

MAKING HOMES THAT WORK

Planning, Design and Construction of
Person-Centered Environments
for Families Living with
Autism Spectrum Disorder

George Braddock
John Rowell

ABOUT THIS BOOK

This book was made possible by the pioneering efforts of families who have transformed their homes and shared their experiences. The methods and recommendations presented here are drawn from over 25 years of experience working on more than 1,500 projects for families and individuals experiencing disability.

George Braddock, President of Creative Housing Solutions LLC, pioneered the application of person-centered planning principles to the design and construction of homes for people with disabilities. In addition to developing welcoming and inclusive single and multi-family homes for people with ID/DD, George's recent work involves developing inclusive, authentic communities for all citizens and assisting families by creating living situations that allow individuals and their families to remain together and flourish for as long as they choose.

John Rowell, AIA, NCARB, is a principal with Rowell Brokaw Architects, PC. in Eugene, Oregon, and is a licensed architect. He is an Associate Professor in the Department of Architecture at the University of Oregon. John has been designing and researching environments for persons with developmental disabilities for 17 years, many in collaboration with George Braddock. He is currently working on innovative projects that integrate family housing in sustainable communities.

This book is intended to provide information and recommendations in regards to the subject matter covered. Information and recommendations are provided in good faith but the authors do not warrant, and assume no liability for its accuracy, completeness or fitness for a particular purpose. It is the responsibility of the user to apply their own judgment and professional knowledge in the application of the information contained in this book, and to seek expert advice when appropriate.



George Braddock



John Rowell

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Foreword

Many years back, George Braddock gave me a tour of a home he and John Rowell had designed and constructed for a young man with a lot of autism and two disabled housemates who did not have autism. I heard people's stories about how their lives had improved. That same day, I saw another home George and John designed for a man with complex physical disabilities, and I saw an accessible tree house that was obviously designed and built with great love.

I had a few minutes in the tree house by myself. It was easy to imagine the canvas roof pulled back to provide a view of the stars, and then it became easy to imagine other things, too. It became easy for the first time in my life to imagine a home where my own son, Charlie, could live as adult and have the supports and freedom I so badly wanted for him.

By that time, I had seen enough of the service system to know that I was seeking something more than "services outside the family home." Like de-institutionalization, moving away from a family home is often seen as a goal in itself – but the real goal is not leaving, it is going someplace better. I knew how hard it was to meet Charlie's needs for assistance with eating, transferring, toileting, bathing and often sleeping through the night. Even with help at home we were barely making it. Love can only make up for so much. Seeing those houses that day, I began to understand how our little house failed to give him the freedom he craved, how it failed to support him in key ways, and how it failed to make caring for him safe for us, too. Our home worked for us in many ways, and we had achieved ADA-level access after many years of making adjustments and rigging solutions – but we needed ADA Plus. We had accommodated some of Charlie's physical disabilities, but not the sensory and behavioral problems that affected him so deeply.

Of course, I wish I had seen these possibilities when our boys were little. Maybe I could have incorporated more of the ideas into our family home and made raising Charlie easier and better for all of us. But I was glad to learn about them then, as Charlie was becoming an adult. For the first time, I could picture a house where he could have the freedom to move around and control whether he was with others or by himself; to be bathed and toileted with

out risking back injury for his assistant or worse for him; to sleep through the night because extraneous sound was eliminated; to be able to live with others because there would be enough separation and enough common space.

Charlie now lives in a house with most major design features based on George Braddock's work. It is located in a place George helped to choose: in a diverse and energetic neighborhood near us, but not too near us; within walking distance of Starbucks (not because he needs the coffee, but because he needs the kind of neighborhood that supports a Starbucks); near public transportation; near a grocery store, a library, a community center, and not too far from an accessible public pool. I think we are able to keep the support costs low for Charlie and his two housemates because the house itself is supportive. All three men rent using housing vouchers from the Housing Opportunities Commission, which owns the house. Furthermore, there are design features in the house intended to help preserve its value over time by avoiding the wear and tear commonly associated with homeowners who use big wheelchairs. The design helped make the financing possible.

We know we need more houses like this in our communities. As people age in place with disability, as wounded warriors return to live with their families, as young people with complex disabilities grow up and leave the family home, and as children with more complex disabilities are supported to live, grow and thrive with their families, it is wise to recognize that better housing design and better housing availability will matter – a lot.

To the end of creating communities that can support all members well, I hope this book will be read by developers, contractors and construction managers, foundations, bankers and other financial backers, policymakers and city planners as well as by developmental disability leaders and support providers. Most important, I hope this book finds its way into the hands of people with disabilities and their families so that they, too, can imagine the stars above them and new possibilities before them – starting with homes that work.

Sue Swenson

*Sue Swenson serves in the Obama Administration
and lives in Bethesda, Maryland*

Chapter 1

WHY HOUSING DOESN'T WORK

Most people with Autism Spectrum Disorder (ASD) can live with their families independently or with supports, and do well in conventional housing. But for people with significant ASD and additional medical or behavioral challenges, conventional housing does not work—it was not designed or built for them. These individuals, their families and their caregivers experience increasing stress and fatigue because of the inadequacies of their homes. At a certain point, the situation is no longer sustainable. We believe the wrong physical environment is a major contributor to the breakdown of the family. Ultimately, this leads to an out-of-home placement.

This book makes the case for a balance between traditional human supports and appropriate environmental modifications. People experiencing significant ASD can continue to live in their own homes for as long as they wish—provided they have appropriate support *and* they have the right physical environment. This book describes successful, cost-effective methods for making houses that work for people with significant ASD. With appropriate modifications to their homes, combined with necessary supports, people with significant ASD are able to live more satisfying lives, in their own homes, on their own terms.

The values and assumptions that guide this work:

1. People with ASD have the right and ability to live in community and with their families.
2. The unique and enduring relationship of family must be respected.
3. Families are committed to supporting and enriching the life of their family member with ASD.
4. People with ASD should be able to participate in the activities of daily living, including caring for themselves.
5. The environment should offer meaningful opportunities for a person to make decisions and exercise choice.
6. The unique interests and activities that bring joy and happiness to a person with ASD should be facilitated.
7. When the environment doesn't work, it is not the person's fault.

HOW TO USE THIS BOOK

This book offers ways of assessing and planning environments that are person-centered, and that respect the diversity of family and individual situations. It identifies patterns of activity and interaction with the environment that are common to many people with SASD. These are the basis for the “Six Common Modifications” recommended for many persons with SASD to support them to live successfully in the home. Most of the issues that families face can be improved by completing one or more of these modifications.

At times, specific challenges may arise that go beyond the Common Modifications. The book describes strategies that have worked for families in the past to address “Specific Challenges” that often present as behaviors or aggression co-occurring with ASD. Case studies included at the end of the book describe in detail how families have modified their home and seen substantial improvements in their quality of life and ability to live together. A cost comparison of these improvements with out-of-home care is also included.

The “Assessment and Action Plan” is the heart of the book. It describes a process for identifying concerns from different points of view, and is intended to be a tool for working with families and caregivers. This section provides a wayfinding matrix that connects concerns and issues to common modifications. It is helpful to review all six common home modifications to become familiar with design elements and construction assemblies that many families have found useful.

These recommendations are based on real projects. Many of the homes referenced in this guide have been in use long enough to demonstrate which design modifications have the most impact, which materials and assemblies perform best over time, and how environments must continue to evolve as individual's and family's needs change over time.

MAKING WAY FOR CHANGE AND GROWTH

Every parent knows that raising children is a time-consuming, expensive, and often exhausting undertaking. Raising a child or caring for an adult with Autism typically far exceeds this expectation in monetary costs, duration, and human impact. One parent calls it the “Autism surcharge for daily living,” and it is more than just the cost of a bigger garbage can for adult diaper disposal or the additional utility costs for many baths a day. The continuous and intensive engagement required to support an individual with Autism and complex behaviors is a major contributor to caregiver fatigue, injury, insolvency and out-of-home placement.

As children with ASD grow up, families may find themselves needing more support from the physical environment. By early adolescence, if toileting issues have not been resolved, housekeeping becomes a monumental challenge. As teens develop to physical maturity, they become stronger and are more likely to damage the home, get hurt, or injure someone else. Young people are frequently less willing to comply with demands or requests, and parents sometimes need to intervene, redirect or restrain.

Some individuals will begin to test the strength of their physical environment by banging on walls or windows, slamming doors or breaking furniture. Elopement, self-injury or aggressive behavior can strain relationships to the breaking point. In some cases, the home environment becomes damaged, dysfunctional or unsafe. Maintenance costs rise rapidly and the family may become discouraged or overwhelmed. In desperation, families may do things they know are unsafe or dangerous. It is at this point of exhaustion when out-of-home placement becomes a conceivable alternative.

LEAVING THE ENVIRONMENT OUT

When things aren't working, families call for help. Existing support systems tend to respond by deploying human service specialists focusing on training and crisis intervention. Respite providers, crisis intervention teams, behavioral specialists, psychologists or doctors are engaged to provide training and supports. Families are encouraged to “stick it out.”

“Our home feels like a battle zone. We love our daughter and want her to stay with us but vigilance and duct tape aren't enough anymore.”

– Anna's Parents

“[Physical] accessibility issues are easily understood in a way that Autism-related needs are not.”

— Mary Ann, mother of a 22-year-old daughter with significant Autism

“You cannot fix a problem behavior in a broken environment.”

— George Braddock

Professionals in the disability community have traditionally relied on people-power to provide the care and services necessary to support individuals with ASD and their families. Investing in the right supportive physical environment increases the likelihood that these services and supports will succeed. Families are more likely to remain intact, and individuals more likely to enjoy satisfying lives on their own terms when their homes work and make sense for them.

THE PHYSICAL ENVIRONMENT IS NOT PASSIVE

The problem with relying on people alone is that even the best programs and the best efforts of families and professionals often cannot overcome basic inadequacies in the built environment. Assessment methods and support strategies tend to leave the environment out of the equation. However, when the environment itself is broken, there is a limit to how much people can do, and how much burden families can bear.

Modifications to the home are not a replacement for necessary human help, and the individual with Autism and their family will continue to need support systems. However, including the environment in the assessment process and modifying the home so that it serves the person and the family can make a profound difference. In some cases, this is the difference between a person staying with their family and needing out-of-home placement. No one disputes that it is in everyone's best interest to support an individual's choice to remain in the family home.

HOMES THAT WORK

People are adaptable and can survive in many different situations, but thriving is another matter. The home that works gives a person control over his or her own life: it has the things that people need, and it is a good place to do the things they enjoy. It is a sustainable, welcoming place to be with friends and family.

THE KNOWLEDGE GAP

Compared to the gains made by the ADA to accommodate physical disabilities, there has been little progress in the effort to persuade decision-makers that modifying the environment to accommodate people with ASD can have equally empowering results. When the parallel between the need to spatially accommodate physical and intellectual disability is understood, the inadequacies of conventional housing for people with ASD become obvious. Obvious as well is the untapped potential of the right physical environment to support an individual's opportunity to live a safer, more self-directed, satisfying life.

The need for specialized knowledge goes beyond families and their supports. Design and construction professionals involved in implementing home modifications also need to become informed, experienced and knowledgeable about the needs of individuals with ASD. All too often, designers and builders unfamiliar with Autism will resist measures that need to be taken. The techniques don't fit the mode of the conventional home. In short, they are not familiar with designing or building the unique and sometimes unusual modifications that Autism can require, and that can become a barrier to getting the work done correctly.

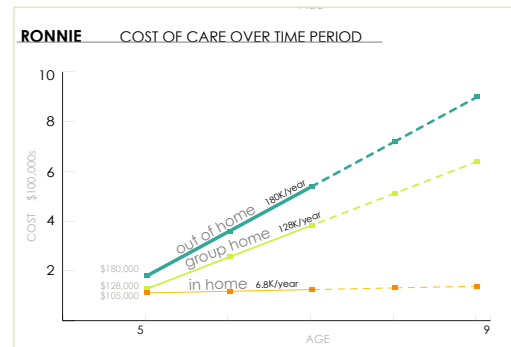
THE FUNDING GAP

The cost of out-of-home placement for any individual are high. The predictors of out-of-home placement among people with developmental disabilities are well known: caregiver fatigue and diagnosis of Autism combined with behavior problems lead the list. Although funding is typically available for respite, therapies and intensive behavior management training, only limited resources are allocated for "minor home and vehicle modifications."

The critical role of the physical environment in supporting families and individuals with neurological differences is under-appreciated. As a result, it is under-funded. But when the cost of doing even major in-home environmental modifications needed to sustain the family is compared to the cost of out-of-home placement, the financial return for the state is usually realized in the first year or two.

"Investing in the well-being of these individuals, from a human perspective, is the right thing to do. From a financial perspective, it's the smart thing to do."

— Cyndy Hayes, Director and Founder, Aging with Autism



COMPARISON OF COSTS

In-home care with modifications compared to any form of out-of-home placements demonstrates the savings realized by sustaining the family.

“Most home modifications for a person experiencing significant ASD can be justified to support health and safety, or to avoid crisis by intervening before it occurs. For Anna, the fence around our yard kept her from engaging in life-threatening pica. Her bathroom was made into a waterproof “safe place” for when she was in crisis. Both of these were health and safety modifications. They are justified because they keep Anna out of the ER.”
— Anna’s mother

For individuals with more complex ASD and behaviors, remaining in their family home may require more extensive modifications. In most state plans, funding for modifications is typically capped at \$5,000 per person over three years. Long lists of exclusions, presumably to protect taxpayers’ money from being misused, are included. Government funding generally excludes improvements such as flooring, furniture, exterior fences, or additions. This means that the environmental modifications most often needed to support a person with significant ASD staying in the home—including the “Six Most Common Home Modifications”—will likely be excluded.

There is a compelling financial case for funding environmental modifications that allow individuals to remain in their homes for as long as they want. Not only do these modifications tap into an underutilized potential to reduce the number of out-of-home placements, but project after project has demonstrated that person-centered environmental modifications are cost-effective and increase the ability of individuals to live safer, more independent, and self-directed lives.

SUPPORTING THE WHOLE PERSON

People with significant behaviors are more likely to learn, to mature and to succeed in safe and supportive home environments that meet their needs and accommodate their individual wants. Modifications to the home can often reduce the cost of supports, and avoid the need for more help and more costly interventions. Creating an environment that works for the individual should be more than a crisis measure or a one-time-only response to a problem. It should be an integral part of a person-centered plan.

RONNIE

Ronnie's father was always right at his son's elbow. Ronnie experienced significant ASD and, left on his own, he would tear up the house. His family never left anything out that could be broken or thrown; all of the food was stored in the garage; there was a chain and lock on the refrigerator. If Ronnie went to the bathroom alone, he would flood the room, flush household objects down the toilet or tear the towel racks from the walls. Ronnie's brothers and sisters had hook and eye locks on their doors to keep him from coming in and tearing up their rooms. The family was in crisis.

Ronnie's needs were so intense that he was being evaluated for possible admission to an institution for people with developmental disabilities. The needed programmatic supports were brought to the family and a decision was made to remodel the family home. The hope was that the family could avoid out-of-home placement. A suite of rooms was created for Ronnie at the back of the house. For the first time in his life, he had his own bedroom, bathroom and living space. Specialized construction assemblies resulted in an environment where he could live the way he wanted without hurting anyone or damaging the house. Ronnie's parents' room was positioned at the joint between his suite and the rest of the house, with a door between their bedrooms. At night, his parents could lock the second door that connected Ronnie's suite with the rest of the house. This required Ronnie to pass through their room when he ventured out in the middle of the night. Ronnie's father would wake up and guide his son back to bed. This gate-keeper position was critical to keeping everyone safe until Ronnie was able to develop and exercise self-control.

At first, Ronnie's access to clothes and food needed to be managed by family and caregivers. But over time, Ronnie assumed control of his life and environment, and he now does most things without the need for constant supervision. Now, when he invites them, Ronnie's siblings enjoy coming to his "apartment" to watch television or play games. In turn, they can have friends over without fearing that their brother will ruin the visit. His siblings don't have to lock their bedroom doors anymore. Eight years later, Ronnie is still a challenging individual, but he continues to live safely in the family home and his family experiences less stress.

>> *Learn more about the modifications made to Ronnie's home in Chapter 7 - Family Stories.*