



Ronald McDonald House Charities® is Keeping Families Close®: A Unique Role in Family-Centered Care

By Nicole Rubin, MHSA, and Linda Franck, RN, PhD

Position Paper



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FAMILY-CENTERED CARE IS A PHILOSOPHY that places the highest value on health care that is provided in the context of the strengths and needs of a patient, their family and community.¹ It is also a model of care for children, wherein the patient and his/her family members are fully involved — in partnership with the health care team — to make informed decisions about the medical care and support services the child and family receive. In family-centered care, all aspects of care are oriented towards supporting and involving the family with the goal of improving quality, psychological well-being, clinical outcomes and the overall patient and family experience. Today, there is general consensus on the importance of family involvement in high quality care for hospitalized children,¹ but this was not always so, and the degree to which family-centered care is implemented in hospitals and health systems varies across institutions, countries and regions.

The vision of Ronald McDonald House Charities® (RMHC®) is a world where all children have access to medical care, and their families are supported and actively involved in their care. Ronald McDonald House Charities has been at the forefront of the family-centered care movement since before the movement was given a name. The purpose of this position paper is to review the research that demonstrates the impact of RMHC programs on families, children and their health care experiences, and to clearly state the unique and important role Ronald McDonald House Charities plays in enabling, facilitating and supporting family-centered care for hospitalized children. RMHC and its chapters are committed to working collaboratively *for* and *with* families and with local and national children's health care partners to advance family-centered care and support services worldwide.

Before family-centered care became a recognized movement in health care, the Ronald McDonald House® (RMH) program was founded with a mission to keep families of seriously-ill or injured children physically and emotionally close to the place where their child receives medical care. Over the years, a growing body of research has provided strong evidence that demonstrates the value of that mission, highlighting the physical, emotional and social needs of families with a hospitalized child and confirming the importance of proximity, involvement, education and partnership that are the cornerstones of family-centered care. This position paper describes the unique role of Ronald McDonald House Charities in enabling, supporting and facilitating family-centered care in current health care delivery systems worldwide. Although it is not the primary mission of RMHC to provide direct health care services for children, RMHC enables family-centered care by supporting families throughout their health care journeys. The accommodation and support services RMHC provides to families of hospitalized children are not only beneficial; they are essential to high-quality and effective health care.

History of the Ronald McDonald House Charities Model of Family Support

The first Ronald McDonald House program opened in 1974 in Philadelphia at the urging of Dr. Audrey Evans, a world-renowned pediatric oncologist at Children's Hospital of Philadelphia. As families traveled near and far for Dr. Evans to treat their children with cancer, she realized the crucial need for families to stay close to their sick children and for housing to facilitate that proximity. Dr. Evans was introduced to the Philadelphia Eagles, where one of their beloved players, Fred Hill, had a daughter who was being treated for pediatric leukemia. The National Football League team rallied behind Dr. Evans, the Hill family, and Children's Hospital of Philadelphia and encouraged the local McDonald's owner/

operators and regional office to get involved. With this community of support, which remains a hallmark of the program today, the first Ronald McDonald House was built, offering a "home away from home" for families with seriously-ill children in a communal setting in close proximity to the hospital. Today, there are over 365 Ronald McDonald Houses in more than 40 countries and regions around the world. The program cares for a diverse population of families whose children are faced with the full range of pediatric acute and chronic illnesses, including cancer, prematurity, heart conditions, trauma, organ and tissue transplant, and many other serious conditions.



Expansion of the Ronald McDonald House Program

As the RMH program grew in geographic reach and range of services, RMHC and its network of local Chapters sought new ways to provide family-centered support. Extensions of the RMH program were developed, including the Ronald McDonald Family Room® (RMFR) within hospitals. These rooms are designed to provide quiet respite, away from the busy clinical care units, where family members can relax, shower, get a snack, attend to personal and family business, or even — in some locations — sleep overnight, while at the same time staying near their hospitalized children should they be needed. As the most rapidly growing RMHC program, today there are more than 215 Ronald McDonald Family Rooms located in over 23 countries and regions.

Another RMHC program expansion is the Ronald McDonald Care Mobile® (RMCM), bringing primary medical and dental care, and vision diagnostic and clinical services, to underserved children

in their neighborhoods. Currently more than 50 Ronald McDonald Care Mobile units operate in 10 countries and regions in collaboration with local medical partnerships.

RMHC grew exponentially because of the universal and unmet need for families to stay close to and be involved in their hospitalized child's health care. At the founding in 1974, no one could have imagined that RMHC would one day enjoy the reach and relevance it has achieved in such a broad range of geographies, health care systems and settings. With the support of more than 389,000 volunteers annually, RMHC programs offer much more than accommodation. They provide meals, activities, peer support, support for siblings, respite, laundry and many other services to take care of families. RMHC and its local Chapters now serve more than 5 million families annually through core programs, global grants and other efforts.



The Evolving Needs of Families of Hospitalized Children

With the growth of outpatient primary and specialty care, children who are hospitalized today are generally very sick and many require multiple hospitalizations or long stays. Specialty medical care is often regionalized, and the best experts for any given condition are often unavailable in a family's local community. Access to care in these cases requires more than an appointment.² Parents face enormous challenges in negotiating the necessary referrals, insurance authorizations, financial requirements, government approvals and time off work to take their child to appointments and receive treatments from multiple providers. In addition, they often must arrange for care and support for other children at home during extended absences for their sick child's specialty care.

When the necessary pediatric specialty care is not available near home, transportation and accommodation uncertainties, challenges, and costs can become sources of extreme emotional and financial stress for families.³ Even when top medical care is available locally, families still face a wide range of needs that go beyond the direct care of their child. Adequately understanding and working to meet each family's accommodation, psychosocial and basic daily needs is important so that parents are able to focus more fully on the child and the child's care.



Research Confirms the Importance of Family Proximity in Family-Centered Care

Over the past few years, several research studies — some of which were funded through grants by RMHC — have confirmed the value of family proximity to a hospitalized child and what helps the family-centered model of care to be successful. These studies describe, for the first time, where families stay when their child is hospitalized and provide evidence that keeping families both physically and emotionally “close” improves the quality and experience of the care of the child and the well-being of the family, while reducing the family’s stress, sense of isolation and financial burden.

1. Families want to stay close when their child is hospitalized and believe it improves their child’s recovery. Families of seriously-ill children want to be with their child receiving treatment and do not want to be separated from spouses, partners and other children for extended periods of time.⁴ Franck, Gay, and Rubin (2013) examined the importance of accommodation and proximity among more than 2,000 families in Southern California, finding that families who stayed together for at least some portion of their child’s hospitalization believed more strongly that their presence nearby improved their child’s recovery. Families also believed that availability of accommodations at a RMH uniquely helped their family to remain together strongly as a unit in close proximity to their hospitalized child.⁵

2. Accommodations designed with family needs in mind provide parents with essential rest while enabling proximity to their hospitalized child. Franck et al. (2014)⁶ measured sleep quantity and quality in parents in the United Kingdom who stayed in a RMH and those who slept at the child’s bedside. Parents who slept in the child’s hospital room had poorer sleep (more awakenings and feeling less rested after a night’s sleep) than parents who slept in the RMH. Nearby family accommodation may facilitate parent/child proximity during a child’s hospitalization while also providing parents with opportunities for restorative sleep.



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3. Families who stay in a RMH report more positive hospital experiences and a greater ability to participate in their child's care.

Franck, Ferguson, Fryda, and Rubin (2015) studied the influence of family accommodations on patient experience at 10 hospitals (5,105 families) providing pediatric services across the United States. The most common accommodation for parents of inpatient children was at the bedside (76.8%); and, for infants in neonatal intensive care, parents were most likely to stay in their own home or the home of a relative or friend (47.2%). Yet those families who stayed in a RMH reported significantly more positive experiences for their child's hospital stay, were more likely to recommend the hospital, and were more likely to view their accommodation as being helpful to staying involved in their child's care than

parents who stayed at the child's bedside or their own homes.⁷ This study highlights how nearby, purpose-built accommodations, which include family peer-to-peer and other support services, can help improve the quality of the hospital experience for families. Similar findings have also been demonstrated in a study of 10 hospitals (1,240 families) in the province of Ontario, Canada, particularly as it relates to accommodation enabling families to be more involved in the care of their child.⁸

4. Hospital leaders worldwide increasingly understand that nearby purpose-built accommodation and support for families contribute to high quality, family-centered care. Hospitals are appropriately focused on providing excellent health care to those they serve, and increasingly understand that



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quality and safety can be enhanced through family-centered care. An international survey of 530 hospital leaders in 16 countries with RMH program affiliations found that the vast majority of the leaders believed that caring for the whole family promotes better health care for pediatric patients.⁹ In this survey, hospital leaders reported positive opinions about the contributions of an RMH program affiliation to their ability to serve seriously-ill children and their families. More than 95 percent of those surveyed reported that their RMH program affiliation enhanced family-centered care. Their responses also reflected strongly positive views of important outcomes of an RMH stay, such as reducing feelings of isolation for families, getting enough sleep, coping with the stress on the family and reducing hospital social work resource burdens associated with RMH program assistance with lodging, food, transportation and sibling support.

Proximity, lodging, and a reduced financial burden are important to families of hospitalized children. The RMHC program experience provides these benefits and so much more. These purpose-built accommodations are designed to provide a private, comfortable and uninterrupted night's

sleep and create shared spaces where families can find solace in and strength from each other. Activities and meals at a RMH provide a break from the stresses of daily caregiving, create a shared experience with other families facing similar challenges and help reduce the financial burden these families face. The sense of isolation a family can feel as they experience the difficulty of having a seriously-ill or injured child cannot be understated. To be able to share this journey with other families can make it not only tolerable but can also help a family become more active and engaged participants in their child's care and recovery. Dedicated family-centered support services, such as those provided by RMHC, are essential to enable parents to be physically and emotionally available and to be actively involved in care for their hospitalized children. These services are extended through the RMFR and RMCM programs. The mission and vision of RMHC is further validated by this growing body of research that demonstrates these benefits to families, children and health care partners.

Note: This position paper was adapted — in part — from an article that originally appeared in *Pediatric Nursing Journal*, September/October 2017. The valuable input from the RMHC Global Advisory Council and the RMHC Board of Trustees Program Management Committee is gratefully acknowledged.

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² Penchansky R, Thomas JW. The concept of access: Definition and relationship to consumer satisfaction. *Medical Care*. 1981;19(2):127-140.

³ Daniel G, Wakefield CE, Ryan B, Fleming CA, Levett N, Cohn RJ. Accommodation in pediatric oncology: Parental experiences, preferences and unmet needs. *Rural and Remote Health*. 2013;13(2):2005.

⁴ Van Horn ER, Kautz D. Promotion of family integrity in the acute care setting: A review of the literature. *Dimensions of Critical Care Nursing*. 2007;26(3):101-107.

⁵ Franck LS, Gay CL, Rubin N. Accommodating families during a child's hospital stay: Implications for family experience and perceptions of outcomes. *Families, Systems and Health*. 2013;31(3):294-306.

⁶ Franck LS, Wray J, Gay C, Dearmun AK, Alsberge I, Lee KA. Where do parents sleep best when children are hospitalized? A pilot comparison study. *Behavioral Sleep Medicine*. 2014;12:307-316.

⁷ Franck LS, Ferguson D, Fryda S, Rubin N. The child and family experience: Is it influenced by family accommodation? *Medical Care Research and Review*. 2015;72(4):419-437.

⁸ Franck LS, Ferguson D, Fryda S, Rubin N. The influence of family accommodation on pediatric hospital experience in Canada. *BMC Health Services Research*. 2017;17:561.

⁹ Lantz PM, Rubin N, Mauery DR. Hospital leadership perspectives on the contributions of Ronald McDonald Houses: Results from an international survey. *Journal of Health Organization and Management*. 2015;29(3):381-392.