New South Wales

Special Commission of Inquiry into Healthcare Funding

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Commissioner of the NSW Government Inquiry into Healthcare Funding
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About Ronald McDonald House Charities

Ronald McDonald House Charities (RMHC) is a not-for-profit and registered charity supporting seriously ill and injured children and their families across Australia through a variety of programs and services.

Across NSW, we currently have seven Ronald McDonald Houses, seven Ronald McDonald Family Rooms and one Ronald McDonald Hospitality Cart which all operate and support families with seriously ill or injured children in NSW Hospitals. For over 25 years we have also run the Ronald McDonald Learning Program which supports NSW students with serious health conditions to catch up on the schoolwork they have missed due to their illness. Additionally, we have two Ronald McDonald Family Retreats in Forster and Bateman's Bay, where families can enjoy up to a week of free accommodation per year when they might otherwise have been unable to afford any time out due to the pressures of caring for their seriously ill or injured child. In 2022, our NSW Programs supported 7, 642 families. Those accessing medical care for their children via House and Family Rooms was 6,940. Collectively, our services play an essential role in enhancing family-centred care and are important parts of the healthcare and education systems in NSW.

The patient and family accommodation provided by RHMC gives families a place to live and rest while their children are undergoing ongoing treatment for serious illness or injury. It also provides a place for children to stay in between treatment. These services both improve the experience of families and allow for a more productive use of hospitals resources, including hospital beds.

While RMHC receives no direct government funding, families who are eligible for the IPTAAS (Isolated Patient Travel and Accommodation Assistance Scheme) staying within our Houses utilise this funding which contributes to covering the cost-of-service delivery. RMHC's policy is to not charge families to access any programs including staying in our Houses and relies on donor support to fund our programs.

In addition to our Ronald McDonald Houses, our Ronald McDonald Family Rooms provide direct benefit to families and indirect benefit to their seriously ill or injured children to from additional support services within NSW hospitals during difficult and stressful times. They serve as a place to relax and are located in close proximity to paediatric and neo-natal intensive care wards where children are being treated, and are accessible to parents, carers, family members and friends supporting a seriously ill or injured child.

At RMHC, we want to ensure equal access to treatment where no child and their family are left without accommodation or unable to stay together when they need it most, enabling family centred care to occur within NSW Hospitals.

Executive Summary

We welcome the opportunity to provide a submission on behalf of RMHC in response to the NSW Special Commission of Inquiry into Healthcare Funding.

RMHC's vision is a world where all children have access to medical care, and their families are supported and actively involved in their children's care. We always aim to ensure that no child or family goes unsupported while undergoing treatment for serious or ongoing illness or injury while away from their homes.

While there is substantial unmet need for our services, it is clear from our own data that when the choice is available, families with a seriously ill or injured child will overwhelming elect to stay in a Ronald McDonald House while their child undergoes treatment.

At RMHC we are proud of the work we do; we believe that while our focus is on families, our services play a dual role of improving patient outcomes and lowering costs within the hospital system.

While our impact is substantial and demand for our services high, our integration within NSW Hospitals is varied. The availability of RMHC relative to the need for our services has been in decline for many years; as hospitals across the state have been built and redeveloped, RMHC has not been able to maintain the same footprint, and in some instances our services have been removed.

We believe there is consensus across Australia and indeed the world that a move towards care that is better integrated, and patient centred delivers better patient outcomes and reduces system costs.

This submission includes a focus on:

- The role of accommodation services in ensuring equitable access to healthcare for children and families, the current unmet need that exists for these services, and the importance of considering the accommodation needs of families in service system design and procurement processes.
- The ability of accommodation and other step-up, step-down services to improve patient experiences, and reduce system costs including those associated with bed blocking.
- The importance of a flexible, patient and family centred approach in relation to the care of children, specifically as it relates to the IPTAAS eligibility criteria.
- The role of support services, including RMHC Family Rooms play improving patient experience and outcomes as well as reducing costs for families with children undergoing treatment.
- Opportunities to ensure Local Health Districts do not face disincentives to supporting partnership opportunities including with non-government organisations.

and recommends:

- Greater recognition of the importance of accommodation and support services and acknowledgement of the existing unmet need within the NSW Health System.
  Further examination of the social and cost benefits that could be gained by supporting

additional, systematic provision of accommodation for families within or close to hospitals.

- Considering greater flexibility options for families with seriously ill or injured children within the distance eligibility criteria of the IPTAAS.
- The inclusion of accommodation services as a core consideration as part of hospital development and redevelopment projects.
- Need to include a dot point or two on the benefit of Family Rooms in Exec summary recommendations, with more focus on this throughout the whole document.
- Consideration of changes that could ensure LHDs are not disincentivised from engaging in partnerships that could improve the experience and care of patients.

In doing so we respond to the following terms of reference.

A. *The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care, and health services to the people of NSW, now and into the future;*

B. *The existing governance and accountability structure of NSW Health, including:*

    i. *the balance between central oversight and locally devolved decision making (including the current operating model of Local Health Districts);*

D. *Strategies available to NSW Health to address escalating costs, limit wastage, minimise overservicing and identify gaps or areas of improvement in financial management and proposed recommendations to enhance accountability and efficiency;*

E. *Opportunities to improve NSW Health procurement process and practice, to enhance support for operational decision-making, service planning and delivery of quality and timely health care, including consideration of supply chain disruptions.*

RMHC would welcome the opportunity to be involved in further work where it can be of use to the Commissioner and Inquiry team in working to determine their recommendations.

Response to Terms of Reference

A. The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of equitable and accessible patient-centred care and health services.

At RMHC, we want to ensure equal access to treatment where no child and their family are left without accommodation or unable to stay together when they need it most, enabling family centred care to occur within NSW Hospitals.

Without access to adequate accommodation and other in-hospital support services i.e. Family Rooms, patients and their families from regional areas are faced with unfavourable barriers that hinder their ability to receive the health services they need in an equitable and accessible way.

Diagnosis and treatment of serious illnesses or injuries for children can place a significant financial burden on families during an already-stressful time. Parents need to take extended leave from work to travel to major hospitals to support their sick child, often at short notice. In an unfamiliar place, families incur significant expenditure including on food, laundry, transport, and parking.

To address these challenges, the NSW Government provides travel and accommodation subsidies through the Isolated Patients Travel and Accommodation Assistant Scheme (IPTAAS). IPTAAS provides financial assistance to patients that travel for over 100km one way or 200km within a week for medical appointments that are not available locally.

The IPTAAS subsidises access to Ronald McDonald Houses which provides a home-like environment at no cost for families. For families, being able to access a room at Ronald McDonald House results in a significant reduction in stress levels as well as improved physical, emotional, and financial wellbeing.

However, despite Ronald McDonald House being the accommodation service of choice for most parents and families who have the option, there is significant unmet need within the network of houses currently available (see appendix B).

In NSW the growing costs of accommodation and housing as well a general lack of availability in some high demand areas means that at times it is just not possible for parents and families to find adequate accommodation. Across major capital cities there are growing instances of family members sleeping in cars while their children are hospitalised.

Our national Social Return on Investment Research (SROI) (see appendix A) conducted in 2020 has shown us that for an average stay of 11 days in a Ronald McDonald House, a family will save around $1,265. The proximity and facilities of our Ronald McDonald Houses (including specialist isolation rooms and units) also allow hospitals to delay admission, or discharge patients a little earlier resulting in significant cost savings to both the families and the hospitals.

There are significant opportunities to look at ways to better integrate accommodation services with

health services and ensure patients are supported holistically throughout their time in the NSW Health system, suggested approaches are included later in the submission.

In addition to the availability of accommodation, some patients face barriers due to the eligibility criteria of the IPTAAS scheme which was designed with adults rather than children in mind.

Various research and reports have shown that there is an increasing number of families that just miss out due to distance eligibility requirements, but unfortunately still have hours to travel which hampers their ability to return home. RMHC recognises there is a group that has been termed "Bedside Families" (see appendix C)– those families who are unable to benefit from saying at a Ronald McDonald House due to not fitting the criteria of distance under the IPTAAS – who spend a significant time "living" by their child's bed.

While an adult can reasonably manage if they are required to be 100km from home for hospital treatment, a child cannot. By way of example, a family from Kiama, Shellharbour, Gosford, or the Blue Mountains are all less than 100km from Sydney CBD. However, a parent (sometimes they are single parents) with a 1-year-old in hospital and a 3-year-old at home cannot reasonably travel back and forward daily for months at a time while supporting a critically unwell or injured child.

Based on our own experience we believe greater flexibility within the distance eligibility criteria of the IPTAAS (for children only) would significantly improve the lives of families with critically unwell or injured children, enhance the importance of family-centred care in the NSW health system, and improve the overall delivery of accessible and equitable health services.

RMHC would welcome recognition of the importance of accommodation services in ensuring equitable access to health services for NSW children and their families.

In addition to accommodation, services such as Family Rooms support the delivery of patient centred care by reducing costs of basic services for families as well playing a critical role in supporting parents to care for themselves. Parents report that the presence of a service like a Family Room that is near the ward substantially reduces stress levels and provides a lifeline and sense of normalcy at an otherwise challenging time. Parents who are better supported are in turn more able to support their children.

The existing governance and accountability structure of NSW Health, including:

i. the balance between central oversight and locally devolved decision making (including the current operating model of Local Health Districts)

RMHC understands and supports the benefits of a governance model that enables local input, as well as management as currently delivered in NSW through a decentralised model that allows for local decision making.

However, there are several structural issues which, as RMHC believes, present barriers to service integration and the holistic consideration of patient needs.

As they are currently structured, LHDs can partner with non-government organisations such as RMHC to deliver services such as Family Rooms or Ronald McDonald Houses to patients.

However, in many if not all instances, direct support from the LHD would result in a loss of funding from the LHDs' own balance sheet creating a direct disincentive to collaboration that could improve the experience of patients. While the position is understandable from the perspective of the LHD that has many budget pressures, it results in missed opportunities and should be reviewed.

In addition, when funding or collaboration is being considered it is often unclear whether it is NSW Health or an LHD that has final decision-making powers. RMHC would welcome clarity in relation to key decision-making processes when funding applications or requests for space within hospital redevelopments are being considered.

RMHC recommends consideration of changes that would help ensure LHDs are not disincentivised from engaging in partnerships that could improve the experience and care of patients.

RMHC would also welcome state-wide recognition of the criticality of accommodation and other support services like a Family Room for families with children undergoing treatment away from home over extended periods, and the inclusion at a policy level for these services to be included in any hospital development or redevelopment.

Strategies available to NSW Health to address escalating costs, limit wastage, minimise overservicing and identify gaps or areas of improvement in financial management and proposed recommendations to enhance accountability and efficiency.

In NSW, bed blockers (patients who can be discharged from a medical perspective but have nowhere to go) contribute significantly to increased costs, system inefficiency and challenges for staff.

The impact of bed blocking cannot be underestimated. It results in increased wait times in emergency and for ambulances and can delay elective surgery.

While there is no one silver bullet that will solve this issue, there are opportunities to increase the availability of step-up/step-down services as well as co-located accommodation services to help ensure that people are only taking up a hospital bed when they absolutely need to be. In almost all cases, patients prefer to be outside of a hospital environment when they can be, which is especially true for families and children.

Facilities such as the Ronald McDonald Houses and Family Rooms are effective programs that support NSW Health to address costs, wastage and overservicing issues associated with running the health system. The proximity of the House – including specialist isolation rooms – allow hospitals to delay admission, or discharge patients a little earlier resulting in significant cost savings for NSW Health. In addition, in instances where a patient is undergoing ongoing treatment, they may be able to be discharged in between treatments. Across Australia between 2018 and 2019 the proximity of facilities of the House (including specialist isolation rooms) resulted in 18,000 avoided bed nights and $31.8 million per annum in reallocated resources for partner hospitals.

RMHC's programs are also vital to reducing the mental load of hospital staff, whose attention can be refocussed to serve other patients when seriously ill or injured children are discharged to Ronald McDonald Houses. Hospital staff also experience reduced mental load and are better able to focus on clinical outcomes when families are well rested and less stressed.

It is evident that the step-up and step-down model of care takes a significant amount of pressure off the health care system in NSW and is therefore an existing strategy available for consideration.

A failure to prioritise accommodation, support, and financial relief for patients, particularly in the case of families with children suffering from serious illnesses or injuries, places a significant burden on the public health system. In addition, missed opportunities to improve patient outcomes and experience often result in higher health system costs at a later due to readmissions.

The provision of Family Rooms within close proximity to paediatric wards and neonatal intensive care units in hospitals provides families with a place away from the ward to relax, have a meal, do laundry but be close by should they be needed by their seriously ill or injured child. Staff are also able to refer families to the Family Room when they need a break. For long-term hospital stays, providing adequate support for families within the hospital reduces the burden on staff to care for the families, allowing them to concentrate on the patients.

RMHC recommends the inquiry further consider the social and cost benefits that could be gained by supporting the additional, systematic provision of accommodation and other support services for families within or close to public hospitals.

Opportunities to improve NSW Health procurement process and practice.

RMHC believes there is an opportunity to look more holistically at procurement, particularly when redeveloping or building new services to ensure there has been adequate consideration of the entire patient journey. It is our view the involvement of not-for-profit, charity and other partners such as RMHC throughout service planning and procurement processes for new hospital builds would result in better outcomes for patients and staff.

It is well established that improving the quality and experience of care for sick patients has an overall impact on the delivery of quality health care. As such there is a lot to benefit from including partners – such as RMHC – which work to fill gaps in the patient's health journey that otherwise may not have been considered, in the overall procurement and service planning process.

While NSW Budgets over the past decade have included billions of dollars for hospital infrastructure, there has been no allocated funding to expand the services of RMHC or like services. We consider these services to be a vital element of hospital infrastructure, allowing families not only to receive treatment for their critically ill or injured children but to be able to be nearby and supported while doing so.

Over the past decade RMHC has experienced a broader a move away from co-design and partnership approaches. While RMHC always welcomes the provision of additional health services, the growing need for both additional Family Rooms and RMHC Houses is not being met, in part due to a lack of engagement in the procurement of new redevelopments.

With the current investments being made across the state in health infrastructure, we know the demand for our services will continue to increase.

RMHC would like to see further consideration of support services including those provided by non-government services within procurement processes and system design, to ensure that the provision of accommodation and support services are not inadvertently excluded.

We thank the NSW Special Commission of Inquiry for the opportunity to provide this submission and look forward to additional collaboration and discussion in the future as we support seriously ill children and their families. Please feel free to reach out at any time on [redacted] or via email at [redacted] with any questions or requests for additional information.

Warm regards,

Barbara Ryan
CEO of Ronald McDonald House Charities Australia

Appendix

A. SROI Data – 2020

Below are the relevant excerpts from the report. The full report is included as an attachment to this submission.

About this report

The Social Return on Investment (SROI) methodology was used to identify, measure and value impact of the RMHC Programs for each stakeholder, including families, sick children, hospitals, and the volunteers.

SROI is an internationally recognised, principles-based approach for understanding and measuring the impacts of a program or organisation. It provides a framework for accounting for a broader concept of value than is traditionally measured.

The methodology and the approach used to conduct this evaluation were approved through the Sydney Children's Hospitals Network Human Research Ethics Committee.

The outcome of the SROI analysis is a story about the value of change created, relative to the investment. The SROI ratio is a shorthand for all of the value for all of the stakeholders. For example, a ratio of 3:1 indicates that an investment of $1 delivers $3 of social value.

This report provides a summary of results from four individual Social Return on Investment analyses, for the following programs:

- Ronald McDonald House
- Ronald McDonald Family Room
- Ronald McDonald Learning Program
- Ronald McDonald Family Retreat

Executive Summary

RMHC provides much more than just a place to sleep.
RMHC provides holistic support to families throughout their child's journey with illness or injury.

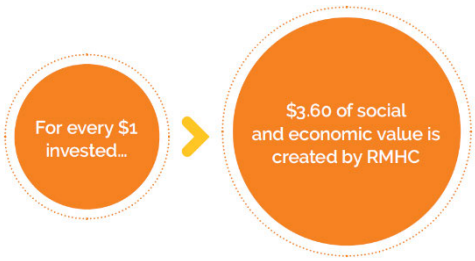
RMHC is there for families during the hospital stay.
When a child is in hospital, the Ronald McDonald House and Family Room help families to stay connected and focus on the child's recovery. These programs provide valuable practical and emotional support to families during a difficult and stressful time. By having this support, families experience improved physical, emotional and financial wellbeing and are better able to support their child's clinical journey and engage with hospital staff.

RMHC also supports families in between and after hospital stays.

When a child leaves the hospital and returns home, the Ronald McDonald Learning Program plays a vital role in assisting school aged children return to school-life and minimising the impact of any time away. The Ronald McDonald Family Retreats create the environment for families to connect, have fun and process the significant changes they may be experiencing between or after hospital stays.

Together, these programs play an essential role in enhancing family-centred care; and form an essential part of the healthcare and education systems.

When the total investment from RMHC's donors, government, volunteers, and corporate partners is compared to the social value created for families and the community, the result is an SROI ratio of 3.6:1. That is:



The SROI analyses of the RMHC House, Family Room, Learning Program and Family Retreat identified that RMHC creates value for a range of stakeholders:

Sick children experience an improved clinical journey as a result of physical and emotional proximity to the family.

RMHC's suite of programs enable a family-centred approach to caring for sick children from the time they are in hospital to transitioning back to school and everyday life.

Parents and family members feel better connected and less stressed, improving their capacity to focus on supporting their child through treatment.

RMHC's Programs remove major stressors, and help families spend time together in family-friendly environments.

Hospitals experience a reduced mental load and save on resources.

RMHC's Programs have become a vital part of the hospital infrastructure. Hospital staff can discharge patients to a nearby location and are therefore able to serve more people. Hospital staff also experience reduced mental load and are better able to focus on clinical outcomes when families are well rested and less stressed.

RMHC has the trust and goodwill of the community, which are essential for sustainable operations.

RMHC has been consistently rated as one of the most trusted charities in Australia. This trust is important to charities as it helps attract funding and volunteers both of which are essential to the sustainability of the charity and its ability to meet its purpose.

Volunteers and tutors have a rewarding experience that gives them a sense of purpose.

Volunteers and tutors are essential to the delivery of RMHC's Programs. Their work primarily benefits families, but also provides the volunteers and tutors themselves with a sense of purpose and job satisfaction.

B. Turnaway rates – NSW Ronald McDonald Houses

Outlined below are the number of families who have requested accommodation with a Ronald McDonald House and been turned away at each NSW location for 2023 as a minimum, and 2022 where the information is available. These do not reflect the entirety of the unmet as many families are aware there is not availability and do not approach our services as a result.

Ronald McDonald House	Turnaway rates	
	2022	2023
Greater Western Sydney	415	379
Sydney	163	204
Wagga Wagga	-	44
Newcastle	-	313
Orange		11

C. Understanding the needs of "Bedside Families" study

Below are the relevant excerpts from the report. The full report is included as an attachment to this submission.

Executive Summary

Ronald McDonald House Charities Australia have long recognised that a group of parents exist in the paediatric hospital system who despite having significant unmet needs, through circumstance, have less access to available services. Specifically, the interest has been in a group that has been termed "Bedside Families" – families who are unable to benefit from staying at a Ronald McDonald House, but often spend extended time "living" in a ward, by their child's bed. Following on from earlier research and the reported experience of Chapters, this research report seeks to better understand the greatest needs and

challenges of this group.

Three hospitals participated in the study - Queensland Children's Hospital (QCH), John Hunter Children's Hospital (JHCH) and Perth Children's Hospital (PCH) – providing access to members of their Family Advisory Councils or groups. A semi-structured interview approach was taken to asking questions, with prompts provided around some of the RMHC existing programs (such as Family Rooms) as well as potential projects like the Hospitality Cart concept. Data saturation was quickly reached with the participants repeating very similar challenges regardless of location. A thematic analysis highlighted the key concerns and provided an opportunity to share the words of the participants to illustrate these issues.

The challenges that relate to access and limitations or wariness from parents about leaving the bedside are also discussed. Ultimately, it is apparent that the concerns of RMHC about Bedside Families is justified. Not only is there a substantial list of unmet needs, but the ongoing impact of them on families can be highly detrimental. The financial, physical, social, and emotional impacts are wide reaching and may have long term consequences for these families.

Key findings

1. Feeling unseen by the health system

"...we fell outside of everything; we've been unable to get any form of help and there's not much about from others. I was really shocked. With outpatients I saw a lot more support you know – taxis and people running around for you and whatnot. I was given the social worker number, but she did nothing for us really. She listened to me once when I was really struggling, but so what. What am I going to with this in the longer term?"

2. Ongoing financial impact

One participant, who has also been on a hospital committee investigating costs to families, spoke about how the committee had calculated it was over a $120 per day for a parent when meals, parking, etc was factored in (and that was without considering the financial loss if a parent had to stop working).

"The whole experience was, was quite expensive to put it bluntly. Like if you can't work, you know, and you got to pay for parking. And then you have food, you got to pay for every single bit of food you're eating. You know, it's just a very expensive time being stuck in hospital."

3. Comments on the Family Rooms

The participants recognised that the Rooms meet a number of their key needs with food, sleep, and the chance to have a shower, all being consistently mentioned.

"The other thing besides to sleep and having access to showers was it was really good to have the facilities just to there was a frozen meal. You know, we didn't have to think about what food we ordered.

There wasn't Uber Eats at the time, we couldn't just think about what to eat and get it delivered to the hospital. So, it was really great. But that was all available. And we didn't have to find what we were going to bring in that day and have it all prepared. So, we could have a hot meal".

It appears that there is still some lingering confusion about the Family Rooms and who can access them "don't you have to be staying at House to access services?".

Even for those families that do know about the Family Rooms, there are barriers. The use of them seems to pose a conundrum for a significant number of Bedside Families – while they would like to access the Room and make use of the facilities (and they know they are welcome to), it still feels unattainable for them. For some it is the challenge of leaving their child, even for a few minutes. Many mentioned that having to leave not only the ward, but the floor was problematic.

"I think having the family room would make a huge difference to specifically the oncology ward, or any type of ward that has immune compromised kids that can't leave the ward. I just think it was a lot of parents talk about it now from the Ward how much it's missed. Because it was, you know, a place that other family members could come in and you could leave your room and go meet them there and just share, share and evening together or family time together, which is really hard to do now without that, and definitely just helped with meals. For parents. I just stuck in the ward. And like, even if they're not stuck, it's just such a financial burden to have to. You know, it's hard to actually go shopping for food, like yes, you have to get what's at the hospital otherwise you have to leave the hospital."

4. Access to accommodation

Included high on the list of needs for the participants was somewhere to sleep. They spoke of the gruelling hours without rest and having to take in information and make decisions while mentally incapacitated by tiredness. The quality of any rest gained by their child's bedside was poor due to lack of comfortable place to rest, the noise and constant interruptions. Some had slept in their cars.

"Generally, the kids are being monitored overnight so you're constantly being woken up … and you don't get sleep trying to juggle on that bed".

"We ended up starting to take in our camping gear for me to sleep on".

"Because you're so tired. And even though I'm only a few kilometres from the hospital, it certainly would not have been safe for me to drive myself home".

"The most important thing to know is we don't necessarily need a room overnight. We don't need it 24 hours a day, we're looking for an hour or two nap. And as parents, we're happy to lay our head anywhere where there's not a beeping monitor a screaming child. We only need an hour sleep just to be up to function and make medical decisions again, for our children".

All participants were keen for an option of somewhere close (preferably with in the hospital, and ideally on the same floor) they could access for a short rest. They wanted a "safe" space and were happy for it to simply be a sleep pod as long as it is clean/hygienic. They offered suggestions of booking systems.

"Sleep pods, the most horrendous things for any parent, like that person was saying is, and others will say, is sleep deprivation. We just need a place where we can go in close the door, know that it's clean, hygienic, and close our eyes set the alarm for one hour to get back up, get back up to the kids. And having that access is just so important. And these don't need to be big areas. Like some of these parents don't sleep for 72 to 92 hours, they're awake the entire time that listening to every monitor every beeping noise, they need to walk away, they need to make the most of the time when they're walking away. So, you don't want to spend an hour sitting down in the dining room you want to spend an hour with your eyes closed and passing out. So yeah, cold water and clean bed to lay on. Because I'm pretty sure there was one or two times where I know other parents who have gone and slept in our cars in the car park just to close their eyes. And that shouldn't be the case at all."

5. Access to Ronald McDonald House

While some participants brought up the subject of accessing the House themselves, we also specifically asked if families would choose to access the House for options like meals or showers if it was available, We specifically asked if they would be comfortable to leave hospital (and their child). There were quite mixed reactions.

"I have been into the one the Ronald McDonald House, next to the Children's Hospital. And I mean, it is beautiful. And crikey, I would have loved to have been able to go in there and just, you know, relax, spend time away from the hospital so that I had a break".

"I would have been happy to walk across the road to be able to cook something and bring it back to both my son and I, because it's not just the parents that get sick of the food and no offense. The kids get sick of the food, no matter what improvement we make, to that food cart, etc. The kids want their Mum's cooking."

However, others recognised that they would find it challenging to leave their child. They spoke about how even leaving the ward to get something from the café was difficult, so going to the House (even though they could articulate the benefits) was seemingly too hard.

"My daughter was just so anxious that I couldn't leave her side ever. So, it was really difficult".

"I mean, it would have been wonderful. I just don't know how practical, depending on the situation."

Understanding the needs of "Bedside Families"

Report for Ronald McDonald House Charities

October 2022

CLAIRE TREADGOLD
CONSULTING

Research report on understanding the needs of "Bedside Families"

Executive Summary

Ronald McDonald House Charities Australia have long recognised that a group of parents exist in the paediatric hospital system who despite having significant unmet needs, through circumstance, have less access to available services. Specifically, the interest has been in a group that has been termed "Bedside Families" – families who are unable to benefit from staying at a Ronald McDonald House, but often spend extended time "living" in a ward, by their child's bed. Following on from earlier research and the reported experience of Chapters, this research report seeks to better understand the greatest needs and challenges of this group.

Three hospitals participated in the study, providing access to members of their Family Advisory Councils or groups. A semi-structured interview approach was taken to asking questions, with prompts provided around some of the RMHC existing programs (such as Family Rooms) as well as potential projects like the Hospitality Cart concept. Data saturation was quickly reached with the participants repeating very similar challenges regardless of location. A thematic analysis highlighted the key concerns and provided an opportunity to share the words of the participants to illustrate these issues.

None of these themes will be of surprise to those involved with RMHC. They are consistent not only with earlier research, but with the experience shared among Chapters, team members and volunteers. Access to food, somewhere safe to sleep, and practical services such as laundry, storage, and a place to gather as a family, all feature heavily. The need for better and timely information about relevant supports and services is strong. As well as exploring these themes in more detail, this report also explores the participants insights into the Family Rooms and access to Houses.

The challenges that relate to access and limitations or wariness from parents about leaving the bedside are also discussed. Ultimately, it is apparent that the concerns of RMHC about Bedside Families is justified. Not only is there a substantial list of unmet needs, but the ongoing impact of them on families can be highly detrimental. The financial, physical, social, and emotional impacts are wide reaching and may have long term consequences for these families.

Context

Ronald McDonald House Charities Australia (RMHC) has long recognised that a group of parents exist in the paediatric hospital system, who through circumstance have less access to available services (including RMHC programs) but yet have equally high and unmet needs. Specifically, the interest has been in a group that has been termed “Bedside Families” – those families who are unable to benefit from staying at a Ronald McDonald House due to proximity to the hospital or other reasons, but often spend significant time “living” by their child’s bed. These families not fit the criteria about distance, but can unfortunately still have hours to travel, hampering their ability to return home. Or even if physically closer, simply due to their child’s condition feel unable to leave them even for short periods of time. The existence and challenges of these Bedside Families has been previously identified by the organisation in reports such as the 2019 Program Gap Analysis (2019) and the Families Room Report by UNSW (2017).

Methods

While RMHC team members have shared anecdotal evidence from families they have interacted with, in order to gain a better understanding of what the specific needs of this group are, a research project was designed. Initially it was planned that two hospitals would be chosen as representative of the group and their Family Advisory Committee (FAC) or equivalent body would be asked to participate. However, one of the initially targeted hospitals was reticent to involve this group without first having formal ethics approval granted. Given this is an internal report and not for journal publication, seeking ethics approval was not considered a worthwhile exercise (with the lengthy time and commitment involved in securing it). At this point, all RMHC Chapters were approached and asked to use their relationships with hospitals to identify potential participants. While unfortunately not all the hospitals that were nominated at this stage resulted in family involvement (due to challenges such as competing priorities and inactive groups), the additional contacts and support by the Chapters to arrange them were appreciated.

Three hospitals ultimately provided successful access to families, ensuring a varied geographical and socio-economic sample. They were the Queensland Children's Hospital (QCH), John Hunter Children's Hospital (JHCH) and Perth Children's Hospital (PCH). It is worth noting that while more sites and families could have been sought, the strong similarity of responses that came from these sites and the participants involved quickly reached “data saturation” point – where consistent themes were identified and reiterated. From a formal research perspective, adding further participants once this point is established would fail to provide any data of significant difference.

Format

In terms of format, QCH and JHCH both arranged additional time on the agenda of their regular FAC meeting for a consultation/focus group session. These groups were conducted over video conferencing. Questions (see Appendix 1) were provided in advance in order to allow participants to not only consider their own answers, but also to give an opportunity for them to canvas other families they may know of with similar situations – ideally, extending the input and data available. The third site was Perth Children's Hospital and they took the approach of advertising the project via their consumer newsletter, encouraging families to directly contact the researcher to get involved. The outcome of this was three, one-on-one phone interviews.

All interviews and focus groups were recorded and transcribed for accuracy, but the participants and hospitals have been de-identified as agreed in this report. While some

participants had accessed RMHC programs (including Family Rooms and the Learning Program), none had been eligible to stay in a House.

Research Questions

A semi-structured approach was taken to the focus groups and individual interviews, allowing flexibility and a natural flow. As previously mentioned, a set of questions was provided in advance to all participants to prompt ideas and contributions. The questions (see Appendix 1). were workshopped with RMHC in order to ensure the appropriate nuances could be captured. Prompts were given around some of the RMHC existing programs (such as Family Rooms) as well as potential projects like the Hospitality Cart concept.

It is worth nothing that in the case of both the QCH and JHCH focus groups, a small number of health professionals were also involved in the discussions. While in theory, their role in the Family Advisory Groups was as facilitators and observers, in both cases it became clear that they also had insights to share and a genuine interest in engaging in the discussions. They provided examples from both their own and family reported experiences. Where appropriate, they also assisted discussions by acknowledging any feedback provided by parents that was more directed at the hospital and its services than appropriate to scope of this project. An example of this is the cost of parking (which was raised by every group) and access to basic medications (such as Panadol) for parents after hours.

Analysis

A thematic analysis of the data was conducted and detailed below are the major themes that emerged. As with any group, there was a diversity of experience, meaning in some cases very specific suggestions were made that may not have direct relevance to a larger group. Where it was considered that these might still have some wider application, they have been included in the discussion. Illustrative quotes have been used to directly share the voice of the parents.

Results

As previously mentioned, this project follows on from the previous identification of this group and their needs in existing research. As such, there may be little of surprise contained in the findings. Rather, the key themes will likely both resonate and reiterate what RMHC team members have experienced or heard. There will be familiarity with the topics listed below such as access to meals/food, somewhere to sleep, practicalities like laundry and not being aware of what services they can access.

It is worth noting though, the sense of gratitude the families reflected in being acknowledged by this research project. Many spoke of how they feel like the ’fall through the cracks’ and are unseen by the health system.

> *“…we fell outside of everything; we've been unable to get any form of help and there's not much about from others. I was really shocked. With outpatients I saw a lot more support you know - taxis and people running around for you and whatnot. I was given the social worker number but she did nothing for us really. She listened to me once when I was really struggling, but so what. What am I going to with this in the longer term?”*

These Bedside Families also noted that where family and community support might initially sustain them with visits and deliveries, often if the situation warranted long stays, this support would fall away. And this was even more the case for those with chronic or complex conditions requiring repeated hospitalisation.

The ongoing financial impact of having a hospitalised child was consistently noted and brought up in relation to many of the key themes below. One participant, who has also been on a hospital committee investigating costs to families, spoke about how the committee had calculated it was over a $120 per day for a parent when meals, parking, etc was factored in (and that was without considering the financial loss if a parent had to stop working).

> *"The whole experience was, was quite expensive to put it bluntly. Like if you can't work, you know, and you got to pay for parking. And then you have food, you got to pay for every single bit of food you're eating. You know, it's just a very expensive time being stuck in hospital."*

Underpinning these overarching concerns, were a number of interlinked issues that added to the challenges and stress felt by these families. They spoke of the weight of the combined burdens, the stress and strain created, and the physical and mental toll taken. Listed below are the key themes.

Family Rooms

One of the most positive findings of the report was the gratitude and warmth towards the RMHC Family Rooms from those who had accessed them, *"we certainly appreciate how much we need that room".* The participants recognised that the Rooms meet a number of their key needs with food, sleep and the chance to have a shower, all being consistently mentioned.

> ***"****The other thing besides to sleep and having access to showers was it was really good to have the facilities just to there was a frozen meal. You know, we didn't have to think about what food we ordered. There wasn't Uber Eats at the time, we couldn't just think about what to eat and get it delivered to the hospital. So, it was really great. But that was all available. And we didn't have to find what we were going to bring in that day and have it all prepared. So, we could have a hot meal"*

Participants spoke highly of the volunteers in the Rooms and the level of support they provide. They noted that they provided informal support and social connection and helped to establish a comforting environment.

> *"The volunteers at Ronald McDonald are amazing. So hard during COVID when the volunteers were not on site".*

> *"Thursday was the day that guy would kind of make brownies for everybody to take the kids now. So just little tiny things that someone else? Absolutely. I'm taking out for Thursday the same group. So, it just makes such a difference being added to that other parents because I don't think that that's there anymore. There's no congregating say for other purposes and grab a cup of change on the ward. It seems to be dissipated away".*

And the Covid19 closures reiterated to many the value of the Family Room for families, "when the room was closed it highlighted the need for it with families. Having options for gathering and for private space".

Unfortunately, not all families who could benefit, had heard about the Family Rooms , "I have never, definitely never been told about them". And it appears that there is still some lingering confusion about the Family Rooms and who can access them "don't you have to be staying at House to access services?".

Even for those families that do know about the Family Rooms, there are barriers. The use of them seems to pose a conundrum for a significant number of Bedside Families – while they would like to access the Room and make use of the facilities (and they know they are welcome to), it still feels unattainable for them. For some it is the challenge of leaving their child, even for a few minutes. Many mentioned that having to leave not only the ward, but the floor was problematic.

> *"I think having the family room would make a huge difference to specifically the oncology ward, or any type of ward that has immune compromised kids that can't leave the ward. I just think it was a lot of parents talk about it now from the Ward how much it's missed. Because it was, you know, a place that other family members could come in and you could leave your room and go meet them there and just share, share and evening together or family time together, which is really hard to do now without that, and definitely just helped with meals. For parents. I just stuck in the ward. And like, even if they're not stuck, it's just such a financial burden to have to. You know, it's hard to actually go shopping for food, like yes, you have to get what's at the hospital otherwise you have to leave the hospital."*

For others it's the problem of not physically knowing where to go and concern about not being able to access the room when needed. Or not being able to access it due to health concerns. Uncertainty about opening hours was mentioned, but also the limit of them, ensuring it was not always a viable or suitable option. If you wanted something to eat during the night or a shower, it wasn't viewed as not possible to use the room.

> *"The room is phenomenal but there was no food for families and this was especially hard for longer stay families and the accommodation was not available even if the family is staying long term. This meant that there was nowhere to go and have a lie down even when there 12-14 hours a day".*

> *"Having the family rooms on the family room on the ward was, was great, because we had our own safe place to go to. Having that…that's just crazy that because the oncology kids, they can't leave, they walk, you know, immune suppress, like, it's just crazy that they'd have to walk through the hospital to go to the family room.*

> *"Sorry, we don't spend a lot of time there. Because my son's immune compromised. So, I'm really very careful where I go when, etc"*

> *"I think most families don't know that's there, or they don't know, they're allowed to access it if they're not staying at Ronald McDonald house. But so having some of*

those things, a clear booking system, so, and the reason being, depending on the size of the space, so obviously advertise it more. But if you've got a child who's oncology, immune compromised, you know, where you're really reluctant to, for whatever the reason, bring them, you know, into a general area. You know, there's a lot of anxiety from the parents, sometimes from the child, depending on the age. So, knowing that it's a safe space where they can go and the family can go, My child has never ever been to Starlight room, like any of the rooms within the hospital. Because when he's there, he's at his lowest, and I can't control who else is there. So having a safe space, you can book and feel confident, really important. And not every family would need that. But having it as an option would be really good".

Many ideas that came from the participants for addressing their needs seem 'purpose fit' for the Rooms. For example, there was discussion about needing a space for activities that would happen in someone's kitchen or lounge but didn't work by the bedside. They talked about having somewhere to *"have some private time or do some family stuff like wrapping Christmas presents for family members"* or having a gathering space for family time or celebrations

"...if you actually could make it feel like someone's living room, it would just make you detach from that kind of clinical environment for a bit at least"

Access to meals/appropriate food:

As can be seen in the section above, food was often at the centre of the discussion of need. Easy access to healthy and affordable meals or snacks were the most common theme that emerged across all sites. The cost of what food was available was considered prohibitive to most. And there were concerns about the quality and healthiness of it, not to mention the lack of choice or repetition for those with long or frequent stays.

While delivery services like Uber eats have made it easier in some respects, many reported as well as costly, it was unreliable and meal often went astray in the hospital setting (one participant joked about how some Doctors were benefiting from lost orders).

"…when it comes to food I wouldn't eat because it was just anything I'd have protein shakes in my handbag that I'd make once you fall asleep just to feel full to go sleep but meals were just gave up the kids with can't leave the ward with two kids in the room. Take the child sick if they're in isolation You can't leave which is a lot of times just getting a meal it's just thankfully bought in one per family revenue per family per fortnight one fortnight so Wow That to me is huge"

"Yeah, the meals. I just used to try and stock the freezer up and get my husband to drop off stuff"

"Something that I hear time and time again, is availability of home and like homestyle cooked food, that's affordable. And this is something that the hospital has grappled with for quite a while. The other thing that I hear is families, you know, siblings and others talk about wanting a space where people can go and sit and have a meal as a family" "

The desire to be able to eat as family was mentioned frequently. The participants talking about how it can help in providing some sense of normality, particularly for siblings. This was highlighted further by those who mentioned wanting to be able to prepare their own meals, both for practical reasons, but also for comfort. Some mentioned it would be a mental break, others spoke of the familiarity and potential comfort to unwell children of having Mum or Dad cook for them.

> *"A meal is actually an opportunity where you can engage with the other families in a in a, you know, an organic environment around food".*

> *"Eating can be a very big problem for a lot of children. And so just normalizing it in that sort of space can also bring a lot of benefits as well."*

> *"And, you know, and just other families on the wards that we're staying at the Ronald McDonald House. You know, I'd hear them on the phone saying, we're not going to make it back in time. Can you save us some dinner and knowing that they could just pop across to get some dinner and like, eat? It was a little bit hard. It was hard because we were in a similar situation. Not as, you know, we haven't left our regional home and family and things like that, but you still couldn't just pop home for dinner. So, it was like, Oh, I wish we had that too"*

> *"Somewhere to cook will have been handy when we're in long stays. So, I know that you guys have got those amazing kitchens over there at Ronald McDonald House, and they rarely in use. But just somewhere that you could cook something that wasn't microwave"*

When probed about whether they would be willing to leave the hospital if meals or opportunities to cook for themselves was made available at the House, there was some hesitancy (with mention that in the hospital would be better). However, some were keen and could see the possibilities of more social interaction as well. It was a very individualised response, heavily related to their child's condition and their comfort levels.

> *"You've got to go, it's at the front of the ward outside the doors, they have to be open for you. So, you've got to go out into the parent room to use the microwave. I have been out there at eight o'clock at night to heat up my food, and it's taken me 15 minutes to get back in because there's no staff available to let you back into the ward where your child is. So, I've stood there and eaten my food."*

> *"I know this would be a hard one. But just going back to the meals, because I know that there's so many parents who aren't able to leave the room long enough, you know, I don't know. Sorry, to even heat up a meal without giving you exactly. So maybe I just don't know how you would get a hot meal to those people. But you know, because I know that a lot of everyone are using Uber Eats and things like that. But you've still got to go downstairs to an emergent outside emergency that pick it up and then get back up into your room."*

Those who had accessed prepared meals from a Family Room expressed their gratitude. They appreciated the home cooked nature and ease of it, as well as the financial assistance. One participant spoke about how even getting a freshly baked muffin there was important to her.

"*My, my daughter was just so anxious that I couldn't leave her side ever. So, it was really difficult. Just really difficult to eat like because, you know, as a parent, you have to provide your own food and had kids when she was diagnosed, I was heavily pregnant. And I had my second daughter two and a half weeks after she was diagnosed. And I really appreciated the time that someone had dropped off freshly baked muffins and things like that. It was just a nice thing to, you know, pick your morning up or just a helpful little thing.*"

Somewhere to sleep

Included high on the list of needs for the participants was somewhere to sleep. They spoke of the grueling hours without rest and having to take in information and make decisions while mentally incapacitated by tiredness. The quality of any rest gained by their child's bedside was poor due to lack of comfortable place to rest, the noise and constant interruptions. Some had slept in their cars.

> *"Generally, the kids are being monitored overnight so you're constantly being woken up … and you don't get sleep trying to juggle on that bed"*
>
> *"We ended up starting to take in our camping gear for me to sleep on"*
>
> *"Because you're so tired. And even though I'm only a few kilometres from the hospital, it certainly would not have been safe for me to drive myself home"*
>
> *"The most important thing to know is we don't necessarily need a room overnight. We don't need it 24 hours a day, we're looking for an hour or two nap. And as parents, we're happy to lay our head anywhere where there's not a beeping monitor a screaming child. We only need an hour sleep just to be up to function and make medical decisions again, for our children".*

All participants were keen for an option of somewhere close (preferably with in the hospital, and ideally on the same floor) they could access for a short rest. They wanted a "safe" space and were happy for it to simply be a sleep pod as long as it is clean/hygienic. They offered suggestions of booking systems.

> *"Sleep pods, the most horrendous things for any parent, like that person was saying is, and others will say, is sleep deprivation. We just need a place where we can go in close the door, know that it's clean, hygienic, and close our eyes set the alarm for one hour to get back up, get back up to the kids. And having that access is just so important. And these don't need to be big areas. Like some of these parents don't sleep for 72 to 92 hours, they're awake the entire time that listening to every monitor every beeping noise, they need to walk away, they need to make the most of the time when they're walking away. So, you don't want to spend an hour sitting down in the dining room you want to spend an hour with your eyes closed and passing out. So yeah, cold water and clean bed to lay on. Because I'm pretty sure there was one or two times where I know other parents who have gone and slept in our cars in the car park just to close their eyes. And that shouldn't be the case at all."*

Only a few participants were aware of Family Rooms with bedrooms, and there was confusion around who can stay in the bedrooms if available (disgruntlement even in some instances). There were also a few questions raised about whether rooms at the Houses could be used if available for this purpose.

> *"And is there any way that Ronald McDonald could actually advocate for that, because I think it's a big issue, trying to tell families who wants to be with their children, and some gets to stay on site in the bedroom and some don't"*

> *"One of my child children was in the NICU over there (the USA) for like four days, but we got discharged after one day. And what they allowed me us to do was actually rent the hospital room if there was no need, like if it was vacant. And so, we paid $75 for the night, which I think was the cleaning fee. And we could stay there until we got kicked out, which was at 6am, the next morning, but it gave me the opportunity to stay overnight for that extra eight hours with my baby in the NICU. If there is vacancy in in the Ronald McDonald House that you could almost like rent the rooms out?"*

Laundry facilities

Access to a laundry and the ability to have clean clothes was a popular suggestion. It was noted that some hospitals did provide facilities to do your own washing, but participants complained that the machines often didn't work and that it was not safe to leave clothes there as they were either moved out of machines while still washing, or even taken. Physical distance to the laundry (often located on a distant floor) and reluctance to stay away from the child for too long were both factors.

> *"The fact that the laundry - that's all the way on another floor far away. I just I used to struggle to get up there to get back all the rest of it. That was just a nightmare. Trying to get clothes washed and whatnot. I really struggled with that aspect"*

> *"And I usually have to wait till my hubby comes up on the weekend. He stays with the little one whilst he's having his treatments in there. And while I go upstairs for two hours and do the washing and you'd have to take a book because if you can't, you can't just leave it good idea to walk away."*

> *"They're often not working. And things get pinched out of washing machines, and they'll take out wash that's halfway through to put something else in, you can't really control the bad behaviour of other families that sometimes happens. But there's often things that are out of order for a long time and that set your alarm for 3am and go down. That's what I used to do"*

Access to Ronald McDonald House

While some participants brought up the subject of accessing the House themselves, we also specifically asked if families would choose to access the House for options like meals or showers if it was available, We specifically asked if they would be comfortable to leave hospital (and their child). There were quite mixed reactions.

Some were very keen to be able to utilise the Houses.

"I have been into the one the Ronald McDonald House, next to the Children's Hospital. And I mean, it is beautiful. And crikey, I would have loved to have been able to go in there and just, you know, relax, spend time away from the hospital so that I had a break".

"If I could stay there, close by at Ronald McDonald House rather than at the hospital. Because, you know, the cost of parking, the cost of food, for me, that sort of it just adds up on top of everything. And I haven't worked for since he was born. Because I just haven't been able to, I've been going over in and out of, you know, hospital with him. So, I get it. They are always busy. Ronald McDonald House, but even if they could let families come across, if it was encouraged, if there was a, an option to come across and just use the facilities for dinners or break. A TV, you know, to watch a movie - just some sort of time out. The impact on carers would be huge. You know, it'd be they're still close enough to the hospital that they could go running back. You know, if my son texted me, I could go back there. And, you know, quickly check on him and be there for the you know, for the staff if they needed me, because I wouldn't be too far away. I could say to them. I'm just heading over to Ronald McDonald House to grab a bite or to have a break. And then yeah, it would just be ideal."

"I think when you're in for a long haul, you just desperately need something that you cook yourself, even just to scramble some eggs would have been in there that kind of already got excited about that. But in that circumstance, I think I probably would be willing to go across the road because it wouldn't be every night. But I don't know if that's even a possibility. I didn't know that whether that would be available even though I know the kitchens there didn't even occur to me to ask. So, one in the hospital would be better"

"I would have been happy to walk across the road to be able to cook something and bring it back to both my son and I, because it's not just the parents that get sick of the food and no offense. The kids get sick of the food, no matter what improvement we make, to that food cart, etc. The kids want their Mum's cooking."

However, others recognised that they would find it challenging to leave their child. They spoke about how even leaving the ward to get something from the café was difficult, so going to the House (even though they could articulate the benefits) was seemingly too hard.

"My daughter was just so anxious that I couldn't leave her side ever. So, it was really difficult"

"I mean, it would have been wonderful. I just don't know how practical, depending on the situation."

Some participants identified that in this situation, it would be beneficial if they could be visited by team members or volunteers from the House, particularly to bring meals to them.

"I don't think it would be practical for a lot of families because of the age of the children. I mean, if the kids, if the kids are well enough, they're generally trying to get them home. But if they're not well enough, you need to be on the ward. And you

couldn't drag an IV pole down to Ronald McDonald House, it's too far for most of the kids. Well, if you could box up a meal and go for a run, and do delivery that way, I mean, a benefit, you know. You could have a poster with a number you text if you're stuck without a meal. To let volunteers, know, I don't know that that to me would be more beneficial than heading out. I'd love to be able to say that. That would be wonderful. In an ideal world it would."

Others wanted to know if they could access the Houses for just short periods.

"Is there any option for families that are not eligible for stays to be considered for stays? Is there any ability to rent the rooms if they are not being used? Especially if in ICU as there is pressure to leave"

Information about/promotion of services

Families where aware that they were potentially missing out on a range of support from different organisations or even the hospital's own initiatives ("You don't know, what you don't know"), but were unsure of how to get more information. Even during the course of the focus groups someone would mention a service that they had used or heard of (e.g., a washing machine in Family room) and a chorus of "I wish I had known" would inevitably follow. Another parent gave the example of an art class that was offered only after 7 months into their stay. Some parents sought information through other parents (and then passed it on, even creating their own lists of useful information and "tips" to share with others) and others formed community led Facebook groups related to the hospital they were at.

"I give them like the pointers of you know, how to get about, how to navigate what services are good in the hospital depending on If you're in oncology you're not. If you've got a reference point like this, it is what's helped me - it might not help you but like parenting, here's some advice Take it or leave it see whether it fits with your family or not"

"…where to access help, so the Facebook group, groups I know that that's one that I get lots of questions about. Like what Facebook group will help me for this or that the other and I've got a variety of different illnesses that helps. I'm trying to think what else you know, silly things like where to heat up a baby bottle formula, or those are common questions that come back to you. "

There was also a sense that coming from a multicultural or non-English speaking background exacerbated this issue. One example was given of a recently arrived migrant, single parent who was struggling with multiple children. Another parent ultimately arranged help from a local community service. Indigenous families were also mentioned specifically, with some concern about the cultural aspects

"I just wonder whether there could be better supports in place for these people and more practical in a cultural aspect as well, because it's a completely different journey for an indigenous woman to birth in the city comparative to someone that lives in Bella Jura, or Clarkson, completely different experiences".

Some families thought RMHC could play a role in promoting what was available, *"they could be the ones reaching out to the hospital and finding the services that are available and*

communicating that to families." While admiring of the work done by the non-profit organisations in the hospitals, there was also a sense that at times they could coordinate better to support the families. This was most prominent from the health professionals.

> *"Every one of them works separately. So, we have all these separate relationships but they all they all are forming a service for families. And I just think that at some stage it's really nice that some of those organisations can work together to really think about which bits of the journey they are supporting. Because sometimes there is an overlap".*

Exercise options

Access, or encouragement to exercise was raised in all sites, but with different levels of enthusiasm. All recognised the value it could have, but some also struggled to see how they could achieve it (or it came further down the list in priority terms). But the majority were supportive of the idea of being offered the means and opportunity, through access to space and equipment, particularly if it was in close proximity to their child. Having a gym in the hospital (or at a Ronald McDonald House) they could use was popular. Other suggested providing information on local services (like free community yoga classes).

> *"I used to think that I would love an exercise bike or a treadmill to be able to be walk, like just wheeled into the room. We sign a disclaimer and the beeping and everything doesn't matter. Because it's during the day. And it sounds again, I'm sounding ridiculous, but I would, would have loved for an exercise bike or a treadmill"*

> *" I understand where you're coming from and treadmills and bikes that do have and they're great exercising like that. But even just on a bit of a lower level, just a yoga mat and an app that does yoga. Just a half an hour yoga session for a stretch and to move your body after sitting down for so long. And that's something that you know, I see you I agree, you would definitely not get away with walking in yoga mat out and doing a downward dog. But in other words, that could be the capacity to be able to do that kind of stuff".*

> *"I'd be bringing in the boxing bag."*

> *"Access to the gym. That is one thing that would be handy."*

A "Mental Health" Menu

During one of the focus groups, the discussion about exercise then flowed into the idea of creating some kind of service directory, but with an emphasis on listing self-care options to promote better mental wellbeing. The group was very enthusiastic about the idea of keeping an updated list of options, particularly those you could do 'bedside', circulated regularly. They also expressed interest in the "Take A Breath" program concept.

> *"We need a mental health menu. So, you basically have a list of things that you can have access to. So that could be from mindfulness, music, all the way through to yoga mats, to you know, the massage chairs that you can get to massage your neck or anything like that. Anything, all the way down to the exercise bikes, having access*

to book an exercise bike down on the rehab ward. So yeah, you don't necessarily need to do it in the room, it's great to do it in the room, but especially when your child is in that part. But a mental health menu, which is this is what you can have access to this is what we can support you with to have that family centred care, that would be cool".

"So, it's that novelty of when you go on a cruise or when you get to a resort and they give you a catalogue of all of the things that may relax you or may help you or inspire you. Imagine putting that in a hospital environment. Going, this is a mental health menu, we do this, we do that, these are our current times. And the way to get around the adjustments is that it can be short. So essentially on boat cruises, they stick underneath your door, what's available today"

"Especially if you're just getting on an app and you go oh, this is available today. I'm going to take my other daughter (not the one that's currently in hospital) and then take my other daughter and do mommy daughter yoga or something like that. I'm seeing how you could do that with Ronald McDonald House you could do and there are meals available tonight. And there's an art class available for siblings, etc".

RHMC Hospitality Cart

While only a few participants volunteered ideas like the Hospitality Cart concept, when it was specifically mentioned as an innovation, all expressed keen support. They appreciated that not only would it come to them at the bedside, but that it would provide much needed things at no cost. One participant had experienced something similar at Townsville Hospital offering "snacks and drinks, magazines and activities for the kids" And they also noted that the Emergency Department had offered a box for breakfast with "a muffin, juice box and a sandwich which is fantastic as the I had not eaten in 24 hours. Really important to have snacks available in NICU".

The participants were prompted to suggest what would be useful to have on the cart. Some mentioned that they had previously been offered a toothbrush and toothpaste which was very helpful, but there were certainly other items that would be greatly appreciated. These included ear plugs and sleep masks (the noise of the wards and trying to sleep was often mentioned as challenging), socks for warmth, and charging stations or cables for mobiles. Water and healthy snacks were considered a good idea. The 'nice to have' items were related to entertainment and distraction either for themselves or their child/ren – magazines, craft packs, etc. And a few participants mentioned having some basic medications for headaches or heartburn for parents but were cognisant that RMHC would be unable to provide this for legal reasons (and this suggestion was redirected to the hospital representatives).

"*Even just some like two-minute noodles, just something of carbohydrates, so bellies, feel full. Because I know, I've known families to be homeless in their car living out of their car, you know, relocating from parks. They don't have a fridge. And yeah, that would be hugely beneficial to those families. I'm thinking of in the instance that they can't go and afford a $7 box of chips on the hospital floor"*

“I do remember there being like little toiletry bags. I don't know if that still happens. But that was really handy because quite often, you're you just go into chemo for the day and then all of a sudden temperature spikes and that's an automatic two day stay in hospital and if you don't have a hospital bag pack it it's you know, you've got nothing so a little toiletry bag. really sticky brushing teeth, or what have you”

“Yeah, absolutely anything that can come to them. Yeah, like even just bottles of water. Yeah. You know, it's, it's definitely helpful. Yeah. Yeah. And, you know, magazines or something like that because it gets so boring. And if money was no object like a chocolate or a treat.”

“Also, charging cables, maybe if even if they're just to borrow, because the time you forget them? Or extension cords, that sort of thing. I know, even if they could have the packet coffee so that you can make your own”

“Definitely magazines. And I know for a while there, there was these craft packs that would come in. I don't know why they stopped it stopped when we moved but it was craft so that I could sit and help my son with so that just for something different just so that he wasn't either watching TV or doing schoolwork. But something fun, you know”

“Anything that I say like an airline, you get on the plane, you get your little blankie you get your toothbrush, your toothpaste, and a pair of socks. And you just have a great sleep, put the sleep mask on and you're done”

“You walked around with just your purse because you just turned up in an ambulance. You've got no warm clothes, you've got nothing on your feet, you turned up in your work high heels even some days covered in vomit. All you want is a toothbrush, a comb, brush your hair, and then a pair of socks on a bit. But yes, ear plugs and face masks are really great”.

Practicalities

A range of smaller, but important ‘practical’ matters were consistently raised by the participants. Often these were included int the context of larger concerns, but as having a cumulative detrimental effect on their experience. These included the following issues.

Parking

As previously mentioned, the cost of parking was mentioned in every consultation. Participants recognised that it was not something that RMHC could necessarily influence but felt that it had to be mentioned for the financial strain it caused.

Babies needs

Some participants spoke of the challenge of juggling having a sick child and also coping with the needs of another (well) baby. Having somewhere to physically put the baby down was

raised as a problem, with suggestions that the loan of a port-a-cot or similar equipment would be appreciated.

> *"I walked into the hospital with her and three-month-old. And she was raised on the hospital floors. She was one of three and I also had to get pregnant in that time to have a baby to have stem cells on standby. So, I also had a second child that was raised on the floors of oncology".*

> *"Simple things like just putting the kids down and like the little babies down on the floor because obviously they have chemo, and the floors are washed but you just don't know. And obviously, the absorption being a nurse I knew that it wasn't a safe, sensible thing to out some particular couple of layers down and just simple things like a little porta cot to throw them in would have been brilliant".*

Mentions were made at all sites about the need to provide somewhere for mothers to breastfeed or pump milk. The combination of lack of privacy and comfort left some parents trawling the halls, or in one case a woman even attempting to fit in pumping while driving to the hospital to see her other child. One woman did mention using the RMHC Family Room, but not feeling certain it was appropriate.

> *"I am looking for a quiet spot anywhere in this hospital where I can just go and pump or just go and feed my baby without you know, having to struggle with blankets and covering them and feeling uncomfortable and all the rest of it and I still haven't found a good spot. Sometimes the bedrooms which are like part of the Ronald McDonald Room, they will be empty and we'll pop them in like when I've been there. I'll say Oh, go check out those rooms that they have free jumping in there, but it's kind of like camping on unknown ground. I don't know if there is a dedicated breastfeeding room anywhere in the hospital"*

Fridge space

Harking back to the issue about having access to food, some participants noted that when they were able to bring their own from home, having somewhere safe and clean to store it was often a barrier. There were multiple stories of food going missing.

> *" <meals> is the storage of them. We're lucky, we're lucky because there are four fridges in the hospital for the CF wards …but if there's eight CF kids in, there's only four fridges so I don't know if maybe there's a way, they could possibly add funding to buy more fridges or supply families with portable fridges"*

> *"We ended up buying a camping fridge to take in simply because I needed my own sort of milk. I needed to somewhere to store leftovers so that I could reheat them not only for myself but for him because you know what, they don't always want to eat lunch and dinner when it comes around"*

> *"And if you leave, and it's terrible, because it's a hospital, but if you leave food out in the fridges that are supplied, but it goes, and it can be in your own Tupperware containers and everything, and people will take it and they will heat it up and eat it and take container."*

"One time I found a homeless man going through the fridge"

Phone Charging

Quite a few participants spoke about wanting to have somewhere to charge their phones, or to be loaned a charging cable (having often rushed to come to the hospital without one). Given many weren't comfortable leaving their child, they wanted this to be available bedside.

Privacy

The challenge of finding a private space was raised. Families were seeking somewhere they could have a quiet conversation uninterrupted or make private phone calls. As one participant stated, there is *"nowhere to make a private phone call or have a private conversation when sometimes there is not good news".* Many reflected the difficulty of speaking while hiding their emotions and wanting to be able to conduct conversations away from their child's hearing or sight.

Access to outdoor space

Having access to the outdoors, preferably a green space was raised in all sites. Again, it was recognised, this may not necessarily be the role of RMHC, but it was something that people struggled with during longs periods in the hospital. *"If possible, access to outdoor space as well. People are very claustrophobic in hospital for a long period of time".* This desire was often couple with a request for a play space for visiting siblings.

Storage

The issue of storage space was discussed in a few different contexts. There was the experience of families who had dealt with the loss/theft of food and/or other belongings. The suggestion was that having a locker would be really helpful, especially to counter the challenge of having to bring things in and out of the hospital constantly.

Some spoke about how cumbersome this was, particularly for families who had regular hospitalisations. They often needed help lugging belongings between wards and their car or other transport option. One family said, "we ended up buying a trolley", having wished there was one they could borrow.

For others they requested a location they could have deliveries sent to, confident they would be accepted and stored until they could collect them. For example, one participant spoke about wanting to get deliveries of nappies and formula and how useful it would have been to have somewhere to send them. There was a reference to how some local community Facebook groups had been set up to do this kind of delivery but it is still challenging to arrange to meet and handover the goods.

Siblings

The majority of participants referenced the challenge of being by the bedside of one child while balancing the needs of their siblings. Parents are highly aware of how the siblings are disadvantaged in multiple ways by the experience, however, feel they have limited options.

The desire for some kind of childcare or babysitting close to the ward was raised (some specifically requested a place where adolescents siblings could "hang out" without supervision). In some cases, it was as simple as parents wanting their other children looked after for a few minutes so they could speak with the doctors privately and/or uninterrupted.

> *"The final thing that comes up all the time is that parents have got sick children and tried to look after them and look after their other children at the same time. And I really believe that at some stage we have to think about how do we care or provide a service where we are responsible for providing some care. But well children because it then allows families time with their sick infants and sick children."*

> *"When siblings come to visit, sometimes, like my husband would bring the other kids in, and they would get bored at bedside within a minute or two and be wanting to go and find something else to do. And I would send them out looking, you know, just go for a walk. There was never any where to send them. But it often meant that my husband would leave before he really wanted to because he wanted to have a proper talk with me. And he wanted to hear what the doctors had said, but the kids would be going "Dad, we're bored. We've had enough we want to leave". So, if there was somewhere if they were able to access the adolescent space, that'd be really good".*

There was gratitude expressed towards RMHC (and other organisations) for the programs that were provided for siblings. Just the fact that siblings were thought of and included was welcomed and any that provided additional support of any kind, were appreciated *"those little things that make a huge difference to them".* One participant suggested providing movie tickets or similar activities to promote a break away from the hospital. Others noted any materials or entertainment options to distract them was helpful.

> *"Children, all they remember at the moment, we might have problems down the road, but at the moment, all they remember is all the wonderful things they get given when they come to hospital. So, the art, the art supplies that were always available. And one time we came in, they've got given like a brand-new toy from someone and they like you can totally buy my kids affection and love and it's worked tremendously and I will be ever grateful to the hospital"*

It was noted that siblings were at risk for longer term issues as the inadvertent result of parents being unable to spend time with them. And this of course created concern among the parents, but without any capacity to alter the situation.

> *"…it can leave lasting effects on children, a huge journey afterwards with obviously there was separation anxiety, then it causes all different issues for the children who are well, as you say, for separation anxiety, and, and all the trauma as well. And obviously, when they're young, they don't understand that you know. It's not, they see, sometimes there's been a choice who you spend on that child with it with at a time when they don't see the bigger picture because they're obviously children".*

Limitations

It is worth nothing that this study has a number of limitations. The families that participated were either already motivated to be part of an advisory group or were actively receiving materials from the hospital about advocacy activities. This could mean that voices of less confident or even simply time poor families are not captured. This risk is slightly lessened though by the reflection of the themes in other relevant literature. Similarly, by only accessing three sites (and all of them major paediatric tertiary hospitals) there is some bias in the sample group. However, again, consistency with previous research reduces this. There was limited diversity in the participants which could lead to under representation of some issues (such as language or cultural barriers) and it was only parents who were representative of the family voice. Siblings or even grandparents or other carers may have been able to add more nuance. However, the literature regarding the needs of these groups is consistent with the findings of this report.

As mentioned throughout the report there were issues raised that even the participants were aware are beyond the scope of RMHC, but that they still felt were important to be voiced. In one case, a parent hoped that this discussion might be used to advise the hospital, **"***I'm hoping even though this is Ronald McDonald House is that they might be able to feed it back to the hospitals as well".*

Conclusion

This research reiterates and adds weigh to previous reports and the concerns of RMHC Australia about the challenges faced by Bedside Families. The findings clearly demonstrate that this group is indeed struggling with their circumstances and have significant unmet needs. The impact of these needs is having detrimental effects on the physical and emotional wellbeing of families. The strain on finances, relationships and family dynamics is well documented elsewhere and was reflected in the participants insights shared with this project.

It is some of the most 'basic' needs that are providing the biggest challenges for these Bedside Families. They lack access to homecooked (or affordable) food and meals, somewhere to take a nap, wash their clothes, shower, charge their phone or safely store their belongings. They would love to be able to share family time in more comfortable settings, better include siblings, talk to other families, and look after their physical and mental health. They also lack access to accurate and timely information about the different support programs and services. Many participants were unaware of options that already existed and would be of value (including Family Rooms). And there are families for whom these services need to be available predominately at the bedside, as they do feel unable to leave their child.

As well as being grateful to RMHC for acknowledging their existence and needs through this project, many participants have had some interaction with the organisation through a Family Room experience or involvement with the Learning Program. For those families, this involvement was highly spoken of. Sadly, there remain some families that either didn't know what support was available or had been misinformed about their eligibility, or even the purported "cost" of programs.

Overwhelmingly, there was a sense that it is the ‘little things that matter the most’ and that any contribution to making their experience easier, would be meet with appreciation. More importantly, initiatives to address these needs could have a significant impact for these families, lessening the financial burden, improving their physical wellbeing, easing distress, and supporting them both socially and emotionally.

APPENDIX 1

FOCUS GROUP DESIGN

Protocol: Focus group utilising Hospital-based Family Advisory Councils. Semi-structured questions. Where possible sharing some of the questions in advance (or a description of aim e.g., “we’d love to learn more about what would have helped make life easier for you”) to allow people to consider and come prepared. Even encourage them to ask other families they may know who have been in same situation. At beginning of group reiterate purpose and reiterate this refers purely to non-clinical/hospital care.

Recommended Format: 45-60 min facilitated group (recorded to ensure accuracy of quotes). Approx. 6 participants. As well as the external facilitator, a RMHC representative may be present. If the group doesn’t know each other brief introductions will be held. The facilitator will provide a quick explanation of purpose of activity and how it will work (i.e., not necessary for each person to answer question in turn, feel free to add on previous answer, etc). Facilitator to ‘draw out’ any quieter members of group and use additional prompts to questions where necessary.

Suggested Questions:

- Tell us briefly about your situation, your child and why they were in hospital and for how long
    - Prompt: where do you live, what other support did you have
- Can you share your experience of being on the ward in the hospital?
- Looking back, what stands out about your experience (good or bad)?
    - Prompt: Why? Can you tell us more about that?
- What would you describe as the challenges?
    - Prompt: Did you have access to food? Time out? Cost?
- Was there something that worked well?
    - Prompt: Rest area? Access to tea/coffee?
- Can you think of any additional help or resources you wish you had access to on the ward? What did you need?
- With the benefit of experience, what do you wish you knew then, you now know?
- Did you know about or use any RMHC programs?
    - Prompts: Family Room? House? Learning Program?
    - If not, would you like to have? (If so, what/why?)
- If RMHC offered <insert idea e.g., cart/dinner at House> would you use it?
    - Can you think of any barriers to you using it?
    - Can you think of anything that would make it more likely?
- Using your knowledge and experience, if you could improve the experience for the next family what would you introduce or change? Or what advice might you give a family just starting a similar experience spending long amounts of time on the ward?
- Anything else you can tell us you think might be helpful?

Ronald McDonald House Charities® Australia

Social Return on Investment (SROI) Report

Ronald McDonald House Charities® Australia

March 2020

SVA Social Ventures Australia

Foreword by RMHC® Australia

Our mission is to support the ever-changing needs of seriously-ill children and their families. This report reveals the impact of the multiple ways in which we seek to fulfil this mission.

Since our first Ronald McDonald House opened in Sydney in 1981, we have continued to expand the programs we offer, and the locations we offer them. Over that time, these programs have become an essential part of the healthcare infrastructure in Australia. Families rely on us during some of the most stressful periods of their lives, and the hospital system relies on us to help them focus on treating the children in their care.

This report is an important moment for RMHC. It allows us to step back and understand the many ways in which our work impacts the lives of families, and the health and education systems. I continue to be touched by the scale of the impact that RMHC has on families. This is only possible through the ongoing efforts of thousands of people: families; volunteers; our staff; hospital and allied health staff; and our corporate partners.

Barbara Ryan
CEO

Ronald McDonald House Charities® Australia

Ronald McDonald House Charities® Australia

Foreword by Social Ventures Australia

This report is the culmination of several months of work to understand the many ways in which RMHC impacts the lives of families with seriously ill and injured children. In preparing this report we heard from over a thousand people, who shared their experiences with us. We have synthesised those experiences to tell the story of RMHC's impact in the following pages using the Social Return on Investment (SROI) methodology.

SVA is Australia's leading practitioner of SROI, which is an internationally-recognised framework for understanding, measuring, and valuing social, economic, and environmental outcomes. We remain at the forefront of developing and implementing outcomes management and SROI frameworks and evaluations for social purpose organisations.

We thank all those who generously contributed their time to help us develop this report: families; volunteers; staff; doctors; social workers; and many others. And we hope that this report provides useful insights that will help RMHC to continue to refine and build its impact.

Simon Faivel
Director, Consulting

Social Ventures Australia

SVA Social Ventures Australia

About this Report

RMHC Australia commissioned SVA Consulting to undertake an evaluation of its programs – RMHC House, Family Room, Learning Program and Family Retreat - to determine the socio-economic returns for all stakeholders.

The Social Return on Investment (SROI) methodology was used to identify, measure and value impact of the RMHC Programs for each stakeholder, including families, sick children, hospitals and the volunteers.

SROI is an internationally recognised, principles-based approach for understanding and measuring the impacts of a program or organisation. It provides a framework for accounting for a broader concept of value than is traditionally measured.

The methodology and the approach used to conduct this evaluation were approved through the Sydney Children's Hospitals Network Human Research Ethics Committee.

The outcome of the SROI analysis is a story about the value of change created, relative to the investment. The SROI ratio is a shorthand for all of the value for all of the stakeholders. For example, a ratio of 3:1 indicates that an investment of $1 delivers $3 of social value.

This report provides a summary of results from four individual Social Return on Investment analyses, for the following programs:

- **Ronald McDonald House®**
- **Ronald McDonald Family Room®**
- **Ronald McDonald® Learning Program**
- **Ronald McDonald Family Retreat®**

The analyses looked back at 18 months of the programs' operations and activities between January 2018 to June 2019.

RMHC Australia

We keep families together and close to the care their child needs

When a child is diagnosed with a serious illness, it can have a devastating effect on families. On top of the uncertainty and fear, there's added stress for families who don't live close to the medical care their child needs.

RMHC Programs and Services

RMHC has a wide range of programs which help families to stay together so they have the support of loved ones when they need it most.

RMHC Australia Programs are delivered by

11	~240	~2145
Local Chapters	Staff	Volunteers

Ronald McDonald House

Ronald McDonald Houses are located adjacent to hospitals and provide family-friendly accommodation and other support at no cost for families with a seriously ill or injured child being treated at the partner hospital.

18 Houses in seven States and Territories

Ronald McDonald Family Room

The Ronald McDonald Family Room Program is designed to support the physical, emotional and practical needs of families during their child's hospital stay. As of December 2019, RMHC had 19 Family Rooms in operation across Australia. The Family Rooms are located close to the hospital wards where infants and children are being treated. All family members, including the child that is undergoing treatment, as well as friends can access the Family Rooms.

19 Rooms in five States

Ronald McDonald Learning Program

The Ronald McDonald Learning Program assists students in a mainstream class who have missed school due to serious physical illness or injury catch up on missed education.

8 Local RMHC Chapters operate a Learning Program

Ronald McDonald Family Retreat

The Family Retreats Program provides families with an opportunity to getaway from the everyday, where families can rest, recharge and reconnect as a family. The Program is offered to families with a seriously ill child or families who are grieving the loss of a child.

Families can enjoy up to seven days of free accommodation, offering an escape for those who might otherwise be unable to afford any time out due the pressures of caring for a seriously ill child.

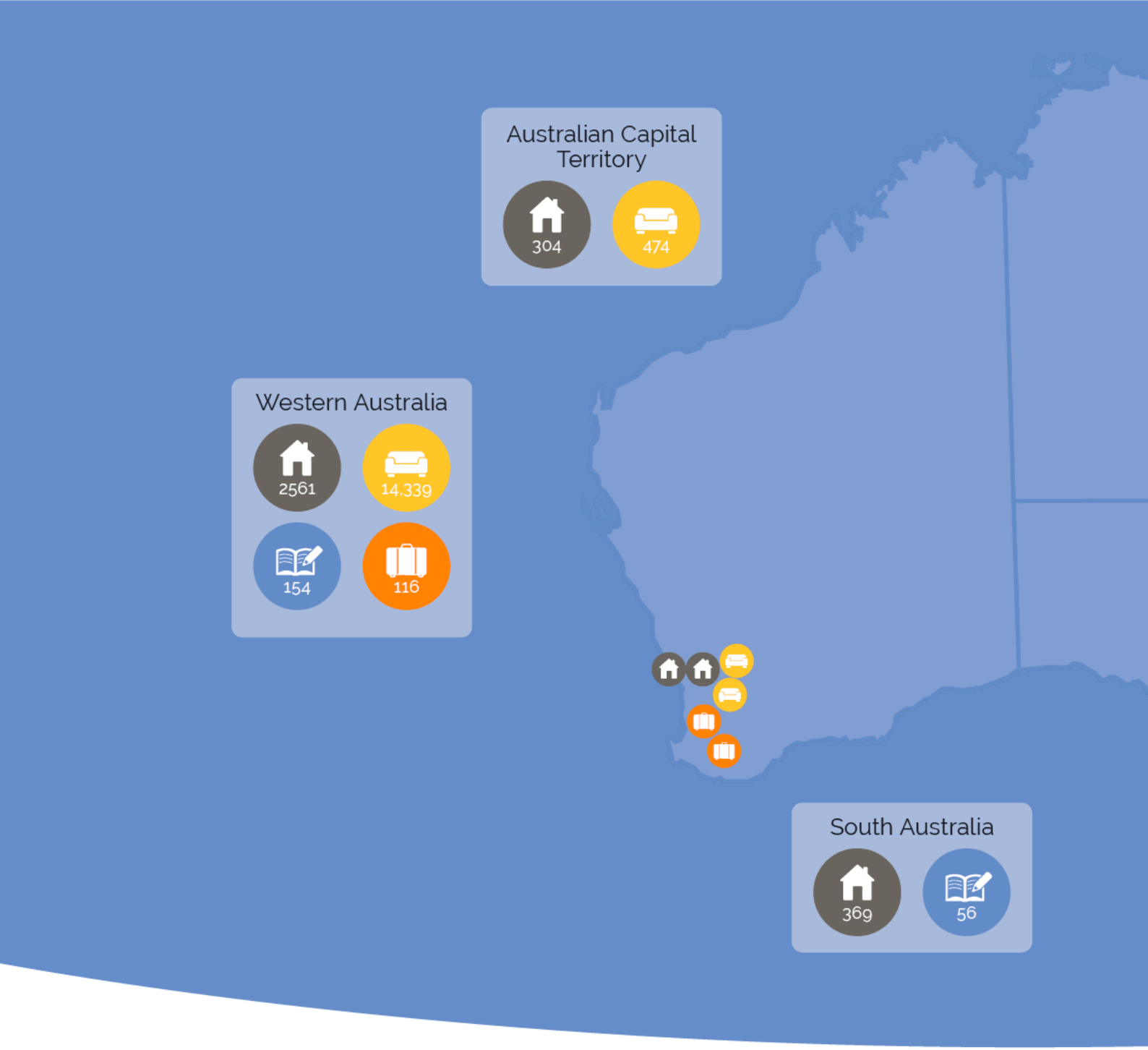
5 Retreats in QLD, NSW, WA

Ronald McDonald Care Mobile*

Children living in rural and remote communities don't always have access to health care near their home or school. The RMHC Care Mobile, in partnership with Royal Far West, regularly visits rural areas of NSW, allowing children access to health care.

1 Care Mobile

*This program was not evaluated as part of this project



Ronald McDonald House

No. of families who stayed at a House

Ronald McDonald Family Room

No. of families who visited a Family Room

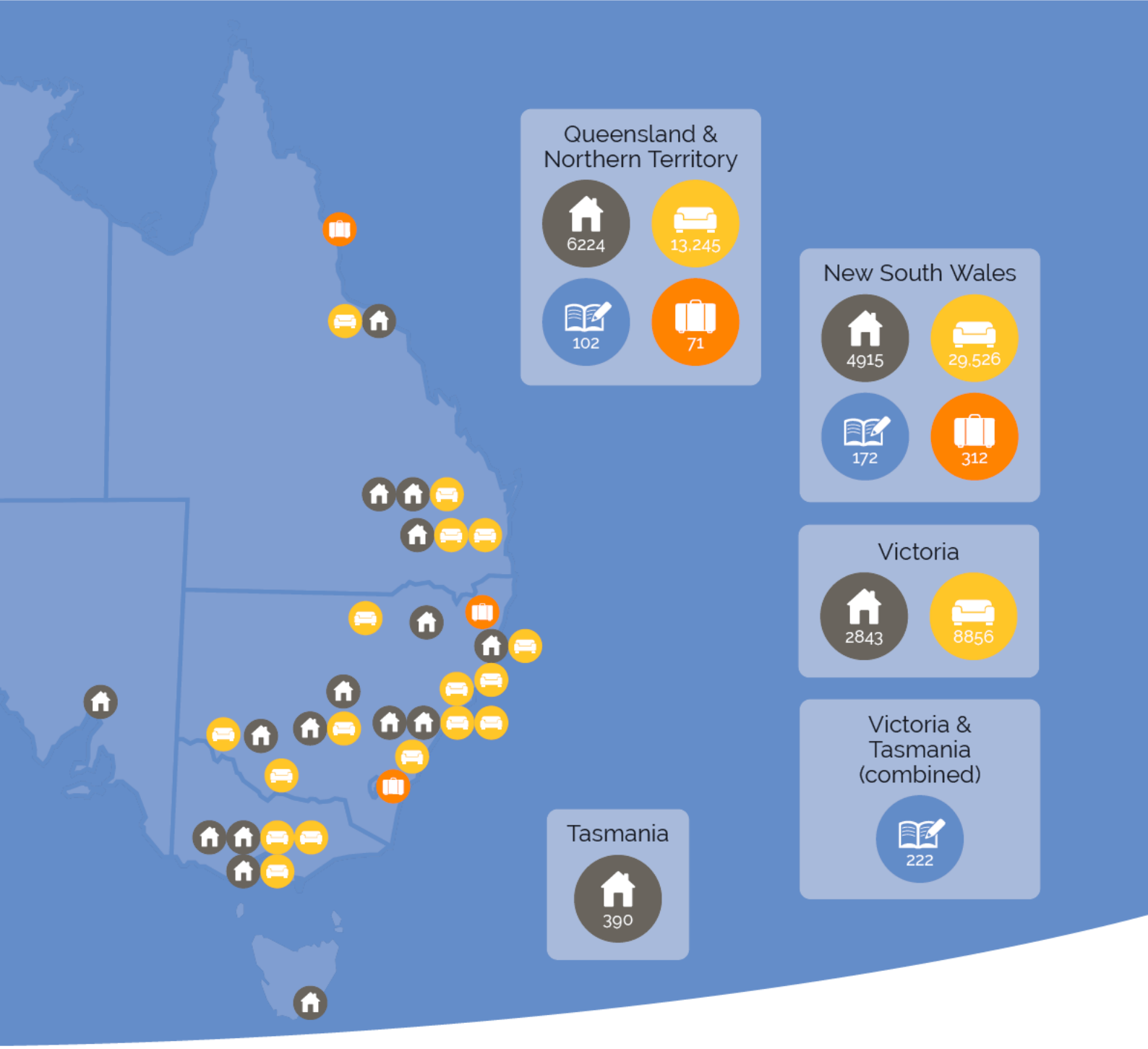
Ronald McDonald Learning Program

No. of children who completed 40 hours of tutoring (equivalent)

Ronald McDonald Family Retreat

No. of families that had a holiday at a Family Retreat

*The Learning Program has children continually starting, completing and suspending their participation in the program. Rather than using the total number of children 'enrolled' in the program, this analysis calculated the equivalent number of children that would have received all 40 hours of tuition –i.e. 'completed' the program.



Between January 2018 and June 2019 approximately...

- **17,600** families stayed at a House
- **66,440** families visited a Family Room
- **700** children completed 40 hours of tutoring in the Learning Program*
- **500** families had a holiday at a Family Retreat

Executive Summary

The SROI analysis tells a powerful story about the impact RMHC Programs have on families, communities and the health and education systems.

RMHC provides much more than just a place to sleep

RMHC provides holistic support to families throughout their child's journey with illness or injury.

RMHC is there for families during the hospital stay

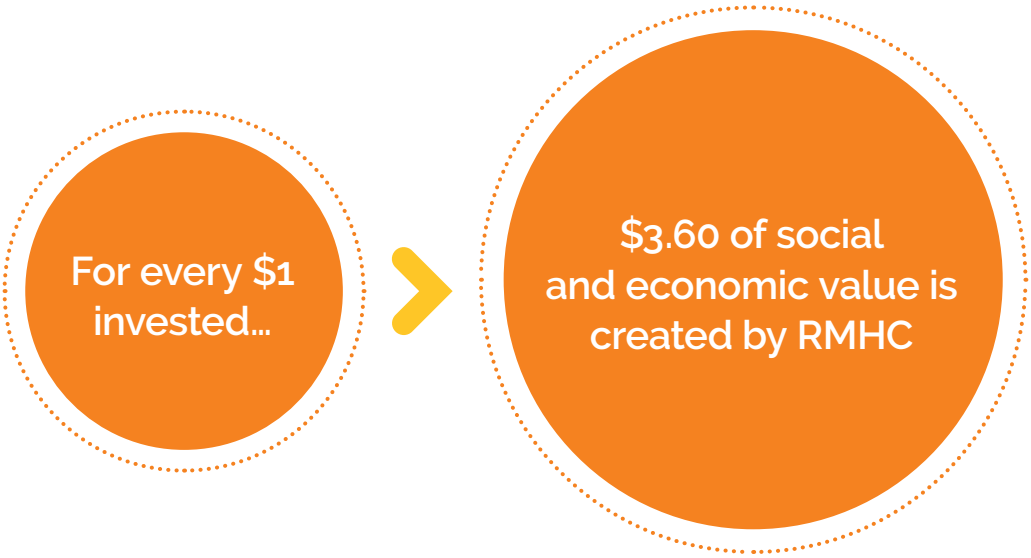
When a child is in hospital, the Ronald McDonald House and Family Room help families to stay connected and focus on the child's recovery. These programs provide valuable practical and emotional support to families during a difficult and stressful time. By having this support, families experience improved physical, emotional and financial wellbeing and are better able to support their child's clinical journey and engage with hospital staff.

RMHC also supports families in between and after hospital stays

When a child leaves the hospital and returns home, the Ronald McDonald Learning Program plays a vital role in assisting school aged children return to school-life and minimising the impact of any time away. The Ronald McDonald Family Retreats create the environment for families to connect, have fun and process the significant changes they may be experiencing between or after hospital stays.

Together, these programs play an essential role in enhancing family-centred care; and form an essential part of the healthcare and education systems.

When the total investment from RMHC's donors, government, volunteers, and corporate partners is compared to the social value created for families and the community, the result is an SROI ratio of 3.6:1. That is:



"[RMHC] do an amazing job, providing a foundation of support for families when they are managing some of the hardest times. Your staff are always bright and friendly, and go above and beyond. Thank you for all you do." – Hospital Worker

Executive Summary

The SROI analyses of the RMHC House, Family Room, Learning Program and Family Retreat identified that RMHC creates value for a range of stakeholders:

Sick children experience an improved clinical journey as a result of physical and emotional proximity to the family.

RMHC's suite of programs enable a family-centred approach to caring for sick children from the time they are in hospital to transitioning back to school and everyday life.

Parents and family members feel better connected and less stressed, improving their capacity to focus on supporting their child through treatment.

RMHC's Programs remove major stressors, and help families spend time together in family-friendly environments.

Hospitals experience a reduced mental load and save on resources.

RMHC's Programs have become a vital part of the hospital infrastructure. Hospital staff can discharge patients to a nearby location and are therefore able to serve more people. Hospital staff also experience reduced mental load and are better able to focus on clinical outcomes when families are well rested and less stressed.

Education system avoids some of the costs associated with students who miss significant periods of school.

Ronald McDonald Learning Program helps government and schools avoid the cost of students repeating school, and avoid the lifetime costs associated with students not completing school.

RMHC has the trust and goodwill of the community, which are essential for sustainable operations.

RMHC has been consistently rated as one of the most trusted charities in Australia. This trust is important to charities as it helps attract funding and volunteers both of which are essential to the sustainability of the charity and its ability to meet its purpose.

Volunteers and tutors have a rewarding experience that gives them a sense of purpose.

Volunteers and tutors are essential to the delivery of RMHC's Programs. Their work primarily benefits families, but also provides the volunteers and tutors themselves with a sense of purpose and job satisfaction.

Impact Snapshot

The benefits that the different stakeholders experience include wellbeing outcomes, educational outcomes and cost savings for the families, healthcare and educational systems.

Parents and Families

The House is much more than a just a place to sleep: the home-like environment and support from other families and staff improves family wellbeing

88%
of parents said the house helped them feel less stressed or anxious

The Family Rooms help relieve some of the physical toll that a child's illness has on parents / guardians

90%
of families experienced improved rest and physical wellbeing

The House relieves some financial pressures that families face when staying far away from home

$1,265
in net savings per family during an average House stay of 11 days (or $115 per night) on accommodation, parking, food, laundry

The Learning Program helps parents understand their child's learning needs and how to support them

90%
of parents report being better able to support their child's learning needs

Hospitals

The proximity and facilities of the House (including specialist isolation rooms), allow hospitals to delay admission, or discharge patients a little earlier resulting in significant cost savings

~18,000
in avoided bed nights p.a.

Resulting in

~$31.8m p.a.
in reallocated resources for the partner hospitals

RMHC

RMHC has gained a significant trust and goodwill of the Australian community which is essential to its sustainability and ability to deliver services aligned to its purpose

7th
Most trusted charity in Australia in 2019

This trust is valued at

~$27m p.a.
based on the value of raised funds and donated goods

Children

For each student that completes the 40 hours of tutoring provided by the Learning Program

~$47,000
Social and economic value is created

At a critical point in transition back to school, the Learning Program supports children simultaneously build self-confidence and engage with their learning

86%
of parents believe their child had improved self-confidence

94%
of parents believe their child's education benefited

Having well-rested and less-stressed parents staying close by to sick children in the Family Room and House has positive impacts on the sick child's wellbeing

69%
of parents thought the House helped their children experience more positive clinical outcomes

Education system

The Learning Program supports children at risk of repeating a year or dropping out of school to continue to stay engaged in school at the level of their peers

45
children per year estimated to avoid repeating school

41
children per year estimated to have avoid dropping out of school

$3.1m p.a.
of government expenditure saved due to improved education attainment

Volunteers

Volunteers want to give back to their community, and felt a sense of purpose as a result of their work with the House and Family Room Programs

~82,000 hours
contributed to the Houses and Family Rooms by volunteers

The value of volunteer time is estimated at
$1.6m p.a.

The six steps of the SROI Analysis

Understanding change

Engage stakeholders, including:

- Ethics approval from the Sydney Children's Hospitals Network Human Research Ethics Committee, with site-specific approval provided by the human research ethics committees at the hospitals where site visits were conducted
- Interviews with 35 families, 24 staff, 13 volunteers, and 6 clinicians
- Site visits to Houses in Sydney, Melbourne, and Perth
- Survey responses from 852 families, 245 teachers and allied health professionals, 73 hospital workers (including doctors, nurses, social workers, and administrative staff) and 348 volunteers
- Organisational data and documentation

1 Define the scope

Define project scope including:

- Timing of the analysis
- Stakeholders to be consulted
- Ethics requirements.

2 Understand the change

Engage with stakeholders to understand what changes they experienced.

Understand relationships between inputs, activities, outputs, and outcomes. Define the logic model.

3 Measure the change

Identify and measure the material outcomes that are likely to be experienced by stakeholders through the program.

Scope

This report covered:

- 18 months, January 2018 to June 2019
- All Houses, the Family Rooms, the Learning Programs, and the Retreats operating in Australia during the period of analysis
- Outcomes for sick children and their families, volunteers, health and education systems, and RMHC itself

Measuring

Using the evidence collected, we

- determined who experienced change / outcomes, what change has happened,
- how much of the change was experienced by different stakeholders.
- We documented this in the Impact Maps.

Value Change

Through analysis of interviews, survey data, and 3rd-party research, we identified material changes for each stakeholder group, and identified financial proxies that estimate the value of that outcome to that stakeholder.

Tell the story

This report is a summary of the four individual program reports that were prepared for the RMHC House, Family Room, Learning Program, and Family Retreat Programs.

The report is structured to present both the consolidated story of change, as well as the summary of the individual Program analyses.

4 Value change

Understand the relative importance of changes. Identify relevant financial proxies to value the outcomes. Determine if the change would have happened anyway, or is a result of other factors.

5 Calculate SROI

Calculate the adjusted value of the outcomes.

Compare to the investment.

6 Tell the story

Synthesise and share the story behind the numbers.

Calculating the SROI

Comparing the value of investments with the value of the social and economic value created allows us to calculate an SROI ratio. The SROI ratio is a shorthand for all of the value for all of the stakeholders. For example, a ratio of 3 : 1 indicates that an investment of $1 delivers $3 of social value.

Ronald McDonald House

Ronald McDonald Houses enable family-centred care for families with a seriously ill or injured child. The House reduces stress, and helps families feel connected and focus on the recovery of their child.

$3.30 Worth of economic and social value is created for every $1 invested in the House

Improvements in wellbeing for parents, other family members and sick children

The Ronald McDonald House provides families with significant wellbeing benefits through family centred care, such as reduced emotional and financial stress.

The family-focussed design of the Houses creates an enabling environment for positive outcomes for sick children and their families. This is particularly the case for families in long-term treatment, for whom the House becomes a second home, and a source of fun, friendships, and happy memories.

"By being able to stay at the House has meant that we have been able to deal with our son's diagnosis together as a family unit, rather than having to shoulder the burden in isolation. Be being able to stay connected as a family, our son feels better supported and we all have a greater understanding of each others needs." – Parent

88% of parents felt that staying in the House helped them feel less stressed or anxious

Selected outcomes:

- Reduced mental load for parents
- Improved emotional wellbeing
- Sick children and their siblings are happier and less stressed
- Family members feel better connected to one another
- Hospital staff have reduced mental load

Cost savings for families

By offering substantial cost savings, Ronald McDonald House helps relieve a major source of stress for families. Hospital treatments can result in disruptions to work and financial strain.

Accommodation and meals in a House help families focus on their child's recovery.

"If the Ronald McDonald House was not available for families, there would be an immense gap because finding affordable accommodation near the hospital is almost impossible." – Hospital Worker

$1,265

Net savings per family during an average House stay of 11 days on accommodation, parking, food and laundry

Selected outcomes:

- Cost savings to families

Savings for the healthcare system

Ronald McDonald Houses have become an essential part of the hospital infrastructure, creating substantial value for hospitals and the health care system. Doctors are able to discharge children to a House, knowing they are close-by in the event that further treatment is needed.

Children are then able to recover in a more family- friendly environment, and that hospital bed can be used by another child in need.

"Without a House at the hospital, there would be a greater burden on hospital staff to provide care to in-patient children and babies because parents would be around less. Children would feel lonely. Parents would be more likely to sleep rough, like in a chair next to the bedside or on a friend's couch – meaning they would be less rested and more troubled."– Hospital Worker

~18,000

Bed nights avoided p.a.

Selected outcomes:

- Hospitals are able to discharge certain patients to a House
- Hospitals able to discharge immuno-suppressed patients to an isolation room at a House

Ronald McDonald Learning Program

The Ronald McDonald Learning Program takes a holistic approach to helping children return to school from illness and injury, providing tailored support that helps boost children's confidence and recognises the role of the family and school in the child's recovery journey. By delivering this critical support at the right time, the Learning Program impacts the lifetime outcomes of many children.

$4.50 Worth of economic and social value is created for every $1 invested in the Learning Program

Improvements in wellbeing for children and their families

One-on-one support concurrently builds confidence and reduces learning gaps.

A child's educational engagement and attainment is intrinsically linked to their confidence and self belief as a learner. Over time, tutors in the Learning Program build a strong and trusting relationship with students that provides a solid foundation to effectively target critical learning gaps and build confidence, with incremental progress generating improved self-esteem for children.

"Our tutor created a tailored program to help my son close some of his learning gaps from missing so much school. He really looks forward to his weekly sessions and is so proud of the achievements he has made. His learning outcomes have soared and we are so grateful." – Parent

86% Of parents say their child had improved self confidence

Selected outcomes:

- Students more likely to finish school and fulfil potential
- Reduction in stress and mental load for parents

The Learning Program helps parents understand their child's learning needs and feel empowered to support their child's learning. As a result, parents feel less isolated in their journey; more hopeful for their child's future; and are better able to advocate for their child's needs with the school, during and after the program is completed.

Tutors also support schools and teachers to better understand and address students' needs by providing practical support, transition planning and information as they progress through the Program and beyond.

90% of parents report being better able to support their child's learning needs

94% of parents believe their child's education benefited

Selected outcomes:

- Better able to support their child's learning
- Improved educational outcomes

Savings for the education system

The Learning Program has lifelong impact. By providing support at a critical point in time for children, the Learning Program is a springboard from which children's progress continues after completing the 40 hours of tutoring. The Program can also have lifelong benefits due to the early intervention that addresses additional learning needs and education gaps at the time the problem is occurring.

"It affects their [the children's] whole life. If the supports are put into place at a young age when the problem is happening, it affects their life trajectory. If you make a change by one degree at that age, the child will achieve different things across their whole life." – Hospital Worker

$3.1m of government expenditure saved per year due to improved educational attainment

Selected outcomes:

- Professional development for teachers
- Schools better equipped to support sick children
- Teachers are less stressed
- Avoid costs of children repeating a year
- Avoid lifetime costs to government to support people who disengage from school

Ronald McDonald Family Room

The Ronald McDonald Family Room Program supports the physical, emotional and practical needs of families during their child's hospital stay, better equipping families to support their child's clinical journey. This support is greatly valued by all family members, as well as the hospital staff.

$4.90 Worth of economic and social value is created for every $1 invested in the Family Rooms

Improvements in wellbeing of family members

The Family Room Program offers unique and valued services and amenities that are not otherwise available in hospitals, including: a place for families to rest, shower, do laundry, prepare meals and access complimentary snacks; as well as a place for families to connect and siblings to play and have fun. With the support offered by volunteers, families are also able to switch from the role of carer to being the recipient of care and support.

Together with a family-focused design of the facilities, Family Rooms contribute to family's improved physical and emotional wellbeing, and help maintain normality.

"The Family Room was like a sanctuary. It was a welcoming environment and after a long day, a place to go to that was homely and relaxing. All the volunteers knew us and were really friendly – it was always really special walking in there and the volunteers would come to you with open arms… It was also a safe and child-friendly place, so my other kids loved going there too!" – Parent

87% of families experienced improved emotional wellbeing

Selected outcomes:

- Improved emotional wellbeing
- Families are more rested and physically well
- Families maintain a sense of normality and control

Cost savings for families

The Family Room Program helps families save money by providing access to complimentary snacks; a kitchen to prepare home meals; and a place to complete practical activities of daily living (e.g. take a shower or do laundry). For families with children who have longer hospital stays, and families who have to change their work routines, these costs can add up over time, creating significant financial stress.

"I am on a carer's pension, so I don't have the money to go and buy meals from the hospital cafe when we are at the hospital - especially when we are there on a longer admission and the food costs really add up. The Family Rooms always offer us fruit, tea and coffee and we often make our own meals. This has helped us save a lot of money and stress over time." – Parent

$5.7m

Savings to families as a result of the Family Rooms over the 18m period

Selected outcomes:

- Families save money

Savings for the healthcare system

Family Rooms generate meaningful value for hospitals and have become an important part of the health system. When families experience improved wellbeing and a greater sense of control over their lives, they are better able to engage positively with hospital staff. In addition, the Family Rooms provide families with a much-needed place to take a break from the clinical environment - this creates more time and space for hospital staff to focus on executing their clinical responsibilities.

"Having the Family Room is not only beneficial for families, it can help the hospital and staff a great deal too. Most importantly, when families get time out, this puts them in a better frame of mind to care for their child and engage with staff. This helps to take the pressure off the team so they can focus on their clinical work... " – Hospital Worker

77%

Of hospital staff felt the Family Rooms reduced their mental load

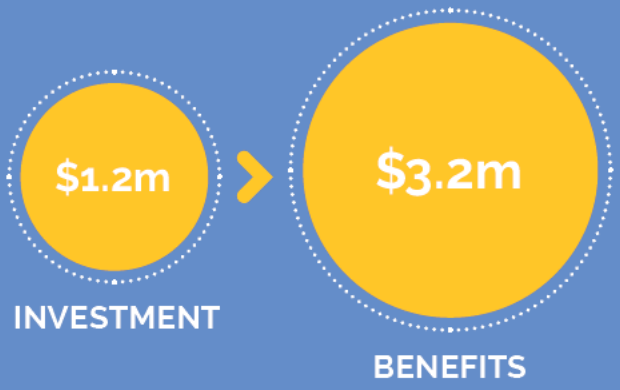
Selected outcomes:

- Hospital staff have reduced mental load

Ronald McDonald Family Retreat

The Family Retreat Program creates the environment for family members to connect and care for each other, kids to just be kids and families to adjust to changes in life circumstances.

$2.60 Worth of economic and social value is created for every $1 invested in the Family Retreats



Improvements in wellbeing for family members

The Family Retreat accommodation and location provides a calm and relaxing environment for families and sick kids to relax and recharge – helping to reduce stress and fatigue. In addition, the opportunity to spend quality time together creates the time and space for families to be together and feel better connected. Importantly, the Family Retreat creates an opportunity for sick kids and their siblings to have time away from focusing on illness and enjoy time with each other. This gives the space and time for kids to 'feel normal' and 'just be kids again', which has positive effects on a child's recovery and / or overall physical and emotional wellbeing.

"Having the time to be together as a family was such an important and unifying experience for us. The Family Retreat was also a very calming place - we were able to relax and take naps, play games and go for walks on the beach. We came back from the holiday feeling so fresh and happy. It was wonderful!" – Parent

81% of families experienced improved physical and emotional wellbeing

Selected outcomes:

- Families experience improved physical and emotional wellbeing

Cost savings for families

The Family Retreat Program provides families with free accommodation and holiday activities.

Families may also be provided with complimentary passes to activities such as tickets to the movies or local theme park. These activities give families access to experiences they would otherwise not have been able to afford. By taking away the financial stress of having a holiday, families are given the opportunity to spend time together and create positive memories as a family.

"Having the opportunity to go to the Family Retreat was fantastic - we wouldn't have been able to afford or justify a holiday for ourselves and wouldn't have been able to take a break if it wasn't for the Family Retreats. We feel so thankful for the experience." – Parent

75% of families would not have been able to afford a holiday

$3,000 is the average savings per family visiting a Family Retreat

Selected outcomes:

- Cost savings to families

Acknowledgments

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This report has been prepared by Social Ventures Australia Consulting

Social Ventures Australia (SVA) is a not for profit organisation that works with innovative partners to invest in social change. We help to create better education and employment outcomes for disadvantaged Australians by bringing the best of business to the for-purpose sector, and by working with partners to strategically invest capital and expertise.

SVA Consulting is Australia's leading not-for-profit consultancy. We focus solely on social impact and work with partners to increase their capacity to create positive change. Thanks to more than 10 years of working with not-for-profits, government and funders, we have developed a deep understanding of the sector and 'what works'. Our team are passionate about what they do and use their diverse experience to work together to solve Australia's most pressing challenges.

This report has been authored by SVA Consulting with oversight from Kateryna Andreyeva (Principal) and Simon Faivel (Director).

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