of what the clients' needs were when they came to their respite service and of the outcomes of care. In addition, key questions from both the referral agents and client interviews were included in the staff questionnaire to ensure a triangulation of opinion on the same topics.

Audit of hospital admissions

An integral part of the respite research was the audit of hospital admissions for clients who had used the respite service. The number and length of admissions to acute wards per annum that clients had had prior to using the respite service were compared with admissions after using the respite service. All clients who had been to respite six or more times, had at least 21 days in one year and/or were emergency referrals only, were included in this audit. In all, 62 clients met the criteria for tracking hospital admissions. The data on these clients were provided by the acute in-patient hospital (Hillmorton), with the proviso that no client could ever be individually identified.

This audit of clients admitted to hospital was conducted with the approval of the Canterbury District Health Board (CDHB) Ethics Committee. This approval, gained in April 2001, ensured patient confidentiality.

Clients turned away from the service

In November 2000 an attempt was made to investigate what happened to emergency clients who were not accepted to the respite service due to the service being fully booked. To explore their subsequent care pathways or, more simply put, what happened to them next, we kept a log of emergency referrals unable to be admitted.

Results

Profile of the respite clients

By 31 December 2000, 321 clients had been admitted 737 times into the Stepping Stone respite service. The average length of stay was 4.5 nights and each person came on average 2.3 times. The busiest times were weekends and holidays and June/July were the busiest months. 62% of all respite clients came in on a planned basis, 24% came in as an emergency referral, while the carer support referrals were as low as 14%, although they stayed the longest at 5.3 days.

- 65% or almost two-thirds were women;
- 58% were between 30–49 years of age, 16% were 20–29 and 14% 50–59; only 7% were 60+ and 5% were 16–19 years;
- 38% of respite clients had depression (including 11% presenting with a major depressive episode); 21% had a bipolar disorder and 20% presented with schizophrenia, delusions or a schizoaffective disorder; 7% presented with a borderline personality disorder and there were 14% with other diagnoses; and
- 28 people have visited more than six times – 22 women and 6 men.

A 'typical' client of the Stepping Stone Trust respite service was most likely to be a woman in her 30s or 40s with depression or a bipolar diagnosis referred by a community mental health team. She was most likely to be funded through a planned respite staying 4.5 nights. She was likely to return 2.3 times a year.

Clients' views

Clients, when asked what their reasons for coming to respite were, indicated that they used respite because they:

- needed time out (5 men, 5 women);
- needed to stop stressing out (6 including 2 men);
- needed a rest (4 women, 1 man);
- were getting depressed; were feeling suicidal; or
- were dealing with a death or some grief.

Clients valued planned respite because it offered them a time out from the stressful environments they were in; as one said³, *'It refreshes and helps and I have control over when I use it'*. They also preferred respite care to hospitalisation; as one said, *'I had attempted suicide and got sent there before*

being sent to hospital. Interestingly it was the men living alone who most wanted social time with people.

Clients were asked what would have happened to them in crisis, if they had not had respite care. Their responses are listed in Table 1.

TABLE 1: CLIENTS' PREDICTIONS WHEN NO RESPITE AVAILABLE

Response	No. of responses (n = 15)
Would end up in hospital	5
Would die/commit suicide	4
Would take an overdose	2
Other	4

One client summed it up with, *'I would have ended up in hospital or dead'*. This statement and the fact that clients had such strong comments to make about the value of emergency respite are significant. The depth of perception around preventing major harm shows very clearly that crisis respite is extremely valuable to clients. Clients were also clear that respite was helpful in preventing a crisis or admission to hospital.

Clients were asked what advantages or benefits respite care had for them over a hospital admission. Some comments are listed in Table 2.

TABLE 2: CLIENTS' PERCEPTIONS OF ADVANTAGES/BENEFITS OF RESPITE CARE OVER HOSPITALISATION

- *'I feel like I've failed in hospital – but not in respite.'*
- *'I hate hospital and prefer Stepping Stone ... I am a person and I'm important ... In hospital I'm a shift ... and I might not be as sick as others but I am still treated the same.'*
- *'I am still part of the world at Stepping Stone, whereas in hospital you are definitely in a mental hospital.'*

The responding clients obviously valued Stepping Stone respite service and the individual care and respect from staff.

Fourteen clients, or almost half of the interviewees had stayed at other respite places in Christchurch. Three respondents replied with, *'Stepping Stone knows me better now'* and *'I interact more'* and *'I feel welcome and looked after'*.

Client satisfaction/feedback survey results for 2000

All respite clients are asked to fill out a satisfaction feedback form at the end of each stay. In 2000 a total of 137 clients filled out the questionnaires; a response rate of around 40%. The three key questions on the survey were:

- things the client has enjoyed most;
- any problems during their respite experience; and
- any suggestions for improvements.

Clients made a total of 146 comments about things they enjoyed, or more than one positive comment per client filling out the questionnaire. The clients enjoyed the staff (n = 40), the place (n = 40), the food (n = 22), the company of others (n = 19) and the rest and relaxation (n = 16). Clients reported that staff were (in order): caring, supportive, very approachable/helpful, available, and have time to listen and talk. Clients enjoyed the environment especially the peace, quiet, lack of stress, the socialising on the verandah, the meal times, the smoking and drinking of coffee.

There were a total of 29 problems listed in the 137 feedback forms, which means that 108 people or 79% of respondents had reported no problems at all. The key problem areas for the 21% were other clients, the household, the staff and other. The nine problems with other clients related to: snoring, people being hard to live with, noisiness, loud talking in the morning, and so on.

The total number of suggestions for improvements for the year 2000 was 59. The comments were mostly cosmetic and related to the running of the household, the kitchen and meal portions, the bedrooms and bathrooms, the need for more gardening and colour in the garden, and new fences.

Referral agents' views

The referral agents value the supportive environment that the skilled staff creates. They rate highly the staff's ability to monitor mental state, manage risk and provide a safe environment for all. Referral agents value the professionalism, the staff's mental health knowledge base and their therapeutic skills and crisis interventions.

A key question of this research was exploring if respite care made any difference when the clients return home. The referral agents' views on the differences or benefits for clients are listed in Table 3.

According to referral agents, clients residing in respite have an experience of safety and an opportunity to experience a calm environment at a time of major turmoil. One referral agent argued that respite offered clients *'greater self resilience especially using planned respite because the client feels in control and that is empowerment working'*.

The social aspects of respite such as the clients' having someone to talk to rated highly, as did clients' having a fresh or neutral look at their lives. One person mentioned there were *'staff who are objective with problem solving at a semi crisis time'*. Further, clients do not have the stigma of being in the acute in-patient hospital and they received more individual attention.

Four referral agents talked about how some clients wanted to develop the revolving door and dependency on respite, particularly those with

Borderline Personality Disorder and those living alone.

Interestingly the Stepping Stone respite service is known by these mental health professionals as a place that ‘accepts clients for themselves and not as patients’, a view that matched that of the clients themselves.

Staff views

At the time of the research there were five nurses and six social workers working either full- or part-time at the respite service. They were asked what the clients’ needs were when they came to their respite service. The most common answer was that they needed time out, a safe place, rest and relaxation, therapeutic support and company. These sentiments echo comments from referral agents and clients themselves. The staff also commented that clients need ‘a place where their physical, emotional, social, mental and spiritual needs can be met’.

The staff pointed out that the planned respite is very effective in preventing a crisis or admission to hospital because it:

- offers change, support, and time out at critical times;
- offers a break for family/caregivers and company for those who live alone;
- gives clients time out and enables them to focus on future activities and goals they may want to do;
- offers a halfway house between home and hospital where clients may not meet the criteria for hospital admission, yet cannot abide home at that time.

Crisis prevention work with clients is done in ‘partnership with clients ... to ensure safety in their vulnerability’. Staff reported that they are more intentional in their interactions, noting signs of distress and changes in mood or behaviour and intervening when needed. Staff believe listening to clients and anticipating any changes adds to effective prevention of escalating crisis.

In brief, staff enjoyed working with the clients the most and the administration work the least as it takes their time away from the clients. They enjoy working from an empowerment framework where clients set their own agenda to meet specific needs and they are able to practise holistically, incorporating hospitality.

Echoing the clients’ feedback on the theme of knowing that respite is available, one staff member said, ‘It gives clients the peace of mind knowing that there is a good option rather than just a hospital one’ and ‘clients know that in their hard times people do care and want to help them’. Another

TABLE 3: REFERRAL AGENTS’ VIEWS ON DIFFERENCES/BENEFITS FOR CLIENTS

Response (§)	No. of responses (#)
Knowledge that they can go back again if needed	9
Chance to take stock, problem solve and plan	8
Emergence of strength to carry on	4
Fewer hospital admissions and less resulting trauma	4
Feeling in control of the process	4
Opportunity to feel refreshed and more able to cope	4
Improved social skills and networks	3
Greater self-esteem	3

(§) Responses self-initiated (#) Multiple responses allowed

staff member said clients get ‘an organisation that treats them as guests, that provides an environment of nurturing growth, good food and good staff’.

Audit of client in-patient admissions

Of the 62 clients whose hospital admissions were tracked, 39 had had no acute admissions at all in either 1999 or 2000. The other 23 clients had acute hospitalisation in addition to accessing the respite service during 1999 and 2000. Seven of the 23 clients had spent periods of more than two months in acute in-patient care with the longest period of care required by a client being 215 days. This level of need is far more than the respite service can meet. The longest ever stay at the respite service has been 38 days.

With the data for any client with an episode of continuous in-patient care lasting over two months excluded from the data for the year in which that in-patient care occurred (thereby ensuring comparability of the in-patient and respite services), the figures for acute in-patient care for 1999 and 2000 are 23 clients requiring 349 days and 23 clients requiring 283 days respectively; a potential saving of 66 days in hospital admissions in the second year.

Acute hospital admissions for people with mental health problems can occur for a variety of severe problems and needs at any given time. It is therefore difficult to accurately explain differences in acute hospital admissions for any one client from one year to the next. Therefore, caution must be used in ascribing a causal relationship between the provision of respite care and the reduction in the demand for in-patient services, or funding mental health respite services based on subsequent savings to acute in-patient admissions. However, the preliminary evidence is consistent with the hypothesis that that hospital admission rates do increase if 24-hour supervised respite care is not available when ‘support at home’ is not sufficient.

Tracking of emergency client referrals turned away

Since the Stepping Stone Trust short-term respite care service opened in January 1999, clients in crisis have required 782 of the total bed nights (24%). However, there have been occasions when there have been no beds available and clients have had to be referred elsewhere or to hospital. As part of this evaluation respite staff were asked in November 2000 to keep a log of all emergency client referrals 'turned away'.

During this month, eight emergency clients were admitted to the service and eight emergency clients were 'turned away'. Interestingly, even though weekends were most often the busiest times, seven out of eight were turned away on a Tuesday or a Wednesday.

The eight clients turned away had not been referred to Stepping Stone respite service previously and, despite repeated attempts to track these clients to determine where they went, in only two cases was follow-up achieved. One had spent the next night in a different respite facility before being transferred to yet another facility for a further 5 days; and one had been admitted, informally, to in-patient hospital care.

Conclusions

This evaluation was conducted to assess the effectiveness of the Stepping Stone Trust respite service. In addition to obtaining quantitative data on the clients and the services provided (including hospital admissions data), surveys were used to obtain contemporaneous qualitative data from three stakeholder groups, clients, referral agents, and staff.

The data gathered in this study suggest that three key stakeholder groups, clients, referral agents and staff, perceive the Stepping Stone Trust respite service positively, and as providing quality, necessary care.

- The clients appreciate the environment, the food, the company, the rest and relaxation opportunities provided, and the support from staff. Clients think staff are caring, supportive, very approachable and helpful, available and have time to listen and talk.
- Referral agents consider the service to be the preferred provider for clients with mental illness requiring short-term respite care in Christchurch and that it offers *'respite with treatment'*. The referral agents consider the professional trained staff as the key asset to the successful outcomes for clients of the service.
- Staff, working holistically in an environment where clients can set their own agenda, reported that they can see signs of distress and changes in mood or behaviour at an early stage and can intervene when needed to prevent escalating crises.

- The data did not show conclusively that respite stays decrease in-patient stays overall because other factors influence outcomes. However, the data are consistent with the proposition that if respite care was not available, then hospital admission rates would increase.

Which were the most useful components of the evaluation?

The more 'useful' individual components of the multiple approach evaluation proved to be:

- the client database which profiled clearly the most typical respite clients and type of respite and referral teams. This information will prove very useful for targeted activity in the future;
- the survey of the respite clients themselves; the 'soft' data provided by this survey was invaluable for establishing, for the other stakeholders, how important respite was as an option for clients;
- the interviews with referral agents who do not refer to the service, to actively seek negative opinion;
- staff views, which offered congruence of opinion and a perspective not generally sought in this type of evaluation; and
- the comparison of opinion and data on the use of the respite service with 'hard' data from the hospital admissions audit provided a possible indication of a linkage between respite care and reductions in hospital admissions and the cost savings that might result.

The less 'useful' components of the multiple approach evaluation proved to be:

- the client satisfaction surveys; much of the data from these related to cosmetic and domestic concerns and did not provide substantial data for analysis;
- the attempts to track clients whom the service could not accommodate; the inability to track most of these clients was frustrating and disappointing.

This evaluation established the value of conducting contemporaneous interviews of groups of stakeholders (as distinct from satisfaction surveys), and the importance of linking these to related 'hard' data. There are indications, in the differences in the responses of individual stakeholder groups, that had we relied solely on the 'soft' data gathered from surveying the three stakeholder groups, particularly if we had concentrated on just staff or clients, the evaluation may have led to a different, or distorted appreciation of the value of the respite service. In turn, the directions or decisions resulting from this perhaps 'biased' evaluation may have been inappropriate. This research clearly established both the necessity for a full (that is, all three key

stakeholders) evaluation and avoided the risk that a partial evaluation could mislead or, indeed, lead to less than accurate conclusions.

What has happened as a result of the research?

The most useful outcome for the respite service has been its increased confidence in the value of the work it does. In addition, the database developed during the research continues to highlight trends and patterns in service usage. The database also identified the groups who seem to be under-represented in respite, for example men and people with schizophrenia.

Staff were particularly interested in the feedback from clients and referral agents, while the Board and management were most interested in the audit of hospital admissions data. Clients were most interested in the comments from other clients and the fact that two-thirds of the service was used by women. Many wondered what was happening to the men and why they did not come into the service.

The 'hard data' and perspectives from the three key stakeholder groups clearly answered the questions posed at the beginning of the study. The answer to the unasked question was one of the most useful and richest in the whole evaluation.

Where to from here?

Since the evaluation was completed, the respite service has doubled in size. The Trust is now operating two respite facilities, one with six emergency beds at the weekends and a second service offering nine beds for planned, emergency and carer support respite every day of the week. The increased capacity for emergency beds has been a welcomed development. Interestingly with the new service developments a lot of new service users have also emerged, highlighting the increasing need and usefulness of respite services.

There remains a lot of work to be done in the area of using respite services to their fullest economic and social benefit (Shantz 1995). However, it is important to take note that other factors may influence the respite benefits, such as severity of illness, medication, other outpatient treatment when looking at outcomes of respite care.

Finally, it is important to remember, too, that services need to maximise change arising as a consequence of evaluation and research (Vuori 1991). The Stepping Stone Trust management requested a list of any suggestions for improvements from all sources in this evaluation to work on. This was a healthy response to feedback from their stakeholders. The Stepping Stone Trust continues to be committed to ongoing improvement within their respite service delivery.

Notes

- 1 The Editors acknowledge the technical assistance of Dr Herbert Stock, of the Flinders Institute of Public Policy and Management, in the finalisation of this paper.
- 2 For this research 20 women and 10 men were interviewed. In total 56 people were contacted (up to three times each) which yielded us a 70% response rate from women and a 40% response rate from the men.
- 3 In order to clearly identify participants' comments, such quotations have been italicised.

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