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REVIEW OF RAINBOW PLACE  
CHILDREN AND YOUNG  
PEOPLE'S SERVICE,  
HOSPICE WAIKATO



November 2011



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# INTRODUCTION

I was asked by Hospice Waikato to assess the current ‘state’ of Rainbow Place now that it is established within its new premises, to determine how its services are perceived and experienced by the families and children that it serves, to explore how it is understood by a range of key staff, services and stakeholders, to consider how best it might develop its services in response to clear community needs and to make recommendations that would strengthen and enhance its functioning and services.


Hospice Waikato and Rainbow Place took an open, reflective and unfailingly honest approach to this evaluation. From the outset it was made clear that what was wanted was not a piece of “PR fluff” but an honest assessment.

It is a hallmark of a credible, responsive and trustworthy health service provider that it not only tolerates but actively seeks out such external scrutiny and critical assessment. Hospice Waikato and Rainbow Place are already regularly accredited, benchmarked and externally assessed by The Ministry of Health, the DDA group, Health and Disability Standards, HealthShare and QPS. They have now undergone this external, independent evaluation. The people of Waikato Region and the DHB can have real confidence that this is a service worthy of their continuing support.

I am extremely grateful to the many people who supported and enabled this review. Hospice Waikato and Rainbow Place were unstintingly helpful and supportive and engaged with the review in a real spirit of excitement about the future as opposed to institutional defensiveness. I am grateful to the families, whānau, children, volunteers and numerous stakeholders who helped by responding to our survey and/or sharing their ideas and experiences in interviews and conversation. People were candid and honest in their views and generous with their comments, ideas and suggestions.

Hospice Waikato’s Kaumātua, Koroneihana Cooper could not have been more gracious, generous and supportive of the review and was always available to any Maori participants who may have sought his help.

Our partner in this review, Waikato Institute of Technology and the School of Health & Social Practice, exemplified the best of how higher education can work with service providers in furthering meaningful, collaborative research, evaluation and service improvement. Helen Nielsen and Ros Sanders provided tangible and invaluable support for the project throughout its various stages. WINTEC’s ethics approval process was a model of rigour, collegiality and efficiency their Research Office made sure that the process of transcribing the many interviews was speedy and accurate.



I make my observations and recommendations to help Rainbow Place ‘raise the bar’ in the fulfillment of its considerable promise. I have no doubt that both Rainbow Place and Hospice Waikato have the capacity and drive to rise to such a challenge. Rainbow Place and its staff can thrive in a culture where clear expectations of creative, enthusiastic, non-bureaucratic, quality service provision are the norm and where Hospice Waikato, as the ‘parent organisation’, provides the requisite expectations, encouragement, enabling structures, support and autonomy.

Florence Nightingale famously remarked that: “*Reports are not self-executive*”. Hospice Waikato and Rainbow Place will now consider this report and formulate their responses. They should initiate debate and discussion but also insist on action.

I wish Rainbow Place and its future initiatives every success.

Professor Philip Darbyshire, Adelaide, November 2011



# EXECUTIVE SUMMARY

Health care organisations the world over are becoming more aware of the need to review and evaluate their services. It is no longer acceptable to create services and somehow 'hope' that people will find them valuable. Hospice Waikato and Rainbow Place initiated this review of Rainbow Place and its services in 2011 because they wished to discover how Rainbow Place was understood, viewed and experienced by the people most closely involved: the children and young people, the parents and families/whānau, its staff and its external colleagues and stakeholders and to use these insights as an informed basis for future developments.


The key review aims were to assess the development of Rainbow Place to date, to assess how well it is working and to suggest how it can best evolve in the future to meet the needs of the Waikato community.

The review was undertaken between March and August 2011 by Professor Philip Darbyshire in collaboration with colleagues from WINTEC and with the support of Waikato DHB. Information was collected from children, parents, families/whānau, staff, volunteers and stakeholders through a range of individual and group interviews and informal discussion. Parents and families/whānau, children and young people, staff, stakeholders and volunteers also completed their own specific online survey.

## Key Findings

### Parents and families/whānau

- (1) Parents and families/whānau who had used Rainbow Place were overwhelmingly positive and appreciative. In all of the parent and families/whānau interviews, surveys and conversations there was not one related example of what might be considered to be 'poor care'.
- (2) Parents and families/whānau found Rainbow Place to be caring, welcoming, flexible, safe, responsive and non-judgmental. They also valued the specific children's nursing, health and counselling skills and expertise that were available.
- (3) Where families/whānau had any 'criticisms' of Rainbow Place this was often related to availability of additional services they would have appreciated or to design or emphasis features of the facility.

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- (4) Some parents felt that Rainbow Place could have more activities and facilities for younger children but the most frequent comment and request was for more 'teen-friendly' environmental features, resources and activities. Echoing teenagers consulted in the review, parents generally felt that Rainbow Place's facilities were more aimed at younger children and that there should be more of a focus on what teenagers and young people would want to see at Rainbow Place.

## Children and young people

- (5) Consulting children and young people about their views and experiences of service provision is a clear obligation for any organisation that claims to have children's well-being at its heart. To overlook or ignore children's voices is untenable.
- (6) The children and young people who took part in this review were both willing and able to describe what they valued and liked about Rainbow Place and to suggest where improvements could be made.
- (7) For a large majority of the children, Rainbow Place was 'better than they thought it would be'. They appreciated the various activities that were offered such as art work, the 'teen group meetings' and of course, the various parties and social events. 'Fun' was a word that the children used repeatedly to describe Rainbow Place and it is a credit to Rainbow Place that they appreciate the importance of fun in children's lives and manage to create such opportunities.
- (8) The children also understood that Rainbow Place had a serious purpose in helping them with difficult and challenging issues in their lives. Once again, they were very positive about the various counselling activities and 'talking approaches' that were available. Perhaps the ultimate compliment came from the child who commented that 'at Rainbow Place you're having counselling but you don't know you're having it'.
- (9) Children and young people were also asked how Rainbow Place could improve its services and their suggestions mirrored those of parents. The main criticisms were that Rainbow Place looked too 'childish' and did not appeal to teenagers or older children. The other 'visual suggestions' made were that it would be good to include some Maori or Pacific artwork or design features within Rainbow Place.
- (10) The young people's other main requests were to have more 'teen stuff' available, the equipment that young people love using such as Play Stations, Wii, X-Boxes, i-pads, laptops, wireless internet, better DVDs, a selection of good teen magazines and some interesting 'outdoor spaces' such as an exciting 'play area'.



## Referral criteria


- (11) There was considerable confusion and uncertainty around Rainbow Place's referral criteria. The fundamental questions of 'What does Rainbow Place do?' 'Which children and families/whānau does it help?' 'Who can access the service (and who cannot)?' were not clearly answered in the minds of some staff and families and for the majority of health colleagues and external stakeholders. If unresolved, this will be a major impediment to the development of Rainbow Place.
- (12) Considerable confusion was expressed by stakeholders regarding the similarities and differences between Rainbow Place and True Colours. This was often framed as a 'Who do we refer to?' dilemma for health professionals.
- (13) However, when actually referring to Rainbow Place, stakeholders found the process and experience to be very positive and 'easy', with Rainbow Place staff being approachable, non-bureaucratic, available and willing to help.
- (14) Where referrals to Rainbow Place had 'not worked', reasons given by stakeholders tended to be because of Rainbow Place's 'criteria' or because the request was somehow 'out of hours'.

## Usage patterns of Rainbow Place

- (15) 'How well used is Rainbow Place?' was a recurring question in many participants' interviews and survey responses. Many respondents considered Rainbow Place to be too 'quiet' and underused.
- (16) There is a paradox evident that while Rainbow Place has accommodation and facilities, it is not primarily an 'inpatient unit'. Much of its focus and work is in the community and in families/whānau homes and thus less 'visible'. Nonetheless, my overall assessment is that Rainbow Place and its facilities could be more widely and valuably used in ways that would enhance rather than detract from its community and family/whānau focus.
- (17) The respite or 'sleepover' service was an example of where an excellent and much sought after provision was felt to be underused. This particular aspect of Rainbow Place's services has considerable potential and in my view, the issue is not, 'should this service be expanded' but how and how quickly this should be done.

## Rainbow Place's position within Hospice Waikato

- (20) Rainbow Place occupies a fairly unique position within the world of children's palliative care and bereavement services. Few, if any such services worldwide are co-located and managed within the 'campus' of a wider adult hospice facility. For some respondents this was a distinct advantage while for others




the mere proximity of a children's service close to an 'adult facility' seemed anathema.

- (21) The advantages identified included the ability to share services, the ease and availability of support for the children of adult hospice patients and the potential for good transition arrangements when required for 'older' young people and young adults.
- (22) A recurring issue and concern was with the very term 'Hospice' and its connotations, especially in the public mind. Many respondents felt that this 'negative association' would be discouraging for families and children who may otherwise benefit from Rainbow Place's range of services and expertise.
- (23) Rainbow Place and Hospice Waikato could, if they wished, simply accept that words such as 'hospice' or 'palliative' will never be accepted by the community and avoid their use in favour of euphemism. The alternative is to take seriously their educational mandate and to consistently challenge the negative stereotypes by showing, telling and demonstrating to the community the positive, supportive, helpful, caring and life-enhancing work that the words 'hospice' and 'palliative' involve.
- (24) As a relatively recently 'merged' organisation it was perhaps unsurprising that a sense of 'them and us' between Rainbow Place and the Adult Hospice surfaced in several interviews and survey responses. There is a subtle balance to be achieved within Hospice Waikato between the need for a distinctive, tailored children's service within a wider organisation where adult and children's services share a common vision, aim and sense of purpose.

## **Rainbow Place: Awareness, Profile and 'Getting out there'**

- (25) Of all of the issues identified by respondents in this review, this was the most frequently raised by both staff, families/whānau and external stakeholders. In a nutshell, Rainbow Place currently seems to be the 'best kept secret' in Waikato children's and health services. People spoke of its 'low profile', that they had not heard of it until this review, that they vaguely knew about, that other organisations had much higher visibility and presence in care settings and more.
- (26) There is little point in creating and delivering an excellent service that no-one knows about. This is a marketing issue and therein may lie some of the problem, as health services and clinicians traditionally do not consider 'marketing' to be high on their list of priorities. Rainbow Place cannot afford to make this mistake.
- (27) Rainbow Place has a professional, moral, educational, organisational and public service responsibility to bring its range of services and expertise to the attention of colleagues, families, children and young people and the wider Waikato community. This is not an option or some kind of 'bells and whistles'



luxury. It must be an essential element of Rainbow Place's service and 'core business'.

## The Potential of Rainbow Place

- (28) Rainbow Place has considerable potential and scope for developing its services, bringing its expertise to support a wider range of children and families/whānau and becoming one of New Zealand's leading centres of its kind. Numerous suggestions were received throughout the review as to ways in which this could be done, both internally within Hospice Waikato and externally throughout the Waikato region.
- (29) One significant 'gap' in Rainbow Place's service provision was mentioned above all others and by almost every group who took part in the review. This was where Rainbow Place's criteria precluded children receiving grief and bereavement support if their parent, sibling or loved one died from accidental or traumatic causes. This led to a situation where children whose parent had died from a 'medical condition' or whose parent was currently a patient in the adult hospice could receive help and support but another child whose parent or sibling had been killed in a car accident or who had committed suicide could not receive help at Rainbow Place.
- (30) Not one person during the review believed that this situation was justifiable or acceptable and for those involved in providing bereavement support it was a source of extreme frustration and disquiet.


## Conclusion


- (31) Hospice Waikato and Rainbow Place should be immensely proud of the facilities that they have created and the services that they provide. It is quite remarkable in a review of a health service to receive almost entirely and exclusively positive and appreciative comments and accounts from those who use the service.
- (32) The challenges that Rainbow Place faces in the future thus relate to how it can grow and develop the quality services and special expertise that it has in order to further help and benefit the families/whānau of the Waikato region. It is time for Rainbow Place to move from being a cosy 'cottage industry' to becoming the recognised service of choice and a national leader in its field.



## Recommendations A-Z

- A. Rainbow Place is doing a great deal that is 'right'. It now needs to find ways to identify, share, publicise and celebrate these aspects of the service which make it so valued and appreciated.
- B. Hospice Waikato must enable the support, autonomy and leadership development required for the staff of Rainbow Place to take its services to the important 'next levels' identified.
- C. Rainbow Place should explore ways to extend and expand services at either end of the age spectrum both for younger, pre-school and early primary children but most importantly, for the older teenage and young adult group.
- D. Institute systems whereby families/whānau and children and young people are given a more active 'voice' in the governance of Rainbow Place. This will ensure that their experiences, perspectives, ideas and involvement are 'hardwired' into the culture and everyday 'running' of Rainbow Place.
- E. Consider ways in which the design and 'look' of Rainbow Place can be made more appealing to teenagers and to Maori/Pacific young people. Use this as an opportunity to actively involve children and young people in creating these design modifications.
- F. Invest in more 'teenage' equipment and resources, again with advice and input from young people themselves.
- G. Rainbow Place's future approach to developing its services is too important to leave to an ad hoc approach. It must formulate a clearly thought out 'marketing, publicity and information' strategy.
- H. Rainbow Place's 'admission' and service criteria are currently unclear and confusing. They must be clarified and publicised so that families/whānau, colleagues and external stakeholders are in no doubt as to 'What Rainbow Place does and for whom'.
- I. A key feature of Rainbow Place's marketing, information sharing and general 'getting out here' should be a newly designed and dedicated 'Rainbow Place website'. This should be paired with free broadband wireless internet access within Rainbow Place. Following the requisite staff training, this website should be maintained and controlled by Rainbow Place staff with ongoing technical advice from the respective web design company.
- J. Rainbow Place should develop a social media policy and strategy that will engage, involve (and protect) its staff, families, children and young people.
- K. There should be no notion of in or out of hours at Rainbow Place. Support and help should be available for families/whānau who require this at any time of day or night. This is a challenge but also an opportunity to explore more creative and collaborative ways of working with existing services and other key areas.

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- L. Rainbow Place must make better and wider use of its excellent facilities and collective expertise. It is 'under-used' at present. Expanding its services is not 'being flooded', it is growing and thriving.
  - M. The respite or 'sleepover' facilities are excellent and there is little doubt that these facilities would be more widely used if they were 'opened up' to a new range of uses that would still fall within the remit, purpose and expertise of Rainbow Place. This should be a priority area in any future development considerations.
  - N. Consider some of the ideas suggested by participants in this report, such as using the rooms for neonatal transition care, increasing flexibility of use within the wider Hospice Waikato, allowing greater use by teenagers/older children and helping rural or other families who require to attend multiple hospital appointments.
  - O. Staffing issues are crucial here. Rainbow Place and Hospice Waikato should explore the possibilities of 'shared staffing' and mutually beneficial partnerships with the DHB and the region's Paediatric Services.
  - P. Rainbow Place must develop strategies and approaches not only to 'getting out there' but to bringing colleagues, stakeholders, young people and families/whānau and the wider community 'into' Rainbow Place.
  - Q. Investigate the possibility of offering 'room space' at Rainbow Place where paediatricians and other health colleagues could hold regular clinics for the client groups who use or may use Rainbow Place's services. Such a community clinic could have significant advantages for all concerned.
  - R. The co-location of Rainbow Place and the adult hospice will always be controversial for some. I see no sound reason why Rainbow Place should consider 'breaking away' from the wider Hospice Waikato organisation.
  - S. Hospice Waikato and Rainbow Place must maximise the synergies and benefits afforded by their proximity for the benefit of all clients and families/whānau who use the service.
  - T. A unique opportunity exists for Hospice Waikato, Rainbow Place and their health service colleagues to create excellent transition systems and arrangements for young adults. Now would be the ideal time to initiate such planning discussions.
  - U. Hospice Waikato and Rainbow Place must continue their public awareness and education role in improving community knowledge and understanding of the concepts of 'hospice', 'palliative care' and 'grief and bereavements support'. They are ideally placed to undertake this work.
  - V. Relationships between the 'adult' hospice and Rainbow Place are not as close and cordial as they should be and in some quarters a sense of 'them and us' is apparent. The entire organisation must foster and nurture the informal, social, fun and collegial opportunities and events that will enable both 'sides' to build a true community of friends and colleagues.

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- W. Hospice Waikato and Rainbow Place must consider how to expand the grief and bereavement support service to include any child or young person who requires this service, regardless of the circumstances of their loved one's illness or death.
  - X. Discussions with the DHB about how best to fund, sustain and evaluate such an expansion should also take place.
  - Y. Rainbow Place and Hospice Waikato should begin discussions with WINTEC School of Health & Social Practice regarding mutually valuable collaborations and partnerships, especially within their Counselling and Nursing programmes.
  - Z. Rainbow Place must seek to become a genuine 'Centre of Excellence' in its field and to have this national reputation extend internationally. The people mentioned on the following page deserve nothing less. This is Rainbow Place's 'social return on investment' that will repay the faith, support and efforts of the Waikato community.



# 1. REVIEWING RAINBOW PLACE

## People. First and Always.

This review is about people. It describes evaluation approaches, it reports participants' comments, views, attitudes and experiences, it discusses current evidence, opinion and research and suggests strategies, changes and recommendations. It is however, ultimately about people because Rainbow Place is about people, people like these who shared their experiences with us:

It is about the little boy whose kindy friends “keep on telling him he has no dad”.

It is about the parents whose attempts to carefully manage their child's degenerative illness have “turned to custard”.

It is about the little girl “crying in the corner at school” saying “my mummy's dying” to her teacher “who couldn't say anything”.

It is about the girl who found her father dead in the garden having “cut himself” but for whom there was “nothing available”.

It is about the grandmother who is dying but “making sure her mokos are being taken care of”.

It is about the parents who “can't tell our children that their mum is going to die without crying”.

It is about the 3 year old sister who “wants to buy a pink ladder to go and play with her brother in heaven”.

It is about the relative “in his 30's who has tried to kill himself” and who, years later, has “never recovered from the death of his grandmother” who was “the centre of his world”.

It is about the bereaved dad raising his children alone and seeing his daughter helped to change from “something out of The Exorcist” into “a blessed little gift”.


In children's palliative care and bereavement services, we often struggle to acknowledge this emotional heartland of our work. We try, with the best of intentions, to find comforting euphemisms that will cover over the naked horror of serious or life-threatening illness, or 'unfair' and untimely deaths.

Language matters. During this review I promised people a report in plain English. I hope that it is largely free from the jargonistic excesses that blight so much of health care.



## The background and purpose of this review

1. Health & Social Care Services worldwide must be evidence-based and informed, reflective and questioning, relentlessly 'patient-centred' and have a desire for quality that regularly evaluates and assesses how their services and programmes are perceived, understood and experienced by those receiving them.
2. Asking 'How are we doing?' in a systematic way may once have been seen as 'icing on the cake' or a luxury but no longer. This is now as much a part of a modern health organisation's 'core business' as care provision.
3. Hospice Waikato and Rainbow Place sought a 'fresh eyes', external, objective appraisal of their current services to identify possible areas for improvement and future development.
4. The overall aims of this review were to assess the development of Rainbow Place, to consider its current functioning and to suggest ways in which the service should evolve in the future to best meet the needs of the children and families/whānau of the Waikato Region.
5. The specific aims were:
  - I. To determine, from families and staff, if and how well the palliative and therapeutic care needs of families and children affected by life threatening conditions, or children who were receiving grief and bereavement support, were being met.
  - II. To discover any barriers or facilitating factors associated with the provision of high quality palliative and/or supportive and therapeutic care as experienced by both parents and service providers.
  - III. To discover the family/whānau perspective of Rainbow Place. To find out the support, help, information and services that they particularly value and that helps them manage their child's palliative and/or supportive or therapeutic care
  - IV. To hear the voices and experiences of children and young people who use or have used Rainbow Place services and programs
  - V. To inform and drive the development of improved palliative care, therapeutic and bereavement support services for families and young people by providing an evaluative research basis firmly grounded in their experiences and expressed needs.
  - VI. To promote the research benefits of collaboration and cooperation with various other colleagues, sectors and services
  - VII. To explore ways of 'hardwiring' this evaluation/inquiry culture initiative into the service to improve its continuity and sustainability


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6. The review was triggered by Hospice Waikato and Rainbow Place's appreciation that service evaluation is a vital element of service provision.[2-4] A service that focuses all of its efforts on 'getting the work done' and fails to ask vital evaluative questions about if, how, when, where, why and under what circumstances its services are working (or not) is seriously out of balance.
  7. This review was also timely as Rainbow Place is now established in its 'new premises' and was developing its range of services. This was an ideal time to find out from staff, children, stakeholders and families/whānau how well Rainbow Place was 'travelling'.
  8. The review was supported by Hospice Waikato, WINTEC and Waikato DHB.

## The review approach

9. An organisation and its culture share values, symbols, processes, practices and assumptions. Such an organisational culture can encompass several differing 'sub-cultures', for example the culture of Rainbow Place may differ from that of the Adult Hospice and may differ from its culture when it was based in the old Von Tempsky Street premises.
10. The culture of the Rainbow Place may also be revealed in its communicative and social practices. These include the 'facts' that staff, families and stakeholders hold dear, the activities that are cherished or disparaged, the vocabularies, metaphors and stories that are used to 'tell about' Rainbow Place and the rites and rituals that enact the culture.
11. I sought to discover both the 'big picture' and the local nuances of Rainbow Place. This is an organisation that must connect and interact with a wide range of other organisations and professionals, from health and education sectors to NGOs, the media, supporters and sponsors and of course children, families and the wider community.

## Collecting the information

12. The review used an electronic survey and qualitative interviews as the prime modes of data collection. A predominantly qualitative approach was used because this evaluation's research questions were best approached interpretively.[5-9]
13. In March and April 2011 I spent 2 two-week periods in Hamilton, based at Rainbow Place. From here, myself and Ros Sanders from WINTEC undertook the bulk of the data and information collection for the review. Ros Sanders conducted the last four interviews alone in late April.
14. All staff of Hospice Waikato and Rainbow Place, any parents or families/whānau, any children or young people and any stakeholders were able to meet



or speak with me informally at any time during these periods or to contact me by email or phone at any other time.

15. A specifically tailored electronic survey was created for each of the main groups of review participants:
  - I. Staff of Rainbow Place and wider Hospice Waikato
  - II. Rainbow Place's key stakeholders in the region
  - III. Volunteers within Hospice Waikato and Rainbow Place
  - IV. Families/Whānau who use or have used Rainbow Place
  - V. Children and young people who use or have used Rainbow Place
16. Each survey asked between 18 and 27 questions pertinent to each group. Questions were a combination of open and closed questions with opportunities given for open comments, suggestions or views. A total of 83 electronic surveys were completed. 55 by stakeholders, 4 by volunteers, 8 by children and young people, 9 by parents and 7 by staff.
17. A total of 53 formally recorded interviews were conducted with families/whānau, children and young people, volunteers, staff and stakeholders. These were a combination of individual, parents and small group interviews. Interviews were conducted by Ros Sanders and myself and each interview was transcribed for accuracy. Each interview was a conversation where participants were able to tell us their views, experiences, perceptions, understandings and suggestions regarding Rainbow Place.
18. During my periods of 'fieldwork' in March and April I also had numerous informal conversations with staff, parents, children and young people, families/whānau and various 'stakeholders'. I also had full access to any required Hospice Waikato and Rainbow Place documentation. I did not access any patient/client medical records or case notes as part of this review.
19. A note on numbers. By national survey or clinical trial standards these may be considered 'small numbers'. However, judged by local evaluation and qualitative evaluation research standards they are very respectable.



## 2. PARENT AND FAMILY/WHĀNAU PERSPECTIVES

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*“Me and my husband, as soon as we walked in here it’s like this totally different feel, they’re so friendly and the caring side of thing - the impression they give, it’s not just their job, they actually do really care”. (Int. #41)*

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### Valuing parent and family/whānau perspectives

20. Times have changed for the better in evaluation and health service review. It is not so long ago that this was a ‘professionals-only’ activity that excluded patients, clients, parents and families on the basis that they lacked the knowledge and understanding to make a meaningful contribution.
21. In a similar vein, service users’ accounts of their experiences were once dismissed as mere ‘anecdotes’. While user experiences are not the only form of information and feedback that health service providers require, attention to what is generally termed ‘patient experience’ is now an indispensable element of any serious quality and improvement strategy.
22. Within palliative care and bereavement support, obtaining parent, family and latterly children’s perspectives has traditionally been ‘difficult’ due to concerns around ‘vulnerability’, potential harm, gatekeeping and possible ethical dilemmas [10-12]. More recently however, the benefits of involving parents, children families/whānau in research, evaluation and quality initiatives are now widely accepted in a growing body of research [13-19].
23. In this review we interviewed 15 parents and 9 parents completed the online survey. For the interviews, families/whānau were invited to take part whose child is currently receiving care at Rainbow Place or whose child had died since January 1<sup>st</sup> 2004 and who had previously used the services of Rainbow Place.



## Families'/Whānau's positive experiences of Rainbow Place


24. Respondents' comments and experiences were overwhelmingly positive and appreciative, not only of the services available but of Rainbow Place's flexibility, availability, caring, sensitivity, skill and thoughtfulness. Comments such as these were typical:

*"It's fantastic. It's great for what they're offering and they have helped us tremendously and things. It was really great. And they're not intrusive on us or anything". Int. #32*

*"Straight away me and (X) knew that was the right place for us at the time, for me and the kids and the family". Int. #45*

### Rainbow Place as welcoming and caring

25. At a time in a family's life when someone as loved and precious as their child, or as central to a child's life as their mum or dad, is threatened with serious illness and the possibility of a premature death, welcoming and caring take on an importance within a health service that cannot be underestimated. These are not some trivial, 'touchy-feely' qualities that play second fiddle to other more hard-edged or easily measured 'skills'. When parents or children mention how good it is to be "pleasantly greeted at reception" by "staff who are friendly" and that, "Staff always stop and say hello, use our names, ask how **we** are (and not just mum/dad!!)", they are acknowledging a quality of service that large corporations spend millions of dollars trying to achieve.
26. The principle of creating "a homely and welcoming environment where children and young people with life-limiting or life-threatening conditions and their families feel nurtured and rested" [20] (p.3) is a central aim of a children's palliative care service, regardless of whether the service is 'stand-alone' or home-based service.
27. 'Welcoming' is a vital feature of a physical environment but also a much valued human skill and attribute. When these combine, as they did in Rainbow Place, a genuinely welcoming culture and climate are created where parents and families/whānau feel comfortable, capable and cared for. Parents spoke of how 'relaxed' and 'comfortable' they felt with the 'personalised' service they received both at Rainbow Place and when meeting or working with Rainbow Place staff 'on site' or in their homes.
28. Families/whānau appreciated the sense of 'safety' that was part of Rainbow Place's culture of 'welcoming'. When parents spoke of Rainbow Place being a 'safe place' they often meant this specifically in relation to their child's physical safety. The children's nursing expertise available at Rainbow Place was especially highly valued here. Parents could rely on and were reassured that their child would receive knowledgeable and attentive care from experienced



children's nurses. This was especially valued in the respite/sleepover services offered. As this mum commented:

*“The thing that just ticked all our boxes again for Rainbow Place was there was going to be a nurse on duty all night. And you can't have children with (child's name) needs without that. They're so volatile and they can just hit with a 40 degree temperature within an hour. Seizures can just completely take over.” Int. #34*


29. Parents, families/whānau and children also described the other important dimensions of safety and feeling safe at Rainbow Place. Participants explained how Rainbow Place was a 'safe place' to bring their children to and a 'safe environment' within which they could share, discuss, question and seek help from people who were very much “there for us”. One parent articulated this well when they described Rainbow Place as “A safe place where our family situation is normalised, where we each feel heard and supported”.

## Rainbow Place as flexible and accommodating

30. Flexibility, responsiveness and a 'yes we can' ethos and approach are key quality principles for children's palliative, supportive and bereavement services nationally and internationally [20-23]. Waikato DHB also identifies these in its [Standards for Youth Transition](#). In one staff interview, the importance of flexibility for Rainbow Place was made very clear:

*“The fact that they are going to get decent support wherever they are. If it's too hard at home, there is somewhere to come to rest and recuperate. If they choose that they want their child to die at home, we can transfer the whole service to the home or if they choose to come in, because that's a safe place for them to be in and that's what they like, then the service goes wherever they are. If they live too far away to access our whole service, then we can offer that wraparound with the district nurses and GPs, so for me, it's a flexible, adaptable service that meets the children and families where they are at and that there are options for changing your mind. You're not set in stone”. Int. #8*

31. Families/whānau valued this flexibility in Rainbow Place's approach. They spoke of a service and staff who would 'go that extra mile' for them, who would find ways to say 'yes, we can help here', who were 'there for them' when needed, who would listen to their ideas and suggestions and incorporate them where possible, who would try to fit the service around the families needs rather than vice versa and who achieve this while never seeming to be 'intrusive' or 'pushy'.
32. Specifically, families appreciated that Rainbow Place staff visited them in their homes so that they did not always have to travel to Rainbow Place:



*“The flexibility and convenience of professionals being able to come to us is huge!!”*

33. Families also appreciated a service where flexibility is neither ‘grudged’, nor a drama. It was very clear from the review participants’ accounts and comments that Rainbow Place is meeting this ‘family centred’ imperative. These parents’ stories were typical:


*“I’m so busy and a lot of things change in my day to day...if something comes up they just can change, like an appointment, just like that; it’s no hassle, they’re just nice.” Int. #45*

*“The nurse was just amazing; she was really, just really nice. They keep coming and seeing us and seeing if we were okay and do we need anything, which we didn’t even know what we wanted. Every now and again they’ll just ring and see how we’re going, and so it’s good in that way. Int. #41*

34. All families’ survey responses indicated that they were either very or reasonably happy with the wider ‘health and social system’ that exists to help and support their child. The majority of families also assessed the care and service that they received from Rainbow Place as being equal to or ‘much better than’ other health services that they had experienced and most families/whānau would recommend Rainbow Place to others ‘without hesitation’.

## Where Rainbow Place could improve

35. In both survey and interviews we asked parents and families/whānau about any negative experiences of Rainbow Place. We asked if there were things that it did not do so well and whether there were services that it should be providing that were absent. We also asked about any barriers to receiving services and support.
36. At a time when many health services worldwide are beset with ‘scandals’ and reports of poor care[24, 25], when even the best of facilities still receive occasional complaints and when even Children’s Hospices are implicated[26], it is noteworthy that there were no instances at all, either in surveys or in interviews, where respondents described poor care or treatment of any sort from Rainbow Place. As one family commented, “So far we have no complaints whatsoever. All our family needs are well and truly met 100%”.
37. Rather than having ‘negative experiences’ to relate, the review participants mentioned several areas where they believed that Rainbow Place ‘could do more’. Several services for the children and young people were mentioned. At either end of the age range, some parents asked for help specifically for pre-



school and younger children while others felt that there were not enough programmes that specifically cater for teenagers and ‘older young people’.

38. The need for a clearer and more specifically ‘teenage’ range of services was mentioned by some parents whose teenage children had not responded to the existing services as they felt that they were too ‘childish’. For example:

*“Unfortunately, both our child and his/her siblings resisted attempts to help. Our youngest refused to grieve when (sibling) died and no amount of counselling at Rainbow Place or elsewhere could help. They felt that many of the approaches were childish”.*

39. This sense of Rainbow Place being too obviously a place for young children that may not appeal to teenagers was also echoed by some stakeholders.
40. Other suggestions made by families/whānau in response to the question about what Rainbow Place could do better included:
- I. Clarify for parents that they can sit in on counselling sessions.
  - II. Help parents balance the child’s confidentiality and their own need for feedback with respect to counselling sessions.
  - III. Have alternative approaches to offer teenagers who do not want individual or group counselling.
  - IV. Have more regular groups and activities for teens.
  - V. Have more information or sessions for children to help them understand their parent’s/grandparent’s/sibling’s illness.

41. It is appropriate and important here to mention to the pivotal role and contribution of Rainbow Place’s manger, Penny Parsons. This is because she was mentioned so frequently and so positively by every group of respondents; stakeholders, children, parents, staff and volunteers as being key to Rainbow Place’s ‘ethos’. In many ways Penny is the ‘heart and soul’ of Rainbow Place:

*“We would have been completely lost if it wasn’t for her. It’s hard enough going through it, but going through it absolutely on your own with nobody other than yourself, it’s just unthinkable.” Int.#17*



### 3. DISCOVERING CHILDREN AND YOUNG PEOPLE'S PERSPECTIVES

42. Children and young people are no longer 'seen but not heard' in health and children's services. The views and voices of the young people who use services created in their name cannot be overlooked or dismissed by adults. Health services worldwide are recognising the importance and value of encouraging and enabling children and young people to 'have a say' and services are richer when listening to children and young people is 'hardwired' into the organisation.
43. This review acknowledged the importance of giving children and young people the opportunity to take part and to have their voices heard. Sixteen children and young people took part in interviews and 8 completed the online survey. Those who took part commented that they had enjoyed the experience and one parent noted that:

*"I think it was really awesome that when they did the survey they had a child version of it to try. So they loved that. That was really friendly that they got to sort of be in charge of their own opinions and experiences." Int. #51*


#### What children and young people liked about Rainbow Place.

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*"When someone dies, or has a terminal illness, life feels like it has gone haywire. The best thing is that Rainbow Place provides an anchor when things get tough and just helps the transition of dealing with this unexpected tragedy in our life".  
(Children's Survey Response)*

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44. The children and young people who took part in the survey and interviews were extremely positive in their assessments of Rainbow Place and the support and assistance that it offered. Children became quite animated and excited as they described the 'fun' parts of Rainbow Place; the artwork sessions, the Christmas parties, the movie nights, the chance to meet famous rugby players and sometimes just 'hanging out' with other kids.
45. Perhaps surprisingly, many children also mentioned that they enjoyed the counselling aspects of Rainbow Place, largely because the counselling approach was not what many of them had anticipated or had, perhaps,



experienced elsewhere. This was usually articulated as the counselling being good 'because no-one was forcing you to talk about your feelings all the time'.

46. Children and young people were asked if Rainbow Place was what they thought it would be. For almost all respondents it was much better. They told us that<sup>1</sup>:

- It is good because you can meet other kids.
- It was magnificent we did art I especially liked the food and drinks but my favorite was hanging out with Rainbow Place leaders and one more thing YOU ROCK!!!!
- I think it was much better because it is friendly fun and also helping you prepare for sad moments in life. It is warm welcoming and is very beautiful I love the different rooms and the art room it is awesome
- No-one was forcing you to 'talk about your feelings' unless you wanted to.

47. When asked if Rainbow Place and the staff helped them, the children and young people provided an extensive 'list' of what help and support look like from a child's perspective:


- They tried to give us fun activities to take our minds off our situations
- They helped me control my sadness and emotions
- Support when times are tough
- They gave us time to speak and really listened to what we were saying
- They helped me in the sad times by doing Thursday programs to help get through
- You were always greeted with a smile.
- By making me smile and laugh a whole lot
- Counselling helps because I can express my feelings and getting to know people is good too
- You never felt like they didn't enjoy their jobs they always had a smile when you walked through the door"

48. Children were then asked the converse, if there were things about Rainbow Place that they did not like or that had been unhelpful. A fairly clear theme in these responses related to the 'childlike' environment of Rainbow Place and the desire for more 'teenage' activities and facilities. This may reflect that the survey respondents were aged between 9 and 17. Typical comments here mentioned the 'childish' decor and lack of 'teenage toys' such as computers, X-Boxes, Play-stations etc.

- It did not really look like a teen age room as much as it is a child's playroom.
- I love playing playstation3 and couldn't play there
- There is all little kids toys not many teenage things, that we could do or play with.

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<sup>1</sup> Please note that in this section I have not corrected any of the children's comments or spelling. Their meanings remain very clear.



49. The children and young people did not focus exclusively on toys or ‘gadgets’. Some of the other things that they ‘wished Rainbow Place had or that they would like’ were:

- maybe an inspirational talk about the future? I want to be a surgeon/ doctor and I LOVE school and maths, even if that is a bit nerdy :)
- Um a place where people can play but cant get hurt like a grass feild with bikes and scooters in a bright fence
- A play ground A water fall or water feature
- Maybe have more meetings or something with children your own age.
- young person's group
- Maybe have a bit more time at rainbow place
- Have a phone number we can call without it costing money
- Do more teenage things
- Have more times to talk about whats happening
- Be able to book times to go to Rainbow Place
- Maybe have extra lessons for people that really need rainbow place help


50. During my data collection visit in April, the ‘Teen Group’ came to Rainbow Place for a combined ‘Pizza night’ and group interview/discussion. During the evening, I asked the group to take Ros Sanders and I on a guided ‘tour’ of Rainbow Place. This is an excellent method for enabling young people to ‘take charge’ and to let them ‘show and tell’.

51. Few of the teen group had seen the bedrooms of Rainbow Place and their comments were informative. Generally the rooms were ‘cool’ and they liked the layout of a bed/space for the young person with an adjoining area for a parent or nurse. Some commented again that decoratively, the rooms appeared designed for younger children and were a bit too pink and ‘girly’ for some.

52. They suggested that the rooms could be used for ‘teen sleepovers’ where, for example there might have been an event during the day or movie night evening and the rooms could be used for the young people to sleep over.

53. As we toured the various art and therapy rooms other suggestions were that there needs to be more computers, especially laptops and familiar teen games such as X-box, Playstation, and Wii. Having SKY or cable TV was also high on the teen wishlist as was broadband and wireless internet access. Other suggestions included popular girls’ magazines such as Cream and Girlfriend, some musical instruments and a DJ ‘starter kit’ (perhaps with a view to forming a Rainbow Place band?) and a small pool or spa if space and funds were ever available.

54. Rainbow Place may be a bright and cheerful environment but it has a serious purpose and the children and young people appreciated this. From both survey and interview responses, it was clear the children and young people were very appreciative of the ‘talking’ and counselling that Rainbow Place offers:

- 
- Because i like meeting new peolpe espshliy the leaders and parents i know like aunty (X) aunty (Y) and lots of others.
  - I do enjoy talking to the leaders at first it was scary but now they are nice and friendly to talk to
  - They provide advice from a source who isn't in the family and doesn't feel like they have to say it to make you feel better.
  - They don't judge you, I feel really safe

55. Counselling with children and young people is different. A children's service cannot be based on a set series of 30 minute appointments where the children will come along and oblige by 'talking about their feelings'. This point becomes germane again in the section of the report that deals with the usage and 'busyness' of Rainbow Place. Children who have a life-threatening illness or condition, or children who are facing the death of a sibling or parent require different approaches from a counselling and support service. From the children's perspectives elicited in this review, Rainbow Place is meeting their needs extremely well.
56. What children and young people told us about Rainbow Place and its services is important but perhaps of greater importance is the principle of listening to children and young people, enabling and supporting them to be active members of Rainbow Place and valuing their contributions. It is this aspect of 'involving children and young people' that should be 'hardwired' into the policies, processes and practices at Rainbow Place.



## 4. RAINBOW PLACE'S CRITERIA AND REFERRALS

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*"I think about Rainbow Place, when we do get service from them it's absolutely brilliant. (...) It just would be nice to know what the entry criteria is. Int. #48*

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### Introduction


57. It became very clear early in the review process that there was some confusion and uncertainty around the criteria that Rainbow Place uses for 'accepting' a child or family into their service.

### Confusion between Rainbow Place and True Colours

58. Let me be clear at the outset. This is **not** a review of 'True Colours'. I have neither the mandate, nor the knowledge and information that would entitle me to do this. It is however, almost impossible to explore Rainbow Place and its work without hearing various views regarding both of these organisations. I therefore restrict my mentions of True Colours to reported observations, views or comments from the review participants that pertain directly to Rainbow Place and its work. Given that Waikato has these two organisations offering what many people adjudged to be ostensibly similar services it would have been seriously remiss not to have asked people for their views on this situation.
59. Stakeholders were asked how they viewed having both Rainbow Place and True Colours available as services. Responses and comments ranged across the continuum from 'not a problem at all, it is wonderful that we have both' to 'unnecessary duplication' with many shades of opinion in between.
60. There was a general agreement among respondents that True Colours had a stronger and more consistent presence than Rainbow Place, "the inside running" as one put it, particularly within Waikato Hospital and that it was almost custom and practice to refer new families to True Colors:

*"We're terribly aware that on the ward we have a very high profile from True Colours and a much lower profile from Rainbow Place." Int. #4*

61. Regarding their respective services, respondents often reported being confused and uncertain as to exactly what services were provided by what



organisation and what, if any, unique differences existed between them. One senior health manager called the situation, “A state of utter confusion” and many stakeholders agreed:

*“I think it is very confused. I think a lot of people are confused”.*  
Int. #27

*“I think people get a little bit more confused over, “who can we refer to and which way do we go?”. Int. #36*

*“It’s hard for the health professional, just imagine what’s it’s like for the little people, the young person and their family”. Int. #46*

62. There was no confusion however regarding the esteem that stakeholders had for both organisations. Several respondents commented on how ‘lucky’ the people of Hamilton and Waikato were to have such passionate and dedicated services for children and young people that would “crawl across broken glass” to help their children and families. This respondent’s view was typical:

*“The two overlap somewhat but are complementary and both Team Leaders are exceptionally dedicated, hard working, experienced and professional”.*

## Confusion for parents and families/whānau

63. Most parents and families/whānau who took part in the review were referred to Rainbow Place by either a health professional or another organisation. The greatest confusion facing families seemed to be at around the time of their child’s diagnosis or their early encounters with the health system. This was typically at the point where the child would be in hospital and hospital staff were faced with the dilemma (for it was often a dilemma) of whether to refer the parents to Rainbow Place or to True Colours for ongoing help and support.
64. It was often simply too difficult for busy hospital staff to try to work out the possible differences between the two services and thus the easiest option was to give parents a copy of each organisation’s respective pamphlets and ‘let the parents choose’:

*“I basically just offered both and just say, ‘Hey you make your own mind up’.” Int. #46*

65. Health staff know how the period around a child’s diagnosis or at other times of great stress and anxiety, are particularly bad times for ‘decision making’ about services. One parent described this beautifully as worrying at one point that she may have “got on the wrong bus”:

*“I’d been thinking, ‘Maybe I’m with the wrong place’, you know it’s possible (child) could die but...I’ve got on the wrong bus.” Int. #41*




## Confusion for hospital staff and other stakeholders

66. Most stakeholder survey respondents felt that their understanding of what Rainbow Place offered was generally good. Confusion and uncertainty about Rainbow Place's role and referral criteria were however widespread and apparent in many stakeholder survey responses and interviews. Various stakeholders who have a key role in potentially referring children and families/whānau to Rainbow Place told us, for example, that:
- Rainbow Place would not accept children unless they were going to die within the next 6-12 months
  - Rainbow Place is part of the Waikato Hospital's Palliative Care Nursing Service
  - Rainbow Place "does not cover" children with life-threatening or limiting disorders (such as metabolic disorders) unless these are fatal in the short term
  - Children can only receive grief and bereavement support if their parent is or has been a patient at the adult hospice
  - 'Oncology children' won't be accepted by Rainbow Place / Rainbow Place takes predominantly 'oncology children'
  - Rainbow Place does not 'do palliative care'
67. Such misunderstandings and lack of clarity around referral criteria are issues that Rainbow Place must address, both in relation to its own essential role and to how it communicates with its key stakeholders and partners across all children's and family services within the region.

## Referring a child or family to Rainbow Place

68. More than half of the key stakeholders who completed the survey had referred a child or family to Rainbow Place. Those who would be likely to refer in future would most likely refer for grief and bereavement support for children, support for siblings, palliative care provision and respite care. Most respondents who had referred to Rainbow Place felt that the actual referral process had been positive and successful and stakeholders were similar to parents and families in that their experiences of working with Rainbow Place were almost entirely positive:
- "I think they are a great service and are always available for a chat or referral".
  - "There are limitations because of the range of conditions they are set up to support. Within those limits there are no issues".
  - "I have always had a very positive reception and response whenever I have approached the service".

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69. Reasons given for why some referrals had been unsuccessful included; that the families concerned believed that they did not need such a service, that the children mentioned did not meet the 'criteria' as they had a disability and chronic condition but were not 'palliative' or that Rainbow Place could not respond quickly enough to meet the families' needs at the time. (Such times may have a been a Friday evening or Sunday morning).
70. There may be understandable reasons why a more timely and immediate response could not be made in such 'emergency' situations but this should not be the norm. As one respondent observed, "People are not going to die between 9 and 4 Monday to Friday".
71. These 'out of hours' times are often the darkest and most frightening for children and families/whānau. A modern Paediatric Palliative Care and Bereavement service should offer parents, families and children support and availability on a 24 hour / 7 days per week basis.<sup>2</sup> This is internationally accepted as a standard to attain[21, 34, 35]. It is also highlighted in Waikato DHB's Palliative Care Strategic Plan 2005-2010 where it proposes:
- "the implementation of the 24 hour / 7 day week medical palliative care specialist and specialist palliative care nurses on-call consultancy services" and notes the need for a "management plan for out of hours and when and who to contact when assistance is required." [36]
72. There are clearly financial and logistical challenges in ensuring that Rainbow Place can provide a 24 hour, 7 day paediatric and palliative care and bereavement service for the region but these should not be insurmountable. The development of such a 24 hr service is an opportunity to create new ways of working and collaborating, not only within Rainbow Place's existing staff but for new appointees, for Hospice Waikato's new GP partners and for Rainbow Place's hospital and health service partners.

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<sup>2</sup> <http://www.wales.nhs.uk/documents/Palliative-Care.pdf>

<http://www.nhpco.org/files/public/ChIPPSCallforChange.pdf>

[http://www.nursingcenter.com/library/JournalArticle.asp?Article\\_ID=737897](http://www.nursingcenter.com/library/JournalArticle.asp?Article_ID=737897)



## 5. THE RAINBOW PLACE ENVIRONMENT

### Introduction


73. Rainbow Place and Hospice Waikato are proud of their new building and facility and many would say, 'rightly so'. It has been a wonderful community and fundraising effort and the people of Waikato now have a resource whose current value can be exceeded by its future potential.
74. Rainbow Place has now been opened for approximately two and a half years and this has been very much an 'establishment' and settling in phase. Just as when we move into a new house or home, it takes time to see how the house 'works' and to discover all the adaptations and changes that we need to do to make it work better for us. It also takes time for a new place to lose its 'show house' look and become more 'lived in'.
75. This review is an opportunity for Rainbow Place to consider what adaptations and changes might be needed within its 'new house' so that it can continue to fulfill its mandate and to develop its services for the future.

### Whose 'place' is Rainbow Place?

76. This is a pertinent question and indeed many of the comments and responses that we heard during the review touched on the 'place' of Rainbow Place, both as a physical building and more 'existentially' as a place for children and families. Is Rainbow Place primarily an 'adult' and 'staff' place that occasionally welcomes children and families or is it a children's, young people's and families' place where other adults and staff support, facilitate and enable? How this question is answered can determine how Rainbow Place will consider any future adaptations and changes to its environment.
77. As would be expected, there were a full range of perceptions and views regarding Rainbow Place, from those who believed that the building was a "big white elephant" (Int. #2) to those who thought "This place is fantastic. It just looked unbelievable. It really, really opened our eyes to what they're about". (Int. #34.)

### A personal observation

78. When I visited Rainbow Place in March 2011 as part of this review, this was my first visit to the new premises, having last visited at the old von Tempsky St. Building. The new building is certainly spacious and impressive with excellent spaces and places for various activities. I did sense however that the building looked as if it was a children's place created by adults who 'know what children like'. Children's artwork and designs, even on the walls, seemed overshadowed by those of adults. At times the cuteness and pinkness seemed a little too much and the toys just too neatly arranged. I wondered




how an average 14 year old 'goth' or 'emo' kid might feel walking through the door.

79. Where Rainbow Place excels, and this is in no small measure due to the quality of the staff, is in being a warm, caring and welcoming place for children and families - a welcoming that extends to colleagues and other visitors. This may seem obvious or even banal. How could a service for children with serious or life-threatening illness be otherwise? There is however, a skilled and subtle balance to be achieved here lest the service slip into a tyranny of 'niceness' that perhaps unconsciously tries too hard to compensate for the unspeakable pain at the heart of such a service - that one's child may die. Many years ago, Peter Speck called this phenomenon in the hospice world, "nice people who are caring for nice dying people who are going to have a nice death in a nice place".[45]
80. What Rainbow Place must guard against is the possibility of losing its small, informal, 'family' feel as it grows and develops. Concerns have been raised within adult palliative care that services are becoming more bureaucratic and 'policy and procedure' driven as they try to emulate and blend with existing health services[46-48]. What Rainbow Place does not need is to become the 'Department of Children's Whatever' within a large hospital or health organisation.

## Improving Rainbow Place's physical environment

81. Most survey and interview respondents were positive in their comments about the new Rainbow Place building but we pressed people to consider aspects of the design and 'look' of Rainbow Place that could be improved. Most comments and suggestions can be grouped under 4 main themes or headings:
  - The 'childlike' feel of the building
  - The need for more specifically teenage/adolescent 'spaces'
  - Creating more 'outdoor' features, such as a swing-park
  - The need to incorporate more Maori and Pacific design elements
82. There were several observations that Rainbow Place was very 'childlike', 'girlie' or even "for babies" in its overall look. This connects to earlier comments and suggestions that Rainbow Place needs a space or area that is more specifically and purposefully teen-friendly if it is to appeal to what is often a very difficult group to attract to a service.
83. This is not an 'either-or' dilemma for Rainbow Place as, with some imagination and planning, it would be possible to create such adolescent-friendly areas without making the facility unwelcoming to younger children. I am also aware from my discussions at Rainbow Place that such adaptations and initiatives are already being actively considered.
84. Previous comments and suggestions from some of the adolescents who use Rainbow Place have already suggested ways in which the environment could be made more 'teen-friendly', especially in relation to decor and available 'equipment' and resources.

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85. Another crucial aspect of a teen-friendly environment is that it needs to be a comfortable, casual place where adolescents can safely ‘hang out’[49-53] and “chill”. A great ‘hanging out’ environment is so important for adolescents that it should be a specified national service quality standard. These parents understood this absolutely:

*P1: “That’s something you need to put in a pamphlet, a funky little flyer for the teen to read and say, ‘Well, I can access counselling if I want. I can come along just to have some respite, just to hang out’, just so they know...”*

*P2: “Just to hang out, to chill”.*

*P1: “Cause I don’t think my daughter knows that, she came home and said, ‘Mum, did you know some of the girls from our teen group actually pop in after school and just sit down in one of the rooms and have a drink and...’ she goes, ‘I didn’t know you could do that mum’”. Int. #51*

86. Several review participants felt that Rainbow Place had an excessively ‘European’ look (more LA than NZ as someone remarked) and that it could be made more visually appealing to Maori and Pacific children and young people.

*“For the users it would be cool if it was a bit more adolescent and young adult friendly and a bit more culturally communicative of where we are”. Int. #46*

87. As with the adolescent design features, creating a more visually welcoming ‘look’ for Maori and Pacific young people is a wonderful opportunity for Rainbow Place to engage with young people locally and in the region who could help with both the design and implementation of any new features.

## 6. RAINBOW PLACE BEING USED AND ‘THE KEVIN COSTNER FALLACY’

*“If you build it, they will come.” Field of Dreams (1989)*

### Introduction


88. How well ‘used’ is Rainbow Place? This is a question that generated considerable comment and a diverse range of views and opinions during the review. It is a question that many other children’s hospice and palliative care services are asking. In the UK, a recent national review report noted that:

“Increasingly children’s hospice services go well beyond services that are provided within a building. Nevertheless, for some hospices there is some concern that the resource of the building should be used as effectively as possible”. [54] (p.4)

89. At the core of the views and concerns expressed in this review are several paradoxes. The first is what I have called ‘The Kevin Costner Fallacy’, that ‘if you build it, they will come’. They (being the children, young people, families/whānau that Rainbow Place seeks to serve) will not simply, ‘come’. Nor will the stakeholders and professional colleagues working within children’s health and other services that Rainbow Place needs to have within its network.
90. The second paradox is that if children’s palliative, supportive and bereavement care and services are to be predominantly or exclusively ‘home based’, then Rainbow Place becomes a very elaborate ‘office’ from which to travel.
91. In this section I report and consider some of the main issues raised around Rainbow Place’s use and suggest ways that the above paradoxes may be resolved.

### Where are all the children?

92. “Where are all the children? Where are all the families?” (Int. #3). This was a frequently expressed concern throughout the review, that Rainbow Place was very ‘quiet’ and that children and families were rarely seen there. These questions were asked by families who wished that the facility could be ‘used more’ but most frequently (and I have to say, most forcibly) by stakeholders and Hospice Waikato staff themselves. During my visits in March and April, I asked Rainbow Place the same questions. As a ‘stranger’ coming to see this new facility for the first time, I too was surprised that there were not more ‘activities’ and ‘services’ happening within Rainbow Place itself.
93. That people are asking such questions was not news to Rainbow Place staff, for they too were aware of this paradox. They acknowledged that “the bulk of



our work is outside the building” and that “it’s probably not being utilised as well as it could be”. One staff member recalled that a phrase had been coined that ‘An empty Rainbow Place is a busy Rainbow Place’. It is unlikely that such a linguistic sleight of hand will address these expressed concerns. Nor is it likely to convince those responsible for funding services. As one senior external stakeholder commented:

*“Are they busy? Well I don’t know. And when I look across the car park and I see no-one in here, I really do wonder. Int. #52*

94. There seemed to be an almost polarised divide in respondents’ survey and interview responses. There were those who celebrated that Rainbow Place’s ‘busyness’ and activities were predominantly in people’s homes. As one stakeholder commented:

*“There is still a bit of a lack of understanding that to me yes, this is a beautiful facility and yes, they do work here but actually the bulk of the work is in the schools, in the home, within the community. To me the workplace is out there not in here, but we all need a home to come back to.” Int. #11*

95. For others, Rainbow Place’s ‘emptiness’ and ‘quietness’ indicated failure and suggested that little work was being done e.g., “I still find it difficult to understand what the staff do all day”.

96. There seems to be an unreasonable assumption underlying such polarised views, that Rainbow Place can **only** provide **one** ‘kind’ of service, i.e. that it ‘must’ be either community and home focused OR residential and Rainbow Place located. This makes no sense within contemporary children’s palliative or bereavement care. It is absolutely appropriate and in keeping with current standards of children’s palliative and supportive care that services offered are essentially (but not exclusively) home-based. An equally important service imperative is that families must have choices and alternatives, including those ‘in house’ options that Rainbow Place and its facilities offer.

97. Rainbow Place is not a day surgery unit or GP centre and it is absurd to think that it should have children and families banked up in the reception area awaiting their appointments. As one staff member noted:

*“I guess a lot of people’s perception when this place was built was that we were going to be 24/7 looking after sick kids”. Int. #7*

98. However, there can be little doubt that it is currently under-used in relation to its potential and that it has the capacity for future growth and development.

## “Out of hours” services?

*“Do we have to start at 8 o’clock here? I would actually be looking at: why don’t you start at 10 and go till 6 or have some*

*days where actually it doesn't really open until the afternoon and actually have people here in the evening. Int #18*

99. Rainbow Place does provide services 'out of hours'. The 'Teen Group' for example met during my visit and I was able to join them for a group discussion one evening about Rainbow Place and its services for adolescents and young people. Rainbow Place staff also visit children and families/whānau in their home 'out of hours' if required but this would not be the 'norm' for contact.
100. If staff time is spent predominantly visiting families 'during the day' then it is unsurprising that Rainbow Place seems so 'quiet' during 'office hours'. This, however rather relegates activities and programmes that could be taking place outside of these times and within Rainbow Place to the realm of optional extras or to whenever "we can make it work". Making the facilities of Rainbow Place 'work' better may require resources. What is more certain is that it will require *resourcefulness* on the part of the staff and the wider organisation.
101. Nurses, for example, have never questioned the idea of working non-traditional hours as many of our health services require 24/7 staffing. There seems to be no sound rationale for why Rainbow Place should not develop more of a 24/7 service ethos as its norm. As one person commented, "just because you've done it that way doesn't mean to say you have to keep doing it that way".
102. By the same token, because visiting families at home may be the current norm or standard service delivery mode, does not mean that this should be exclusively or forever so. Rainbow Place, for example, has yet to explore the exciting possibilities offered by telemedicine and online counselling, both with children and young people and adults.[55-60].
103. The Rainbow Place of the future should be a thriving and vibrant centre showcasing everything that is innovative and excellent in children's palliative and supportive care and bereavement support. Its guiding philosophy should never be: 'Here are the services that we have, which ones would you like?'. Instead, it should be: 'What is the best kind of life you and your child and family/whānau want to live, and how can we help and support you to do this?'. Children and young people will be meeting there regularly, not only for 'therapy' and support reasons but for fun (as might their parents and families). Their friends and siblings will be so impressed and excited by what they hear that they will want to come along too.

## **Rainbow Place's bedrooms and respite facilities**

*"It's such a beautiful facility and it's just going to be so wonderful for other families to have it. I just hope they open it up more". Int. #34*



## The Procrustean Beds?<sup>3</sup>

104. A key issue in this review was Rainbow Place's bedrooms and respite facilities. As with the general issue of Rainbow Place's 'use', opinions were divided and suggestions were numerous. Respondents offered many suggestions for how this asset could be best used to serve the children and families/whānau of the region.
105. One unusual and perhaps unexpected feature of some stakeholder comments, was that these rooms seemed to take on an almost symbolic power, as if they were visible manifestations of a particularly 'poor' palliative care ideology. One survey respondent suggested that "having inpatient beds for end of life care" was, one of the things that Rainbow Place "did not do so well".
106. Beds and residential facilities are neither 'good' nor 'bad' in themselves. How they are used is the important consideration. Almost every national and international policy and report on children's palliative care emphasises the need for choice, flexibility and 'family-centredness'. There can be no place for a Procrustean 'one size fits all' approach that would either proscribe or prescribe 'beds'. They are only one of a range of services available for children and families to choose. Home and 'residential' respite care for children have both "benefits and limitations"[61, 62] as would be expected. Neither is a panacea. Similarly, for the recipients of a respite service, "respite benefits each caregiver in a unique way and is not the same for all caregivers".[63] (p.629)
107. Respite at Rainbow Place involves the family travelling, they will need to learn to trust and be comfortable in a new setting and they may need to bring all the child's 'special equipment' with them. Home respite brings its own set of dilemmas[64] and raises the problematic dynamics of power and communication when health professionals are 'guests' in a home.[61, 65]
108. A respite or sleepover service has the potential to benefit everyone. This is not a service solely designed to 'give parents a break'. Siblings can benefit from becoming part of Rainbow Place and its support programmes as can the child or young person's friends. Crucially perhaps, this a service that should help the child or young person themselves. This should be something *for them*. A recent UK report highlights the "huge benefits" for children and young people of such a non-home based respite and 'sleepover' service [66] (p.29).
109. Rainbow Place owes no apology for having 'beds' and a respite facility. Failing to use these well to benefit families would be another matter.

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<sup>3</sup> Procrustes in Greek mythology was a bandit who forced travellers to lie on his bed. If they were too short he stretched them and if they were too tall, he cut off their legs. His bed is now synonymous with an arbitrary system, rule or standard that is rigidly enforced with no regard for individuality or difference. (<http://dictionary.reference.com/browse/procrustean+bed>) <http://en.wikipedia.org/wiki/Procrustes>



## Whose respite?

110. As with the broader topic of Rainbow Place's use, there was considerable discussion and comment by participants on the question of Rainbow Place's respite facilities, how these are currently used and how they could be used in the future. Families and stakeholders agreed that this was a wonderful resource that should be more widely and fully used. This health professional spoke for many:


*“There is a serious lack of respite for medically fragile infants in the Waikato, and personally I would like to see this service much better utilised”.*

111. Respite care is a key element within a children's service and one that is particularly valued for parents whose child has a disability, complex medical and care needs or who requires palliative or supportive care[67-74]. As with other aspects of a paediatric palliative care service, flexibility, ease of use and sensitivity to particular families' needs are key. As a New Zealand review of paediatric respite care noted, within such a service “Different options will suit different families”. [70] (p.104). I would also add, ‘at different times, for different purposes and during different circumstances’.
112. Mirroring the confusion surrounding Rainbow Place's ‘criteria for referral’, there was a similar lack of understanding among stakeholders and other services as to the respite facility's purpose and eligibility. Some believed that these rooms were solely for “end-of-life care”, some thought that they “were for kids only” while others were unsure whether ‘their’ client groups for example, neonates, parents requiring to visit the hospital regularly with their child, children with disabilities, or even teenagers and young people with partners were ‘eligible’ to use them. This is an important issue that Hospice Waikato and Rainbow Place need to address and clarify. It is philosophically important as it goes to the heart of ‘what Rainbow Place is for’ and who can access and use its services. It is also practically important for families, stakeholder colleagues and services because:

“Referral criteria need to be overt and available to all referring agencies so that families are not referred inappropriately, leading to bitter disappointment if they do not meet the necessary criteria.”[61] (p. 3201)

## Families/whānau experiences of the respite/sleepover service

113. Using these rooms for what Rainbow Place calls ‘sleepovers’ is an inspired idea. Parents can be reluctant to use any ‘respite service’ if the ‘tone’ of the service sends a negative message that ‘this is a service for parents who are not coping’. It is surprising how many services make this mistake.[75] A respite service is far more appealing and welcoming when it is clear that this is something that should be enjoyable and beneficial for the child and which at the same time may benefit the whole family.



114. There was no doubt at all from the parents and families/whānau who had used the sleepover service that it was valuable and appreciated. These families' accounts are notable, not simply because they show how valuable the sleepover service is, but because they tell us that there is a sense of fun and excitement there. Fun and excitement: two more 'standards' to include in any assessment of a children and young people's service:

*"We did a trial night, all of us, the whole family stayed and yeah, that went well. (...) It was good. It was a bit like we're out in a motel, you know. Gives you a bit of a thrill". Int. #17*

*"P1: "We're real excited, we really want to come and stay as a family. The environment is so good cause it's not really noisy and they've got like a sensory room for him to play and stuff like that".*


*P2: "Yeah that's what I like about it; it doesn't feel like we're just dropping him off somewhere; it's like, "Oh yay, you're gonna go and play". Int. #41*

115. Respondents in this review suggested several ways in which the sleepover and respite service could be broadened and expanded. Some of these suggestions were:

- Rural parents whose child required regular hospital visits and appointments could use the service to minimize travel to and from the hospital
- Parents with several children could use the service to care for and work with the siblings while their other child was having their treatment/appointments/clinics at the hospital
- Sleepover events could be scheduled for younger children as there was a view that these seem to be mostly for teens and older children.
- Children of parents or grandparents who are in the Adult hospice could use the sleepover service more.
- Parents whose child has been recently diagnosed or who has complex medical needs or who has a new 'technology/device' that the parents need to learn could use the room/respite facility as a kind of 'step-down' or transition facility that would enable them to leave hospital quicker and more gradually and safely transition back to their home.

116. This mum's story will resonate with many parents:

*"There were times that we were told we could leave hospital and we were petrified. We were absolutely petrified. We could have gone to Rainbow Place. Spend another 24 hours or another 48 hours just to feel that we could deal with this. He was on 11 meds morning, nine meds night, three at lunchtime. He was suctioned. He had chest therapy. He was seizing. He was gagging constantly. He was not sleeping during the night. We're supposed to deal with that; that's his day. Int. #34*

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117. The scope and potential for expanding and developing the existing 'rooms' and respite/sleepover services is as wide as it is exciting.

### Staffing an expanded respite or sleepover service

“Any service seeking to provide support to parents of children with complex health care needs will need to grapple with the balance between maximizing the families on the caseload on the one hand, and being able to offer more responsive support, possibly to a smaller number of families, on the other.” [64] (p.609)

118. It must be stressed that Rainbow Place has not been 'lazy' or 'unwilling' to make better use of their respite facilities. There are genuine difficulties involved in, for example, staffing such a service. Staffing is a 'deal-breaker' for almost all parents who would wish to use Rainbow Place's respite and sleepover service. It is difficult for families to learn to trust strangers and new facilities/services with the care of their child. It becomes significantly harder when your child has a complex medical condition and needs almost constant care, observation and attention:


*“Yeah we do have to find someone that will be willing to look after him and there's a lot of people that don't want that responsibility. Even my mum, she loves him but she's really frightened”. Int. #41*

*“Even if we're getting some time out, if ain't right for him he don't come. That's the end of it”. Int. #32*

*“We couldn't give (child) to anybody else who was not trained or had experience”. Int. #34*

119. Having qualified and experienced children's nurses available to staff the respite or sleepover service for such children is not a luxury or an option, but a necessity if families are to use the service and to feel that it is a genuine 'break' that they are experiencing. The 'Catch-22' for Rainbow Place, as staff appreciated, was that with only 3 children's nurses on staff (including the service manager) it is not possible to provide the necessary nurse cover that would allow this part of the service to expand. One stakeholder explained what this meant for her in practice:

*“This is a complex patient and the only thing that the parents have asked for would be to have respite at a weekend. So we negotiated with Rainbow Place but they didn't have the resources to be able to provide that as in nurse cover. So this one hasn't, a year down the track, hasn't had any respite overnight. So it's disappointing because I can understand. You need the resources to be able to get people in, but you can't get people in cause you haven't got the resources”. Int. #39*

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120. Hospice Waikato cannot simply employ several new children's nurses in the hope that the respite and sleepover services (and other services for seriously ill/sick children) somehow 'take off', nor can Rainbow Place invite more families to use the service without such guaranteed staffing support in place. This dilemma will make it difficult to recruit skilled and experienced children's nurses if they feel that there is 'no work' for them or if they feel that their clinical skills will not be used. It will also be problematic for existing staff who will find it difficult to keep their existing skills and expertise current.
121. Resolving this dilemma will require some creative thinking, 'silo-busting' and alternative approaches. One approach could help resolve this staffing conundrum while also helping build closer and mutually beneficial relationships and partnerships with Waikato Hospital, 'Waikids' and the region's paediatric services.
122. Hospice Waikato and Rainbow Place should initiate a dialogue with the Paediatric Services to consider ways of sharing their respective resources in ways that will benefit both organisations and will enable more families to benefit from the rooms, respite and sleepover service. It may be possible for children's nurses from the hospital to accompany and support families and children who are staying at Rainbow Place in a partnership arrangement. Several specialist nurses and pediatricians who spoke with us were very clear that they had families and children who would greatly appreciate and benefit from being able to access such a respite and sleepover service. One health leader described how families could benefit from such a partnership:


*"We have a lot of babies discharged from (hospital) with ongoing health issues and some of it's just about parents' confidence in dealing with that and knowing that they've got somewhere safe to go to, perhaps when they are struggling. (...) I think often some of the needs are around youth, and we do youth really badly, we don't have youth beds, we don't do an awful lot for those kids well. But even in a palliative sense, they're the ones that have got the needs and they're in that struggle between childhood and adulthood, and they don't want to come in to a children's facility, but they don't want to be in a true hospice, so maybe there's a way to ... I mean it's beautiful now, but funk it up more for youth, that adolescent group, and maybe some of the sleepovers are actually with some of their friends, not so much family, you know it's just that period of normality really. Int. #27*

## Opening the flood gates?

123. I noted concern within Rainbow Place and Hospice that if the criteria for respite and sleepovers was widened 'too far', that the service could be "flooded".

*"If we open the floodgates we'll be flooded". Int. #18*

124. This is often a genuine concern for any small organisation, either an NGO, health service or business. How to you grow and develop without being



somehow 'overwhelmed' and risk compromising quality or becoming something 'different' and losing your identity or 'character'? My view is that **not** expanding and broadening the respite and sleepover service is not an option. The only question facing Rainbow Place is what the expansion should look like and how it should be effected. If the service is broadened and the response is positive, with more service colleagues and families keen to take advantage then so much the better. In building any business case for additional staff required to enable such expansion, it will be essential to demonstrate that the services are required, valued and effective.

125. There is another possible dimension to this potential expansion and 'fear of flooding'. When we see a hesitancy or reluctance in an organisation it is tempting to attribute this to a 'fear of failure' and a desire to hold on to the status quo. There is another 'fear' that can be equally constraining however and that is the fear of success.<sup>4</sup> There needs to be a change in mind set, a twist of the kaleidoscope at Hospice Waikato and Rainbow Place. That change would see the expansion and development of the respite and sleepover service not as 'being flooded', but as thriving, as enabling more children and families to benefit from an excellent facility and initiative and as building a growing partnership bridges with other services and colleagues.

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<sup>4</sup> <http://www.livestrong.com/article/14659-handling-fear-of-success/> fear of success

<http://www.houd.info/FOS.pdf>



## 7. RAINBOW PLACE WITHIN HOSPICE WAIKATO

### Introduction: strange bedfellows?

126. Rainbow Place and Hospice Waikato. Is their co-location on the same site and their organisational unity, a marriage made in heaven or a Faustian pact? This section explores the relationship between the two parts of Hospice Waikato, highlighting both the current situation and the future potential.
127. Their situation is very unusual in the worlds of hospice, children's palliative care and children's grief and bereavement support. The UK, for example has some 46 Children's Hospices but these are mostly 'stand alone' organisations.
128. Respondents who were critical of this arrangement felt that Rainbow Place would always suffer or be a kind of professional 'poor relation' due to their perception that the wider hospice's orientation was "adult-centric":

*"Sometimes I get the impression that children are secondary to Hospice's main work with adults and not as much of a priority."*

129. In almost complete contrast, some hospice staff believed the exact opposite - that Hospice Waikato was too 'Rainbow Place-centric', favoring the children's service over the adult hospice.

### The combined potential of Hospice Waikato and Rainbow Place


130. Where some saw conflict, inequity and tension, other saw possibilities and 'synergies'. One of the benefits of having the two services on the same site is that parents and families/whānau who come to adult hospice will be able to easily access Rainbow Place's help and support for their children should they wish this:

*"It's perfect to my mind (...) You've got adults and you've got children that all need to deal with that and you're all doing it under the one umbrella. Int. #29"*

131. Another benefit of having a genuine synergy between the adult hospice and Rainbow Place relates to the thorny issue of transition care for young adults.<sup>5</sup> There is widespread international agreement that:

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<sup>5</sup> See for example, the presentations at this 'Transitions' conference: <http://www.helpthehospices.org.uk/our-services/running-your-hospice/education-training/past-events/transition-conference/>



“The increased life expectancy of young people with life-threatening and life-limiting conditions has raised the importance of transition to adult services for young people with such conditions”. [76] (p.78)

132. The specific service access and continuity problems facing this group have been well documented [76, 77]. The most recent systematic review of youth transition in palliative care noted that:


“Fragmentation also existed between child and adult providers, with evidence of poor continuity of care, which made it difficult and problematic for many young people to negotiate the transition period”. [76] (p.82)

133. Hospice Waikato, Rainbow Place and the region’s paediatric and child health services have a unique opportunity, not only to shape, but to lead transition services for these young people now and for the future. This will not happen if the paediatric services community believes that hospice is an ‘adult-centric’ dinosaur with little understanding of young people’s needs and lives, or if they themselves are unable or unwilling to ‘let go’ [76, 77] of ‘their’ children. Nor will it work unless Hospice sends clear signals, through all of its policies, practices, criteria, collaborative arrangements and services, that it does appreciate and cater for the unique needs of children and young people and their families/whānau. The ‘good transitions’ ball is in both courts.

## Dealing with ‘the H word’

134. A more commonly expressed concern regarding Rainbow Place’s association with Hospice was simply the word ‘Hospice’ itself and its all too well known negative connotations and overtones, especially for parents and families.[18, 19, 23, 35, 54, 61, 78]
135. Put bluntly, ‘hospice’ in many people’s minds is wrongly associated with immanent death, with ‘old people dying’, with ‘terminal cancer’, with ‘giving up’ on care and treatment and with the abandonment of hope. A picture of Rainbow Place then emerges as a site of death and all-pervasive grief where small white coffins will line the driveways. Little wonder that parents and families/whānau can be ‘put off’ Rainbow Place - in the absence of a compellingly articulated and publicised alternative picture.
136. ‘Hospice’ and its close relative ‘palliative care’ have what marketers would call ‘an image problem’. Author Helen Garner wrote recently that the phrase ‘palliative care’ still “strikes fear into many hearts” [1]. One mum’s explanation of her reactions to first hearing the phrase ‘palliative care’ was as graphic as it was distressing:

*“Total fear, total panic, despair, dismay. Didn’t believe... disbelief, total disbelief. Last days, terrible, terrible last days. Palliative doesn’t give a nice ... I guess now that I know more about Rainbow Place, I certainly understand palliative care. But for us, that’s why I was so not ready to hear those words. Because I*



*thought palliative meant at home...dying, the district nurses coming just to give you Morphine. That's what we thought." Int. #34*

137. Children's services, Hospice Waikato and Rainbow Place have a choice to make. One option is to simply accept that parents and families/whānau will never accept the words 'Hospice' or 'Palliative Care' due to their negative connotations. Hospice can then retreat into euphemism, searching for ever more sugar-coated ways of trying to say the unspeakable.
138. Rainbow Place and Hospice Waikato have more to gain by continuing to challenge the myths and misconceptions around hospice and palliative care than they do by capitulating to them. This is part of its educational and leadership role and mandate within the community. Hospice Waikato's current strategic plan echoes the credo that: "Hospice is a service, not a building". If 'Hospice' is indeed a philosophy and a vision[79, 80], and being one of the region's leading services, if Hospice Waikato and Rainbow Place do not spearhead this challenge, then who will?
139. Rainbow Place can challenge the misconceptions surrounding children's palliative care, grief and bereavement by further enhancing, developing and extending its excellent services and its presence and influence within the Waikato region. It can show children, families/whānau, stakeholder colleagues and the wider community how life-affirming, positive, vibrant, loving, helpful (and yes, even happy) a children's serious illness, palliative care, bereavement and hospice environment can be.

## Rainbow Place and 'Adult side' tensions


140. Tensions within organisations are hardly news. There is unlikely to be a hospital, university, school or private company anywhere in the world without its share of small resentments, distrusts, scuttlebutt, misunderstandings and more. Hospice Waikato staff generally stressed a basic unity of purpose:

*"We're all doing the same job. Yes there's a difference between children and adults but we're actually, fundamentally all after doing the same job, the same purpose of a job". Int. #1*

Some, however were more pessimistic about the state of collaboration and understanding between the two services:

*"There is definitive divisions. I wouldn't say it's a different culture but there is just divisions". Int. #11*

141. My own view formed during my visits was that there was indeed a sense of 'them and us' apparent within the broad organisation. This may at least partly arise (and I say this as a children's nurse), not from the insistence that 'children are different' and require a different service approach and a particular orientation, but from HOW this insistence may be articulated and perceived.



There is no higher court than perception. A clue here were some staff comments that Rainbow Place was seen as being somehow 'special' or 'precious'. A discourse of 'specialness' can be a double-edged sword. In emphasizing and clarifying the distinctive nature of children's services, it is vital not to inadvertently convey the sense that other services are therefore 'ordinary' or unremarkable.

142. To the credit of Rainbow Place and their staff, I believe that they do not make this error. In all of my meetings, interviews and discussions with them and during our informal lunches and coffees, I heard nothing other than respectful comments and praise for the work of their 'adult' colleagues. While they often wondered whether they were 'getting the message across' about the work of Rainbow Place, they regularly acknowledged and appreciated the work of their colleagues in the 'adult side'



## 8. RAINBOW PLACE: AWARENESS, PROFILE AND ‘GETTING OUT THERE’

*“We’ve never been public, really out there in the public, but in order to get to the next part of our development, we have to go public and we have to be seen to be strong.” Int. #8*

### Introduction

143. Rainbow Place is at a crucial stage in its development. It has grown from its early days in von Tempsky Street to its new place and premises but in many ways it continues to have the ‘feel’ of a “Cottage Industry”. It has all of the benefits of being small, homely, personal and friendly. The downside in any Cottage Industry however, is that it can become insular, comfortable and limited in its thinking and goals. Rainbow Place should have no desire to be Waikato’s ‘best kept secret’ but according to many of this review’s participants, that was the essence of its profile.

### The profile of Rainbow Place

144. Within Rainbow Place itself and Hospice Waikato there was a clear sense of frustration that this genuine asset was not more widely known and used among the community who had responded so well to the campaign to create it.

*“No doubt that there would be families out there that could use the service that aren’t. Why aren’t they? They may not know about us”. Int.#6*

145. Throughout the review there was a consistent ‘message’ received: that Rainbow Place has a ‘low profile’, that few people seem to know about it (and are clear about its services) and that it is failing to ‘get across’ information about its services and their value to stakeholders and the wider community:

*“Rainbow Place should get out there and be aggressive. Maybe they need to do more visits (to the hospital) if they can. We also need them to come out and say, “We can do it. We can do this, we’re ready, go.” Int. #39*

146. Parents and families/whānau too wondered why Rainbow Place was not more well known within e.g., the disability community, within the conductive education groups, within ‘special education’, or within any of the networks that their child was associated with:

*“The only reason we found out about this place is cause we said to “Mary”, ‘is there somewhere for the kids to access*

*counselling’? If we didn’t ask we might not be here. It probably is under utilised simply because parents don’t know it exists”. Int. #17*

147. Rainbow Place’s main approach to ‘getting out there’ cannot be, to be prepared to respond to people when they are approached and asked for information or services. Such approaches may be rare and waiting to be asked is not a marketing option.

148. ‘Getting out there’, as one respondent noted, does not mean having an exclusive focus on relationships with ‘the hospital’:

*“Forget about the hospital, we’re a community service. Get out to your GP’s, get out to your practice nurses, go and see the mobile practice nurse, go to the Marae”. Int. #18*

149. It is hard to disagree with this and valuable to add several more key groups and organisations to the list. There are numerous new ways in which Rainbow Place can improve its presence, marketing and ‘getting out there’. If Rainbow Place genuinely believes that it has the skills, expertise and services that will benefit and support children and families who have clear and unmet needs, then it has a moral and professional obligation to bring its services to the attention of stakeholders, fellow professionals, families/whānau and the wider community. To have such services available and **not** make people aware of them would be a dereliction of responsibility. Promoting Rainbow Place and supporting new approaches to ‘getting out there’ should be an integral part of every staff member's role. Rainbow Place’s future approach to increasing awareness and developing its services is too important to leave to an ad hoc approach and needs a clearly thought out ‘marketing, publicity and information’ strategy.


## Changing Hospice Waikato?

150. If Rainbow Place is to respond and move into its next phase of development, it will face challenges, as will the wider Hospice Waikato organisation. Rainbow Place cannot do this in isolation.

151. Historically, children’s palliative care services have fared badly within a ‘general’ hospital or hospice model. The nadir of this situation arose predominantly in the USA where families who wished to access children’s palliative or hospice care were then essentially forced to ‘give up’ all access to other treatments. This resulted in:

*“Families being left with the cruel and inhumane choice between ‘trying to cure the child’s disease’ and ‘managing pain and focusing on quality of life’” [81] (p.313)*

152. Such restrictive and inhumane ‘criteria’ and restrictions were condemned by almost all children’s health professionals:



“These restrictions are directly counter to optimal palliative care for children because they do not take into account the medical needs or preferences of the child and his or her family due to the nature of life-limiting conditions in children”. [82] (p.3)

153. Fortunately, more compassionate and innovative funding approaches are now being developed to avoid families being placed ‘between a rock and a hard place’. [82] Hospice Waikato has an opportunity here to consider its development over the coming years as many of the issues raised in this review may not pertain solely to Rainbow Place.
154. The perennial issue of the role, purpose and nature of hospice has been thrown into sharp relief. If hospice is indeed a philosophy or an approach to care and not simply a building or place, then what is that philosophy and how is it changing? Developments in children’s palliative care can influence and provoke new thinking within the wider and adult hospice world. Hospice Waikato rightly stresses in its Strategic Plans and Frameworks that flexible care and services for children must extend from ‘diagnosis through to bereavement’. This is exactly the kind of thinking and approach that can help counter the stigma and negative perceptions that hospice or palliative care services often face. Taking a more holistic and child and family centred, rather than a criteria centred approach will help Rainbow Place and the children’s service and could pay similar dividends within the adult service.

## 9. THE POTENTIAL OF RAINBOW PLACE


### Growing an even greater service

155. Rainbow Place's potential is considerable. A developmental analogy might propose the von Tempsky Street years as its infancy. Moving to its current new building and location has been a fascinating childhood, full of new learning and growing. Now however, Rainbow Place is growing up and needs to take more autonomous and independent 'young adult' steps. Building the service now takes priority over servicing the building.
156. Throughout the review, we received numerous suggestions and personal experience examples of how Rainbow Place could grow and the kinds of services that it is well positioned to offer. These are only some, but if only some of these were pursued, there could be a significant positive impact made on child and family health, on paediatric palliative care and on children's bereavement support within the Waikato region.
157. I paraphrase a group discussion here that wanted to see greater informality and a more relaxed flexibility of use *within* the hospice campus.

*"Why couldn't a child come over from being with their parent in hospice and sit down in the big room (in Rainbow Place) on a bean bag and watch TV and just chill out, get away for an hour or so? They could just hang out, sit and talk to some other kids, do some drawings, watch some TV, play a few computer games. That's not a 'misuse of resources' or a distraction, that's what the facility should be for and doing that shouldn't be a drama.*

*Hospice has a broad population. We might have someone dying here whose daughter's arrived with her new baby from the UK and they're jet-lagged. Where is she going to breastfeed? Unless they're in one of the double rooms in hospice, then Rainbow Place is the perfect place. Look at being able to go and lie down in one of the family rooms, or even in one of the beds when there are no children there with your baby or with your little two year old who needs an afternoon nap. Now that would be an integrated service". Int. #18*

158. Not only does Rainbow Place need to 'get out there' to promote its services but it also needs to develop ways of enabling the community to 'get in here' to Rainbow Place. This is two-way traffic. How better to break down the previously mentioned stigmas and negativity around the ideas of 'hospice' 'palliative care', grief and loss etc, than to have 'the community' invited to and able to see and hear about its work. Rainbow Place has already taken valuable steps in this direction, e.g. working closely with the Brain Tumour Support Group.

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159. There will be several other network groups, support groups, advocacy bodies and others who would also be keen to use Rainbow Place in this way. This is not a 'dilution' of Rainbow Place's purpose or a 'non-core' activity but an excellent way to build and develop Rainbow Place's networks and influence within the region for exactly the children and families/whānau that it should serve.
160. During our discussions with paediatric services at Waikato Hospital we found, amid the confusion about 'criteria' and role, a real interest in working more closely with Rainbow Place and in using the existing facilities more effectively. One way of working more closely with pediatricians, child health specialists and specialist nurses could be to offer room space within Rainbow Place, where clinics could be held. This may benefit families as it may be more convenient than attending the hospital and once again, it brings people into Rainbow Place who may otherwise be unaware of its services. It is also another way to build strong collegial relationships with paediatric colleagues.
161. Several nurses mentioned the potential for having Rainbow Place rooms used as a kind of 'transition' for new parents learning to care for their new baby who may have complex health needs that the parents must learn to manage at home:


*"If there's a family in the newborn unit and they're getting used to all the pumps and bells and whistles and they live two hours away but they don't want to go home straight away, they're feeling kind of confident, but not enough, ... to be able to come here and use Rainbow Place's services and have the sleepovers and know that there's a nurse next door". Int. #39*

162. Here again are clear benefits for everyone. Parents can gradually learn to care with confidence rather than feeling 'thrown in at the deep end'. The Newborn Unit can see the benefits for their families of not keeping them as 'inpatients' longer than is necessary. Rainbow Place are enhancing their services for seriously ill children, establishing early relationships with the families and building strong relationships with another clinical area.
163. Some of these suggestions have staffing and resource implications and this is an opportunity to engage directly with existing service areas to explore the ways in which possible 'staff sharing' with Rainbow Place could help create new models and approaches to helping children and families.

## Gaps in Rainbow Place's services

*"There is an open hole in Hamilton". Int. #2*

164. Every health service thinks that it could 'do more'. It is almost part of our DNA, to grow services. While there were several suggested areas where Rainbow Place could extend its services, there was one area which was mentioned repeatedly and above all others by almost every group that we consulted. That



is grief and bereavement support for children whose parent or sibling dies from accidental or traumatic causes.

165. It was indeed surprising to learn that this group of children did not fall within the remit of the existing “change, grief and loss” programme. Respondents described the situation as: ‘If you are a child whose mum or dad dies from a “medical condition”, or if they are a patient in Hospice, then you can receive grief and bereavement services from Rainbow Place. If however your mother is killed in a car accident on the way home from work, or if your father has been murdered, or if your brother has committed suicide, then sorry, we cannot help you’.
166. I am not being glib or harsh here for this was the situation as reported by several respondents, ranging from those who commission and provide health services to those who had direct personal examples to share. Even an experienced bereavement counsellor acknowledged that, “I don’t know where those kids end up getting help”. Not a single respondent suggested that this situation was acceptable or tolerable.

*“Dad was in a car accident last night, can we get counselling for the child? No sorry, because you don’t fit under our current criteria.” Int. #2*


*“I’ve had a tragic situation where my (relative’s) children lost their (parent) in a car crash and they couldn’t use Rainbow Place. If you don’t match criteria, tough”. Int. #3*

*“I can see all these glaringly obvious gaps like the children who are losing or have lost somebody for other reasons apart from medical, I mean that’s glaringly obvious that we should be doing that”. Int. #8*

167. To say that this situation must be frustrating or even embarrassing for Rainbow Place would be an understatement. Here is a service with acknowledged expertise in providing grief and bereavement support for children and yet it must effectively ‘discriminate against’ and say ‘No’ to those children affected by accidental and traumatic deaths:

*“I’ve done talks in Intensive Care, the first thing they say to me is do you do trauma? When I say we can’t right now, they don’t want to listen. They don’t want to know.” Int. #13*

168. There are obviously funding and staffing issues that must be considered here and such an extension of Rainbow Place’s bereavement support service cannot just be wished into existence. A strong business case needs to be made and part of this may be a challenge as it seems that key data such as ‘how many children and young people in Waikato region are affected by the accidental or traumatic death of a parent (or sibling)’ could be difficult obtain or collate.

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169. From a counselling and service perspective there should be strong case made for using the best available evidence as to, for example:
- i. What are the most effective current approaches in children's and youth counselling, particularly for trauma-related events?
  - ii. Is there an optimum 'programme length' or number of sessions required in such traumatic grief counselling?
  - iii. Is face to face counselling the optimal approach?
  - iv. What is the place of and benefits of online counselling for this group
170. Hospice Waikato and Rainbow Place should discuss such an extension of the service with the DHB and seek funding support. Such support cannot be 'open-ended' or 'blank cheque' and should be for a specific programme or range of credible and evidence-informed programmes. It may be valuable to 'pilot' such a scheme, perhaps for 2-3 years with an inbuilt evaluation element that would assess the success or otherwise of the programme(s).
171. The extension of this service could also address two other issues that arose during the review. Many people were conscious that with a currently all female staff, Rainbow Place may be missing a chance to connect with some older boys and fathers, who may prefer to talk to another man. Several respondents also commented that it would be a plus for the service if there were a Maori counsellor available. If additional counselling staff are being recruited to a newly expanded programme then this would be an excellent opportunity to redress these noted 'gaps' in Rainbow Place's staff profile.
172. This situation presents a clear opportunity for Rainbow Place to strengthen its valuable links with WINTEC who have a noted Counselling programme within the School of Health & Social Practice where faculty have particular interests and expertise in these areas. (see e.g.<sup>6</sup>)

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<sup>6</sup> <http://researcharchive.wintec.ac.nz/975/>




## 10. CONCLUSION

*“Make no little plans. They have no magic to stir men's blood. Make big plans, aim high in hope and work”.<sup>7</sup>*

173. This is a review of Rainbow Place and its work in the present but what is more important is its future. Hospice Waikato and Rainbow Place should be immensely proud of the quality of service that Rainbow Place provides to its families/whānau and children. There are very few reviews in health care where current standards of service and care are **not** the most pressing concerns.
174. Rainbow Place faces a clear choice. It can remain a cosy, ‘cottage industry’, serving its existing families/whānau and networks, within existing ‘criteria’ and thus it can avoid ‘being swamped’ or ‘opening the floodgates’ to new clients, new demands, new ways of working and new pressures. It can do this, but would it wish to? Imagine being swamped by new challenges and ideas, being flooded by gratitude for removing a block to accessing care or opening the gates to ways of working and thinking of which you had previously been unaware. The passion, enthusiasm and deep caring for the children and families/whānau who use and who should use Rainbow Place has driven its development this far. In some ways, what seems to be holding it back are its own fears, whether these be fears of failure or success.
175. If the developmental analogy holds and Rainbow Place is now entering a new ‘young adult’ phase, it must have the greater autonomy and responsibility that this requires. Rainbow Place also needs to take on new leadership challenges. What this review has highlighted is that client care and service delivery are excellent. What Rainbow Place does, it does exceptionally well. Much of this review highlights another range of challenges that need to be addressed if Rainbow Place is to move to its ‘next level’.
176. Some respondents believed that Rainbow Place should ‘break away’ from Hospice Waikato and be independent. I do not share this view. Rainbow Place can have the level of autonomy that it needs to ensure the distinctiveness and difference that a children’s and young people’s service requires, while also being a valuable part of a broader Hospice Waikato service, with all of the synergies afforded for breaking down ‘fragmentation’ of services, for helping hospice parents support their children and for improving transition care for young adults.
177. In responding to the many suggestions and possibilities within this report, what is needed is a ‘big picture’, strategic approach. It is very difficult to pick one or two ideas and try to implement these in isolation, especially if any impeding aspects of the organisation’s culture remain forceful.

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<sup>7</sup> Daniel Burnham, American architect and city planner.




178. This review is primarily of Rainbow Place but I am sure that many of the issues raised and suggestions made will be relevant to the 'adult side' and to Hospice Waikato generally. This is all to the good as change processes are rarely unidirectional.

179. Rainbow Place's aim should be to become a genuine 'Centre of Excellence' in its field and to have this national reputation for its work extend worldwide, not for egotistical reasons but because the people and community it serves deserve nothing less. In achieving this, Rainbow Place's will repay the faith, support and efforts of the Waikato community.


Philip Darbyshire, Adelaide, November 2011


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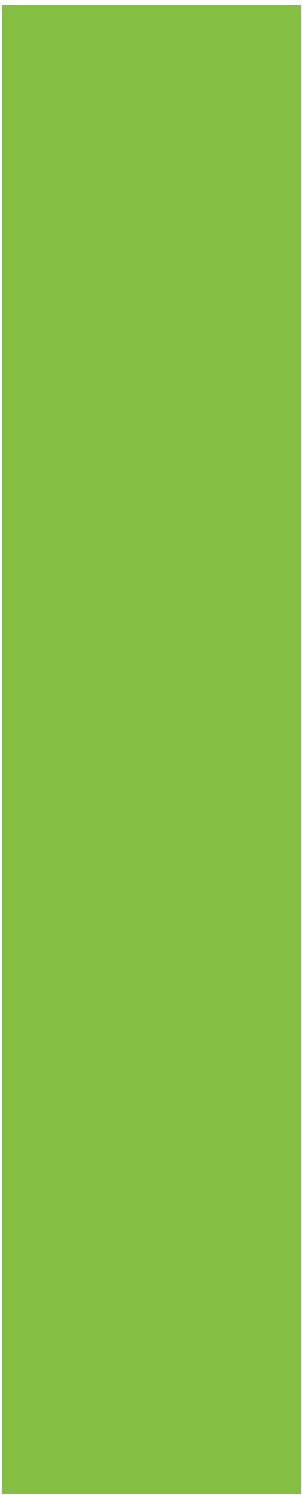
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