

# Breaking Barriers

everybody belongs • everybody serves

## **Relational Renters, Lifelong Dividends**

by Mark Stephenson

CRC Disability Concerns

Ralph Bus's life changed dramatically the first six months after he developed juvenile rheumatoid arthritis (JRA) at age 13. This auto-immune disorder attacked and ate away his cartilage and joint structures, causing painful swelling and difficulty in movement. Seven years after onset Ralph had a serious flare-up. For the next four years he was immobile; on good days he could feed himself. Ralph viewed this as his journey through the desert, a period of his life turned into a wasteland by being angry with God.

Three months after starting a new medication regime, he was able to stand again. His spiritual life changed too. The anger he felt toward God for his disabling condition subsided, replaced by a deep-rooted peace and an understanding of the eternal, non-ending life God intended for him. Since then he has had nearly 20 major operations, most of them joint replacements, but his desire to serve God has not waned.

Just as he was getting back on his feet, two friends asked him to share a rental. Because Ralph wanted to live as independently as possible, he moved in with those friends. Four years later, he purchased a condominium with two

friends, then bought out their shares during the next four years.

Usually, Ralph has worked three days a week and operated a computer business on the side, but Ralph says that the most important support in his life comes from “my Father in heaven and his help from day to day.” Still, the basics of owning a home had to be covered, including paying the bills, housekeeping, shoveling snow, and changing light bulbs. Ralph met these needs by becoming a landlord.

Not content with a mere tenant-landlord relationship, Ralph journeyed alongside the people who rented from him. He offered reduced rent in exchange for commitments on the part of his renters, such as:

- helping with housework, especially tasks that the JRA prevents Ralph from doing
- living with one another according to the biblical principle of respect
- stating their goals in life and periodically updating Ralph on their progress toward those goals. (For example, some used the savings on rental costs to further their education; others saved the money for an upcoming wedding or down payment on a house.)

Ralph has served as a mentor and friend to more than 30 people who have rented from him over the years.

For anyone considering a landlord/mentor/friend

relationship with renters, Ralph (who lives in Ontario) has several words of advice:

- Ask yourself, “Am I comfortable with sharing my living accommodations with renters? Am I willing to be flexible?”
- Be more than a friend. Communicate expectations clearly, before someone moves in, and be the landlord when the situation requires.
- Be willing to accept disappointment. Ensure that all parties (including yourself) understand the Christian walk and live faithfully with God.

## **Customizing a Home Takes Time**

**by Pam Menton**

Bethany Reformed Church, Albany, NY

Finding the right place to live can be a stressful yet exciting time. When you add accommodations as a “must have” to meet the needs of a loved one with a disability, suddenly your list of suitable candidates can be significantly shortened. Or you may need to make changes to your home due to a disability that occurs after you have lived there for several years. Accessibility needs can be as simple as a small ramp to accommodate a walker or wheelchair, or as major as creating a floor plan that includes complete Americans with Disabilities (ADA) requirements — wide doorways, bathroom access, stair/chair lifts or elevators, and more. And how do you pay for it all?

We took a long time to find our house. My son, David, has cerebral palsy, drives an electric wheelchair, and needs assistance into the bathroom. We took these needs into consideration when we bought our house, and knew that we would need a ramp and some adaptations to the bathroom. His bedroom was also on the second floor, which meant that we would need a chair glide.

At that time (mid-1990s), the Medicaid waiver — a federal program managed through states — was just taking off. David was assigned a Medicaid service coordinator (MSC) through a large agency that works with people with disabilities. We were told, “Don’t worry, we will provide whatever David needs.” That was easier said than done. We soon found out that this agency was not well versed in the process. After a few very frustrating months and several unpleasant phone calls, I escalated David’s case to another level and another MSC. The next hurdle was funding. The State of New York budget had not yet passed, so we were at another standstill. In the meantime, I did everything I could to make sure all the paperwork was done so that we were ready to move when the money became available.

After six months, we finally had a ramp and David no longer had to leave his wheelchair in the garage and be carried into the house. He could drive into the house and was able to access every room on the first floor by himself. He was much more independent and able to do things on his own.

This process taught me a few things, and the most important was you cannot be too strong of an advocate for your loved one.

## **Finding Ways to Support Choices**

by **Dan DeVries**, spiritual care coordinator,  
Hope Haven, Rock Valley, IA

I enjoy countless choices every day — deciding whether to get up early or sleep in, what to wear, when to eat, what to eat. I decide when to go to work, where to live, even who I live with.

Many who lack the independent living skills that I take for granted do not have the opportunity to make choices — not because of our differing skills, but because of prohibitive rental costs, adjusted regulations, and changing funding rules. As a Christian organization that provides residential and living services for 480 adults with disabilities in 13 communities in Minnesota and Iowa, Hope Haven has encountered a number of these challenges.

When funding rules change, some who qualified at one point no longer can receive services in the settings they prefer; for others, it means an end to rental assistance. If someone chooses to live in their own apartment, it is often difficult to find something affordable. If the only available apartment has two bedrooms, it cannot be rented because their rental assistance provides for only one bedroom.

A growing trend is to move people out of institutional settings and encourage them to move into a community setting. This maximizes their independence and improves the potential for natural supports — mutually beneficial relationships that strengthen the community. Responding to this push, Hope Haven finds that sometimes the daily rate to “house” an individual is capped at a level that’s too low to provide the housing choice of the person being served. Appeals can be made to the funding provider, but appeals can take 3-6 months to be resolved. This puts stress on an individual looking forward to having more choices and a more interdependent lifestyle.

In the practice of person-centered planning, Hope Haven wants to absorb the impact of changing regulations, delays, and waiting lists. Person-centered planning provides a road map for moving a person closer toward the life he or she envisions — in this case, toward the person’s preferred residential setting. Often it is in the person’s best mental-health interests to assist in each transition and minimize the effects of a move to their chosen and preferred living environment, even if the move is made before the funding stream is certain or an appeal is decided.

Hope Haven’s mission is to “unleash potential in people through work and life skills so they may enjoy a productive life in their community.” Regardless of their abilities, we believe all people should be able to choose where they live.

## **Letter**

I have many age-related disabilities (Parkinson's, arthritis, auditory deficiency, macular degeneration in my left eye). I am beginning to have amnesia, which I hope does not progress to something like Alzheimer's, which I dread.

I go on only by God's grace and support from my daughter, her husband, and four grandchildren. I am able to go to church, provided I am escorted. For spiritual strength, I read Christian booklets, but I cannot read the Bible easily for more than a few minutes without the use of my magnifying glass. I have used this magnifying glass to write this letter, to make sure that I do not miss writing a word.

I go to physical therapy two or three times a month, and attend a support group meeting once a month conducted by the therapists. This is very good and gives me and others a lot of encouragement and awareness about how to improve/cope with movement disorders like mine through proper breathing techniques, movement of the limbs, neck, spine, balancing, and proper walking to avoid falls.

I can understand the disabilities of mobile impairments, stenosis, mental and physically challenged, hearing deficiency, dementia, etc. In fact, for many years I used to visit persons who were house bound due to some of the above problems.

Anyway, I admire how Cindi and Terry are deeply involved in disability advocacy as she ministers despite hearing insufficiency. Congratulate Cusacks, Liddles, Roons, and Fran Daniels for always leaning on the Lord; he alone is the protector, provider, comforter.

Regards, God bless, and please send the next *Breaking Barriers* bulletin.

—Alvin Cordiero, Chembur, Mumbai, India

Editor's note: In Alvin's article, "Accessibility on the Cheap," (*Breaking Barriers*, Summer 2011) he describes creative accommodations he has made for himself and others at a very low cost.

## Themes

**Spring 2013 — Housing.** This issue explores ways that people with disabilities are managing to meet their needs for housing, including the financial challenges of living independently.

**Summer 2013 — Recreation.** What do you do for fun? How has disability affected your recreation? Our summer issue will feature stories about disability and recreation. Please send us your story by June 20.

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## Editor's Note

### Group-Home Connections

"I'm bringing over a box of chocolates and a box of Kleenex." Jeannie, our daughter Nicole's caseworker, knew that we would both celebrate and grieve the news she had for us. Funding had been approved for Nicole to move into a group home, Harbor House Ministries. (Nicole lives with severe, multiple disabilities and needs total care.)

Nicole was 18 at the time. We had not anticipated her moving out at such a young age, but we knew that it would be best for Nicole to move away from her parents for a variety of reasons. The transition was difficult for all of us at first, but she likes living there now.

Few people have the entrepreneurial skills to start a group home like Harbor House, but residents need many caring people to thrive. Is there a group home near your church? Here are some ways that local people minister to and with the residents of Harbor House (all live with severe, multiple disabilities):

- Sewing quilts and decorating for the holidays
- Leading worship services
- Serving as Friendship group mentors
- Cleaning and landscaping
- Being a friend with residents who get few visitors
- Sharing devotions with residents who get no other spiritual care
- Doing crafts with residents

- Taking pictures of special events
- Organizing and leading a summer day camp, or special activities for residents (one church organized “Olympic” games concurrent with the Winter Olympics).

By connecting with residents in a group home near your church, you can make a significant contribution to God’s work, not only with the residents, but also with the many other people in their lives.

—*Mark Stephenson*

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