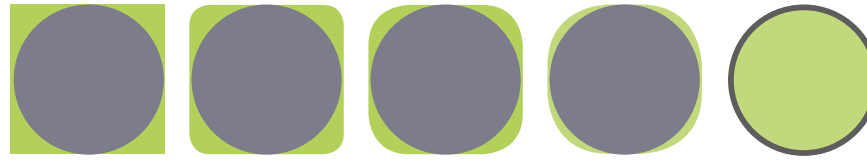

# MAKING HOMES THAT WORK

## A Resource Guide for Families Living with Autism Spectrum Disorder + Co-occurring Behaviors

George Braddock, Creative Housing Solutions LLC
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## ABOUT THIS GUIDE

This resource guide was funded by the New York State Office for People with Developmental Disabilities (OPWDD). It 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 project 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 housing opportunities for people with ID/DD, George's recent work involves developing inclusive, authentic community opportunities 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.

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This guide 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 use of the information contained in this resource guide, and to seek expert advice when appropriate.

## ACKNOWLEDGMENTS

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# INTRODUCTION

## 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, most conventional housing does not work. These individuals, their families and their caregivers often face profound challenges because of the inadequacy of their homes. An inadequate environment can directly influence the decision to place an individual with ASD in out-of-home care.

This guide makes the case for a balance between the 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 resource guide describes successful, cost-effective methods for making housing that works 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 ability and right 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 a person with ASD.
4. People with ASD can 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 GUIDE

This resource guide offers ways of assessing and planning environments that are person-centered, and that respect the diversity of family and individual situations. This guide identifies patterns of activity and interaction with the environment that are common to many people with significant ASD. These are the basis for the "Six Common Modifications" recommended for persons with significant ASD 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 guide 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 processes and recommendations are based on real projects. Many of the homes referenced in this guide have been in use long enough to reveal 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.

"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

## 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."

"[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

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. Invest in the right supportive physical environment, and the likelihood that these services and supports will succeed is increased. Individuals and families are more likely to remain intact and enjoy more 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.

"You cannot fix a problem behavior in a broken environment."
— George Braddock

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

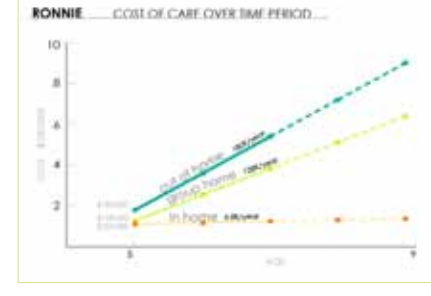
The cost of out-of-home placement for any individual are high. The predictors of out-of-home placement among people with developmental disabilities are well known: caregiver fatigue and diagnosis of Autism combined with behavior problems lead the list. Although funding is typically available for respite, 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 intellectual disabilities 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.

For individuals with more complex ASD and behaviors, remaining in their family home will require more extensive modifications.

"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 disproportionate 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

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 still needed to be controlled 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 in the family home.*

*>> Learn more about the modifications made to Ronnie's home in the **Case Studies** at the end of this guide.*

# Environmental Assessment + Action Plan

An Environmental Assessment and Action Plan will help you analyze your family situation, evaluate your home, and then use this information to make an action plan to modify the home environment. The process is focused on your family's interaction with the physical environment. It is not a substitute for holistic planning, and should be used in conjunction other person-centered planning processes. The Environmental Assessment and Action Plan has five steps:

### STEP 1:
Identify the challenges you face every day in the home as a caregiver.

### STEP 2:
Involve the individual.

### STEP 3:
Assess the home and identify what isn't working.

### STEP 4:
Learn about common home modifications and strategies for specific challenges.

### STEP 5:
Make an Action Plan that is appropriate to your unique situation and circumstances.

## STEP 1: IDENTIFY THE CHALLENGES YOU FACE EVERY DAY IN THE HOME AS A CAREGIVER

In the first step, you will identify activities that are taking place in the home that have negative consequences for you, the person you are caring for, other family members and caregivers, or the home itself.

Review the statements on the facing page, then answer the questions below.

- What are the three biggest stresses you face as a result of your caregiving activities?
- What are the greatest threats to the life, health and safety of the individual?
- Do you need to maintain line-of-sight or be within hearing distance or frequently check in on the individual?

Review the following statements and look for ones that describe your family situation:

- Family member leaves the home or property without supervision and has to be pursued.
- Family member will hurt themselves if you are not keeping an eye on them.
- Frequent intervention is needed to keep things from being broken.
- Unable to leave your family member alone in the bathroom.
- Family member is incontinent.
- Afraid that someone will get hurt if your family member becomes aggressive or violent.
- Family member is often awake and active while you are asleep.
- Family member wants to play in the water all the time.
- Family member is tactilely defensive and can be overwhelmed by too much sensory stimulation.
- Family member has seizures, pica or other disorders.
- You must re-organize the home every day.
- Family member is moving all the time.
- Home smells bad and the piles of laundry are endless.
- Neighbors are unhappy and wish you would move.
- Friends no longer visit.
- You need to make special arrangements to leave the home.

## STEP 2: INVOLVE THE INDIVIDUAL

In this step, you will explore how the individual interacts with her or his environment and what she or he needs. You are also looking for strengths and capacities that can be better supported so that individuals can live more independently and make choices for themselves. Sometimes it is possible to ask the person directly, and we have done this with success. Ideally, you will be able to take the time to simply observe how individuals use the physical environment. It also may be necessary to spend time observing non-verbal communication, and talking with family and friends or caregivers who know them well.

Individuals with significant Autism can and want to make decisions for themselves. The possibility that they will have a more satisfying life on their own terms is more likely if their input is taken seriously. To create an environment that works, the characteristics of an individual's Autism, along with their likes, dislikes and lifestyle, must be taken into account.

"Involving the Individual" is not as straightforward as other steps in the assessment process, but it is vitally important and the rewards can be significant. At the end of this step, you will have a better idea of what the individual needs from his or her environment. This may be a simple list of interrelated requests. The techniques on the following page are meant to support your inquiry. Be sure to answer the following questions:

- What is the circumstance or situation the individual most wants to change?
- What are the most important activities to the individual?
- What are the physical barriers to these activities that the individual experiences?

Ideas for involving the individual:

- Ask, look and listen. Explain what you're doing and take notes.
- Ask the person about preferences using literal and specific questions. For example, "Do you like to sit in a rocking chair?" as opposed to, "What kinds of furniture do you like?" Or, "Are you afraid of cats?" as opposed to, "Is there anything that frightens you?"
- Observe the person's activities, and talk to those who know them well.
- Look for specific sequences of activity or schedules of activity.
- What is the person doing that they seem to enjoy?
- Are there activities they do or want to do that are dangerous, messy, irritating or cause damage?
- Do they like extended water play, repetitive motion, running, throwing things, bouncing, picking, smearing, chewing, putting things in the toilet, making loud or constant noise?
- Does the individual have rituals or habits that have an impact on the physical environment? Pacing or rocking to relieve stress; needing background noise to go to sleep; inability to relax unless all the doors are closed; having to put things to "sleep"; toileting, bathing or eating rituals.
- Do they have fears that seem to be related to a particular space, noise, quality of light or other stimulus?
- Does the individual have a place of respite?
- Does the individual hide, seek quite spaces or stay in his or her room?
- Are there specific physical conditions, sensitivities or medical conditions?
- Are there aversions or attractions related to particular places or qualities of the home such as confined spaces around the toilet or by the bed?
- Is there over-stimulation or sensitivity to environmental conditions such as temperature, drafts or noises?
- Are there color preferences? Observe or present color options.
- Are there furniture preferences? What kinds of furniture do they like, recliners, gliders, rockers? How do they use them?
- Does the individual like or dislike the vacuum cleaner, washing machine or other appliances?
- Are there requirements for any special or adaptive furniture or equipment?
- Is pericare required?

## STEP 3: ASSESS THE HOME AND IDENTIFY WHAT IS NOT WORKING FOR CAREGIVERS AND THE INDIVIDUAL WITH ASD

In this step, you will identify how your home fails to support the individual with ASD and specifically compounds the physical or financial expense of caregiving. You will need to observe carefully and view your environment objectively. Are any of the challenges you experience the result of a deficiency in the physical environment? In what specific ways does the physical environment increase expenses or add stress to daily life? In what ways does it limit choice, control, or participation in preferred activities for the individual? It is not always the case that the activity itself is the problem. Often times, inadequacies of the physical environment cause preferred activities to have negative consequences.

Spend time observing: Look, listen, touch, poke, smell. How does the individual use or want to use their environment? Look for deficiencies that impede the individual living as he or she wants. Look for barriers that cause regular activities to have negative consequences for the individual, others, or the physical environment itself.

Read the questions on the facing page, then analyze your home and answer the questions below.

- What is your biggest problem with your home?
- What are the three things you most want to change about the environment?
- What is causing the most damage to the home?

The following questions are intended to help you assess your home environment:

- Are there safety issues for you or the individual in the home or outdoors, such as tripping, slipping or falling hazards? Do health or mobility issues present risks?
- Is there a need for a basic "safety-proofing" of the house? Is there adequate, safe storage? Are there health risks such as seizure disorders or diseases?
- Are there environmental hazards such as access to toxic chemicals (including cleaning products) or on-site pollutants?
- Are there any signs of dry rot and water damage? Do you smell mildew or mold anywhere in the house? Can you see mold on ceilings or along floor boards?
- Are there other "bad" smells? If so, where are they coming from and what is causing them? Look for damage or discoloration of surfaces, flooring or materials.
- Can the individual safely use the yard? Is it secure? Are there hazards or existing conditions that could be dangerous such as water, utility boxes or equipment?
- Is the home crowded? Do people share bedrooms? How many people share the bathroom? Is the laundry/utility room adequate?
- Does the individual's bedroom provide a safe haven?
- Does the bathroom meet the toileting and bathing needs of the individual? Can the individual safely use the bathroom in the way he or she wants?
- Are the living areas of the home large enough to support the family's activities? Do other siblings or family members have the space they need? Does the home have more than one living area?
- Are family members negatively impacted by behaviors such as screaming, running, pounding or slamming doors?
- Are the entry ways and/or halls cramped or confined?
- Do lighting and acoustic treatments support caregiving? Do they aggravate the individual?
- Is the home damaged: broken windows, walls or doors? Torn flooring or carpet?
- Are basic home furnishings damaged or have they been removed for safety reasons: chairs, couches, fixtures or appliances?
- Are there activities in the home or outside that disturb or anger the neighbors? This might include yelling, screaming, throwing things out of the yard, door slamming, or activities that give them reason to call the police.

## STEP 4: IDENTIFY COMMON MODIFICATIONS + SPECIFIC CHALLENGES

In this step, you will take the information gathered in Steps 1 through 3 and identify modifications that could help solve the problems you have identified. This is the research step that will give you the background knowledge needed to make the action plan discussed in Step 5.

Don't be overwhelmed by the apparent uniqueness of your situation. While all experiences with ASD are unique, many of the issues or challenges you face have been confronted by other families and caregivers. Many of their challenges have been significantly improved by making one or more of the "Six Most Common Home Modifications" included in this guide. They are the basic strategies that every family should consider when transforming the physical environment to support an individual with significant ASD.

The table on the following page is intended to help you connect specific concerns to concrete solutions. We have identified issues or concerns that families often face, and suggested which home modification is most applicable. Often, caregivers have multiple concerns and it may be necessary to explore many of the modifications or delve into strategies related to specific challenges.

Using this table, identify your concerns, then refer to the suggested modification in the next chapter to learn more about possible solutions. *Some families face specific challenges requiring targeted solutions that go beyond what is common. Learn more about strategies that have worked to resolve* ***Specific Challenges*** *on page 41.*

| IF YOUR CONCERN IS: | THIS COMMON MODIFICATION MAY HELP: |
|---|---|
| Broken windows, slipping, falls | Autism-Friendly Home |
| Incontinence, toileting issues, water play, keeping clean, damage to the bathroom, flooding, slipping and falls, poor ventilation, bad smells | The Essential Bathroom |
| Pacing, physical anxiety, stress, running, jumping, chasing, avoidance of social interaction, seclusion, vestibular disorders and spatial relationships | Walking Loop, Connected Home |
| Voluntary engagement, safe boundaries, fencing, preferred activities, eating disorders, fears | Places of Control / Layers of Freedom |
| Lack of visibility between rooms, monitoring activities, ensuring safety, self injury, seizures, medical issues | Connected Home |
| Disorganization, chaos, inappropriate storage, bad smells, soiled furniture, endless clean-up, ineffective housekeeping, exhaustion | Tools for Housekeeping |
| Broken or damaged furniture, special equipment or conveyances, unsafe applications, non-functional hardware | ASD Friendly Home |

| IF YOU FACE THIS SPECIFIC CHALLENGE: | REFER TO: |
|---|---|
| Climbing fences, leaving home, lack of safety awareness, opening locks and gates, hiding, wandering away | Elopement |
| Head banging, hair pulling, biting, eye poking, hair pulling, slapping, drop seizures | Self-Injury + Seizures |
| Damage to walls and/or windows, broken doors and jambs, exposed wiring, damaged furniture and appliances, water damage | Property Damage |
| Threats to life and safety, involvement with police or authorities, injury to others, assault and violence | Aggression |
| Invasion of privacy, yelling, disturbing the peace, neighbor complaints | Neighbor Relations |

## STEP 5: MAKE AN ACTION PLAN

Steps 1-4 have prepared you to make a specific Action Plan. Use the information gathered in the assessment and research steps to identify priorities, constraints, and potential modifications to your home that will meet your individual and family-specific circumstances. The outcome of this step is an appropriate, cost-effective plan for how the home can accommodate the individual's needs and work for everyone.

Before making an action plan, make sure you have completed Steps 1 through 4 in the Assessment Process.

The Action Plan includes the following:

### DEFINE THE PROBLEM:
- Identify the challenges you face every day in the home as a caregiver

### DOCUMENT THE INDIVIDUAL'S WANTS AND NEEDS

### ASSESS THE HOME AND IDENTIFY WHAT IS NOT WORKING

### IDENTIFY RELEVANT COMMON MODIFICATIONS + SPECIFIC CHALLENGES
- *See: Basic Elements from "Six Most Common Home Modifications"*
- *See: Specific Challenges and Environmental Strategies*
- Identify modification in response to specific challenges
- Accommodate unique circumstances and constraints
- Anticipate changing interests, capacity and aging

### ESTABLISH PRIORITIES
- Identify resources
- Establish a budget
- Prioritize individual elements in the scope of work

### IDENTIFY EXPECTED OUTCOMES
- Specific changes expected
- Long term/short term/intermediate

### WRITE A SCOPE OF WORK

### IMPLEMENT THE PLAN
- Engage design professional
- Set a schedule for design, permit and construction
- Engage builder, supplier or fabricator

# ACTION PLAN - SAMPLE

*The following is a sample action plan, using Anna's bathroom project as an example.*

**ASSESS THE SITUATION AND DEFINE THE PROBLEM:**
Anna won't use the toilet. She damages the bathroom with her water play and makes more work for Mom. Anna cannot be in the bathroom alone.

**WHAT DOES THE INDIVIDUAL WANT TO DO?**
Anna spends hours every day in intense water play in the bathroom.

**WHAT DOES THE INDIVIDUAL NEED?**
Anna needs to be toilet trained. Anna needs a bathroom where she can do what she loves without negative consequences.

**IDENTIFY EXPECTED OUTCOMES:**
Anna is able to toilet herself. Anna can spend hours playing in the bathroom with water without damaging the home or getting hurt. Mom experiences less stress and has more time for other things.

**PROJECT GOALS:**
Modify Anna's bathroom so she can be more independent and better participate in the activities of daily living.

**IDENTIFY APPLICABLE ELEMENTS FROM THE SIX MOST COMMON HOME MODIFICATIONS:**
Elements from the "Essential Bathroom": Floor drain, non-skid flooring, tempered glass, scald prevention, enlarge toileting space, grab bars. Commercial shower wand and faucet, new lighting and ventilation, Wall hung toilet with hidden tank.

**IDENTIFY STRATEGIES IN RESPONSE TO SPECIFIC CHALLENGES:**
Elements from "Property Damage": Shelving to support toilet training, Wet storage, continuous hot water, hot water loop, interactive water play features, heated floor.

**ESTABLISH PRIORITIES:**
Ability to clean and use bathroom safely and effectively. Floor drain, non-skid flooring. Need a larger toileting space, grab bars and ventilation.

*Eliminated due to budget constraints:*
Wall hung toilet, hot water loop, interactive water play features.

**SCOPE OF WORK:** Construct bathroom modifications for safety and to support appropriate use and toilet training.

**IMPLEMENT THE PLAN:**
Schedule: 4 weeks for Design and documentation, 2 weeks for permit, 8 weeks for construction
Design Professional: John Rowell to draw plans and submit for permit.
Engage Builder, Supplier or Fabricator: George Braddock to contract and build.

# ACTION PLAN

Use these pages to develop a specific action plan to implement a modification to your home.

## ASSESS THE SITUATION AND DEFINE THE PROBLEM:

## WHAT DOES THE INDIVIDUAL WANT TO DO?

## WHAT DOES THE INDIVIDUAL NEED?

## IDENTIFY EXPECTED OUTCOMES:

## PROJECT GOALS:

## IDENTIFY APPLICABLE ELEMENTS FROM SIX MOST COMMON HOME MODIFICATIONS?

## IDENTIFY STRATEGIES IN RESPONSE TO SPECIFIC CHALLENGES?

## ESTABLISH PRIORITIES:

*Basic elements and potential upgrades are evaluated by importance, cost, and possibility for deferment to a future phase.*

## SCOPE OF WORK:

## IMPLEMENT THE PLAN:

Schedule: _____ weeks for Design/Documentation, ____ weeks for permit, _____ weeks for construction

Design Professional: _____

Builder, Supplier or Fabricator: _____

## A GOOD START TO COLIN'S DAY

For Colin, every day started with a warm shower. To support this activity, Colin's bathroom had been completely remodeled to include a waterproof epoxy floor, floor drain, and an accessible shower. As he grew to adolescence, these morning showers became more and more contentious. When the shower was over and his mother turned off the water, Colin would lunge at her and try to grab her hair. More and more often, his mom struggled with the shower routine and Colin's aggression.

After hearing this story, a knowledgeable friend had the insight that Colin was struggling with the abrupt change in stimulation that came at the end of the shower. This friend recommended that, just before the shower was finished, Colin's mom turn the water on in the sink and let it run, then open the shower curtain and wait a few minutes before turning off the shower. To help the transition from the shower's warmth to the cooler bathroom, Colin's mom also had a heat lamp installed near the sink. With a towel ready to keep him warm, Colin could dry off near the sink and listen to the running water. This extended transition gave him time to integrate and manage the changes in stimuli.  The combination of a knowledgeable friend who understood Colin's needs and an adaptable bathroom that safely supported his bathing needs was key to managing Colin's sensitivities.

# Six Most Common Home Modifications

## FOR A PERSON WITH SIGNIFICANT ASD

If the home is to better support the life of a individual who experiences significant ASD, there are a few "must-haves." Each individual is unique, but environments where people experiencing Autism can live, learn, work and play successfully share many common characteristics. If you ask the right questions and get the fundamental patterns right, the whole environment will work better for everyone. The home will be a safer place, the individual will have more opportunity and choice, other supports can be more effective, and the family can be more stable and resilient to other stresses.

**1 AUTISM-FRIENDLY HOME:** The focus in an Autism-Friendly Home is on reducing risk and anticipating activities. Broken windows, slipping, falls, broken or damaged furniture, special equipment or conveyances, unsafe applications, and non-functional hardware are addressed.

**2 CONNECTED HOME:** This will be a helpful resource if you are challenged by a lack of visibility between rooms, the need to ensure safety, or the need to monitor activities including self injury, seizures, and medical issues.

**3 THE ESSENTIAL BATHROOM:** These modifications can help address the most common challenges related to incontinence, toileting issues, water play, keeping clean, flooding, slipping, damage to the bathroom, and falls, bad smells, and poor ventilation.

**4 WALKING LOOP:** An in-home "loop" designed for pacing and stress relief can also address running, jumping, chasing, avoidance of social interaction, seclusion, and vestibular disorders.

**5 PLACES OF CONTROL + LAYERS OF FREEDOM:** These examples can help address issues related to voluntary engagement, safe boundaries, fencing, preferred activities, eating disorders, and fears.

**6 TOOLS FOR HOUSEKEEPING:** A resource to address disorganization, chaos, inappropriate storage, bad smells, soiled furniture, ineffective housekeeping, and caregiver exhaustion.

## CHOOSE THE RIGHT COLOR, IT MATTERS

When it came to property damage, Curt was known as the toughest man in the institution. When he moved into a group home, everyone believed this challenge had been prepared for adequately. However, Curt was able to tear through the walls of his home, even though they were covered with fiberglass reinforced plastic and structurally reinforced.

Determined to make a wall that Curt could not damage, we started over at the framing and reinforced all the connections with metal brackets. We then installed 3/4" marine-grade plywood to the heavy framing with 3" screws and glue. Over this we applied a fiberglass reinforced plastic paneling (FRP), a material commonly seen in restaurants, public restrooms and commercial applications. It's not particularly "homey" but it does provide industrial strength. In Curt's case, we installed a light blue FRP. When he came home and saw the room, everyone stood back to see what would happen. He walked around the room, and then said: "Nice color!" He would not even let his staff push the bed up against the wall, for fear it would mar the blue wall. We were left to wonder if, all along, Curt had just wanted a bedroom that was a color he liked.

## LOVE AND PROTECTION OF THE COLOR ORANGE

Edson liked to shred cloth. Cotton towels were his favorite. He would chew the cuffs and collars off his clothes, sheets, pillows, curtains—you name it.

Edson's family usually dressed him in coveralls to make it hard for him to chew or shred them. But eventually, they discovered that orange was his favorite color; he did not shred or chew orange things. Armed with this insight, the family went about replacing bed spreads, sheets, curtains and other home decorations and any other fabric in Edson's home. All are now shades of orange, and Edson is not interested in shredding any of them.

# 1 Autism-Friendly Home

## REDUCING RISK AND ANTICIPATING ACTIVITIES

Many people with ASD share common characteristics including sensory and perception problems, organizational problems, communication issues and impaired thinking abilities. Unfortunately, conventionally available home environments can be confusing, over stimulating, frightening, upsetting, or too restrictive for these individuals.

An individual's preferred activities and their coping mechanisms can result in property damage, put people at risk or irritate the neighbors. These become labeled "problem behaviors." The real problem is often the inadequacy of the house. This is why Assessment Step 3, which identifies what isn't working in the home for the individual, is so important. Failures of the environment should not be presumed to be someone's fault.

Providing a home environment that anticipates common use patterns will result in a more ASD-friendly home that works and makes sense for the person, reduces stress and workload, and improves health and safety.

Every home is full of items that can hurt people. Ensuring the health and safety needs of a person with disability should, at a minimum, meet the life and health/safety requirements of the modern building code. Look at individual circumstances and address any unique safety concerns.

### ELIMINATE OBVIOUS HAZARDS

- Secure toxins such as paints, solvents, fuels, chemicals, medications or poisons such as insecticides, cleaning products, detergents or bleach in closed and locked cabinets.
- Firearms and ammunition must be under lock and key.
- Install scald prevention devices at tubs, and showers.
- Drowning is the most common form of accidental death among people with Autism. Secure pools, hot tubs, fountains, ponds or other potentially dangerous water hazards in or around your home with lockable covers or fences.
- Inspect your landscape and remove poisonous plants or other toxic materials from the yard.
- Remove or encapsulate any lead paint per local regulations.
- Install carbon dioxide and particle smoke detectors in bedrooms, hallways and living spaces. Select units that give

voice commands such as "Leave the Home" to help avoid confusion. Consider installing "rate of rise" detectors in kitchens and garages.
- Installing arc-fault and ground-fault electrical receptacles will reduce the risk of electrocution from misuse of outlets.
- Grab bars, furniture, exercise/adaptive equipment, swings or other wall or ceiling mounted toys and/or devices need to be solidly attached to adequate backing or framing. When needed, fall protection should be installed.

## ADDRESS PERSONAL RISKS AND DANGERS

Many individuals with ASD have co-occurring conditions that require specific environmental modifications. Do seizures happen? Does the person hurt themselves or others? Are there sensitivities to food or does the person have an eating disorder?

In general, it is a good idea to consider the following:

- In as much as possible, protect the head from injury in the event of a seizure, fall or predictably dangerous behavior.
- Drop seizures suggest the use of built-in or padded furnishings without sharp corners or hard edges.
- Round corners on walls and countertops.
- Pad headboards and bed frames if needed.
- Eliminate places where individuals can get their heads or bodies stuck (e.g., between the headboard and the mattress or the toilet and tub).
- Eliminate access to easily ingested non-nutritive or toxic substances.

## INSTALL FINISHES THAT ARE EASILY CLEANED

Surfaces should be user-friendly and attractive, but nonabsorbent. When a person has open cuts, scrapes, blisters or burns there is a greater need to clean and disinfect surfaces and other materials on a daily basis.

## PROVIDE CONTROL

Provide increased opportunity to regulate the quality of light and air. Individuals experiencing ASD are often very sensitive to drafts, temperature and air quality. Zoned HVAC systems, individual mini-units and high-quality air filtration systems (HEPA filters) are options. Lighting can be fitted with dimmers and curtains are available to provide the full range of light control.

## ANTICIPATE UNCONVENTIONAL USE

The parts of the home that tend to be most frequently damaged and wear quickly are window coverings and drapes, floor coverings, wall and cabinet finishes, and hardware. Alternatives to conventional window furnishings include internal blinds, commercial breakaway curtains or curtains Velcroed to the wall or looped over a reinforced rod. Flooring and other finish surfaces should be durable, smooth, and easy to clean.

Most homes have painted drywall surfaces with a lightly textured finish. These walls are easily damaged and difficult to clean repeatedly. If surface damage is occurring, use semi-gloss or graffiti-resistant paints. Epoxy paint is a good choice in wet areas or areas of extreme use, such as around beds, recreation areas, or transitions. Industrial quality wall coverings may also work. These include vinyl, PVC, and wallpaper reinforced with Kevlar.

*If damage goes beyond the surface and includes making holes, deep picking or chewing, see* ***Property Damage****.*

Plastic electrical switch and outlet cover plates are easily broken. Cover plates made from nylon or Lexan are more durable and not expensive.

## ANTICIPATE WATER PLAY

Water is almost always a source of interest. Inside the home, select faucets that direct water into a basin and cannot be manipulated to redirect water onto the wall, floor, or counter top. If the individual enjoys playing with water, try to make that activity safe and non-damaging. The bathroom is an obvious location for water play, as is the kitchen. If outdoor water play with hoses or sprinklers is a preferred activity, the runoff and splashing will need to be managed to prevent damage and maintain safety.

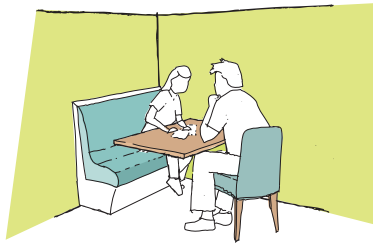
For example, if a person is splashing in the sink or tub, make sure nearby areas are protected. A wet room with a floor drain and sealed surfaces will safely support most water play. The shower door and curtains should be solidly attached and the doors properly adjusted. Any joints should be caulked and maintained. Shower curtain rods need to be strong enough to bear weight and should be attached solidly to the wall. Velcro loops that hold the curtain in the rod can be easily re-attached if pulled loose without damage.

*For more extreme door slamming issues, see **Property Damage**.*

## ADDRESS PROBLEM DOORS

Swinging doors are frequently a problem. They can be slammed and if this happens repeatedly the hinges and door frame will break. They are a danger because a slamming door can hit people and pinch fingers. There are reasonable alternatives. Commercial quality pocket doors and breakaway curtains are two of the best choices. Fiberglass bi-fold doors with appropriate high quality hardware can also be considered.

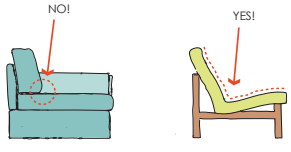
If doors are subject to repeated slamming or attempts at forced entry, make sure the jamb, hinges and stops are solidly attached to the wall's framing. Protect the wall from damage caused by the door knob. Bumpers attached to the door can reduce the noise of slamming, and smoke seals attached to the jamb can slow a closing door. A sweep attached to the bottom of the door that drags on the floor can work in many cases.



PREFERRED DINING + SITTING
A booth mounted securely to walls and floors. A high back that adds to the sense of security and privacy. Fixed table and seating support caregiver safety when assistance is needed.

## SELECT APPROPRIATE FURNISHINGS

Some individuals with Autism like to spin, swing, rock or bounce. Accommodate this interest outside by using swings and other moving equipment that they prefer. Whenever possible, provide cover from the weather to extend usable times. Equipment will need to be upgraded and changed as the individual grows and interests change. Providing opportunities indoors to enjoy this activity is more challenging. Ceiling mounted swinging chairs, rope swings, rocking chairs, and gliders can accommodate this interest. When installing these items, place solid anchor points into framing when attaching to walls, floors or ceilings. Use fasteners, safety chains or straps that are rated for commercial use. Sports equipment such as high jump mats can be made into couches with pillows and slip covers.




DURABLE FURNISHINGS
Padded, reinforced, solid-wood furniture without sharp corners. Cushions should be comfortable, nonabsorbent and durable. Eliminate crevices that can trap food or odors.

Cloth covered furniture and cushions are difficult to maintain and frequently become damaged, stained and absorb unpleasant odors. If furniture damage is an issue, use solid wood or plywood furniture glued, screwed and/or bolted together. Construct furniture to be thoroughly cleanable and avoid having places where food can be trapped. Institutional quality couches and chairs often address these concerns. Vinyl cushions or foam rubber covered in ballistic nylon, often used in boats and equipment seats, may prove appropriate in some cases.

# 2 Connected Home

## INCREASING VISIBILITY AND CONNECTIONS

The overarching concern of families is the health and safety of their family member living with ASD. Fundamental to ensuring their safety is awareness of the person's whereabouts and the ability to monitor what they are doing. In many homes, this requires being with the person most of the time, or constantly checking in. The need for constant vigilance can be overwhelming and is a common cause of caregiver fatigue.

Caregivers need to be able to see, hear and monitor activities inside and outside the home. At the same time, healthy awareness means monitoring without controlling the individual's every move or watching every minute.

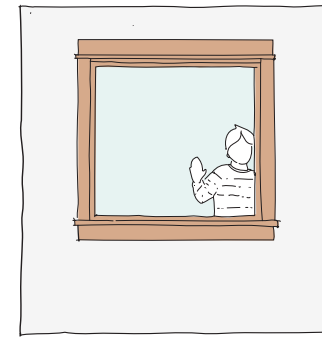
Modifications should provide ways for you to be aware when they are venturing on. Families can relax when they know where their family member is and what they are up to. In most cases this will mean providing a secure perimeter. In all cases there should be a definite boundary that everyone knows is the limit of safe activity.

### VISIBILITY AND OPENINGS BETWEEN ROOMS

It is common to find families struggling to overcome the visual barriers in the home. This is especially the case in older homes that were designed with many separate rooms. Interior windows or "re-lites," with tempered glass or even without glass can help solve this. Where more direct connections are necessary, walls can be opened to create a series of visually and physically interconnected rooms. Pocket doors or curtains can provide separation when desired without losing floor space or having the safety hazards of swing doors.

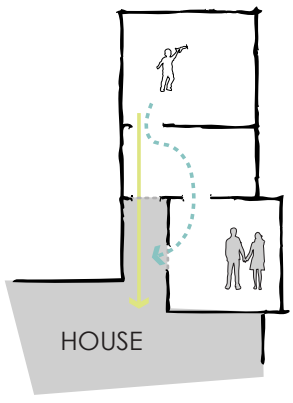
### CONNECTIONS FOR NEEDED CAREGIVING

It is especially important to make good visual and acoustic connections if there are safety risks, seizures or medical issues. In cases that require night-time monitoring or assistance, it can be helpful to locate the individual's bedroom adjacent to the parent's or caregiver's room then make an opening directly between the



INTERIOR WINDOWS allow for privacy from room to room as well as supervision when necessary.

THE DELIGHT OF AN AQUARIUM
One of the most effective connections between rooms is a see-through aquarium. The layer of water and aquatic life provides cover that allows individuals to interact in a more discreet way.




### RUSSELS'S BEDROOM DOOR

*Russel has Prader-Willi Syndrome. His Dad could never get a full night's sleep because he was too worried about Russel getting up during the night and getting into the refrigerator. His bedroom was next to Russel's, allowing a door opening to be cut between the two rooms. At night, Dad can lock the hallway door so his son must pass through his bedroom on the way to the food. Russel is now less adventurous at night and Dad can get some sleep.*

two. Circulation patterns can be designed to allow the individual with ASD more independence during the day, while maintaining a direct visual, acoustic and physical connection between rooms at night.

## USING TECHNOLOGY TO MONITOR SAFETY

Alarms and sensors can improve a family's or caregiver's ability to monitor remotely. Door and window alarms are the most common strategy, and they are most useful for passively monitoring a person's whereabouts. Infrared or motion detectors can be used to track movement, which may be useful in supporting eating disorders, elopement, or problematic interactions with siblings. If it is necessary to monitor a physical condition like seizures, you may want to install sensors in the bed or on the floor.

Webcams, security cameras, and computer technology are often useful and even more appropriate outside. They can allow a person to be in the yard with less direct or even unnecessary supervision. In the house, cameras can be useful in situations where there are significant or life-threatening health issues, but be careful not to rely too heavily on technology and cameras. Technology breaks and becomes obsolete. Ask yourself what information you need, and if there are simpler less intrusive ways to gather it. A new window cut in the wall that gives a view of the yard from the kitchen will always be reliable.

# 3 The Essential Bathroom

## SOLVING THE MOST COMMON CHALLENGE

Modifications to the bathroom are the most common need of families. It is safe to say that the more significant the Autism experience, the more pressure and stress builds up around bathroom mechanics. Balancing the activities that need to occur in the bathroom such as toileting, bathing and grooming with recreational and therapeutic activities such as water play or soaking may be challenging. Bathrooms are subject to water damage, rot and mold. Water also poses safety risks for slip and fall, drowning and burns. Bathrooms can require certain protocols that don't always make sense for people with ASD. Over time, a list of autism-friendly bathroom modifications has been developed that make up "The Essential Bathroom."

### ENOUGH SPACE

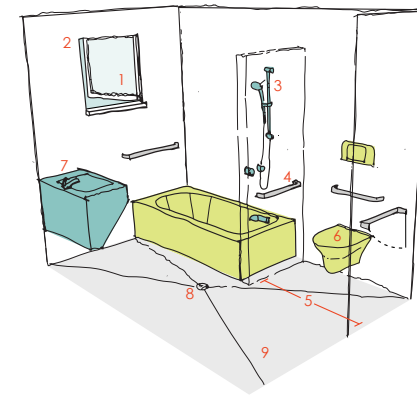
Cramped bathrooms can trigger defensiveness and discourage participation in toileting or bathing activities. In some cases, it is simply the constrained area of the toileting space that presents the barrier to use. Often there is a need to reorganize the bathroom or appropriate adjacent square footage so the bathroom can be transformed to address tactile defensiveness, claustrophobia or sensory overload.

### ADDRESS SAFETY

Address safety issues such as slip and fall, scald prevention, electrical shock and broken glass. Install non-skid flooring such as non-skid tile, coved commercial grade vinyl with non-skid wax or epoxy. Install weight-bearing bars with solid backing. Ground Fault Interrupter (GFI) outlets, tempered glass and mirrors and tempering/ balancing valves.

### INSTALL A FLOOR DRAIN

Splashing water makes the floor slippery; mopping it up to prevent damage and improve safety is labor intensive. The most effective way to control spilled water is to drain it away. By installing a floor drain, water splashed or poured onto the floor can drain away. Installing a floor drain is a very worthwhile and simple modification that can make a big difference.




THE ESSENTIAL BATHROOM

1 Tempered glass
2 Window for light and ventilation
3 Commercial shower wand
4 Grab bars mounted to solid backing
5 Enlarged toileting space
6 Wall-mounted commercial toilet
7 Faucets with scald prevention
8 Floor drain
9 Non-skid flooring

## USE COMMERCIAL OR INSTITUTIONAL-GRADE FIXTURES

This is especially important for the toilet. Installing a wall-mounted unit with the tank and flush mechanism in the wall is recommended. The tank is no longer a problem because it is hidden in the wall. Wall-hung toilets open floor space and provide toe space that allows a caregiver to assume good ergonomic posture when providing assistance. It also makes cleaning around the toilet easier without the floor mounted base. This type of toilet is readily available and is standard in many places in the world.

## ANCHOR FIXTURES AND GRAB BARS

Most bathroom accessories are too flimsy to hold up in a bathroom that is used intensely. Standard residential plumbing installations also don't anticipate the kinds of forces that can be applied with non-traditional activities or to help a person stand or stay seated with every use. If you substitute weight-bearing grab bars for towel bars, one of the problems is solved. Institutional-grade fixtures have special features and extra strength, and they are a worthwhile alternative.

It is important to make strong connections to the wall structure when the wall is open. It costs very little to add extra wood backing before the finish is applied. A good option is installing a continuous sheet of plywood to allow for complete flexibility for solid attachment later. This is not a "standard" construction practice, so it's necessary to communicate very clearly with builders before the wall is closed in.

## OPERABLE WINDOWS AND NATURAL LIGHT

Bathrooms are not always located on exterior walls, but if at all possible, find a way to include natural light and natural ventilation. This is essential to maintaining a healthy, welcoming bathroom when it is intensively used. Exhaust fans alone cannot meet all the needs, but if that is all you have, pick a quiet one with high cfm and vent it to the outside.

## A SECONDARY HEAT SOURCE

Radiant heating in the floor, heat lamps or forced-air electric heaters are some of the best preventives to mold and eliminating slipping hazards. It has the benefit of creating a more welcoming bathroom for people who are temperature sensitive.

## ELIMINATE REGISTERS AND OTHER FLOOR OPENINGS

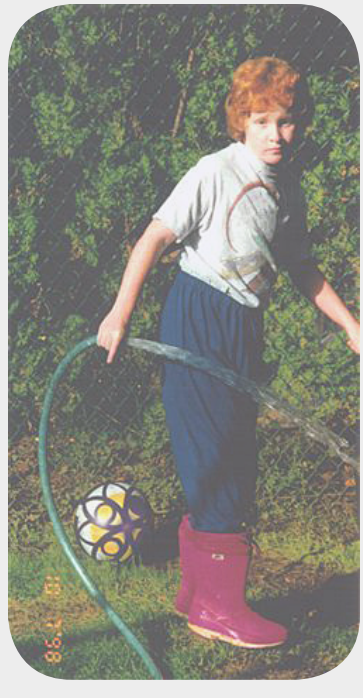
Floor registers collect water and dirt, and are difficult to clean when the toilet overflows. Move registers to the walls whenever possible.

## ANNA

*Anna spent many hours each day in the bathroom in intense water play. This was a source of tremendous stress on her family and resulted in permanent damage to their home. Based on an evaluation of the space, Anna's desires and her family's needs, a remodel plan was developed to improve the layout and technical performance of the bathroom. Grab bars, impervious materials, heated surfaces, improved lighting, durable fixtures and other elements were introduced. The evaluation of the completed project and its effect on Anna's life shows that she can now do what she clearly enjoys without negative consequences. Safety is improved, damage to the building is minimized and her family experiences significantly less stress and more freedom because they spend less time doing intensive supervision and clean-up.*

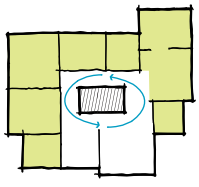
*Anna has exhibited a reduction in behavioral episodes because she experiences more choice, control and independence in her life. Anna's ability to continue to live at home with her family is a substantial return on the investment in physical improvements.*

*>> Learn more about the modifications made to Anna's home in the* ***Case Studies*** *at the end of this guide.*

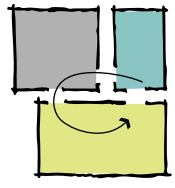


# 4 Walking Loop

## A ROUTE FOR PACING AND STRESS RELIEF



CENTER MASS LOOP
A "core" of the house (a bank of closets, a bathroom, or fireplace chimney) provides the center anchor point of a walking loop.



CONNECTED ROOM LOOP
Using doorways among three or more adjacent rooms, a walking loop can be created. Usually, these loops a mix of shared spaces (like the dining room) and private spaces (a bedroom).

Many people experiencing ASD benefit from large muscle movement by walking, pacing, rocking, running or jumping. To accommodate these activities in the home, look for the opportunity to create a "walking loop." Ideally, this is a path that circles through and / or around several rooms of the home.

In addition to sensory integration and stress relief, a walking loop can give an individual more control over social interactions. The loop makes it easy for them to enter a room, stay, leave or return later on their own terms. To support this kind of control and interaction, try to connect private spaces such as bedrooms and sitting rooms to more public spaces such as living, dining, entry or kitchens. In some cases, the loop can give caregivers a path to move away from stressful situations or confrontations.

### GETTING A WALKING LOOP TO HAPPEN IN A HOME

If you are designing a new home, the loop should be integrated in the layout of rooms. In an existing home, creating a loop often takes more creativity. In traditional houses, the stair is often central to the plan layout, and a loop can easily be developed by connecting rooms around the stair. Other plan types may not prove to be so easy to adapt, but it is usually possible to find a set of rooms that can be interconnected to form a loop.

Most often this involves opening walls or creating passageways that can be arranged so that it allows the individual to circle the rooms or walk down a hall to a room with a turnaround space. Paths need to go where the action is, and lead to safe rooms away from activity. Avoid dead-ends such as hallways to locked rooms. Avoid pinch points where two people can't pass each other without giving ground. Whenever possible, make loops that can also connect the person to outside areas.

### WALKING IN COLIN'S HOUSE

*Colin's house is a good example of a walking loop introduced into a ranch style house that had isolated wings and rooms off of dead-end halls. One side of the loop connects his bedroom directly to the living spaces, the other side connects through Colin's bathroom to the utility/cleanup and the kitchen. The loop has proven to also help Colin's caregivers when Colin is upset. They are able to back away safely and allow him to move until things settle down.*

# 5 Places of Control + Layers of Freedom

## PROVIDING CHOICE AND OPTIONS FOR ENGAGEMENT

People with Autism usually struggle with social interactions. Many prefer being alone. If they feel safe and can interact on their own terms, they are more likely to engage with others and pursue the things they like to do.

### SAFE PLACES AND PREDICTABILITY

Create private places that make the person feel safe and in control. Having the opportunity to retreat, when needed, often results in the person regaining control and being better able to choose more, not less, social interaction. Provide places to display information or post a schedule. Having this information at hand supports routines and allows everyone to know when supports are scheduled; and if there are changes this helps people to feel in control.

The bedroom is the most obvious place of control, although it should not be the only one. Provide the person with as much control as possible in his or her bedroom, including control of the door, choice of favorite colors, and control of light, air and sounds. Provide furnishings, entertainments systems and toys that are preferred. Support coping strategies whenever possible. Frequently, white noise can mitigate sensory overload. Try fans, low music or TV in the background.

Find places within the home outside of the bedroom such as the bathroom or sitting room where the individual has opportunities for meaningful control and choices structured for voluntary participation. Create the bathroom as a safe place they can use independently. One simple modification that allows independent use of the bathroom is the installation of a bidet toilet seat, which reduces the need for caregiver assistance.

### LAYERS OF FREEDOM

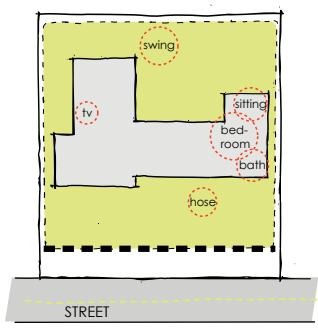
Other areas of the home can be layered to provide opportunities as interests emerge and capacity is built. For example, physical or sensory cues that establish routines for use and participation in the laundry room, garage or kitchen activities can build confidence and encourage independence. This idea extends beyond the interior to include the whole property. Enclosing a porch or patio provides an opportunity for an individual to go there independently and

*These opportunities are only realistic in an **Autism-Friendly Home.***

*If the person makes holes in the wall or breaks windows or doors, see **Property Damage**.*

*If the person has seizures or self injury, see **Connected Home** and **Specific Challenges**.*

feel safe and secure. Moving from the porch to the yard there can be other interesting activities such as a swing, hammock or table. Providing layers of freedom builds an individual's capacity and confidence to engage in activities they enjoy.




HOUSE
Independently accessible. Most secure. Least required supervision.

FENCED YARD
Controlled access. Areas of varied security. Intermittent supervision required.

UNFENCED AREA/STREET
Highly dangerous. Physical accompaniment required at all times.

Be sure each place of control meets the standards of the Autism-Friendly Home and satisfies the unique needs and interests of the individual. For example, if the person makes holes in the wall or breaks windows or doors, their opportunity to live freely in those places is compromised. If the person has seizures or engages in self-injury risk to their health and safety must be addressed first before meaningful opportunity for control or freedom is possible.

## ELIMINATE FEAR TRIGGERS

Recognize an individual's fears as legitimate and determine if there are physical solutions. For example, add lights if there are dark spaces or dark hallways that are frightening. These lights can be motion activated. Add soundproofing or sound absorbent materials if noise is alarming or an irritant. Listen for and mitigate household noises from appliances and equipment that may be frightening. Provide screening and fencing to prevent animals from entering the yard. Don't allow fear to be in control.

## CONTROL ACCESS AND DEFINE BOUNDARIES

Access may need to be controlled or shared in areas where safety is an issue or where the individual is still acquiring the skills and capacity for independence. Defining boundaries might include fencing the yard or restricting access to things in the yard that can be dangerous such as a pool, hot tub, air conditioning unit, or garbage and recycling. The exterior doors are important boundaries and may need to be controlled and monitored. Delayed or restricted egress can raise safety concerns and rights issues. These strategies need to be carefully evaluated in terms of risk/benefit for everyone involved. Safe egress from a building must always be maintained.

## MAKE HOME THE PREFERRED PLACE

Try to make the home the individual's preferred place by accommodating enjoyable and interesting activities inside and around the home. Provide the opportunity to choose from a variety of activities that meet the person's preferences. Think about the seasons as well. Indoor activities may need to expand during winter months and outdoor activities enhanced in the summer. When planning, be open to changing interests and capacities, have patience, and recognize that ritual and routine are comforting and reassuring.

# 6 Tools for Housekeeping

## KEEPING THINGS CLEAN, TIDY AND SMELLING GOOD

Individuals with Autism often have a way of disorganizing the world around them. Chaos can lead to exhaustion for the caregiver and frustration for the individual, sometimes manifesting itself as aggression or property damage.

People acquire life skills at different rates. It is important to be patient and support an individual's development of new capacities at their own speed. Two common strengths of people with Autism are the ability to follow routines and an excellent memory for detail. A well-organized and thoughtfully designed environment can harness these strengths.

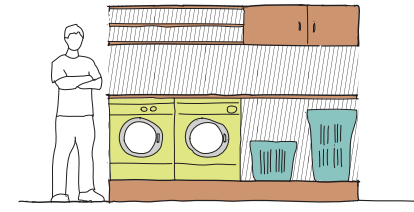
In some cases, the sheer quantity of soiled clothes and laundry can be overwhelming and creates what seems to be a never-ending task. The extra expense of cleaners, large garbage containers, supplies and additional electricity to keep up the house can compound financial and personal stress.

### ADEQUATE STORAGE

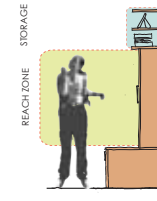
The need for appropriate storage and adequate display space cannot be over emphasized. In many cases, homes fall into disorder simply because these two needs are not being met. Only store items intended for engagement in the "reach" zone. An area approximately 3 to 6 feet above the finish floor is the place where most grabbing, handling, rubbing, and pawing occur. Put stops on the edges of shelves to keep things from falling off. Two old adages work surprisingly well: "Everything in its place and a place for everything." Creative labeling helps organization and visual patterns can support rituals in a positive way. "Out-of-sight is out-of-mind" can be extremely effective: add screens and doors to cover things until they are needed or wanted. A refrigerator concealed behind a cabinet door can also eliminate the need for a point of control.

### LIMIT THE OPPORTUNITY FOR CLUTTER TO MIGRATE

Installing dressers in closets will free up floor space and support safety. You may need to add a lockable door to allow for shared



LAUNDRY CENTER
Commercial front-load washer and dryer, raised off the floor for easy loading. Adequate folding surfaces and storage. Cabinets and storage, some lockable to prevent access to poisonous chemicals.




REACH ZONE
The area from head to knee height is the most tactilely attractive. Items in this range will be handled. Storage and display can often occur above and below this zone.

control of some possessions. Although at times, access to closets and contents may need to be shared. Locks should be a temporary solution. In other rooms of the house, like the kitchen, laundry room or garage, some things may need to be locked permanently for safety reasons. Limit access to places where garbage and trash cans are stored both short- and long-term depending on the situation. Good storage for toys or water- and bathroom-related items also needs to be provided.

## BUILDING IN ROUTINE

Reduce anxiety by arranging rooms in ways that help put tasks in order and cue what activity comes next, and where. Where possible, create a visual non-verbal physical path to communicate the sequence of an intended activity. For example, if a person is going to take a shower, have the dirty clothing hamper on the way to the bathroom door. Placing towel storage just outside the shower encourages patterned use. For people struggling to know where they are in space, providing strong visual cues throughout the home will help them understand patterns of use and support positive routines. Changes in floor coverings helps to identify various rooms.

## BAD SMELLS

Odors can convey how a home is maintained and sometimes people pass judgment based on what they smell. Odors are a common problem and emanate from many sources. Garbage, especially if it contains diapers, soiled laundry and linens, mops, sponges, rags and other housekeeping tools all contribute to bad odors. Drooling, spilling, incontinence and other body odors can cause furniture, carpet, drapes and other absorbent surfaces to take on undesirable smells. Changing areas are soiled often and require continual cleaning. If an individual picks or smears, this too contributes to the clean-up problem.



## FLOORING

Flooring is almost always a major contributing factor when undesirable smells are a concern. Avoid carpeting. Sheet vinyl is an affordable and reliable solution but it can look institutional if overused. If you use vinyl, select a product that can be welded at the seams and coved up the wall. There are cushioned-back products that are waterproof and will help quiet and soften the floor, but they cannot be coved to protect the joint between the

floor surface and wall. In all cases, sealing the joints where liquid will accumulate and protecting any absorbent materials is critical. Seal the transitions between wall and floor. Self-adhering vinyl plank flooring yields good results provided it is well-sealed at the perimeter, edges, and transitions. Regardless of the flooring you choose, it must be well-maintained.

## NEGATIVE AIR PRESSURE OR AIR SEALS

Using low-sone (quiet) fans or other ventilating systems, can negatively pressurize a room by pulling air out and odors in from the rest of the house with its exhaust system. Keep smells down with frequent air changes by using portable fans and opening doors and windows. Good ventilation in bathrooms is essential, but it also is necessary in the kitchen and laundry. Some individuals are particularly sensitive to food smells and off-gassing from cleaning products. Remove soiled mops, sponges, and towels from living areas and store these and other cleaning products and equipment in a ventilated closet. Use airtight containers for wet or soiled materials.

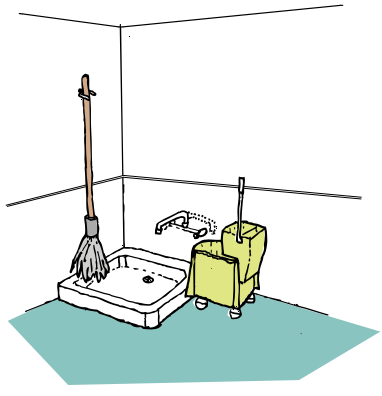
## ELIMINATE FLOOR REGISTERS

Eliminate floor registers if at all possible; most can be relocated to the wall. These are dirty in the best of circumstances because everything goes down and they are virtually uncleanable. When the heat comes on everything is blown back into the room. For an individual with toileting issues a dark hole in the floor is a bad idea.

## MAKE A CHANGING AREA

Does the individual require frequent clothing changes or diapering? How has changing been accommodated to date? Are you using the bed? When changing soiled clothing, especially for older family members, it is best to do this activity in or near the bathroom. However, caregivers need adequate space, and most bathrooms are not big enough to accommodate this activity.

A bathroom changing table saves steps and makes sense. It puts the resources needed to do the job close at hand. Soiled clothing can be transferred directly to air-tight hampers or bins. Access to water, fresh air, and appropriate surfaces will result in fewer bad smells, save time, and reduce stress for everyone.



UTILITY SUPPORT
Include a large basin at floor level and a hook for hanging wet mops over the sink. A pivoting faucet allows for easy bucket filling.

## LAUNDRY AND CLEAN-UP

Most families living with ASD end up doing a lot of laundry. High-quality, high-efficiency washers and dryers rated for commercial use actually save money when compared with the repair and replacement costs associated with residential appliances. A large utility sink is also helpful.

Constant mopping, wiping down and sanitizing contribute to caregiver fatigue. Floor sinks make handling mops and buckets more ergonomic and they have large drains that are harder to clog when doing heavy cleaning or pericare. A mop / cleaning station may be a good solution.

Be aware that odors from cleaning products can be a major problem for many individuals with Autism, particularly those who are extremely sensitive to strong smells and experience physical distress as a result. Use caution when selecting and using these products.

# Specific Challenges

## PROVEN SOLUTIONS IN UNIQUE CIRCUMSTANCES

Challenges that go beyond what are anticipated by common modifications to the home can be addressed by employing specific strategies. The strategies described in this section are intended to be completed in conjunction with some of the common modifications. It is important to implement these specific strategies in the context of making a home that works for a person with ASD, and to remember that all of these modifications can be accomplished without sacrificing the look and feel of a home.

### ELOPEMENT

Climbing fences, leaving home, lack of safety awareness, opening locks and gates, hiding, wandering away

### SELF-INJURY AND SEIZURES

Head banging, biting, eye poking, hair pulling, slapping, seizures

### PROPERTY DAMAGE

Damage to walls and/or windows, broken doors and jambs, exposed wiring, damaged furniture and appliances, water damage

### AGGRESSION

Threats to life and safety, involvement with police or authorities, injury to others, assault and violence

### NEIGHBOR RELATIONS

Invasion of privacy, yelling, disturbing the peace, neighbor complaints

# Elopement

Even the most vigilant parents cannot watch all the exits all the time. Elopement is the number one concern of many parents of children with ASD. The opposite of elopement is choosing to stay at home. If the home is a preferred place with favorite activities and interesting places to be inside and outside, it may discourage elopement. Over time, a strategy that combines prevention of elopement with positive reinforcement for remaining home, almost always addresses the problem.

*For related information, see:* Autism-Friendly Home *and* Connected Home

Some individuals with Autism can easily put themselves in unsafe or life-threatening situations, or find themselves in vulnerable or inappropriate situations in the community. They are often ill-equipped to handle unfamiliar people or situations. Caregivers must carefully balance normal risk with situations that truly threaten an individual's life and safety.

Sometimes, when caregivers get desperate, they have locked people in their rooms or in the house to keep them safe. Alternatives to these kinds of measures need to be implemented. Locks raise life safety concerns, especially if emergency egress is difficult or denied.

No one intends to put an individual at risk or make them a prisoner in the home, but caregivers can't "stand down" unless they know where an individual is and what he or she is up to. The challenge is to assure safety without completely restricting an individual's appropriate freedom of movement. To accomplish this, there may be a need to secure the physical boundaries.

## SECURE THE OUTSIDE

Securing the property perimeter may be necessary to keep people from eloping. Doing so can provide a layer of safety for the person between the house and the surrounding environment. Even in apartments or rowhouses, it is usually possible to create a layer of security outside the home in a common gathering area or with a locked/monitored gate. For detached homes, securing the yard generally requires a fence. Ideally, this fence meets the individual's specific needs, does not draw undue attention to the home, and blends in with the neighborhood.

If elopement challenges persist, fences usually need to be taller and stronger. Sports netting is one of the best no-climb fences. These fences can be up to 15' tall and are usually not restricted by code. Gates, too, will need to be strong and secure, and may require tamper-proof locks that can deter more determined individuals. Keyed locks, combination locks, electronic locks, and other types of gate operations are available depending upon the situation. Be sure the one you select is rated for outdoor use.

Fire safety must always be assured. A person must be able to get a safe distance from the home in the event of a fire, usually 50 feet. Delayed egress hardware is sometimes an option, though securing the perimeter is legally more complicated when you are dealing with adults than with children. The use of any kind of restrictive hardware needs to be reviewed with the Fire Marshal prior to installation.

*The basics of monitoring for security are described in* ***Connected Home.***

## WARNING DEVICES

Alarm systems for doors and windows can be used to alert caregivers when an individual has left the home. Most commercially installed and monitored systems may not be the best choice because of the frequency of "false alarm" incidents. Most private silent alarm systems can provide discreet notification when a window or door has been opened, sometimes giving caregivers enough time to get to a bedroom window or door before the person exits. This allows the person freedom to open the window, as well as the necessary safety for caregiver peace of mind. In conjunction with audible or silent warnings, a motion detector mounted outside the window will let you know when a person has exited.

## LOCKS

Most doors and bedroom windows are egress routes for emergency and should not be locked. Before installing locks, check that the lock function is what you need and does not put an individual at risk.

Sometimes, in desperation, caregivers resort to putting permanent or keyed locks on the doors and windows. Double-keyed dead bolts requiring a key to exit, hasps, wood stops or windows screwed shut are never a good idea if the route is a required egress path. If a lock is necessary to control access, be sure to

check that the lock system meets current building code and fire code requirements.

Some jurisdictions have allowed electronic strikes to be installed on doors. These energized strikes are inter-tied with other safety systems such as smoke detectors, sprinkler systems, and the power supply. The strike will automatically unlock the door in the event of a power outage or an emergency. A similar electronic lock for windows is possible, but not standard. Sometimes doors must be provided directly to the outside if safe window egress is not available.

## TRACKING TECHNOLOGY

If a person is carrying a cell phone, her or his location can be determined using the phone's GPS locator with assistance from the authorities or your cell coverage provider. Write down the phone's identification number and keep it somewhere safe in case this information is needed to locate the phone. Personal locators can be attached to a child's wrist, ankle, backpacks or shoes. These devices will send out a locating signal that can be used to track the child should he or she become lost. Some of these systems are inter-tied to networks that can contact first responders. Use of these devices should be carefully considered and judgment exercised in evaluating potential negative consequences for the individual. For adults, this is usually not a viable alternative and a violation of an individual's rights.

## DISTRACTIONS

Attractive distractions can persuade an individual to not leave the yard. Attractive distractions might include motion activated lights, stereo systems or interactive electronic games. All of these devices can be wired to be turned on by a person or remotely, and should include an over-ride and/or auto-off.

Another strategy is to use an outdoor sprinkler system as an attractive distraction and a deterrent to elopement; when a person approaches a gate, the sprinkler can be programmed to turn on near the fence or in another area of the yard. Use good judgment to ensure that distracting strategies are not aversive or abusive. Interests will change, and things that distract and re-direct an individual one day may prove ineffective the next.

# Self Injury + Seizures

People who have seizures or who participate in activities that result in physical harm need a physical environment that minimizes risk and supports timely intervention and assistance. Head banging, hair pulling, slapping, punching, biting, rubbing and dropping to the floor are the most common activities that cause injuries to the head, body, skin, ears and eyes. Seizures can expose a person to injuries to the head, musculature, and skeletal system.

To help keep an individual safe, you must be able to monitor their condition and activities inside and outside of the home. This might require you to remove walls or doors, cut openings between rooms, or install windows to the outside. Aquariums or windows installed in walls between rooms provide a form of transparency that will afford a caregiver the opportunity for non-intrusive observation.

*To learn more about monitoring safety, see **Connected Home**.*

## SMART HOME

Smart home technology is a further safeguard that goes beyond monitoring and uses computers and databases to identify routines. It can inform caregivers if a person's routine changes. This technology allows for greater freedom and can also reduce the need for constant supervision. As it becomes more portable and wireless, it will be possible to integrate this technology with only minor modifications to the home.

## SOFTENING

Softening the hard surfaces and sharp corners can be done without having to sacrifice the feeling of home. Protect the head and brain from injury by minimizing hard surfaces or sharp corners, such as wall corners, counter tops, or furniture. Select safe and cleanable surfaces and finishes if these are places your family member hurts themselves. Soft walls can be constructed by installing high-density closed-cell foam over the wall and then covering it with a cleanable wall protection material. Other ways to protect your family member from injury when they fall or drop to the floor include mats used for gymnastics or cushioned flooring material.

When possible arrange furniture to keep it away from walls that expose the back of the head to injury from rocking. Eliminate areas where the individual's head can be trapped.

### SOFTENED SPACES

*Jason has a large callus on his forehead from banging his head on the floor, walls and doors of his rental home. Pads, similar to those used in gymnasiums were fitted using Velcro strips attached to the wall. Padding was installed beside Jason's bed and on all the outside corners and other places he had targeted with his head. The wall and floor padding could be removed if the family moved.*

# Property Damage

Holes in the walls, broken sheetrock, smashed windows, inoperable doors, missing or broken plumbing fixtures, exposed wiring, damaged or inoperable appliances, destroyed or dysfunctional furniture: all are common examples of property damage. If a family member is breaking things, the home needs to be fortified to withstand repetitious activity without sustaining major damage. Assess what is being damaged and prioritize what is most important. Safety issues, such as broken glass or exposed wiring should come first.

Sometimes there are no easy answers. Observe and try to figure out what else might be going on that is causing these behaviors. Property destruction can be a form of communication or a symptom of an underlying problem like an allergy, illness, injury or underlying medical condition.

It is important to address even minor damage in the home. Damage that is not addressed often leads to more extensive property damage. Some individuals obsess on trying to fix the imperfection.

BREAKING GLASS

*Nathan loved the sound of breaking glass and to see his family's reaction. One day, his family resorted to boarding up all the windows in his room, which presented another set of issues, including life safety. When tempered glass was installed, this activity lost its allure and Nathan's attention was directed elsewhere.*

## TEMPERED GLASS

To prevent serious injury, use 1/4-inch tempered glass on the inside of double-paned windows and one-eighth inch tempered glass on the outside.  It is indistinguishable from non-tempered glass. The insulated tempered glass panel will fit into most window sashes. Unless the individual is using a tool to smash the window, quarter inch is usually sufficient. Tempered glass is very strong and if broken it shatters into harmless cubes. Sometimes individuals break the glass because they cannot tolerate glare or reflections. In some cases this behavior can be addressed with the use of tinting materials. Define the extent of the problem. Which windows are broken and which ones are left alone? There is a difference if the person is trying to break the window or it gets broken because it's not strong enough. You may need tempered glass in either case, but sometimes safety film designed to prevent break-in's essentially doubling the glass strength will be enough.

## THE HARD WALL

Holes in the sheetrock are a common problem. The right 'fix' is dependent on the specific cause and extent of the problem. Two layers of sheetrock are more than twice as strong as one. This will take your average kick or punch but not a more determined "mule kick." Reinforcing walls by installing half-inch plywood over the wood studs makes an exceptionally strong wall, but it will need to have a suitable finish applied. This can be sheetrock, and because of the plywood backing, this wall construction will withstand almost all kicks and punches. However, the sheetrock itself will mar and easily sustain surface damage. There are many choices in wall finishing materials that can be installed over the sheetrock or even applied directly to the plywood depending on the need and the look you desire. Choices include FRP (fiberglass reinforced plastic), wood paneling, epoxy wall coating materials; various vinyl and PVC (poly vinyl chloride) wall coverings even carpet will work in some instances.

## FURNITURE FOR AN ACTIVE LIFESTYLE

How is the furniture being used? Is it being used primarily for recreational equipment or for more typical relaxing behavior? Select furniture pieces that suit your family member's lifestyle. Depending on your situation, and the stresses applied, commercial-grade furnishings may work. Even robust furnishings won't usually hold up to intense rocking and bouncing activity or a deliberate effort to break the furniture. Tables, benches, dressers and shelves constructed from solid materials, hard-wood, cabinet-grade plywood or ApplePly are better able to withstand rough treatment than chip, fiberboard or soft-wood products. Use bolted connections and reinforce all joints with additional fasteners and glue if you are building something yourself or having it built. Unless secured, the furniture feet can scar floors, and furniture backs, arms and rockers can make holes in walls. Provide adequate protection by installing chair rails and non-skid furniture coasters. Backs need to be tall enough to protect the head from hitting the wall. Evaluate the cushions and springs if the individual has targeted these in the past. Custom cushions may be needed.

WATER + ELECTRONICS

*Anna loved water. She liked to fill her mouth with water and then spit it onto the TV screen to watch it run off. She had ruined a lot of televisions. We built a water-proof entertainment center for her with gussets around the door to keep the water out. Some things had to be locked at first, but the cabinet was built to become more accessible over time. The unit was built into the wall to save floor space in her small room and the speakers were put in the ceiling to keep sound transmission down between the bedrooms. Televisions, stereos and favorite books survived. Now Anna uses the "big" TV in the family room when she wants and the doors are gone from the one in her bedroom.*

## SOFT FURNITURE

Provide crash pads, such as those used for high jumping, gymnastics or pole-vaulting pits. For people who like to run, jump or bounce select padding and cushions that safeguards them and the building. Athletic pads can double as interactive furniture. Adding slip covers, bedspreads or pillows improves the appearance of this unusual 'furniture' in your home. Home fitness equipment can also relieve stress by providing a place for people to burn off excess energy or manage weight gain. Safeguarding health and safety suggests floor, wall and ceiling softening and protection against falls or accidents.

## CUSHIONS AND MATTRESSES

Ballistic nylon is one of the strongest fabrics available for commercial use. Cushions and mattress covers made from this material will withstand extreme abuse, including chewing. This material is superior to most vinyl covers and it will also hold sheets better because of its texture. Securing the zipper inside a double Velcro overlapping flap will prevent most people from getting into the cushion stuffing or mattress.

## ELECTRONICS

Televisions, stereos, interactive games, computers, iPods and iPads can provide hours of entertainment and have greatly increased the opportunities for individuals with Autism and social and language challenges to communicate. Making a place to use these products can help protect them from accidental damage and support safe and convenient use. In some cases, the equipment itself needs to be protected, but access to key boards or touch screens needs to remain available. This will require either a custom made piece of furniture or modification to an existing unit.

Custom entertainment centers built into the wall can provide protection for electronics. Additionally, these centers eliminate sharp corners and keep floor space open for other activities. Use a non-glare tempered glass front to provide protection and improved viewing. Remote control access provides the opportunity to exercise control. Consider installing the speakers

in the ceiling—this not only protects the speakers but also limits unwanted room-to-room sound transmission. Ventilate the cabinet to prevent over-heating.

## SAFE DOORS

For almost everyone, a door slamming is irritating. It's also a safety hazard and often damaging to the home. If you face this challenge, consider installing fiberglass doors that are light-weight and very strong. Safety is improved because the lighter doors produce less force and therefore are less likely to cause serious injury if someone is in the way. The lighter door also makes less noise when slammed while reducing the stress on hinges, jambs, and framing attachments. Integral metal hinge assemblies and strikes improve performance and durability of this assembly. A standard door shoe can be modified by adding a felt drag. When installed to the bottom of the door the felt provides friction against the floor, slowing the door. Commercial door bumpers and smoke seals installed in the frame help quiet operation and reduce the slam effect.

### JUMPING, JUMPING, JUMPING

*Veronica liked to jump, so her family bought a small exercise re-bounder—in essence, a small round trampoline. She spent hours every day enjoying this activity. However, she began to jump on her bed, couches and chairs unless her Mom was supervising. Eventually, everything was broken. The family bought a crash pad like those used by high jumpers, and they made slip covers in Veronica's favorite patterns. They could move Veronica's bouncing couch anywhere in the house, or to the back yard. Recently, her "couch" was handed down to another family because Veronica uses furniture differently now.*

# Aggression

Repeated aggression is unusual, but when it happens and remains unresolved, substantial modifications will be required to keep everyone safe. When physical aggression is happening, it is important that the environment not contribute to or compound the problem. It is necessary that caregivers take precautions and be appropriately trained to prevent someone from getting hurt.

The environment can be a factor in reducing triggers, supporting safer intervention, and even helping de-escalate some situations. It can minimize risk and play a passive role in preventing injuries.

## ADEQUATE SPACE AND EXITS

A family living with ASD will typically benefit from more open living space than is available in most conventional homes. Over-crowding intensifies social interactions, and is a common factor in aggression. Irritating noises, obsessive-compulsive behaviors, and inflexible routines can all be sources of stress and frustration. Adding a quiet space where a person can experience less stimulation can make a big difference. Creating a suite of rooms within the home that "belong" to the individual with ASD can take the pressure off social interaction and reduce episodes of aggression.

Provide adequate open space in the home for maneuvering to help minimize unwanted person-to-person contact, the leading cause of injury. Create adequate circulation space to maneuver safely away from entries and exits and other areas of transition. If possible, include two safe exits from shared spaces such as kitchens and common living areas.

## MAINTAIN LINE-OF-SIGHT

Maintaining line-of-sight and the ability to hear activities can vastly improve safety. Openings or views through walls can be invaluable to providing awareness. Eliminate hiding places and, when possible, eliminate dead-end hallways.

## HAVE AN ALTERNATE WAY OUT

Make sure caregivers and others are able to move out of harm's way and maintain a safe distance. Furniture arrangements need to keep floor space open and provide egress paths whenever possible. Make it safe to move around quickly. The Walking Loop is an especially useful way to maintain a safe distance without losing contact. This feature sometimes allows for situations to de-escalate on their own.

## INSTALL SAFE DOORS

Select exit doors that are not easily damaged and that will allow the caregiver to exit quickly. Select strong doors, such as those made from hollow metal, solid core wood, or fiberglass in the appropriate frame. Outswing doors with hardware that allow exit in one motion without keys improve egress time. There are self-closing doors that can be fitted with electronic latches that will, when activated, close behind you and lock if needed. Any delayed egress system must meet fire, life and safety requirements where you live.

## EXTREME SITUATIONS

Extreme violence and aggression is unusual, but when it happens significant modifications to the home are often required to keep everyone safe. Construction assemblies, hardware choices and security systems will need to be carefully selected to protect both the people and the building.

The home is full of things that can be misused to hurt people or cause damage. To prevent this, fasten everything securely to avoid their removal and inappropriate use. Anchor shelving, pictures, lamps, curtains and clothes rods, trims and hardware to prevent them from being thrown or used to damage property. In some cases, enclosing radios, televisions, and computers in secure cabinets or entertainment centers will support safety if a person has lost control. Window and door trims, salvaged screws, nails, or staples from broken walls, along with pieces of broken wood and plastic, and even toilet tank lids can be removed and used inappropriately. Be observant and either remove or secure anything that may be used as a weapon.

### SENSITIVE TO SOUND

*Donald is young, strong and athletic. He is very sensitive to noise. The sound of someone typing or having a conversation on the phone can "set him off." Usually Donald will start screaming for "Quiet, quiet, quiet" and then attack the first person he sees. Soundproofing was added to walls when possible to keep the usual household sounds to a minimum. Doors were changed to fiberglass with reinforced frames and the swings were reversed so the stop as well as the latch would resist Donald's kicks and blows. Householders learned to keep their bedroom doors closed and locked when they were occupied; the same was true of the bathroom.*

## SAFE ROOM

In the most extreme cases, when aggression turns to violence, a safe room or refuge may be needed to protect the health and safety of family members or caregivers. A safe room must be strong enough to withstand any attack. Rooms built using steel cased doors in hollow metal frames, reinforced framing and wall assemblies cannot be entered without a tool. Tempered glass 3/8" thick will withstand blows from a hammer without breaking. Select hardware that incorporates a three-point locking system. Make provisions for calling backup or emergency services. It is critical that the caregiver remains aware of activities even while they are unable to intervene. Line-of-sight through the home is best; however, audio surveillance and cameras may be necessary to insure safety. An exit door to the outside from the safe room provide an additional path to safety.

### SAFE REFUGE

*Sky was 16 years old. When he became agitated, he would quickly become violent and attack people around him with little warning. He would not stop until he "saw blood." Despite extensive training, members of his family and paid caregivers had been seriously injured while working with Sky. In order to protect everyone's health and safety, a safe refuge was built. The implementation of a safety plan also required home modifications that included adding additional exit doors and specialty locks to the home that would permit his caregivers to quickly move out of harm's way.*

# Neighbor Relations

Positive relationships with neighbors can benefit families in many ways. Developing such relationships allow you share the unique circumstances your family experiences. Sharing your story is one of the best ways to protect the reputation of the individual experiencing ASD and your own. It can be easy for neighbors to draw the wrong conclusion when they see someone running from the house or adults "wrestling" in the front yard.

Some people with ASD will take their clothes off outside, or occasionally yell or scream to let off steam. They may sing loudly or make other noises. They may become active at odd times of day or night. The goal is to reduce the negative consequences of these activities on the neighbors as much as possible.

## A PLACE TO LOAD AND UNLOAD DISCREETLY

Transitions are frequently stressful. Vehicle loading and unloading inside the garage, or in a screened and secure area, can prevent unnecessary drama and be helpful to a person with transition anxiety.

## PRIVACY FENCE, PLANTINGS AND SCREENS

One of the best ways to be a good neighbor is to install appropriate visual barriers. Privacy fences, screens, hedges, blinds, or screened porches can help protect people's reputations and maintain positive relationships. A second layer of fencing or a hedge within the perimeter of your lawn can also help to keep objects from landing in adjacent yards.

## ACOUSTICS AND LIGHT CONTROL

Acoustic management and light control, especially after hours, will be appreciated. Fiberglass tub showers and other hollow items can be filled with spray foam insulation to prevent them from becoming drums. Lubricate moving furniture like swings or rockers. Use heavy drapes or sound absorbent materials if the person is active and noisy at night.

Other caregivers arriving at odd hours can be a common source of irritation for neighbors. Screen headlights and install low-level lights for evening activities that may happen outside.

*For more on strategies that can support positive relationships with neighbors, see* Places of Control / Layers of Freedom *and* Autism-Friendly Home.

# Conclusion

All people with disabilities, including those with significant Autism Spectrum Disorder (ASD), can and do live successfully in their family homes provided they have necessary supports. States recognize the wisdom of maintaining these families both from an ethical and financial perspective for as long as possible. However, because conventional housing does not meet the unique needs of some individuals with more significant ASD, failure of the environment contributes to caregiver fatigue, health and safety risks, problem behaviors, individual dissatisfaction, and failure to thrive. These are some of the major contributing factors in out-of-home placement.

As a way of addressing this problem, this project makes the case for including environmental assessment and home modifications in person-centered planning. The evidence from actual projects and experience in practice indicates that appropriate modifications to the physical environment improves the likelihood that families will remain intact.

Traditionally, the environment has been viewed as neutral, and assistance for families in crisis has focused on human supports such as respite, medical interventions or trainings. This project challenges the prevailing assumptions that human supports alone are enough. It suggests that the right physical environment can help individuals and families experiencing ASD and co-occurring behaviors to live full, meaningful and rich self-directed lives, thereby making human supports more effective.

## SOURCES

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# ANNA'S STORY

In 1997, Anna's parents wrote to us in desperation. Anna was getting bigger, stronger and quicker. She was doing things she couldn't do before. Anna pounded on windows and mirrors, threw objects at lights, jumped on furniture, and would spit water into electronics. She had an intense interest in moving water and her powerful need for constant access to water to calm herself was creating serious health and safety issues. She turned on faucets full blast and played in the water. Anna jumped vigorously in and out of the tub, and she could not be left alone. She liked to take 5-10 baths each day, and the bathroom floor was always wet and slippery. It took 25-30 towels to mop up each day.

Anna playing with water in her back yard

## What Anna liked to do

Anna loved to be active in her backyard. She particularly loved running water and swings. Outdoor furniture was needed that would hold up to Anna and withstand the "plop down factor," as her family described it.

The kitchen in Anna's home has always been the center of activity. When she was little, Anna had to have the water running nearby in order to eat her food. When she was not in the bathroom or outside playing with water, she was at the kitchen sink.

Anna also liked to be in her safe place, which was her bedroom. She liked to watch her movies and look at her books. She liked to bounce on her bed and on the furniture. She had to constantly busy her hands with beads.

Plexiglas sheet installed to protect the living room window

## The home that Anna and her family needed

Based on Anna's needs and preferences and the needs of her family, it was determined that the family needed a home:

- Where they didn't need to constantly intervene or re-direct.
- That reduced stress and workload.
- That kept everyone safe.
- That allowed Anna to use the bathroom in the way she wanted without negative consequences.
- That provided Anna with the choice to engage in preferred activities inside and outside the home.
- That was easily modified and adaptable to the family's changing interests, abilities, needs and lifestyle.

Plan of new bathroom

New tempered glass windows and patio door

"Anna's family needed a home that was easily modified and adaptable to the family's changing interests, abilities and lifestyles."

Accessible ramp to swing

## MODIFICATIONS TO ANNA'S HOME

### Windows

Our work began with the most pressing health and safety concerns. Anna was banging on the large, single-glazed picture window in the living room and kicking the window next to her bed. Other windows had already been broken. The family had put up Plexiglas but they said this made their home "feel like a battle zone."

The sliding glass door and other windows that were a risk to Anna in the house were replaced with tempered glass. Tempered glass is extremely strong and, when broken, it disintegrates into hundreds of small, harmless pieces. Typically 1/4-inch glass is placed on the inside and 1/8-inch glass is laminated to the outside; this will withstand most heavy abuse. If a person uses tools or has significant head banging or kicking behaviors, 3/8-inch glass can be installed and will generally withstand extreme forces.

A window was added to the family's dining room to provide a view to the back yard. It was a critical feature in helping the family know about Anna's whereabouts and activities without leaving the house.

### Back yard

In 2010, Anna started to use a wheelchair, making it difficult for her to get to her swing. A ramp was installed from the deck to her swing so she could get exercise and continue to do the things she loves.

### Fencing

A large Arborvitae provides protection and privacy in the backyard. Unfortunately it is poisonous and can cause seizures if ingested.  By installing a colored wire fence inside the hedge line, both the hedge and the privacy it afforded could be preserved.

### Lights

The home's standard glass ceiling globes had been broken by balls and other flying objects. These were replaced with wire-protected lenses or recessed down lights.

## Bathroom

The bathroom was re-designed to provide additional space and to be bright and inviting. Additional space was created around the toilet to support toilet training. The space needed to be inviting and comfortable for Anna, and provide adequate room for caregivers to assist.

The new tile floor was also installed. This floor is easily cleaned and sanitized, and it has a floor drain to deal with standing water. Safety was further improved with the use of tempered glass mirrors and windows and scald prevention on the hot water. The floor was heated to support comfort and drying and to prevent injury.

Existing vanity storage was replaced with new storage and shelving for drying toys and towels, and to support use of picture schedules.

## Kitchen

Plastic installed to protect walls and counter tops detracted from the feeling of home. A new post-form laminate counter top and cast-iron sink with commercial faucet supported Anna's use of the kitchen without damage. Over time, Anna has developed a love of cooking. She is an expert at pouring and measuring liquids and "she never spills a drop."

Enlarged toilet space

Safe, durable and bright bathroom

Place for wet toys and towels

Anna's "baking center"

Entertainment center

Art desk addition to baking center

Anna enjoying her swing

### Entertainment Center

Anna needed a waterproof entertainment center because she would fill her mouth with water and spit on the TV when she was upset.

The entertainment center designed for her has a water-proof, lockable area for the TV. Vent holes were drilled to prevent over-heating, and speakers were installed in the ceiling to keep the sound from disturbing her brother next door. The unit was inset into the wall to save floor space and ensure a solid connection to the framing. Space was provided for her favorite things closer to the floor.

Anna gained more experience and developed the capacity to use her TV without assistance. With more control came more opportunities. She no longer needs a locked cabinet in her room and freely uses the entertainment center in the family room.

### Flooring

Anna had toileting accidents, food spills and spilled water. Spills in the bedroom caused smells. The carpet was replaced with a commercial grade vinyl. The material was covered up the walls to protect the edges from water. Throw rugs that could be simply picked up and laundered as needed helped to soften the look of the vinyl floor coverings.

### Privacy Versus Peace of Mind

After much discussion of privacy versus peace of mind a wide angle door viewer was installed that enabled the family to look in on Anna without disturbing her.

### Outcome

Anna could do what she clearly enjoyed without negative consequences. Safety was improved, damage to the building was minimized and her family experienced significantly less stress and more freedom because they spent less time doing intensive supervision and clean-up. Anna has exhibited a reduction in behavioral episodes because she experiences more choice, control and independence in her life.

## LESSONS LEARNED

- A preferred activity is not a problem behavior if it occurs in the right environment.
- The environment can provide opportunities for people to exercise meaningful control.
- If families are informed and have the tools, they can make choices that make sense for them.
- The needs and lifestyle of a person with disabilities change over time.
- A supportive physical environment promotes an individual's abilities and strengths.
- Relatively simple, cost-effective modifications can greatly improve health and safety.

## SUCCESS STORY

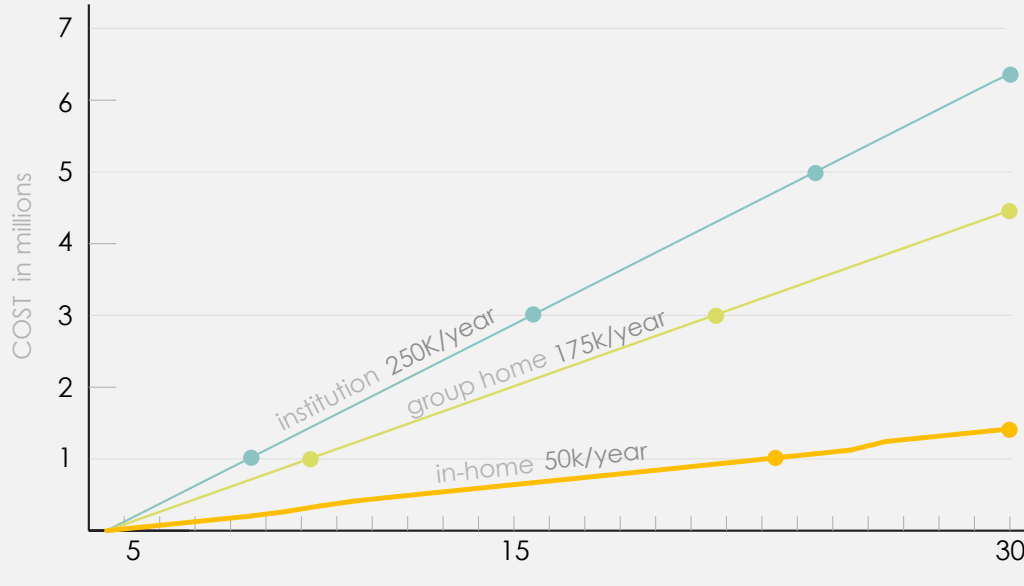
"Anna has exhibited a reduction in behavioral episodes because she experiences more choice, control and independence in her life."

# ANNA

## PROJECT COST INFORMATION

Modifications to Anna's family home began when she was 7 years old, and continue to this day. The series of projects addressed her changing needs and interests. The early projects dealt with safety, water play and toileting. Subsequent projects allowed her to build capacity to participate in the activities of daily living pursue her interests and enjoy her life.

The graph below illustrates the comparison between in-home costs (including costs of modifications) and costs incurred as a result of out-of-home placement.



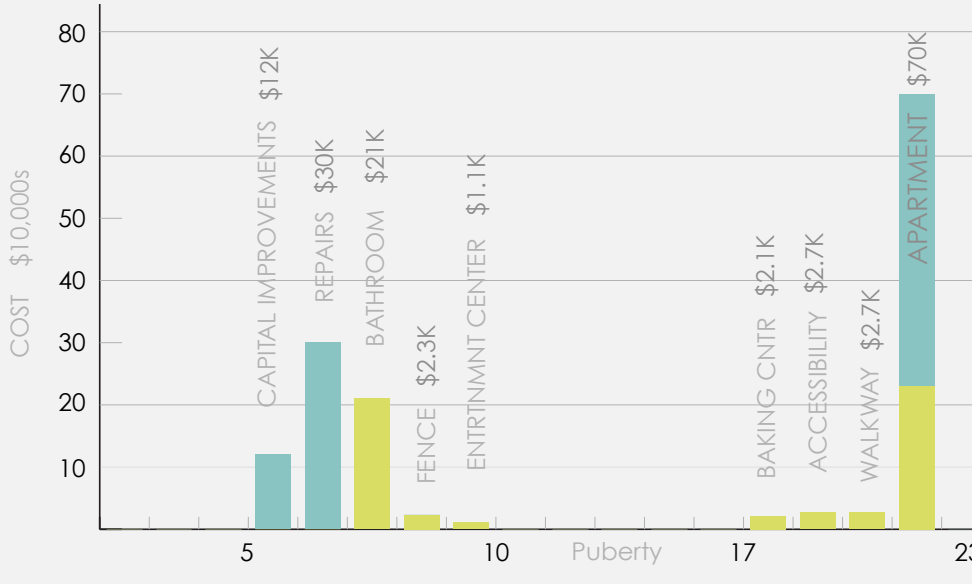

Source: Creative Housing Solutions project cost data and California Regional Center cost data

The bar graph below illustrates individual projects that were completed over a period of years in Anna's home. Anna's needs changed as she grew older, as did the capacity and experience of her family. Her family grew to appreciate the importance and the potential of their home environment. They also learned how to make the case for funding to do the necessary modifications. This model of phasing work may be more financially feasible for many families, and has the advantage of being responsive to changing needs.

1997 - Current
Total Cost: $73,900 (excluding planned apartment suite.)

## SCOPE OF MODIFICATIONS

- Tempered glass windows
- Essential Bathroom ("Superbath")
- Fencing, swing & water play area.
- Entertainment center
- Baking center
- New ramp, flooring & light fixtures




Source: Creative Housing Solutions project cost data and California Regional Center cost data

# RONNIE'S STORY

In 2002, 19-year-old Ronnie was living with his parents and four siblings in an 1,100-square-foot, single-story family home. Ronnie was big, strong, fast and active. There was only one bathroom for 7 people living in this home. The doors to the bedrooms were locked. The refrigerator was locked. The house windows were single glazed glass and had been broken and re-broken. The family food had to be stored in locked cabinets or in the garage. Furniture and mattresses protected the walls. Only the clothing for that day could be in Ronnie's dresser otherwise he would pull the clothes out and toss them all over the room. There was no glass in any of the pictures because Ronnie couldn't tolerate the glare. Without constant supervision everything went down the toilet. Damage to walls and doors was extensive.

## Caregiver and family fatigue

Ronnie's siblings did not have guests over to the house because they were embarrassed. Ronnie's father provided most of the direct support to Ronnie on a daily basis. He accompanied his son everywhere, including the bathroom to keep him safe and focused and to prevent damage to the room. Ronnie had been expelled from school and exhausted his short-stay out-of-home crises intervention option, because of this he spent his days at home with his father at his elbow.

The inadequacy of the physical environment to meet Ronnie's needs or the needs of his family created enormous stress. The family had run out of options, and Ronnie was going to have to move unless significant measures were taken to preserve the family.

## What Ronnie liked to do

Ronnie was very active in his surroundings, and would bang on walls, windows and fixtures. He got stuck in patterns he couldn't stop. He would try to fix any imperfections he saw by picking at them. He needed to fill the holes in things like electrical outlets, locks, drain pipes, appliances, toilets and sinks. He would bang his head on the wall when upset or frustrated.

Nothing could be left out

Damaged window coverings

Locked refrigerator

Hook on door kept Ronnie out

Plan of Ronnie's house and addition (red)

View of Ronnie's addition

Kitchenette

He liked to be involved with water, being outside and looking at himself. He liked bright colors and being with his siblings. Ronnie liked to be with his family when he felt confident and comfortable.

### The home that Ronnie and his family needed

Based on Ronnie's needs and interests, and those of his family, it was determined that the family needed a house:

- Where they all can have a more normal life.
- That will not be damaged by Ronnie.
- Where his brothers and sisters can have friends over without fear.
- That enables Ronnie to do the things he likes safely.
- Where there are fewer triggers to Ronnie's behaviors.
- Where life with Ronnie is not so stressful.
- Where Dad is not always at Ronnie's elbow to keep him safe and protect the household.

### Modifications and Additions

The project added 477 square feet to the home to relieve over-crowding and to create a suite of rooms that Ronnie could control. As a young adult, Ronnie needed to be more independent, and the family needed space so everyone could enjoy a more normal life.

### Ronnie's Suite

Ronnie's preferred place is where he can be safe, live a more self-satisfying life on his own terms without the need for constant supervision and control by others. The parent's bedroom is located between Ronnie's suite and the rest of the house. There are two doors into and out of the parent's room, one leads to the main house. At night they can lock the hallway door. Ronnie must then pass through their room to access the rest of the house, alerting them.

### Kitchenette

The kitchenette and under-counter refrigerator are lockable and part of an instructional program designed to help Ronnie develop new capacities. Hidden doors make it possible to conceal the sink and appliances if desired.

### Walls and Doors

The hallway provides a soft wall construction assembly above the chair rail to reduce injury from head banging. Wall section below the chair rail is backed with plywood and not easily damaged by kicking.

The entertainment center is built into the wall. The TV is installed behind 3/8" tempered glass and operated with a remote. A lockable shutter allows the TV to be out of sight.

### Ronnie's Living Area

Ronnie's living space is attractive and comfortable. Special construction assemblies and techniques do not detract from the residential appearance or welcoming character.. Special features included tempered glass windows, reinforced framing connections, extra blocking, plywood sheeting, reinforced electrical, break-away curtains, oak plywood wainscot and oak trims, nylon cover plates and a table secured to the wall and floor. These features allowed Ronnie to live a safer and more satisfying life without the need for constant supervision.

Built-in furnishings

### Ronnie's Bedroom

Ronnie's new bedroom has a combination of soft wall and reinforced oak wood wainscot. Curtains are attached with break-away hardware. When Ronnie pulls the curtain down he is assisted in re-attaching it himself. The dresser is built into the closet increasing usable floor space, reducing clutter and supporting safety. Access and control to his belongings is shared at first by using a lockable door.

Bathroom supports independent use

### Ronnie's Bathroom

All fixtures are commercial grade, the toilet is wall hung, plumbing and under sink connections are concealed. Shelving is available for instructional materials and schedules. Hot water is on-demand and has scald-prevention. Non-skid tile floor with drain and heat mat support safety, comfort, hygiene and Ronnie's independent use.

### Ronnie's Outdoor and Water Activity Area

The covered patio outside Ronnie's suite provides an outdoor activity area and supports his interest and fascination with running water. This wet area includes a water shut off, clean-out, trench drain and hose bibs with both hot and cold water. The dry-deck floor tiles provide non-skid surface and helps control dirt and mud. The back yard is inviting. Open spaces allow running, playing and exercise. Fencing provides privacy and security.

Outdoor hot and cold hose bibs with dry deck floor mat

SUCCESS STORY

Ronnie's "siblings often choose to hang out with Ronnie and watch movies or play video games in his suite."

Built-in entertainment center

Built-in dresser in closet

### Outcomes

Ronnie's addition was completed in 2002. The day he moved in he left his dad standing in the hallway of the main house and closed the door. For several minutes he explored his new suite. He could be heard opening and closing doors, hitting and kicking the walls, running water, flushing the toilet repeatedly all the while squealing with delight. Finally, Ronnie came out and got his father. Pulling him along he demonstrated how everything worked and the differences in the soft and hard wall assemblies using his head and feet.

Eight years later, the family reported that the design and construction of the remodel has supported Ronnie's lifestyle and contributed to his living a more self-directed life and reduced family stress "more than we could have hoped for."

The walls, doors, finishes, furniture and fixtures have withstood the test of time. Ronnie has the keys to everything now. Ronnie prefers his space and often invites his siblings to join him. They can now invite their friends over and live more normally for the first time while Ronnie is home.

This addition project focused on the suite, and the main part of the house did not receive substantial modifications. Furniture in the main house is still arranged to protect walls. Pictures are glazed with non-glare glass. A keyed dead bolt continues to provide the deterrent to running away. Walls that were not reinforced with plywood and the non-fiberglass door have sustained damage.

## LESSONS LEARNED

- It is important that the layout and new room arrangements support privacy, independence and choice for the person and for the all the members of the family.
- Wall damage typically occurs in the person's bedroom or at transition areas such as doorways, room entrances and halls.
- Interesting things to do outside are as important as what happens inside.
- Supports need to be visually connected to all areas of the home and the yard.
- A young adult will at some point want a space of their own and want more independence.

# RONNIE

## PROJECT COST INFORMATION

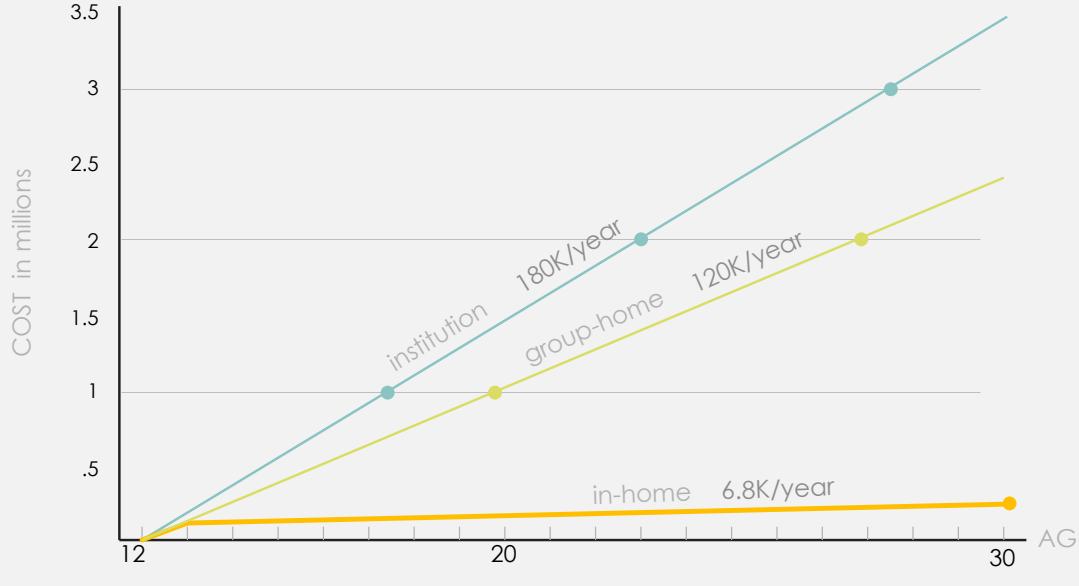
19-year-old Ronnie lived with his parents and 4 siblings in a small house. He was supervised at all times, and access to parts of the home were controlled by locks or off limits. The project added 477 square feet to the home so that Ronnie could be more independent and to eliminate overcrowding. His suite included a bedroom, bathroom, sitting room and outdoor porch that supported his lifestyle and interests.

The graph below illustrates the comparison between in-home costs (including costs of modifications) and costs incurred as a result of out-of-home placement.

2003
Total Cost: $111,440

## SCOPE OF MODIFICATIONS

- Attached suite with Essential Bath
- Kitchenette
- Living room
- Improved partition & door layout
- Materials upgraded for durability and safety




Source: Creative Housing Solutions project cost data and California Regional Center cost data

# KYLE'S STORY

Holes in walls

Holes in ceilings

Kyle with his dad

In 2003, 13-year-old Kyle was living with his mother, father and sister in a 1,300-square-foot house. The family home was severely damaged. Windows were repeatedly broken, there were holes in the walls and doors, and many door jambs had been split and repaired. Vinyl was missing in large areas where it had been pulled up. The back yard was full of large holes that Kyle had dug while imitating the family dog. Kyle could not be left unsupervised in the bathroom or he would damage it. Bars and metal screens were screwed across his bedroom window and double keyed cylinder dead-bolt locks were installed in his bedroom door. The doors to the bathroom and his sister's bedroom were fitted with keyed entry locks to keep Kyle out unless his parents were supervising him.

The biggest issue was Kyle's running away. The family had done everything they could to keep Kyle at home. They were living under lock and key. When Kyle was expelled from school and spent all of his time at home it greatly increased the stress on the family. He was aggressive with his sister. When Kyle finished eating he would put his dishes behind the stove unless his Mom could outrun him. Mom was exhausted and was afraid someone was going to be seriously injured or that her son was going to "fall off the roof, get hit by a car or shot by a neighbor." Mom asked, "Is this the end of the line? Is there no hope?"

## The enduring family relationship

Kyle's Dad said "Kyle is not just problem behaviors, he's a good kid; he's our son." Some of the things Kyle liked to do included playing with water. He was a good swimmer, he enjoyed throwing balls, and spinning and balancing objects. He loved to eat, to have his back scratched and bang on the walls.

Kyle wanted to control who came and went in his space. He wanted his door locked at night or when he wanted to be left alone. Kyle was curious and wanted to watch everything that went on in the house but was generally shy and would rarely engage.

Listening to music and watching cartoons on TV were favorite activities. Background noise seemed to help him relax. Kyle was always warm and would take his clothes off whenever he could.

### The home Kyle and his family needed

Based on Kyle's needs and interests and those of his family it was determined that the family needed a house that was durable enough to support the way Kyle lived. The home needed to be a place where Kyle could:

- Live safely without hurting himself or anyone else.
- Not damage the home.
- Have the opportunity to make choices about how he lived his life.
- Not have to be constantly redirected or restrained by his family.
- Remain with his family for the foreseeable future.

### Modifications and Additions

It was determined that a suite of rooms that Kyle controlled and that met his and the family's requirements was needed. Approximately 420 square feet was added in 2005 at a cost of $84,000. The addition featured:

- Slab-on-grade construction with tile floor and epoxy grout.
- Hard-wall construction with reinforced framing attachments and 3/4-inch Medium Density Overlay (MDO) plywood interior paneling. This product is a high-quality plywood with an epoxy finish layer that holds paint very well and resists surface damage. The suite was finished with a two-part epoxy paint and all the seams were trimmed with 3/4-inch solid oak.
- The new bathroom had a floor drain with tile on the floor and walls. Industrial fixtures were installed. Exposed supply and drain pipes were enclosed to protect them from damage. A wall-mounted toilet was installed with a hidden tank. A special flush control valve was added to keep Kyle from repeatedly flushing the toilet after he plugged it with his underwear.
- All the windows were replaced with tempered glass and the closets, dressers and the bed were built-in. Fiberglass doors were installed to resist slamming.
- A new window into the kitchen connected Kyle to the activity of the home.
- The back yard was secured with a block wall and security gates were installed that keep Kyle from leaving without supervision.

Plan of remodel

Kyle's bedroom

Interior window with tempered glass

MDO did not hold up

SUCCESS STORY

"[Kyle] can now use his bathroom in a way that satisfies him... see everything that goes on in the home... bang on the window, walls and doors without negative consequences... and come and go to his backyard without supervision."

Kyle enjoys his suite

After the initial remodel, the following modifications were made between 2005 and 2011.

- Kyle was able to pick through the MDO wall finish. In 2007, fiberglass reinforced plastic (FRP) was applied over the walls. The ceiling also needed to be hardened and the lights were replaced as were the heating registers and fans because Kyle had destroyed overhead surfaces and objects for the first time.
- A built-in entertainment center was added that Kyle and his caregiver could share control with a remote. Custom furniture and ballistic nylon covered mattress and cushions have been added to prevent Kyle from ingesting the foam padding.

### Outcomes

Kyle can now use his bathroom in a way that satisfies him. He has control of his suite of rooms and who comes and goes. Kyle can see everything that goes on in the home. He can bang on the window, walls and doors without negative consequences. Kyle can come and go to his backyard without supervision. His sister is not attacked any more and she can have friends over to visit. Kyle has lost interest in eating his mattress and the couch cushions because it is no longer possible to eat them.

Kyle now communicates his wants with sign language and he chooses the TV shows he wants to watch and the music he wants to listen to. He even shares the remote with his Mom.

The family has in-home support during the summer and on holidays, and 12-hour respite per week for an average cost of $22,000 per year.

## LESSONS LEARNED

- When issues arise in the home, address them. Don't wait until it's a crisis.
- At a certain point piecemeal solutions will not work. More investment is required, but once the investment is made, the family's situation is sustainable.
- As circumstances for the individual and family change the environment must change as well.

# KYLE

## PROJECT COST INFORMATION

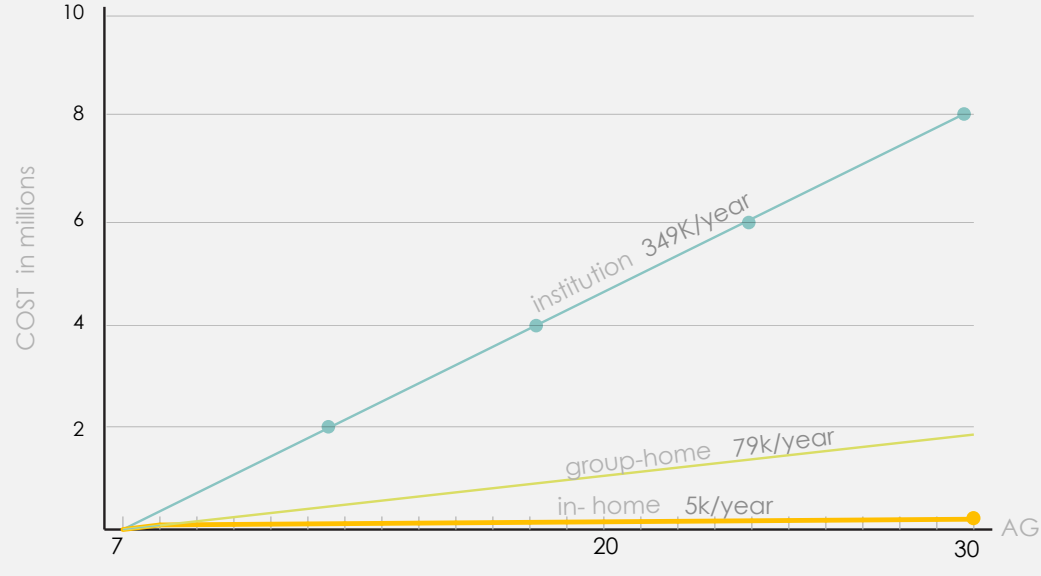
13-year-old Kyle lived with his mother, father and sister. His home was severely damaged and he could not be left unsupervised. The modifications created a suite of rooms that was durable, and allowed Kyle to live safely without hurting himself or anyone else. The suite was connected to the home to allow him to participate in daily activities.

The graph below illustrates the comparison between in-home costs, including costs of modifications, and costs incurred as a result of out-of-home placement.

2005
Total Cost: $87,600

## SCOPE OF MODIFICATIONS

- New home suite with "hard wall" construction
- Essential Bath
- Built-in furnishings
- Tempered glass windows and fiberglass interior doors
- Increased backyard security




Source: Creative Housing Solutions project cost data and California Regional Center cost data

# JARED

## PROJECT COST INFORMATION

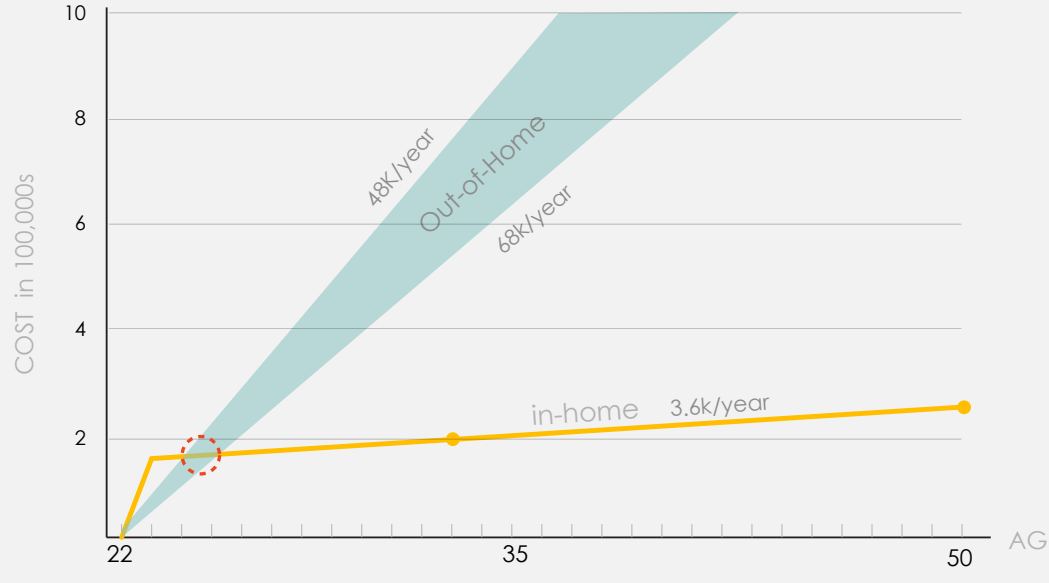
Jared, age 24, lives with his mother, father and older brother. Jared has ASD and Cerebral Palsy. Both parents work full time so they are unavailable to assist in their son's use of the bathroom or his computers. This project included installing a lift and track system between his bedroom and bathroom that allowed Jared to use the toilet independently. Custom cabinets were built to help Jared use computers and electronics without assistance.

The graph below illustrates the comparison between in-home costs (including costs of modifications) and costs incurred as a result of out-of-home placement. In Jared's case, the initial costs of modifications (orange line) was high but the return on investment, indicated by the red circle, could be as little at three years.

2002 - 2007
Total Cost of Modifications: $142,128

## SCOPE OF MODIFICATIONS

- Suite with new accessibility
- Electronics accommodation
- Independent bathroom accommodations suited for an individual with ASD and mobility issues




Source: Creative Housing Solutions project cost data and California Regional Center cost data

# NATHAN

## PROJECT COST INFORMATION

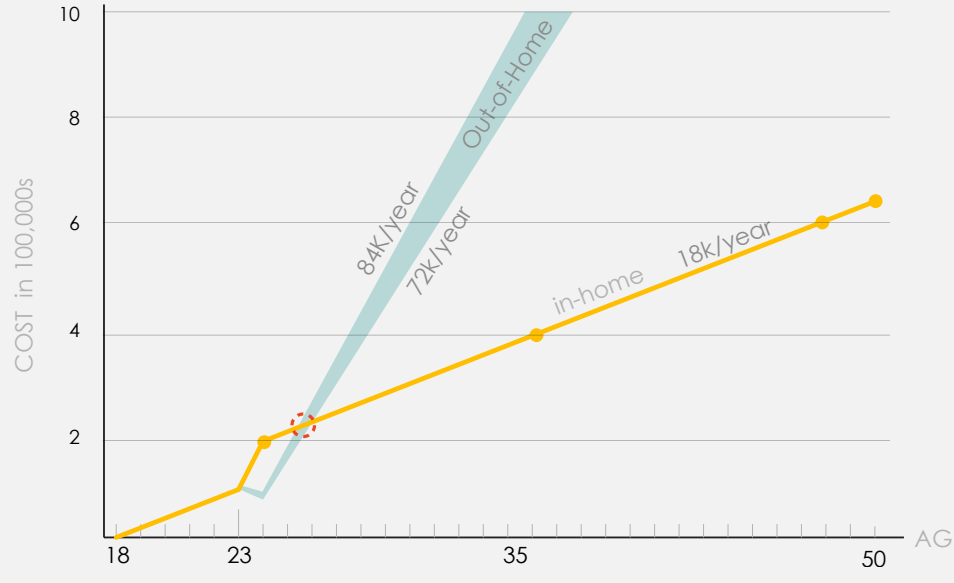
22 -year-old Nathan lived with his mother. Nathan experiences significant ASD and engages in extreme property damage, self-injury and aggression. Modifications to the family home improved Nathan's health and safety, his mother's health and safety, and reduced stress and workload for his caregiver.

The graph below illustrates the comparison between in-home costs (including costs of modifications) and costs incurred as a result of out-of-home placement. The orange line represents the cost of modifications and in-home services, the blue range; out-of home costs. The red circle is the "return on investment" period.

2009
Total Cost: $90,420

## SCOPE OF MODIFICATIONS

- Window, door, and floor covering repairs and upgrades
- Institutional-grade bathroom fixtures and accessories
- Addition of a hard wall




Source: Creative Housing Solutions project cost data and California Regional Center cost data

# RUSSELL

## PROJECT COST INFORMATION

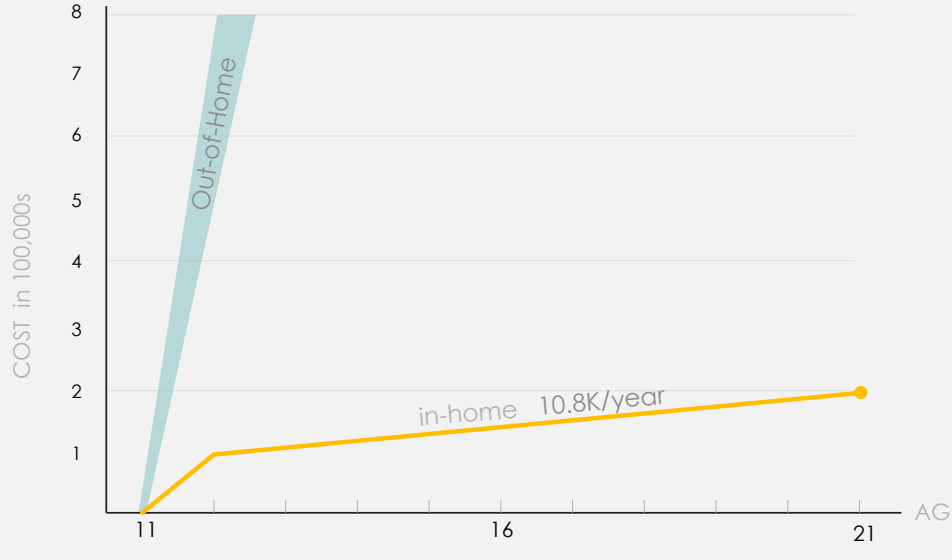
13-year-old Russell lives with his family. He has ASD with Prader-Willi Syndrome and other medical issues related to obesity. Elopement and managing access to food were critical, life-safety issues. This project included upgrading electrical, plumbing and mechanical systems to bring the house up to code, installing an accessible bathroom, and configuring an interior room modification to create a suite for Russell. A second phase of work involved making an outdoor play area and an inside exercise room.

The graph below illustrates the comparison between in-home costs (including costs of modifications) and costs incurred as a result of out-of-home placement.

2002, 2005
Total Cost: $159,500

## SCOPE OF MODIFICATIONS

- Heating, ventilation and air conditioning upgrades
- Upgraded electric
- Bathroom accessibility
- Interior partition arrangements
- Added suite
- Outdoor play area and exercise room




Source: Creative Housing Solutions project cost data and California Regional Center cost data

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