

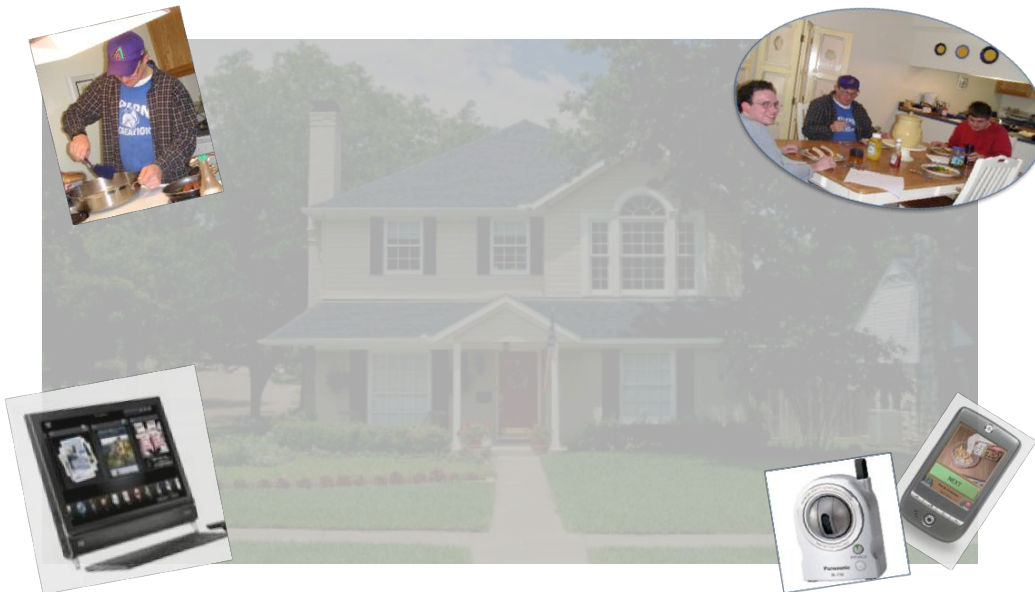


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Linking Employment, Abilities and Potential

INNOVATIVE INDEPENDENT LIVING PROJECT



Written by
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May 2011



Linking Employment, Abilities and Potential

Innovative Independent Living – a SMART way to live

Many persons with disabilities who have low income want to live independently but they face a lower quality of life prospect because of limited choices of lifestyle outcomes or care settings. The Innovative Independent Living Project (IILP) addressed one aspect of this problem by creating a model of community living for persons with disabilities who would otherwise wait years to be served through a Medicaid waiver. There are 27,000 Ohioans on the waiver waiting list.

The Innovative Independent Living Project identified one alternative to the growing problem of increasing need and decreasing funding by introducing an emerging new paradigm for community based living that focuses rigorously on the process of matching technology and services with the specific needs of the individual. The Cleveland Foundation funded Linking Employment, Abilities and Potential (LEAP) to collaborate with other organizations and create a model that meets the needs and desires of persons with disabilities and uses technology in a cost effective manner.

This manual is intended to help parents and others learn about utilizing assistive technology to create a living environment that is designed to build on individual strengths promote growth in skills and confidence and plan for assistance and safety. The utilization of technology, combined with the financial and legal models outlined in this manual create the frame work for replication. The convergence of easily accessible and affordable technology designed for in-home use, reduced governmental funding for supported living, a person centered approach, and a proactive alternative for some of the 27,000 people waiting for a waiver makes the environment right for this new approach to succeed.

With gratitude to all the partner agencies and families that made this project possible,

Kathleen Hallissey
Director of Community Responsive Grantmaking
Cleveland Foundation

Melanie Hogan
Executive Director
Linking Employment, Abilities
& Potential (LEAP)

Reflections from the Project Manager...

When we began the IILP, I had a vision of what needed to be done, but didn't realize how difficult it would be to accomplish. The project time frame went from eighteen months to over three years as the huge task became clearer. Families struggled with whether or not they could make their own dreams of an independent home for their son or daughter a reality. Some tried for a while, and then life circumstances (family illness, the economic recession, job changes, etc.) happened and they dropped out. Many simply could not find other compatible families with whom to partner. Other families discovered what we were attempting to do and asked to be part of it. In the end, because we were trying to meet our project schedule, we went forward with only seven families who were "ready now" and who believed in the concept behind this project: that with the right tools, training and technology, one can create safe and affordable independent community based homes for persons with developmental disabilities.

This manual is for the hundreds of others with whom I have talked that want to create a home for their own children. Most are family members who want to be sure their child or sibling will be safe and happy when they can no longer care for him or her. They all worry about things like how to access the support that might be necessary, where the home will be, how to find compatible roommates and families, how to pay for it all, how to find out the rules for government benefits, etc. (Note: we have used the term "child" throughout this manual for convenience and ease in representing the relationship with the parent or family member, but it is not intended to connote either age or ability levels.)

Lately I am getting more and more calls from professionals in agencies that serve those with developmental disabilities who are trying to reduce cost while keeping a high quality of services. This comes at a time when the principles of Self-Determination, i.e., giving the control over resources and decisions directly to people with disabilities, are becoming generally more accepted, and acknowledged as increasing their quality of life. One of the benefits of this interest is that rules about what can be paid for under many government programs are evolving to include more types of technology.

The manual will also be useful to those who are not planning on developing a new home, but simply want to understand how technology might assist in their daily lives or who want to reconsider how they find other support. The guidelines for choosing roommates are applicable to any housing situation. The Financial Model can be used to help review and quantify living requirements of any type.

Reflections from the Project Manager...continued

This manual and the two videos showing the outcomes of the IILP project¹ are the result of the experiences of all the people who were part of it. In addition to families, we were blessed with many volunteers and professionals who made our success possible. Many were excited by the project concept and wanted to help. Although there are too many to recognize all of them individually here, I would especially like to thank Billie Erickson for her commitment to independent living training and her unfailing belief in the abilities of all her students. Also, Judy Liederbach did an amazing job of making the complex financial implications of our homes easy to understand through creation of the Financial Model (see Appendix I of this manual). Bobbi Burkey of Welcome House Inc. and Barb Sapharas of the Cuyahoga County Board of Developmental Disabilities provided invaluable help to all families and created many of the tools you will find herein.

I am also very grateful to the Cleveland Foundation and the Billie Howland Steffee Family Fund for believing in the viability of our proposal. They have been wonderfully flexible to work with, and it is clear their objective in oversight was to help us succeed.

Although this project has ended, I am more convinced than ever that technology will make a huge difference in the safety and independence of people with disabilities. During the last year, there has been an explosion of new solutions that are being developed for the “baby boomers” who are acquiring disabilities as they age and who are adamant about remaining in their own homes. Many of these can be easily adapted for people with developmental disabilities. I am very excited to continue my search and plan to keep testing creative solutions. I hope you will do the same and share what you learn. Together we can make a meaningful difference in the lives of some wonderful people.



Jeanne Sydenstricker
June 2011

¹ You will find these on LEAP’s web site: www.leapinfo.org
Click on the link to “Independence Through Technology” on the home page.

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The Parent Participation Project Manual: Special Housing for Special People,

was written by staff members at Welcome House Inc. and North Coast Community Homes. It was created to help families plan for the housing needs of their loved ones with disabilities. It includes a wealth of information that is generally not repeated in, but can be considered to be a companion to, this Innovative Independent Living Project Manual. You can purchase the manual by contacting Welcome House, 440.356.2330, <http://www.welcomehouseinc.org/> .

Special Housing for Special People

Parent
Participation
Project
Manual



Chapter 1

Overview: Innovative Independent Living Project (IILP)

In March 2006, a small group of non-profit organizations and parents began meeting to brainstorm housing alternatives for low-income adults with developmental disabilities who wanted to live independently, but who were unlikely to receive government financial assistance soon. Without such assistance, and with the 24/7 traditional model of caregiver support, most families could never afford a home on their own. In September 2007, a proposal for a demonstration project using technology as a primary resource was submitted to The Cleveland Foundation and others by the non-profit Linking Employment Abilities and Potential (LEAP). In November 2007, funding from the Cleveland Foundation and the Billie Howland Steffee Family Fund was received, and the Innovative Independent Living Project (IILP) began.

This LEAP program was carried out under the management of Jeanne Sydenstricker, in collaboration with the following partners:

Businesses and Non-Profits

Ascentia (Jewish Family Services Association)

North Coast Community Homes

Welcome House, Inc.
With special thanks to Bobbi Burkey

Cuyahoga County Board of Developmental
Disabilities
With special thanks to Barb Sapharas

Parent Collaborators
Mary & Dan Hughes
Fern & Loren Kendis
Deb Picker & Rich Greene
Sharon & Marv Schwartz
Jeanne & Mike Sydenstricker
Cora & Declan Walsh

Financial Consultant
Judy Liederbach

Objectives

The overall objectives of the IILP pilot were

- 1) to assist 6-10 families to establish independent living solutions for their adult son or daughter with disabilities
- 2) to develop tools (financial, legal, process) which could be used by families to complete similar projects in the future
- 3) to find feasible solutions to offset prohibitive ongoing support costs, including creative use of technology and family support through a collaborative model

Participation

Potential candidate families for participation in the project were identified from numerous sources. Participants were required to be age 21 or over and not medically fragile. Participants also needed to be either involved in a job or day program, or independently assessed to be able to safely remain home during the day. In addition, participants could not have a history of behavioral issues that could be a danger to themselves or others in the home. These criteria were designed to reduce risk and to control costs in the initial demonstration homes, but are not intended to suggest that people with such disabilities cannot benefit from IILP solutions.

Families had to agree to work hard to collaborate with each other, and to support the project as a whole in addition to creating a home for their child.

Funding

The grants provided support and funding for many aspects of project development. Professionals with expertise in independent living were engaged to help participants and families conduct various structured activities, including identifying compatible housemates and families. They provided tools for families to assess individual participant needs in each new home. Experts assisted in understanding legal and financial implications, and developed tools for families to use to manage these areas. Interns and several wonderful volunteers provided individualized independent living training as well as researched successful housing models. They helped families find and develop community resources and support options. One of the most important areas funded by the grant was the identification, development and trials of applied technology to enhance levels of safety and independence. Thus families were able to test technology to be sure it worked for their child before they invested their own money. A library of items purchased will be available for future families.

Perhaps equally important to understand is what the grant did NOT fund. While the grant covered many aspects of preparation for independent living, families also contributed significant personal resources (time and money) to make each house a reality. The grant did not cover the individual homes, remodeling or modifications, costs for individual supports (either technical or staff), personal living expenses, legal expenses, fees for personal financial planning, or transportation.

Family Commitment

The project was designed to help families of adults with developmental disabilities create independent homes for their children. It was not expected that a group of “experts” would create the homes, although they could be a resource for families. The ultimate goal was not a physical place or a house, but to develop a process and various tools that helped families identify what was needed to successfully create a home in their chosen community. Integral to the process was the identification of compatible

families and housemates. Families had to pledge significant amounts of their own time, as well as personal financial resources, to become part of the project. They also had to commit to sharing experiences and collaborating in good faith with the other families in the project.

Advocacy – Working for Lasting Change

Families in the pilot program worked diligently to support the overall project goals of creating a sustainable housing solution that future families could replicate and/or customize to fit each person’s unique goals and needs. It is expected that partners in the project will become advocates for change in the system, so that eventually the solutions applied here will gain acceptance as legitimate, cost-effective and flexible options for providing support. Lower costs will expand the potential of limited government dollars to benefit persons with developmental disabilities who are ready to live independently in their communities with varying degrees of support.

Results – Where are We Now?

As of September 2009, seven young men with developmental disabilities had moved into three different houses in their own communities. At the time of publishing this manual (June 2011), all remain very happy in their own homes, and both the young men and their parents are amazed at the levels of independence each has reached. In addition, there has been a significant increase in self-esteem which has transferred to other areas of their lives.

All homes still have a fair amount of parental involvement in managing aspects of the households, e.g., budgets, medications, staffing support when desired, fixing things that break, etc.. All the residents also have received Level I Medicaid waivers, which provide \$5000 each toward support care. Some also have been able to access several hours per week of support through the Ohio State Plan program.

The homes use a variety of technology which helps with safety and independence, as well as some traditional staffing. Families continue to expand the levels of independence through various means of

training (e.g., homemade videos of specific areas such as how/when to answer the door at home or how to load a dishwasher) and trying new ways to use technology. Many more options are becoming available now because of the aging of the “baby boomers” and their general desire to remain in their own homes as long as possible.

This manual has been written to provide other families with the tools the pilot program families used in the process of creating their homes. It includes a very detailed Financial Planning Model which is essential in helping estimate costs as well as to help think through all the areas that are involved in setting up a home. It also includes a discussion of legal issues and samples of legal documents that will be helpful (these are intended as samples only and are not intended as personal legal advice).

The project’s success has generated a lot of positive attention from other parents as well as professional organizations who are being forced to examine new ways of providing supportive services to people with disabilities. Dozens of organizations have requested presentations about the project and the technology used. Because these requests continue to increase, we have created two films describing the process and the technology in use in each home during the early part of 2011. That film can be viewed by going to www.leapinfo.org and clicking on the “Independence Through Technology” link on the Home Page.

This manual and the financial model are also available on the web site.

Goal: to develop a SYSTEM of:

INNOVATIVE

- Technology maximized to increase reliability and reduce cost
- Individual matching of needs to supports
- Tools to understand financial implications and to iterate options
- Detailed financial planning model
- Reduced near-term reliance on Medicaid waivers

COMMUNITY-BASED

- Personal choice of location
- Strong circles of support
- Collaboration between professionals and families
- Access to community activities

INDEPENDENT

- Freedom of choice
- Self-determination
- Personally satisfying
- Emphasis on safety, health & maximizing level of independence

LIVING

- Safe & viable long-term solution
- Housing models to fit lifestyle preferences
- Housemate & family compatibility assessments
- Detailed transition planning assistance

SUPPORTS

- Commitment of personal resources (time, money, energy, expertise, skills)
- Identification/assessment of multiple options
- Individualized training for independence
- Opportunity to “try before buy” technology solutions
- Access to professionals and other families with experience

Chapter 2

Reality Checks – Are You Ready?

To succeed in developing a home where your family member can live happily and independently, you must begin with a *realistic* view of what is required to make it happen. If you begin with the idea that it will be easy, or that somehow it will be done “for” you, it is unlikely you will reach your goals. This chapter includes a variety of processes and tools that have been designed to help you assess some critical aspects of a successful venture.

Tools for Assessing Readiness

Accurate and honest evaluation of your child’s and family’s needs and resources is the best place to begin. In this chapter, we will share several approaches and tools that have been useful for families to evaluate their readiness to:

1. make a sincere commitment to move now
2. invest personal financial resources in the home
3. invest significant time and energy to establish the home, and perhaps beyond that time frame
4. collaborate and share information openly with others
5. let go of some control in the life of your loved one with disabilities

6. try out new solutions, which may include technology
7. handle a healthy transition for everyone

Are You Ready...

...To Commit to a Home & Move Now?

This is a question for the heart and mind. Maybe your family has been eagerly looking forward to this transition for many years, or maybe you have just begun to consider options for your child’s future. Whatever the case, now is the time for your child and for each supporting family member to answer this soul-searching question honestly. The decision to move involves an emotional component that colors all practical considerations. Parents also struggle with the need to ensure that their child understands what the move will mean and that he/she is ready to start moving toward that.

Even if you feel ready now, new discoveries along the way may lead you to reconsider your choices. Remaining flexible and trying to continually find workable solutions will help keep you moving forward as you try to implement the optimal living solution for your child.

The remainder of this chapter will walk you through a practical assessment process to determine your readiness in the areas listed above.

... To Invest Financial Resources?

The IILP Financial model is an extensive tool designed to help you clearly outline the financial implications of establishing an independent home for your child. Using Microsoft Excel, it allows each family to create numerous scenarios for the costs of establishing an independent home, and to understand the financial implications of each one. A detailed explanation of the model is covered separately Chapter 3.

...To Invest Significant Time and Energy?

Most likely, your time is just as valuable to you as your money, and equally limited by the huge number of things you have to do. From the experience of the families in the IILP, it is clear that unless you can make creating an independent living home for your child a high priority, you will have low probability of succeeding in the venture. Most of the families in this project had to rearrange their priorities for the several years it took to create viable homes for their children (but all heartily agree it was worth it!)

It is helpful to include other members of your child's circle of support in this endeavor. But clearly identifying who has the responsibility for ultimate decisions will avoid spending excess time debating and draining your energy with no discernable progress.

...To Collaborate with Others?

If you are not prepared to collaborate, this parent-directed housing solution is probably not for you. Whether your child ends up living with housemates or alone, the process will usually require communication and interdependence with other families and/or agencies and professionals to reach your goals.

In establishing a home, cooperation with others is unavoidable. Collaboration is hard work. You will face challenges as you strive, as a diverse group, to meet the needs of multiple individuals. There will be problems to solve, irritations to tolerate and compromises to reach.

This manual was created from the combined experiences of those involved in the IILP pilot project. Consider these families your early collaborators. It is hoped that their collective experience will help guide you along your own path, and that you will share your own knowledge as you move forward.

...To Let Go of Some Control?

You have taken care of your child for decades. You are aware of all the ways that your child is unique and able. You know what makes him or her happy or sad and what brings anxiety or comfort. You may have been doing more for your child with disabilities that is necessary because you are comfortable that way and your family has fallen into a routine that works. For all these reasons and more, taking a step back and letting someone else be in charge--including your child as he lives in his own home--is often hard to do. But it is an essential part of making this transition a success.

Criteria for Success in Family Collaboration:

Work continually to develop mutual understanding.

Care about the whole house, not just your own loved one.

Contribute your own unique expertise and skills to the group.

Establish clear roles and accountability.
(Who will do what, and when?)

Decide on effective ways to handle stress/conflict regarding both philosophical issues & daily concerns.

Protect the confidentiality of other individuals and families.

Reflect on these questions as you prepare for this next phase in your lives:

What caretaking responsibilities do I see being completely taken over by support staff or technological solutions?

What caretaking responsibilities am I NOT willing to turn over to anyone else? How will these be handled when I am not around?

How comfortable am I with other parents and staff members being in the home with my child?

How do I feel about others setting limits for my child?

How comfortable am I with others assisting my child with decision-making?

How comfortable am I with using technologies to support some activities of daily living?

...To Try Out New Technology Solutions

The objective of incorporating technologies in your child’s independent lifestyle is to establish the most cost-effective and sustainable support structure possible, now and for the future. Technology can play a crucial role in increasing the ability to be safe and healthy, as well as have a very positive impact on self-esteem. Ideally, you will be open to trying out different solutions to meet your child’s support requirements. This process of exploration can be a challenge, especially if you have limited familiarity with computers and other technologies. Facing new gadgets and programs can be intimidating, and it can be frustrating if the first solutions you try do not work out. Seeking out others to help with this aspect of independence for your child can be a very helpful solution.

“Most of the important

things in the world

have been accomplished

by people who have

kept on trying

when there seemed to be

no hope at all.”

Dale Carnegie

...To Handle a Healthy Transition?

Moving to an independent home may be the biggest single change event that your child has ever experienced. The transition will likely involve your child’s first time living apart from parents, learning to cooperate with housemates, moving to a different community, building a greater level of independence and using technological assistance. That’s a LOT of transition, all at once!

Be aware of the stress that transitions can bring, and monitor how your child and you are handling it. Parents in our project experienced strong emotions, both positive and negative, throughout the process. The assistance of a social worker or counselor was helpful to some families in the pilot project.

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Chapter 3

Financial Issues & Model

How much will it cost? How will we pay for it? Is there financial assistance we can access? How can we find out more about it?

These questions relate to one of the biggest concerns for most families who want to create their own independent living solution for their child with disabilities. The answers are often very complex; types of funding available to you will vary greatly, depending on your child's disability, age, assessed needs and personal financial situation.

It is beyond the scope of this manual to provide detailed information about all possible resources families might access. However, we have attempted to provide an overview of various categories. In addition, we have created a financial modeling tool that can provide a very good estimate of what your particular house will cost once you input your needs.

Funding Sources

Private

Private funds of course come from your personal and family resources, or from individuals within your circle of support. This is the most flexible of all funding, and other than being somewhat limited for most families, there are no restrictions on how you can spend the money.

Public

Various government benefits are available, and your child may qualify for one or more types of assistance, including Social Security options for people with disabilities, Medicaid, Medicare, and/or government housing assistance programs.

Eligibility, which must be established by each individual for each type of assistance, is determined by the agency which administers each program, which may be the Social Security Administration, Ohio Department of Jobs and Family Services, County Board of Developmental Disabilities or others. There are tests which include income and asset levels; once your child reaches age 18, only his income or assets are counted rather than that of the family.

Chapters 4 and 5 of [The Parent Participation Project Manual](#) include significant detail about various types of financing that may be used for both the physical property as well as ongoing support. We have not repeated that detail here. However, it is worth noting that many of these options are available only in very limited supply and therefore are hard to obtain. Waiting lists can be decades long.

In addition, government assistance comes with many requirements for reporting, maintaining eligibility, rules for how you operate your home, etc. In many cases, some assistance will be crucial to being able to afford independent living for your child. So it is important to understand exactly what is required in the long term as you investigate each resource.

In Ohio, for people with intellectual and developmental disabilities, the County Board of Developmental Disabilities (CCBDD) is a primary resource. They serve a broad range of disabilities and administer Medicaid waivers. One of the first steps to take in searching for public funding assistance is to determine whether your child is

eligible for CCBDD services. To do this, call the Intake Office of your local Board.

One of the most widely used options for assistance with support services is Medicaid. Eligibility gives your child access to a number of possible public funding options including waivers, medical care, and Ohio State Plan in-home assistance. You can have a choice of providers (with some restrictions) while using Medicaid funds. See Chapter 11 for more details.

In-Kind and Volunteer Assistance

Throughout the IILP project, we were blessed with very talented volunteers who helped in numerous ways and contributed enormously to the project's success. Some helped with individualized independent living training, others with technical requirements, research, remodeling or many other areas.

In addition, a number of local non-profits and government agencies whose missions center on serving people with disabilities willingly engaged in problem solving and assistance in areas where families needed some help. Using your network and connections to find these invaluable resources can make a significant difference in the outcomes in the new house.

Universities can also be a resource. Many students need projects for various courses. The project families had some success in partnering with professors in areas related to disability studies and technology. The down side to this, however, is that students horizons often end with the school semester, so projects must generally be focused and short term in nature.

There are also many community organizations willing to partner in various areas. They may be willing to contribute expertise, space for meetings,

materials, or other resources for projects they believe are good for their communities.

Grants

There are many foundations that provide funds for programs that serve people with disabilities. In general, the projects must have a purpose that is long term and beneficial to a broad group, e.g., one which demonstrates a new concept that others can apply to their own situation. Foundations seldom fund individuals, so it is important to form a strong alliance with respected local non-profits or involved agencies. You will need to have a credible project plan and solid budget. It is not easy to get these funds but they can make a big difference in the success of a new idea.

A good place to start your search for possible funders is <http://foundationcenter.org/>. They are an organization dedicated to helping match funders and people with good proposals. They offer free grant writing courses and other instructional information. Some of their programs require a subscription fee, but local libraries often have subscribed and you can thus get it for no charge.

A Financial Model for YOUR Home

The IILP Financial Model is a unique and valuable tool. It was designed to give families a user-friendly way to estimate the total cost of independent living, including housing and support expenses, and to compare it to your available financial resources.

While paper-and-pencil budgets may be good for some financial planning, they are insufficient for the complex financial estimates required to establish a new home for your child with disabilities. You will need to incorporate all the typical household costs such as rent or mortgage, utilities, household furnishings, lawn care, etc. But you will also need to understand how many hours of caregiving or support your child will need, how many others in the house will share the cost of that support, cost and method of outside transportation, and other things that may not currently be part of your own budget.

You also need to understand various options about how you will pay all that is needed. Once you have completed the IILP Financial Model, you will be able to see specific costs and make assumptions about how they will be paid. You will also be able to change assumptions to see the impact each change has on total cost each year. For example, if you invest \$3000 in technology in Year 1 that can reduce the need for caregivers by 10 hours per week, at \$15 per hour you will save \$7800 each year on support costs. Or if you decide to share support costs for 10 hours per week with 3 others in the home rather than have the person care only for your child, you will reduce your share of the \$7800 per year to \$1950. You can run dozens of scenarios very easily. Knowing the financial impact of options helps very much in making decisions.

You will also be able to change assumptions about income levels, support from Medicaid waivers (e.g., how many years you will have to wait to receive a waiver, what costs the waiver will cover), Social Security benefits, etc.

At the end of the model, using all your assumptions about how you want your child's new home to operate, the model will calculate the annual net cost that is needed. It will also show you options about how to fund that amount, i.e., pay it each year from your own funds, buy an insurance or annuity policy, etc. This model will help expand your understanding of the financial aspects. The objective is that you know what you are getting into as you create your child's home and make a conscious decision that this is the right thing for your family.

NOTE:

Use of this tool is not meant to replace the invaluable assistance of a professional personal financial advisor; however, the results can and should be used to supplement and inform your discussions with your advisor.

The Financial Model

If you received a printed copy of this manual, there should be a CD which includes the Financial Model on it. If you are viewing this manual through the internet, you will find a separate Excel file to click on to access the model.

You will need access to a Windows PC with the Microsoft Excel program on it. The Financial Model is an Excel workbook, and has only been tested on a PC (not on a Mac). The model is saved as an Excel 97-2003 Workbook, so your version of Excel must be compatible with that (later versions will work fine as well.) If you are unfamiliar with this program, it may be helpful to have someone who has a basic understanding of the program sit with you initially.

There are very detailed instructions for using the model in Appendix I in this manual. Be sure to follow the instructions for each input item very closely since the outcomes depend on being as accurate as possible with the input. It is important

to understand the input requirements and to use the units requested.

You will not be able to change any of the formulae in the Financial Model. The information from various worksheets is incorporated in many ways into the final results and changing one of them can have unexpected results.

We ask that you do not further distribute the Financial Model. It is the property of LEAP and anyone can come to the LEAP web site (www.leapinfo.org) to download it. However, it is not for sale and/or further distribution under any other person or organization's name.

Chapter 4

Housing Models: Options to Consider

When choosing the type and location of your child's new home, your decision will be based on a combination of personal preferences, collaborative choices, and practical realities. This chapter presents issues to consider and some information about various housing models that were investigated during the IILP Pilot Program.

Location, Location, Location!

A primary factor in most home searches is *location*. You want your child to settle in a safe, friendly neighborhood that will afford as much opportunity for independence as possible. This goal will obviously be different for each individual. Consider the following when evaluating potential communities and locations.

Proximity to important places:

- Community:
 - Work/day programs
 - Medical care
 - Religious practice
 - Recreation/fitness
 - Entertainment
 - Shopping
- Relationships
 - Parents/family
 - Friends
 - Significant others

Neighborhood safety:

- Local police reports
- Sex Offender Registry at www.familywatchdog.us
- Quality of streets/sidewalks
- Public/street lighting
- neighborhood activity - day and night

Transportation options: (just made syntax more consistent with above)

- Pedestrian safety
- Bicycle safety
- Sidewalk accessibility
- Bus Service accessibility
- Community sponsored vans or buses?

Physical Property

What type of physical residence do you want? How many people will live in this home? Does each person need to have a separate bedroom? Do you want something you can own or would you prefer to rent, either at the beginning or always? Do you want access to a yard or do you want to avoid the extra work and expense of exterior maintenance? Is having a security system important for safety?

Be aware that your choices of location may limit the type of physical property you can select, and vice versa. Deciding on your overall priorities before you begin looking for the specific residential options will save time and frustration in the long run.

Consider the following when investigating specific properties.

Property Type

- House
 - Single-family
 - Duplex
 - Buy or build?
- Condo
 - Commercial
 - Consortium-owned group
 - House that is treated as condo, with multiple families buying a share
- Apartment
- Established facility (e.g., senior living complex)

Zoning Regulations

There are many zoning rules for most cities. You will need to be aware of them and determine if or how they might affect your specific house. You should also be aware that many people with disabilities qualify for protection under the 1988 Amendments to the Fair Housing Act. This Act prohibits discrimination against persons with disabilities and requires that cities make a reasonable accommodation for such persons to live in the place they choose. If you think you may be in violation of a city's zoning laws, you should consult with a lawyer who specializes in this area.

Many Configurations Work Well

The IILP reviewed numerous successful housing solutions throughout the country. Many have some common characteristics that enhanced their success, and which the pilot project families selectively incorporated into their own homes. What works best for each family clearly depends on the needs of the person(s) with disabilities as well as the family resources and time/willingness to be involved.

For purposes of this overview, we have grouped options into four main areas:

- Stand-Alone Single residence
- Co-located models
- Distributed housing models
- Rural or Farm models

All can include creative solutions to meet the needs of multiple individuals in a cost-effective way, while promoting the greatest level of independence for the person with disabilities.

Stand-Alone Single Residence (also called a Family Consortium)

In this model, the families of the residents get together and decide who will live together, what services they want, where the home will be located, etc. In general, the families handle all the management of the home, including all finances. They decide what level of support is needed; they may hire an individual or an agency provider or do it themselves. Support, including transportation, for residents can be paid for by Medicaid waivers or other government funding if the residents are eligible.

This model provides great flexibility in how the home is set up, but also generally requires the greatest amount of work on the part of families.

Different cities have different zoning requirements for how many unrelated individuals can live together and it is worth understanding these requirements before buying a residence. As noted above, persons with disabilities may have some flexibility due to the Fair Housing Act, but understanding the community's laws is worthwhile.

Co-Located Model

The Co-Located Model is one in which all residential units are in close geographical proximity to each other. This could be in the same building (house, apartment complex, or residential facility) or in separate buildings very close together (similar to a campus). Being close together can have many advantages:

- Support staff may serve groups of residences; which can be a major cost reduction
- Joint transportation or vehicle sharing is easier
- It facilitates social interaction through planned group events, with a larger choice of friends
- Group counseling is possible
- May have meals prepared and served in a common area
- Can have a variety of ages and disabilities, all able to assist each other (e.g., an inter-generational model)

Any of the property types listed above could be used for the co-located residences, but it is perhaps easiest

to envision a group of apartments in the same building or close to each other in a complex. Several successful programs operated within a senior living complex, in a subset of apartments in a larger apartment building, or in a building dedicated only to apartments for persons with disabilities.

The Co-located Model is one which parents often described as bringing great peace of mind because it is usually very structured and likely has greater staff at less cost than other options. It can also be one of the most difficult and take the longest time to implement if you want a custom built facility. Funding for such construction can be very difficult to find. And because of the number of residents required to make the finances work, participants often have less to say about who joins the group than they might have in a smaller operation.

Distributed Housing Model

In this model, the locations of individual residences are distributed or scattered throughout larger communities. Homes which may be located at some distance from one another, can share resources and management. Any of the property types listed above can also be used for this option; they could be managed by a management group rather than individual families

Many group homes managed by residential providers fall into this category. The residential service provider works with the residents and families to establish what would be best for each person. The provider hires and manages the staff, helps to develop a complete plan for assisting the person with disabilities.

Individual families can also work together to coordinate aspects of daily living for a number of locations. This configuration tends to encourage greater contact and involvement in the wider community, but requires a lot of coordination to make it successful.

Rural/Farm Model

The Rural/Farm Model integrates location and physical property into a holistic setting for work and living. Housing is usually on or near the farm; and residence there may be a requirement for participating in any part of the program.

Specific types of residential units may vary depending on the organization and the resident's level of independence and support needs. They may include a room in a group home, a separate apartment in a group of on-site apartment buildings.

Most of these programs also have an employment component on the same site as the residence. Some programs allow the residents to work off-site as well, and provide transportation.

Social activities are both within the holistic "village" setting and in local surrounding communities.

CO-LOCATED HOUSING: SENIOR LIVING CENTERS (MANY AVAILABLE)

Organization/management structure	<ul style="list-style-type: none"> • Privately owned – for profit • Administrative team oversees facilities • Functions: Housing; residential support services • Families are usually included in decisions regarding individuals
Target population served	<ul style="list-style-type: none"> • Elderly –independent or assisted living • Can also include younger persons with a variety of disabilities
Support staff	<ul style="list-style-type: none"> • Daytime or night time staffing often available as needed • Can pass out medications • Assist with emergency needs • Generally have planned activities; may be willing to hire specifically for persons with disabilities if there is enough of a core group • Staff often not specially trained • Facility staff not chosen by residents but free choice of additional service providers
Funding sources	<ul style="list-style-type: none"> • Personal funds • Government benefits <ul style="list-style-type: none"> ○ Home Energy Assistance Program (HEAP) ○ Lifeline Assistance Program (discount telephone service for low income Ohio residents) ○ Medicaid Waiver – for more significant needs
Physical residence	<ul style="list-style-type: none"> • Type – Apartments or rooms, usually with kitchen and private bath • Locations - Clustered/co-located • Maintenance – on-site, included in rent • Generally have dining room and a meal plan
Quality assessment	<ul style="list-style-type: none"> • No formal structure specific to disability services • Family assists in needs assessment and ongoing care concerns
Level of community integration/access	<ul style="list-style-type: none"> • Often provide transportation as part of rent • May be willing to hire persons with disabilities to work in the facility • Quality of life very strongly correlates with supportive senior management

CO-LOCATED HOUSING: BOSTON MODEL [\(www.specializedhousing.org\)](http://www.specializedhousing.org)

Organization/management structure	<ul style="list-style-type: none"> • Privately owned – for profit • Specialized Housing, Inc. – management company • Functions of the organization: Housing operations; staffing • Cooperative professionals: clinicians, lawyers, and builders work together
Target population served	<ul style="list-style-type: none"> • Adults in Boston Metro area <ul style="list-style-type: none"> ○ Ineligible for state supported assistance ○ NOT a waiver provider • Type of disability: developmental, physical, and intellectual; traumatic brain injury, psychiatric • Severity of disability: Screened for living skills and social abilities • “Some” self-sufficiency expected • All residents work or are in day program <ul style="list-style-type: none"> ○ Staff in house during the day
Support staff	<ul style="list-style-type: none"> • Clinical supervisor manages staff • Shared full-time staff, many with degrees <ul style="list-style-type: none"> ○ Minimal while residents are at work ○ Approved by house members
Funding sources	<ul style="list-style-type: none"> • Public and private funds <ul style="list-style-type: none"> ○ “Owner based model of supportive housing...comfortable...works financially” • Specialized Housing, Inc. tracks funding sources • Low cost (estimated \$12,000/year for support and housing in 2009)
Physical residence	<ul style="list-style-type: none"> • “Condos” (model since 1983) - Families buy bedroom with a share in common areas • 4-12 residents in each house • Individual multi-unit – co-located. Bought/sold as separate real estate entities • Each has own condo association/trust for management/maintenance
Quality assessment	<ul style="list-style-type: none"> • Specialized Housing, Inc. oversees clinical supervisor and all full-time staff • Clinical supervisor is consultant to House Manager
Level of community integration/access	<ul style="list-style-type: none"> • Location – important aspects <ul style="list-style-type: none"> ○ Neighborhood ○ Transportation availability • Socialization & community integration is up to the individual; no “house” functions

Booklet: “Passport to Independence: Home, Work, & Family – A Manual for Families – 2nd Editio

DISTRIBUTED HOUSING: LAMB’S FARM, ILLINOIS (<http://lambsfarm.org>)

<p>Lamb’s Farm is an entire community providing a wide variety of assistance to over 250 people with developmental disabilities. It has been in existence since 1961, and provides help in areas of independent living, residences, employment, and all other areas of life.</p>	
<p>Organization/management structure</p>	<ul style="list-style-type: none"> • Private - Non-profit • Functions of the organization include housing and employment • Management decisions made by Board, Staff & volunteers <ul style="list-style-type: none"> ○
<p>Target population served</p>	<ul style="list-style-type: none"> • Adults • Developmental disabilities with no threat to self or others • Mild to moderate disabilities
<p>Support staff</p>	<ul style="list-style-type: none"> • Daytime supervision • 24 hours in dorms • Apartment residents have access to on-call support staff as needed
<p>Funding sources</p>	<ul style="list-style-type: none"> • Support generally paid by Medicaid waivers • Private pay of rent, utilities, and living expenses
<p>Physical residence</p>	<ul style="list-style-type: none"> • Learn community living • On-campus independent apartments & community residences • Locations – varied. Can be on central campus or in community
<p>Level of community integration/access</p>	<ul style="list-style-type: none"> • Daily activities within Lamb’s Farm community as well as broader geographic area • Health programs, including Physical Fitness Center • Community Employment Program <ul style="list-style-type: none"> ○ Individual placements w/supports

DISTRIBUTED HOUSING: SUPPORTED LIVING INC – CALIFORNIA

Organization/management structure	<ul style="list-style-type: none"> • Private - Non-profit • cooperative family run with highly individualized supports to assure a stable home.
Target population served	<ul style="list-style-type: none"> • Adults with developmental disabilities
Support staff	<ul style="list-style-type: none"> • Live-in as well as other day support available; frequently use university students • House manager handles house finances, insures staff coverage as needed • Often has more than one housemate per home
Funding sources	<ul style="list-style-type: none"> • Support generally paid by Medicaid waivers • Other government subsidies may be used • Private pay of rent, utilities, and living expenses
Services	<ul style="list-style-type: none"> • Build houses • Creative Living Systems – technology • Consulting <ul style="list-style-type: none"> ○ Individuals ○ Government agencies ○ Non profits
Physical residence	<ul style="list-style-type: none"> • Family owned • HUD Section 8 vouchers may supplements the rent paid individually by persons with disabilities. • Houses, condos, and apartments are used according to preference and financial viability.
Level of community integration/access	<ul style="list-style-type: none"> • Residents usually work or attend programs • Integrated community and social activities with housemates are encouraged.

RURAL/FARM MODEL: BITTERSWEET FARMS, OH

<http://www.bittersweetfarms.org/>

<p>Bittersweet Farms is internationally renowned for its superior programs for persons with autism. They have an 80 acre working farm in northwest Ohio. There is a very long waiting list for this program, but other areas are beginning to try to create similar programs. Bittersweet personnel are available to consult in their specific areas of expertise.</p>	
Organization/management structure	<ul style="list-style-type: none"> • Private - Non-profit
Target population served	<ul style="list-style-type: none"> • Adults with autism; may also have other developmental disabilities
Support staff	<ul style="list-style-type: none"> • Speech and language therapist • Behavior specialist • Recreation therapist • Vocational & rehabilitation training staff • Direct support staff (ratio depends on individual's needs)
Funding sources	<ul style="list-style-type: none"> • Support generally paid by Medicaid waivers • Other government subsidies may be used • Private pay • Donations • Sale of products made on the farm
Services provided	<ul style="list-style-type: none"> • Residential & supported living • Vocational services • Consults with other entities on setting up services for adults and adolescents with autism
Physical residence	<ul style="list-style-type: none"> • 3 houses with 8 in each on the farm; 12 apartments on nearby property • Common area for meals • Art facility; greenhouses, barn with animals
Level of community integration/access	<ul style="list-style-type: none"> • Joint ventures with businesses in the area, e.g. supply vegetables • Some participants work in the community • Organize and supervise vacations, field trips, shopping and recreational

RURAL/FARM MODEL: HOPEWELL, OHIO (<http://www.hopewell.cc/>)

<p>Hopewell is a 300 acre farm in northeast Ohio serving primarily persons with mental health disabilities. They have also very occasionally served adults with autism who have dual diagnosis of mental health problems.</p>	
<p>Organization/management structure</p>	<ul style="list-style-type: none"> • Private - Non-profit • Functions include housing & rehabilitation <ul style="list-style-type: none"> ○ Short-term (18 month) ○ Some long-term (3 year) • Management <ul style="list-style-type: none"> ○ Board, Executive Director, Director, Program Director, etc.
<p>Target population served</p>	<ul style="list-style-type: none"> • Adult with Mental illness <ul style="list-style-type: none"> ○ No addiction recovery program • Sometimes serve those with autism and mental health dual diagnosis
<p>Support staff</p>	<ul style="list-style-type: none"> • Daytime supervision • Nurse • Psychiatrist available for consultation • Volunteers
<p>Funding sources</p>	<ul style="list-style-type: none"> • Private • Donations • Medical insurance
<p>Physical residence</p>	<ul style="list-style-type: none"> • 3 individual houses (Main house + 2 separate) • 12 people per house <ul style="list-style-type: none"> ○ Individual bedrooms ○ Meals shared in main house • Clustered/co-located on 300 acre farm
<p>Level of community integration/access</p>	<ul style="list-style-type: none"> • On the farm <ul style="list-style-type: none"> ○ Music ○ Art ○ Equine Therapy • Community access with Group “field trips” & social outings

HOME BUILDING OPTION: DELAWARE CREATIVE HOUSING- DCH INC, OHIO

www.delawarecreativehousing.com

This organization builds low cost homes which are fully accessible and reasonably priced. The homes are built in a modular fashion and can then be set up on a site of the purchaser's choosing. They are located near Columbus, OH	
Organization/management structure	<ul style="list-style-type: none"> • Private - Non-profit – 501 (c) (3)
Target population served	<ul style="list-style-type: none"> • Aging • Individuals with disabilities, both developmental and physical
Functions of the organization	<ul style="list-style-type: none"> • Build houses • Creative Living Systems – technology • Consulting <ul style="list-style-type: none"> ○ Individuals ○ Government agencies ○ Non profits
Funding sources	<ul style="list-style-type: none"> • Private - Ray Jones Memorial Fund • Government/public <ul style="list-style-type: none"> ○ Department of Housing and Urban Development (HUD) – Section 8 vouchers ○ Metropolitan Housing Authority subsidized 811 projects ○ Delaware County Board of Developmental Disabilities ○ Delaware Council for Older Adults
Physical residence	<ul style="list-style-type: none"> • Delaware Creative Housing, Inc. may own and lease property or work with landlords for accessible/appropriate housing • Allows community-based living by offering the Morgan House, a unit that may be built anywhere without zoning restrictions
Quality assessment	<ul style="list-style-type: none"> • Home safety and accessibility inspections
Level of community integration/access	<ul style="list-style-type: none"> • Often provide transportation as part of rent • May be willing to hire persons with disabilities to work in the facility • Quality of life very strongly correlates with supportive senior management

Chapter 5

Legal Considerations

Family directed housing and services offer additional options to families looking to provide long term residential living for their child with a disability that also includes services and supports. This summary, prepared by the Ohio firm of Hickman & Lowder, focuses on the legal aspects of home ownership, employment of service providers, and relationship among the residents and/or their families. It is intended to be an educational overview of the legal issues that accompany a particular independent living arrangement. It is not an exhaustive list of all legal issues that may arise, nor is it to be construed as legal advice. Families are advised to seek legal counsel for advice regarding their own living arrangement concepts.

Home ownership models

Family directed housing can exist in many formats. The three most common variations are

- One family owns, other residents pay rent
- Separate legal entity owns the home
- Third party owns the house and all pay rent

These three options are discussed in more detail below.

I. One family owner

In this model, one family purchases a home for their adult child and allows other adult children with disabilities to also live in the home and pay rent. The family who is the home owner will be the landlord and the adult children residing in the home are the tenants. It is important that the one family owner create and use a lease with each tenant. The lease protects both parties by capturing in writing the expectations. In addition, tenants who receive SSI may be required to provide a copy of the rental agreement to their local social security office. A lease should include the payment terms, who pays for utilities, who is responsible for home maintenance, pet policy, termination provisions, and any other terms. However, a lease should not include terms that could be deemed as discriminatory or are in violation of the Fair Housing Act. A sample rental agreement is provided in Appendix IIA.

If the participating families form a consortium or some other type of unincorporated association, the home owner may instead lease the house to the consortium, thereby avoiding multiple leases and tenants. In this type of an arrangement, the consortium families would be obligated to the owner.

II. Family members create separate legal entity which owns home

In this model, a group of families pools resources to purchase a home for their adult children. Families that prefer to share ownership of the home should consider forming a separate legal entity that holds the real property and protects the participating families from personal liability.

Legal entities authorized under Ohio law include partnerships, corporations, limited liability companies and several other variations. For group family directed housing, a limited liability company (LLC) offers a great deal of flexibility, combines the best parts of partnerships and corporations and may exist with one or more members. The benefits of an LLC, rather than a group of individuals owning a home or multiple homes are many.

A. *Decision-making*

An LLC provides a foundation for decision-making. Depending on the terms of the Operating Agreement (see further discussion below), an LLC may be run by all members (LLC owners), a designated manager, or a combination of elected officers. The members may delegate authority to one or more members to enter into contracts, purchase assets, and make other decisions without requiring each member's involvement. On the other hand, a collection of individuals who have not formed a legal entity must all participate in every decision and legal transaction. This approach tends to be more burdensome.

B. *Continuity*

If an LLC owns real property, it will continue to own such property regardless of a change in its members. Over time, families may come and go, including the tenants. An LLC owned house will continue on in existence allowing it to be an available resource to new tenants, without requiring a transfer of ownership.

C. *Tax treatment*

An LLC is a pass-through tax entity. Unlike a corporation, which must pay its own taxes, the profits and losses of the business pass through to its owners, who report them on their personal tax returns just as they would if they owned a partnership or were acting as sole proprietors. This means that the LLC itself does not pay taxes and does not have to file a tax return. The LLC may be designated as a non-profit under Ohio laws, but will not qualify for the federal 501(c)(3) tax exempt status as long as the members of the LLC are individuals. If the LLC has employees, it will need to obtain a federal tax identification number, also known as an employer identification number (EIN).

D. *Liability*

An LLC protects its owners from personal liability for business debts and claims. If the LLC can't pay a creditor, the creditor cannot legally come after an LLC owner's house, car or other personal assets. Only the LLC assets may be accessed to satisfy any claims or debts. However in limited circumstances, an LLC owner may be held personally liable if the owner does any of the following:

1. Causes injury to another;
2. Personally guarantees a bank loan or debt on which the LLC defaults;
3. Fails to deposit employment taxes withheld from LLC employees;
4. Acts in a fraudulent, illegal or reckless manner causing harm to the LLC; or
5. Treats the LLC as an extension of owner's personal affairs.

To avoid liability, LLC owners should do all of the following:

1. Act fairly and legally;
2. Adequately fund the LLC to meet expenses and liabilities;
3. Separately maintain LLC and personal business;
4. Create an operating agreement that spells out how the LLC will be run; and
5. Obtain a general liability insurance policy that will protect both personal and LLC assets from lawsuits and pay the legal expenses in the event that a lawsuit is filed.

E. *Setting up an LLC*

Setting up an LLC is fairly simple and requires three basic steps.

1. Articles of Organization

The initial step in forming an LLC is to file Articles of Organization with the Ohio Secretary of State. The current Ohio Secretary of State required form is provided in Appendix IIB. It may also be downloaded at

<http://www.sos.state.oh.us/sos/upload/business/>. The Articles of Organization require that an individual be appointed as the statutory agent for the LLC. The statutory agent receives legal notices and, in the event of a lawsuit, receives service of process on behalf of the LLC. The Articles of Organization must be accompanied by the required filing fee. Upon acceptance of the Articles of Organization by the Ohio Secretary of State, the LLC is deemed to be formed.

2. Determine appropriate tax status

The members must elect whether the LLC should be taxed as a corporation, or whether it will be a “pass-through entity” so that the LLC owners report business losses or profits on their personal tax returns. If the LLC will have employees, it will need to obtain an EIN and will be required to pay employee related taxes. The LLC may also be designated as a not for profit entity under Ohio law, although not under federal law. Members should consult with a tax attorney or other qualified tax professional to determine whether there is any benefit to designating its LLC as a not for profit entity.

3. Operating Agreement

An Operating Agreement sets out in writing the terms under which the LLC will operate. It is a legal contract between the members that binds all of the members who must agree to the terms. Although not required by Ohio law, a well written Operating Agreement will minimize disputes among the members as well as define and protect legitimate expectations of the members. An Operating Agreement that is individualized to address the purpose and operation of a given LLC, will be much more useful to its members than one filled with nothing but “boilerplate” provisions. Appendix IIC provides a checklist of issues that members consider addressing in an Operating Agreement. If a later disputed issue is not addressed in the Operating Agreement, the courts will decide the issue in accordance with O.R.C. Chapter 1705; the Ohio statute defining limited liability companies.

III. *Third party owns home*

The third party owner model is very similar to the one family owner model, except that the third party owner is not related to any of the tenants. A lease should be used for the same reasons as discussed above. If the landlord has a separate lease with each tenant, the tenant’s duties and obligations are independent of the other tenants. On the other hand, if the lease is between the landlord and all tenants, all tenants may be obligated equally. For example, if the lease requires that tenants pay all utilities, and one of the tenant’s does not pay his share, the remaining tenants may be legally obligated to make sure the utilities are paid. It is important to carefully review the proposed lease and have a clear understanding of the terms prior to signing. Appendix IID provides a summary of the Ohio Landlord Tenant Laws that are applicable to house rentals.

Liability & Insurance

The landlord has a duty to make all repairs needed to maintain the property in good condition and keep all common areas safe, clean and in good repair. If a tenant or visitor is injured as a result of the landlord's failure to maintain the premises, the landlord may be liable to the injured party. In addition to taking reasonable steps to maintain the premises in good condition, the landlord can further protect himself by purchasing property insurance.

Whether the house is owned by an individual or an entity such as a limited liability company, the landlord should carry homeowner insurance that provides sufficient coverage for property damage and injury that may occur on the premises. For extra protection, the landlord may want to purchase additional liability coverage, referred to as an umbrella policy. An umbrella policy is a liability insurance policy that protects assets over and above the coverage provided by a standard homeowner's policy.

The tenant has a duty to pay rent and not cause damage to the premises. If the premises are damaged as a result of a tenant's actions, the tenant may be liable to the landlord. If a visitor (including a provider) is injured on the premises as a result of the tenant's negligent act, the tenant may be liable.

Families may wish to purchase a tenant's policy to cover their tenant family member, which protects the tenant's personal property. In the unfortunate event of damage occurring to the home, the landlord's policy will not typically cover the tenant's personal belongings. In addition to providing coverage against property loss, theft or damage, a tenant's policy may also cover injury to another person while on the tenant's property.

In the event that the amount of damage or injury exceeds the policy limits, the individual tenant or landlord may be personally liable for the difference. In the case of an LLC landlord, the LLC and not the individual members of the LLC will be liable for any amounts exceeding policy limits, so long as the amount of coverage purchased for the LLC was based on good faith and reasonable actions of the LLC members.

Services

Once a home is secured and roommates/co-tenants/residents are selected, the families must decide on how support services are to be provided. Some residents may need more or less support services than their housemates. In addition to individual support services, there may be a need for other home maintenance services. Each family must determine what the best service plan is for their family member. Families may choose to directly hire providers, or the resident (or her legal guardian) may contract with an agency to provide the service. In some cases, family members themselves choose to provide the required support services. Each option has its own benefits and challenges.

I. Providers as employees

Families that elect to hire individuals to provide support services or home maintenance services have the greatest control over every aspect of the service. As the employer, the family controls the number of hours, how the service is provided, where the service is provided, who provides the service and payment terms. With such power and control of course comes much responsibility.

A. Employer obligations

An employer must obtain an Employer Identification Number (EIN). This is true whether the employer will be an LLC or an individual family member. An EIN application may be filed online at <http://www.irs.gov/>.

The IRS makes a distinction between an employee and an independent contractor. For tax purposes, it is important to determine at the outset whether the individual that the family hires is an employee or an independent contractor. If the hired individual is an employee, then the employer must withhold income taxes, withhold and pay Social Security and Medicare taxes, and pay unemployment tax on wages paid to the employee. If the hired individual is an independent contractor, he or she is responsible for the payment of his or her own taxes. The IRS uses a "degree of

control” test to determine whether a hired individual is an employee or an independent contractor. The presumption is that the hired individual is an employee if the employer can control what will be done and how it will be done. As an example, an individual hired to provide assistance with activities of daily living’s, housekeeping or cooking at specific times as directed by the family, will be considered an employee. On the other hand, an exterminator who provides a monthly service is most likely an independent contractor.

If the worker is an independent contractor, the employer should have the contractor complete form W-9, Request for Taxpayer Identification Number and Certification. It may be used to obtain the correct name and TIN of the worker. If the independent contractor receives payment in excess of \$600 during the year, the employer must complete a Form 1099-MISC, provide a copy to the IRS, and provide a copy to the independent contractor by January 31 of year following payment. Both forms are available and may be downloaded from <http://www.irs.gov/>.

An employer may, but is not required to provide additional benefits such as paid time off and health insurance¹. However, the employer must obtain worker’s compensation insurance coverage for its employees.

Ohio recognizes “at-will” employment. This means that an employee may be hired to work for as long as the employer wants and has need for the employee, and may terminate the employee for any reason, or no reason. However, an employer may not terminate an employee if the reason for the termination is illegal, discriminatory or against public policy. Therefore, the employer should always act reasonably and

be able to show that his or her decisions and actions are lawful.

Both federal and state employment laws regulate wages, overtime, and working conditions. In general, employees providing in home support services will most likely be classified as hourly employees who must be paid for every hour they are required to be working or on the premises. If the employee exceeds 40 hours in a week, he or she must be paid time and a half of his or her regular hourly wage for every hour over 40. If the employer wants the employee to spend the night at the home, the employee must be compensated because he or she is required to be on the premises. If, on the other hand, the employee receives room and board at the home, such room and/or board may be considered as part of the employee’s compensation. *(Note: the IRS guidelines provide that meals and lodging as compensation are not taxable to the employee if they are furnished for the convenience of the employer, or if living on site is a condition of employment. IRS Publication 525 (2010).)*

It is the employer’s responsibility to make arrangements for alternate coverage, if an employee calls off or schedules time away from work.

B. Liability

Employers are required to provide a place of employment that is free from recognized hazards that are causing or are likely to cause serious physical harm to employees. For instance, if a resident is known to exhibit violent behavior toward others, the employer must take reasonable steps to protect any employee from harm. Failure to take reasonable steps may subject the employer to liability. Similarly, employees are considered to be the agents of the employer. The employer is expected to select qualified individuals, conduct background checks if necessary and provide necessary training and supervision. If an employee causes an injury to a resident, the employer may be liable for failure to

¹ The Affordable Care Act of 2010 exempts employers with less than fifty employees from any employer health care coverage responsibilities.

adequately train, supervise or control its employees.

If the employer is an LLC, any liability will be limited to the LLC and not the individual members. If the employer is an individual, he or she may be held personally liable and if without insurance coverage, the individual's own assets may be reached.

C. Insurance

An employer, whether an individual or an LLC, should obtain sufficient insurance coverage to protect personal or business assets in the event of a personal injury or property damage. The following types of insurance are recommended:

1. General liability

A broad term meaning liability insurance, other than automobile liability or employers' liability written to cover professional and commercial risks.

2. Employers' liability

Provides protection for the employer for those injuries arising out of and in the course of employment which were not covered under workers' compensation.

3. Workers' Compensation

Provides both medical coverage and compensation for lost wages to an employee for a work related injury.

4. Employee dishonesty

Provides coverage against loss as a result of acts of employee dishonesty. This type of coverage is not common, may be difficult to obtain and costly, if available.

5. Automobile insurance

Coverage recommended in the event that employer has vehicle and requires employees to transport residents.

II. Providers as vendors

Instead of hiring employees, families may elect to arrange for in home support services by contracting with a variety of Providers to provide the service. Under this arrangement, the Provider is a vendor, an independent contractor providing a service pursuant to a contract with either the family or the individual resident. Typically, the Provider is an agency with employees that come to the residence and provide the services. The services may be paid through a variety of sources, including the resident's Medicaid waiver, County Board of Developmental Disability funds, other available public funds, or family.

The Provider agency is responsible for providing the services as contracted. This includes days, hours, number of staff, etc. If an individual staff calls off or doesn't show up as scheduled, the Provider agency is responsible for providing alternate arrangements. The individual resident or his family may not demand a specific staff provide the service, although many Provider agencies may accommodate such a request if feasible. Most contracts for in home support services allow termination for any reason or no reason.

The Provider agency is expected to provide qualified staff that can provide the contracted services. Although the landlord still has a duty to provide a safe environment for anyone living in or visiting the home, liability for staff acts or failure to act shifts to the Provider agency, as the employer.

It may be more cost effective for a group of residents sharing a home to use the same Provider agency. However, there is no reason that a resident could not hire a different Provider, either as an employer-employee or a Provider agency.

III. Family members as providers

Family members may also elect to provide support services directly to residents sharing a home. Although this arrangement may require the least amount of financial resources, it is much more demanding on family time and energy. Furthermore, it may be a temporary solution at best, as parents age and siblings experience family and job demands in their own lives.

If families of several residents decide to share the delivery of services to all of the residents, they are

subject to the same liability risks as discussed in Section 0.B. above, where the family acts as the employer.

Legal Relationships among Residents

A group of residents sharing living space have a legal duty to comply with the requirements of the lease. This duty is owed to the landlord. Absent any other rules or agreements, the residents do not have any legal duty toward each other. Relationships as we all know are complicated. Where two or more persons share living space, it is best to have a set of rules that address as many potential areas of conflict as one can imagine. Well-written rules that have been accepted in writing by participating families may be legally enforceable, just like a contract.

Families that have formed an LLC may wish to create a separate agreement that addresses the operation of the home and is agreed to by all of the members. Even where there is no LLC, (as where one family owns the property and rents to others), families whose children are sharing a home may wish to form an unincorporated association or a consortium for the purpose of managing the home and having a process that addresses conflict.

The agreement may include as much detail as the families wish. At the very least, it should address duties and obligations of the participating families, and address major areas of potential conflict. It should also provide a method for amending the agreement in the future should circumstances change. The following is a list of key areas that should be considered and adopted either in an agreement, or as separate policies that are referenced in the agreement.

I. Decision-making process

The agreement should identify how decisions will be made. Must decisions be unanimous, majority rule or some other percentage? Will the group meet regularly or as needed? Can decisions be made via email, phone or some other way?

The families may decide to designate officers to handle specific duties, i.e., treasurer to manage an

operating account, secretary to take minutes of meetings and record decisions, president to enter into agreements with providers, etc.

II. Admission/eviction criteria

Families may develop criteria and protocol for determining new admissions in the event of a vacancy, as well as criteria for eviction of a resident. Since admissions and evictions have a major impact on the house, this may be one area where decisions are based on unanimous consent or some percentage higher than majority.

Families may not either deny admission or evict an individual based on illegal discriminatory reasons. Both the Fair Housing Amendment Act of 1988 and the Americans with Disabilities Act prohibit discrimination based on one's disability. There are limited exceptions, such as an individual who poses a direct threat to the health or safety of other individuals or their property.

Appendix IIE provides a sample policy that addresses both voluntary and involuntary departure of a member.

III. Member contributions

The agreement should describe the obligations if family members are required to contribute either financially or in labor.

IV. House rules

House rules help minimize conflict. House rules can be anything that the families agree to; however, as with admission/eviction criteria, may not be discriminatory.

V. Dispute resolution

Families should develop a formal dispute resolution process that will be followed in the event of conflicts. Appendix IIF is an example of a dispute resolution process that may be used where an outside agency provider agrees to act as a mediator.

VI. Succession plan

Families may want to include a policy that addresses successor family members in the event that the original family member moves or dies and the resident continues to live in the house.

VII. Sample Agreement

Appendix IIG is an agreement that illustrates the management and decision-making process of a multi-family consortium where the consortium group is contracting for services with an agency Provider and is leasing the house from one owner. There is no one agreement that fits every situation. Families are advised to develop their agreement based on their own unique living arrangements, concerns and priorities.

Chapter 6

Finding Housemates

Finding potential housemates for your child, and compatible collaborative partner families, can be one of the most challenging aspects of developing a home. Currently there is no easy system for families interested in community-based independent living to connect with each other or to quickly determine compatibility.

Getting this part right is crucial to the success of your home. While changing at a later date is always possible, it will be emotionally and possibly financially difficult. During the IILP process, we held discussions with many families who have been successful, as well as those who have not been happy with the outcomes of their efforts to find partners. This chapter presents a framework you may use to conduct your own search in the hopes that it might increase the probability of building a solid foundation on which to make this important decision.

“Is Anybody Out There?”

Connecting to Families with a Common Vision

For many parents, their vision of long-term independent living for their child with disabilities includes at least one or more housemates. This can be because of the financial burdens of maintaining a separate household and/or because they want to avoid the social isolation that often comes with living alone.

Finding the right partner families can be one of the most challenging and time consuming aspects of developing a home for your child—and one of the most critically important for success. Remember that if all goes well, your child will be living with these housemates for perhaps the rest of his life, and you will be collaborating with the family to make the house the best home possible for your child.

Unfortunately, at this time, there is no central place where people who are interested in creating family-directed housing can list their names and requirements. Therefore the only way to find those with similar objectives is by networking. This means telling anyone you think might be interested or might know of someone else who is searching for a good housing solution for a person with disabilities.

Possible sources of finding other families include

- County Board of Developmental Disabilities
- Churches and other religious organizations
- Family recreation activities
- Your place of employment
- Disability related organizations (e.g., Upside of Downs, United Cerebral Palsy, Fragile X Association, other non-profits, etc.)
- High schools for those about to age out of the school system
- Social networking sites (use caution regarding information you share this way)

Once you find someone who might be interested, you will have to take the initiative to contact them. From that discussion, you will know whether to follow up with more meetings. This process can be very lengthy and discouraging. Some families have been working on this step for 6 or more years. While you will have to make compromises in some things, you must make sure that your core set of values and requirements are met. But the families from the IILP have proven that with persistence, it is possible to make this work

Assessing Housemate Compatibility

Getting to know the residents better

If your child will be sharing a house with one or more others, it is important to ensure a good match among housemates. This does not necessarily mean that they need to do the same things, but in general, both housemates and families must be comfortable with choices the others will make. Everyone needs to be aware of those areas where basic traits differ substantially, and discuss how they will cope to make the home comfortable for all.

Some question to think about

- What is unique to his or her life experience?
- Does he or she currently work?
What type, where and when?
- What is meaningful to him or her?
- What makes him or her "come alive"?
- What creates peace, connection, and engagement for the individual?
- What creates distress or disconnection?
- What would the individual love to be doing with his or her life?
- What relationships are important, satisfying?
- What contributes to his or her sense of safety and security?

“Listen to Me” Booklet

Another good tool for helping you and your housemates think about important characteristics or each person is the booklet “Listen To Me.” It is part of a program developed by professionals at USARC/PACE to help persons with disabilities create meaningful life style plans and can be found online at <http://www.allenshea.com/listentome.html>

Life Style Preferences

Using the continuum below is a good starting place to communicate about the preferences and traits of potential housemates in relation to one another.

Lesson Learned
The IILP families found that it is reasonable to identify workable solutions even for roommates on opposite ends of the continuum if you recognize the issues and deal with them up front.

Lifestyle Preferences	
goes with the flow -----	depends on routine
up & moving early -----	night owl/sleeps in
likes noise/commotion -----	like calm/quiet
neat & clean -----	“messy”/ a slob
on the go/out seeing people -----	homebody

Assessing Family Compatibility

Once you have found someone who might “click” with your family, it is important to get to know them as quickly as possible. Remember that the housemates AND the parents must be compatible to have a successful house. Often only one or the other can work together, and that leads to a high probability of major problems in a home.

The following list of basic “starter” questions can be used to guide an early conversation with the family of a potential housemate.

General Questions

- What is your ideal housing solution for your son or daughter?
- Do you expect your child would do best with one or more housemates?
- Would any/all potential housemates be a person with or without a disability?
- Do you already have someone else in mind as a possible housemate?

Location & Type of Housing

- Do you have a strong preference of city?
- Does the home need to have special accessibility accommodations?
- Do you prefer to rent or own?
- Do you prefer an apartment, condo, or house?
- Is it important to be on a bus line?
- How close to shopping areas do you want to be?

Helping Them Get to Know Your Child:

- Who is important in your child’s life, or part of the circle of support?
- What is great about your child?
- What does your child like about himself or herself?
- What good things do other people say that they appreciate about your child?

Lesson Learned:

Be honest with other families about what is important to you. Many families wanted so much to find partners that they said what they thought the other family wanted to hear. After investing much time and effort, eventually it became clear that these collaborations would not work and all had to start over after having wasted a lot of time and energy.

Family Compatibility: Looking Deeper

You’ve found potential partners and decided to pursue getting to know them better so you can both make a decision about the possibility of a future collaboration. Now you must engage in more detailed and frequent discussion.

It is very important that families be honest with each other in what is important and necessary for them and their child. In this process, you will all be sharing some information which is personal and often hard to discuss with those outside your immediate circle. All people involved in this process need to commit to keeping this information confidential and only sharing it with specific permission to do so.

Below are some questions which might help jumpstart the getting-to-know-you-well process.

Family Background/Routines

- What are your reasons for moving forward now in establishing a home? How soon would you be ready to move if things can be put in place?
- What is your general family situation (work, community involvement, care for other children or aging parents)? Do you have the time to devote to this effort? Are there other family members who will help with this project?

- What activities does your family enjoy together in leisure time?
- What is a typical weekday/weekend like for your family?
- What are your thoughts on food and nutrition? Does your family eat together most nights or does each do their own thing? Does your family eat out often or do you cook at home?
- Which holidays do you celebrate and how? Is it important to you to continue your family traditions in the new home or would you envision your child returning to your house for these?

Your Family's Values

- How important is work to you and your child? Where is your child now during the day? What would happen if that situation changed (e.g. laid off, change of program, etc.)
- How important is recreation? What are your ideas for how this might be incorporated into the new home?
- What are the important factors for happiness for your child?
- Are religious services important to your child? If so, what type and where?
- Can the residents have beer, wine or other alcohol in the house?
- What are the rules about smoking for the residents? Staff? Visitors?

Supervision/Control

- Do you expect your loved one to come home on weekdays/ weekend/ holidays? Always? Sometimes? Never?
- Would you drop your child off in a public place without supervision?

- Can your child remain in the home alone without supervision?
- Can the residents have visitors? What about overnight visitors? What about girlfriends or boyfriends?
- How do you discipline your child if needed? For what types of things do you need to step in? Are you authoritative or permissive?
- Are you willing to transfer authority to other adults (staff and parents)?
- What role do you expect staff to play in your child's household? How do you see your role with staff?

Personal

- How do you handle conflict and stress?
- Is your style more collaborative or confrontational?
- What are your worst fears about this situation?

Family Compatibility Essentials

Collective wisdom from the pilot project families

- Shared Vision
- Willing to work for the good of ALL the residents, not only your own child
- Agreement on what is important and what is not
- Flexibility

Chapter 7

“House Rules”

Deciding how the house will operate is an ongoing process with changes being made continually as your experiences evolve. It is time consuming and often difficult to figure out rules, roles, and responsibilities for both the residents and the supporters of the home. But doing it right at the beginning will avoid problems later on. Respectful honesty is crucial throughout this process!

Answer these questions frankly:

- **What must exist in this future home?**
- **What can never exist in this future home?**

The Process of Making “House Rules”

A healthy home begins with mutual understanding among the residents and families of what is important to each about how the home will operate. Having a stable set of rules and guidelines gives everyone a sense of safety and ownership.

It is hard to know in the beginning of the process exactly what must be a “rule” (i.e., it is absolute and everyone agrees it is too important to be broken) versus a “guideline” (i.e., everyone agrees that they

would like things to operate this way, but they can be flexible and it may change in the future).

What Are Your “Deal Breakers?”

You will need to identify your own “non-negotiables,” i.e., those things about which you believe you have no flexibility in how the house will operate. You should disclose them to potential partners, and discuss the reasons these items are so important to you. The other family will have their own requirements to share. Understanding each other’s needs is the first crucial step to deciding if you want to further explore a long term relationship. Sometimes it makes sense to just agree you will not find common ground and move on to try to find other housemates.

As you discuss issues that might be negotiable, identify how you want them to work. Put them on a list of “Things We Won’t Change Unless We Discuss It” and revisit them frequently. These will be important components of future housemate discussions as the home becomes a reality.

LESSON LEARNED

Some of the items families thought were non-negotiable became areas of reasonable compromise as solutions were found that allowed everyone to meet most of their goals.

Topics for Discussion

The following are examples of questions that can help you explore many issues that families and housemates may encounter. You will not have rules about all these issues, but the questions will help you think through what your home will need and will hopefully lead to better understanding of what is important to each person. And you don’t have to decide everything at the beginning. Rules can always be changed later **if** everyone agrees.

Remember: NOW is the time to be HONEST, to avoid conflicts farther down the road. Look

everywhere for wisdom and help. Talk to professionals and experienced families. They will give you valuable advice, but only you can decide what works for your family.

Oversight and Control

House Rules:

- Will we have house rules (vs. guidelines)?
- How will overall rules be decided?
- Are there any religious preferences which will guide the way the household operates?
- Should the “rules” be only for shared spaces (family room, kitchen, etc.)?
- Who will enforce the rules?
 - Who will be able to discipline your son/daughter if needed?
- How often do you expect to visit?

Decision-Making:

- Will there be regular house meetings among residents? Parents? Both?
- By whom/how will day-to-day decisions be made (what to wear, where to go, what to eat, etc.)
- What kinds of decisions do you expect to make for your son or daughter?
- What kind of decisions do you expect your son or daughter to make for him/herself?
- May residents leave the house and go into the community when/if they choose to do so?

Problem Solving:

- When you became unhappy about something in the house, what will you do?
- What are some situations where you believe your presence would be needed in the house?
- If you became unhappy with a staff member within the house, what would be your first step? What resolution would you like to see come from such a situation?
- How will conflicts be resolved? Which would you want to be involved in? Which can the housemates resolve without you?
- How will behavioral issues, if any, be handled?
- Will you expect housemates to report to parents if something is wrong, or if house rules are not followed?

Sharing Information:

- What aspects of life with your child are you willing to share with other housemates? Staff?
- What types of things will you keep confidential?
- What might be some guidelines?

Staff: (See separate section with more info on staffing)

- Will we have outside staff?
- Who directs shared staff?
- Do you prefer male or female staff?
- Do you prefer an agency provider or to directly hire independent providers?
- Who will do the paperwork associated with staff (for waiver paid options and employer requirements)

Food and Eating:

- Do any diet, health, or preference restrictions exist?
- What kinds of food does each resident like?
- When/how often will shopping be done? By whom?
- Who will decide what food to buy?
 - Which brands?
 - Convenience foods or buy fresh?
 - Who will pay for it?
 - How will the costs be managed?
 - Can they eat all of it or should it be stored separately?
- Will the group eat all/some meals together?
 - Who will plan the menus?
 - Who will do the cooking?
 - Who will do the cleanup?
- What time will they usually have meals: breakfast, lunch, dinner? Weekdays, weekends? Holidays? No work days?
- Are snacks OK? Where can they be eaten?
- Can there be alcoholic beverages?
 - How often can they go out to eat? How will this be paid for?

Housekeeping:

- What tasks will be done?
- What are the residents’ skills/ preferences?
- Who will do which tasks?
- How will residents be kept accountable to completing their tasks?

- How will you handle outdoor space on the property, if any?
- Would you consider hiring a cleaning service for the household? Who will pay for this?

Money:

- Who pays for what (everything needs to be discussed)?
- Who has access to money? How much? Where is it kept?
- Is there a credit or debit card for the house?
- How are accounts kept? Who keeps them?
- Can individuals borrow money from each other?
- Is there a household budget? Who is responsible?

Health and Safety

- What safety rules will you have? How will they be communicated? Who is responsible for being sure they are met?
- Will there be fire drills?
- Will smoking be permitted in the house?
 - Can the staff smoke?
 - If so, where?

Medications:

- Can medications be stored in the shared spaces (e.g. kitchen)?
- If your family member gets sick, who would take him/her to the doctor? How will you be notified?
- Who will pick up prescriptions?
- Who will be sure your family member will get his/her medications every day? How can you verify they are taken as prescribed?

Personal Space:

- Does each person need their own bedroom? Bathroom?
- Can individuals use each other's belongings?
- Will housemates share a telephone? Individual lines? Cell phones?
- Who will play the messages on an answering machine? What is the process for this?
- Who will get/open/distribute the mail?
- Will there be a TV/DVD player? Who decides what will be watched?

- Is too much noise a problem for any resident? How should this be managed?
- How will each resident communicate when he or she doesn't want to be bothered by others?
- What are your feelings about a camera by which areas of the house can be monitored by you or others you authorize?

Location:

- What communities would be acceptable to you for your son or daughter's home? Unacceptable?
- What are the crucial characteristics for about location of the home (e.g., access to community recreation, bus lines, safety issues, etc.)?
- Should they live within walking distance of schools, shopping, restaurants?

People Other Than Staff:

- How will you handle social interaction with people outside home?
- Who decides who can visit?
 - Are non-family visitors allowed?
 - What about boy/girlfriends? Any special rules for these relationships?
- Who decides when visitors should leave?
 - Are overnight visits allowed? If yes, under what circumstances?
- Do visitors have to abide by "House Rules"?
- What will you do if there are behavioral issues with visitors?
- Are the rules different because of relationship (family, parent?)?
- Can the residents have parties?
- Can visitors eat the household's food (within reason)?
- Can visitors smoke?
- Can visitors take residents out?
 - Do they need prior permission?
 - From whom?
 - By when?

Planned Activities:

- What are your thoughts on planned activities?
- What will be the mix between encouraging and/or requiring individual/house involvement?
- Are you interested in any of the following activities? What role would families play in making them happen?

- House nights – i.e. pizza and movie
- Family nights (family in)
- Family nights – home to family
- Games/cards/puzzles: individual or group
- Trips out (restaurants, movie, mini-golf, bowling, shopping)
- Community service
- Individual down time

Scenarios for Parent Discussion

Communication about everything you can think of that might go on in your child's house will help all families understand each other better, and will increase the odds of creating a successful new home for everyone. As part of the IILP project, a group of professionals identified some scenarios that might present problems in the new household.

They are listed below, and will provide for some good discussions among potential housemate families. There is no right or wrong answer, but everyone will have a unique and valuable perspective. Remember, being honest is the only way you will really know if the families you are considering as partners will ultimately work well together. But also acknowledge that the other family has a position which should be equally respected.

Scenario I

Your child calls you upset that they have already spent all of their money for the week; however, everyone else in the house is going to dinner and a movie. They are upset that they cannot go and will have to stay home alone. How would you react in this situation?

Scenario II

Let's say you are in the house visiting your child one day. You see another house member partake in an activity that upsets you. How would you handle this situation?

Scenario III

While on a visit home your child explains some situations where their roommates are engaging in questionable activities. What would you do?

Scenario IV

You stop by the house one day and find that everything is a mess. The house appears not to have been cleaned in a long time and there seem to be very few groceries. How would you handle this situation?

Scenario V

What do you feel needs to happen in order to get ready for move-in when the time comes? How urgent do you feel this is?

Scenario VI

You are working out on a grocery budget. You want healthy fresh ingredients and the other family prefers the ease of mainly frozen prepared items, which aren't as healthy and are much more expensive. How will you decide?

Scenario VII

A house member is stealing. How should the situation be approached? What about if a staff member is stealing?

Scenario VIII

The staff you have selected is carrying out activities you do not agree with or is not doing what you believe he/she has been told to do. How would you handle it? (Provide example if necessary.)

Chapter 8

What Support Do You Need

Assessments of support needs must be completed thoroughly and honestly. The process is time-consuming and will take many hours if approached properly. As much as possible, it is best to include all primary caregivers, as well as your son or daughter. Be prepared for opinions which often differ widely!

Lessons Learned

The up-front investments of time and effort are the key to finding and implementing sustainable and cost-effective support options to match your child's long-term needs.

2. There is no single "Right Way"

Options for Needs Assessment

If you are planning for community-based living for your child, you have already decided that you want to invest in a solution that may be different than the one usually provided by organizations that manage typical group homes in your area. Careful and honest assessment of the specific needs of your child will allow you to consider different types of resources to meet his or her unique needs. To minimize cost, you will likely want to include only necessary supports, and to do so in the most efficient and sustainable manner. You may have hundreds of options of how to provide the right assistance to your child, while encouraging the highest possible level of independence.

Use Current Routines to Help Assess Support Needs

Answering the question "With what does my child need assistance?" is likely to result in mixed accuracy if you do not have a systematic approach.

A very practical way to begin to identify your child's core needs for the best quality of life is to consider his or her current daily routines.

What Can Routines Tell Us?

An individual's routines help us to identify:

- **what is IMPORTANT to that person**
 - **what kind of supports or training may be needed**
 - **what the individual may use for comfort or motivation (certain activities, foods, music, TV programs, etc.)**
 - **what activities or items must be either included or avoided in the home**
-

The simple act of writing down a week’s worth of each time you provide support to your child from waking up until bedtime, will give you valuable insight into what your loved one will need in his/her new home. This information will be important both in your planning and in communicating with new people who become a part of your child’s life, including housemates, other parents, and support staff. You will need to identify ways to meet all these needs in the new home.

How to Record Your Current Routines

You will need to list every time you interact with your child, e.g., if you have to call them 3 times before they get out of bed in the morning or you go in and pull off the covers to get them up, you need to list each time and action rather than “wake them up in the morning.”

You should also identify the level of support provided, i.e.

1. You remind, and then they go away and do it independently.
2. You remind, and you have to stay and continue to guide verbally.
3. You have to help them do it
4. You have to do it for them.

MORNING-Weekdays: Write down each time you interact with your son or daughter’s routine on a typical weekday from the time he or she gets up until he or she leaves home.

AFTERNOON/EVENING-weekdays: Write down each time you interact with the routine on a typical weekday from the time your son or daughter gets home until he or she goes to bed. Add anything that needs to be done during the night.

WEEKEND-each day: Write down each time you interact with your child’s routine on a typical weekend day from the time he or she gets up until he or she goes to bed. Focus on the differences between a weekday and a weekend (such as time to get up, pace, etc.)

SICK DAYS/BAD WEATHER/HOLIDAYS: Write down each time you interact with your son or daughter’s routine on a typical day from the time he or she gets up until he or she goes to bed. Focus on the differences between a regular day and a “special” day.

Gather the Best Information

As you record your child’s daily and weekly routines, remember to describe activities, as well as your support activities, in time order and in as much detail as possible.

Your descriptions should be very specific and should reflect what is important to your child in terms of:

- Rhythm
- Pace
- Things to do
- Things to have
- Relationships
- Rituals

Use the detail from the daily support you currently provide to figure out exactly what needs to be supported in the new house.

Lesson Learned:

Parents assumed that because they have done it all daily for decades, they could easily list all the support they provided for their child. They discovered that actually writing the list of EVERY interaction with their child identified numerous requirements that would otherwise have been missed because parents do them without thinking of them as support.

Other Assessment Options

The following assessment processes have also been used successfully by families in the past.

Step by Step for each area of supports

- 1) Determine current levels of functioning in a variety of areas
- 2) Identify specific activities in which your child will likely need support
- 3) Predict what level he or she might eventually achieve with assistance
- 4) Put together a project plan to help make that happen with the right:
 - a. Independent Living training
 - b. Technology
 - c. Personal caregivers
- 5) Identify specific areas for which your child will likely need people to support him. Can other housemates provide support?
- 6) Define skills you (parents, caregivers) will need
- 7) Estimate the cost of each type of assistance.
- 8) Validate that your child and all potential housemates have high likelihood of predicted success with this model rather than the traditional 24/7 support model (*better to know sooner than later if that is not the case*).

Barrier/Solution Approach

The tool below treats the task of determining support needs as a process of 1) identifying barriers or

challenges in activities of daily living, then 2) finding and evaluating solutions based on whether they are workable and affordable. If you work well with problem-solving tasks, this tool may be a good fit for you.

Design the Environment Approach

The overall goal of this tool is to identify and/or design a total environment that meets the person’s needs, as opposed to fitting a person into a particular environment. It addresses both the *needs* and *wants* of the individual.

Identify NEEDS

Identification of needs requires answering practical questions, such as:

- How much supervision is needed to maintain safety?
- What kinds of daily rhythm and routine does the person need?
- What kind of safety issues need to be attended to and how?
- What exceptional medical and behavioral supports are needed (if any)?
- What skills does the person need to acquire to attain better functioning?

Practical areas that you will assess include: (from Supports Intensity Scale)

- Home living activities
- Community living activities
- Lifelong learning activities
- Employment activities
- Health and safety activities
- Social activities

Identify WANTS:

Identification of *wants* addresses the individual’s personally valued outcomes. Person-centered tools can shed light on the kind of environment that would provide best quality of life for your child as he or she grows in independence.

Put It All Together:

Consider the wants and needs that you have identified to answer this final question:

“What does the environment look like that addresses the issues noted above?”

Unsupervised Time and Daily Living Skills Assessment Tools

Two of the very best tools the IILP project manager found for determining possible areas of required support have been developed by Welcome House, a provider of residential services and project partner (www.welcomehouseinc.org). They have graciously allowed us to include them and can be found in Appendix III of this manual.

The “**Unsupervised Time Assessment**” identifies daily living activities at home and in the community for you to determine your child’s current ability to do them without supervision; it is an excellent guide. It is helpful both for understanding what areas may currently be risky, and for helping you focus on areas in which you may reduce risk through training, technology or staff.

The “**Daily Living Skills Assessment**” is similar in nature, but identifies specific living skills that must be done somehow in a household. You assign a level of performance to each one. For those you identify as not being done entirely independently, you can then identify how to best provide support.

Summary

Most families will use a combination of the above processes. Assessment and determining what supports work best is an ongoing activity, lasting even after your child moves in. You cannot envision every need that will come up once your child moves, but your process should be able to deal with new requirements.

Focus on Safety – Emergency Prevention and Response

You have worked your whole life to keep your child safe and secure. You'll need even greater awareness and creativity as you plan for safety in the new home. Focus on your child's specific "risk factors" – activities and situations that could most likely lead to emergencies and potential harm to people or property. You will then need to develop and implement plans to prevent and/or respond to emergency situations.

Safety Assurance

Safety assurance means taking action to promote the health, safety, and satisfaction of your child and any others who share the home. The process involves

1. Assessing each individual's risk factors
2. Identifying individualized risk management strategies
3. Implementing, practicing and modifying these strategies as necessary

Person-Centered In-home "Risk Assessment"

This tool was adapted from the Risk Assessment documents presented at the Quality Conference of the Oregon Quality Assurance Study.

Goals of Risk Assessment:

- Identify situations that could most likely become an emergency.
- Promote increased level of independence.
- Reduce individual's vulnerability.

Categories of Emergency Risk:

Which factors are most likely to lead to an emergency? Use the checklist below to identify areas of particular concern.

Health

- Safe use of medications
- Vulnerable medical conditions

Behavioral

- Physical danger to self or others

Personal Safety

- Lack of self-protective mechanisms
- Limited access to informal supports
- Vulnerability to natural or community disasters
- Home and environmental safety

Risk Management

The goal of your risk management system is to improve the environment and quality of life for your child and those around him or her.

Steps of risk management:

1. Identify and document potential risks: Consider the categories listed above and others unique to your child.
2. Develop plans to prevent & respond
3. Ongoing monitoring: Plan to keep track of maintenance and safety practice
4. Training: Decide how you will communicate safety practices to residents and staff

Fire Safety

Fire is a significant risk to any home. Fire may be an even greater risk in a home where individuals are learning to use the kitchen and other appliances more independently.

Risk of injury and damage can be greatly reduced by wise use of fire prevention and response systems. These can be incorporated into the new home, and may include:

- Smoke detectors in each room*
 - Sprinkler/fire suppression systems*
 - Fire escape routes and routines that housemates plan and regularly practice
- *More information about these items is included in the chapter "Select Appropriate Technology Supports".*

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Chapter 9

Training for Independence

Successful independent living requires individualized training. The goal is for your child to learn specific and individually tailored skills that will reduce the amount of support he will need in his new home. This is crucial if the new home includes limited or no staff. Training also improves self-esteem and satisfaction for your child.

You have already identified the areas of support that are needed for your child. (If not, see Chapter 8.) You will need to prioritize which areas to work on first since you probably cannot do them all at once. You may also decide that someone other than the parent will have more successful outcomes; this is nearly universal due to the life-long relationships between parent and child.

In the IILP, families were able to take advantage of qualified volunteer teachers as well as interns working with local non-profit organizations. The students enjoyed the learning experiences and made significant progress toward independent living. Because the training began before specific houses or roommates had been identified, there was some concern that the students would not be able to

transfer the learning to their new situation. But in general, this issue was insignificant.

As you identify appropriate training for your child, you will first need to identify *target skills* as well as *training tools* that will be effective in promoting the highest level of independence.

Prioritizing Target Skills

Begin by identifying what daily activities you would most like your child to be able to do without in-person assistance. Which will make the biggest difference in the levels of support needed in the new house? What are reasonable expectations for success in this area?

Possible Target Skill Areas

- Meal prep
- Cleaning
- Laundry
- Personal self-care
- Money management
- Communication/community interaction
- Medication/ medical management
- Bus or other independent transportation

The following questions may help guide your selection of target skills:

- What tasks/activities is your child already comfortable doing independently?
- What independent living skills is your son or daughter interested in or eager to learn?
- What do you do for your child now that he or she might be able to do independently later?
- What tasks do you believe will always require assistance?
- Are there any particular skills you do not want your child to learn?
- Which skills would be the most transferable to multiple situations and needs?
- What skills might you be able to continue practicing at home after initial training?
- What level of independence might be expected 3 years from now?

Try to create specific targets that are reachable, with measurable milestones, rather than general statements. For example, make a goal to “learn to cook scrambled eggs and sausage”, rather than to generally ‘learn cooking.’”

Choosing Effective Training Tools

Independent living training comes in many forms. The most effective learning will result from presenting target skills in your child’s real environment, in a way suitable to his or her learning style. You know how your child best learns since you have been a primary teacher for him/her already. Consider the following as you decide how best to move forward in this important step.

Personal Characteristics

- What are your child’s interests or hobbies?
- What situations or circumstances make him or her uncomfortable?
- In what circumstances might he or she become frustrated?
- How does your son or daughter show frustration?
- What is the best way for a trainer to handle your child/s frustration?
- Are there allergies or other factors an outside trainer might need to know about?

Learning Characteristics

- What is his/her developmental age?
- What is his/her attention span?
- What time(s) of day is(are) attention and attitude best for learning?
- What is your adult child’s learning style?
- How does he/she communicate best?
- Is s/he able to read?
- What kind of teaching or prompting methods have been or might be effective?
 - Note cards with words or pictures?
 - Auditory recordings? – songs or chants? – spoken step-by-step instructions?
 - Video recordings of tasks or procedures?

Some methods that might be useful

- Detailed task analysis. This means breaking down each task into its smallest component

parts, and teaching one at a time, if necessary. It can increase the learner’s sense of success, improve motivation and decrease confusion and frustration.

- Create checklists (daily activities, etc.) and monitor their usage
- Make detailed calendars (paper or electronic). Can be shared for entire household or individual—or both.
- Consider using signs and labels for objects and functions. Put them on cabinets, appliances, etc.
- Make reminder cards for your child to carry with them to help remember what they are to do
- Simple technology can be very valuable in the training process. It can easily prompt your child at each step of an activity, waiting until he has accomplished the prior step before the next prompt. (As an example, see the technology section description of how to use PowerPoint for this.)
- Simple videos, especially ones with your child as the star, can be instructional and motivational. They can be used for such things as how/when to open the door to strangers or how to load a dishwasher. They are easy to upload from flip cameras or smart phones.

Start Right Now!

It is likely that you have already begun fostering independence for your child in your current home. It is very important to think about how these skills will transfer to your child’s own home, and to begin now to incorporate new skills and methods into your lives. These skills will benefit your child in the new home and community, and will make the transition easier for everyone. Work toward creating a present environment that provides as many of the same support structures, routines and reminders as you can that will be incorporated into the new home.

More Detailed Training Areas to Consider

SAFETY

Safety training includes skills that are both

- Responsive (*how to react to an emergency*) and
- Preventive (*how to avoid danger*).

In addition, safety training can ensure that your child identifies safety concerns in the home or community and reports them as appropriate.

Identified below are a number of areas that should be covered with each individual and household. The exact nature of the necessary training will differ depending on the ability levels and aids that will benefit a specific person. But be sure that someone is assigned responsibility for each item.

Emergency Response

- Fire
 - Calling for help – 911
 - Escape routines
- Severe weather
 - Safety routines
 - Contacting help
- Electricity
 - Dealing with power outages
 - Using appliances safely
- Specific protocols for emergency situations (e.g., someone is injured or the toilet overflows)
 - What to do
 - Where to go
 - Who to call (when is 911 appropriate)

Safety at Home

- Doors
 - Entry – unlocking for self
 - Leaving/closing – locking
 - Answering – whom to let in
- Windows
 - Keeping closed when away

- Closing blinds for privacy
- Kitchen
 - Cleaning food preparation areas
 - Washing hands before cooking
 - Safely operating appliances
 - Knives/cutting
 - Discarding old or expired food items
- Phone
 - How/when to answer (if applicable)
 - How to dial & speak into land line phone
 - How to use a cell phone
 - How to use a phonebook or internet search
 - How to deal with strangers who call; what information to avoid providing
- Medications
 - Safe storage
 - Taking only YOUR medicines
 - When/if over the counter medications (e.g., Tylenol, cold medicines, etc.) can be used
 - Taking correct dose at correct time

Safety in the Community

- Transportation
 - Using public transportation, if applicable
 - Following pedestrian laws and safety rules
 - Guidelines about riding a bicycle: when and where to go alone
 - What to do if your ride doesn't arrive
- Communication
 - Precautions/safety with unfamiliar people
 - Reporting unwanted contact from unknown person(s)
 - Who to ask for help when you are unsure of something
 - Guidelines about always carrying and using cell phone, if appropriate

HOUSEKEEPING

Meals

- Menu planning
 - Select balanced diet

- Select appropriate amounts
- Grocery shopping
 - Discard expired items
 - Identify and compare prices
 - Use ads to buy on sale
 - Make lists
 - Identify necessities vs. luxuries
 - Check out (regular and self)
 - Food storage
- Food Preparation
 - Finding and using appropriate cooking utensils
 - Simple snacks
 - Frozen meals
 - Packing lunches to take along
 - Reading & preparing recipes
 - Measurement abbreviations
 - How to measure
 - How to tell if something is done
 - Setting the table
 - Serving (and making sure everyone gets a share!)
 - Using Appliances
 - Microwave
 - Stove/oven
 - Dishwasher
 - Refrigerator/freezer
 - Special items (grill, popcorn popper, etc.)
 - Disposal (use a Batch processor for safety)

Cleaning

- General daily/weekly maintenance
 - Make bed
 - Dust
 - Sweep/Vacuum
 - Mop
 - Trash/recycling
 - Lights – keeping on/off
 - Changing light bulbs
- Kitchen
 - Wash/dry dishes
 - How to put in dishwasher
 - Put away dishes
 - Use/store pots, pans, utensils
 - Wipe counter tops

- Clean stove
- Clean refrigerator
- Supplies (cleaners, towels)
- Bathroom
 - Clean toilet
 - Clean sink
 - Clean mirror
 - Clean shower/bath
 - Sweep/scrub floors
 - Wash/replace towels, cloths
- Laundry
 - Sort
 - Launder items appropriately
 - Wash/dry
 - Iron
 - Fold/put away

SOCIAL NEEDS

Communication

- Phone use/manners
- Mail – distribute/send
- “Get Along” skills for housemates
 - What is confidential and stays in the house
- Computer/e-mail and Skype
- House communication system, e.g. a large board or frequent discussions
 - Consider what parents, caregivers and housemates each need

Having a bad day

- Conflict resolution (among housemates and families)
- Handling daily disappointments
- Handling embarrassments

Shopping/Entertainment

- Where/when can housemates go alone
- Who has permission to go with them
- For each place, include
 - Cost and following a budget
 - What can they buy (snacks, etc.)
 - Requesting assistance
 - Paying: cash, credit/debit card, who pays

- At restaurants:
 - Ordering items
 - Tipping
 - Taking home leftovers

Transportation

- Using schedules for public transportation
- Requesting cab/van
 - What to do if it doesn't come
 - Who will communicate schedule changes

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Chapter 10

Technology – New Options for Independent Living

The goal of incorporating technology is to increase your child’s level of independence at home and in the community, while reducing the need for staff support. Creative and substantial use of technology can be key to a sustainable and cost-effective home. After thoroughly assessing and understanding individual support needs, you can begin exploring technologies to help find solutions.

Your Role and Readiness

How comfortable are you with the concept of using technology in a support role in your child’s home? How knowledgeable are you in this area? Do you have someone else in your child’s circle of support that can help if you need it?

One of the most difficult issues for many parents in the IILP project was that while they conceptually believed technology could help and wanted to use it, they really had no idea what specific things might be available or how to use them. And while most of them used a computer for some tasks, often their knowledge was limited to how to use email or Microsoft Word.

In addition, there were no outside resources found throughout the project that identified either specific helpful items or a process by which to evaluate various technologies for specific needs. Research and testing was done by families, their contacts, and some professionals. This manual identifies those items tested throughout the project, as well as provides information about resources.

Most parents of residents in homes established during the project believe that the technology is essential to the success of the homes, from both a cost perspective and the independence of their children. But it took many months, with help from a number of people, to arrive at that point. So you should not be discouraged if you are not comfortable or knowledgeable about this topic when you begin.

The most important requirement is to have an open mind, be willing to seek assistance, and to test various solutions to see if they work for your child. You know your child better than any gadget company or program developer ever could. Work together to choose the best options through trial and modification. It is often time consuming, but the results in reduced cost and improved self-esteem for your child can be enormous.

As you read this chapter, you will likely have strong views that certain types of assistance must always be delivered by a person, and that other roles might be filled by applied technology. You may be surprised at the breadth of use of the technology!

Starting Point: Evaluate Your Current Level of Technology Use

Use the following questions to assess your family’s current relationship to common technologies. This will give you a general idea of what skills you have now, as well as those you might need to acquire if you want to broaden your range of technological options.

- What activities do you typically do on a computer? (banking, e-mail, shopping, etc.)

- Is your computer Windows based? If not, what is the OS (operating system)? *This will be necessary to know when planning for computer-based supports.*
- Do you or your child have and/or use Word? Excel? PowerPoint? Skype? Calendar programs? iPod? iPad? *Rate your familiarity with each program.*
- Does your son or daughter use a land line phone? Cell phone? *If so, how comfortable is he or she with making calls? Receiving calls? Other features on their phone?*
- Describe your son or daughter's computer use – level of comfort and types of activities.
- Does your son or daughter take medications daily? *If so, does he or she use a device to help with reminders? Compliance?*
- Does your son or daughter use any other technology to help them, e.g., communication devices, prompters, etc.?

Guidelines for Selecting Technological Supports

Obviously, not all needs can be met through technology. It is not our goal to eliminate all human caregiving. However, some types of assistance typically offered by in-person caregivers may be provided by simple devices, strategies, or programs applied to your child's activities both at home and in the community.

The following questions can help guide you as you begin the process of selecting the most appropriate and effective solutions. Don't be alarmed if you do not know the answers right now; just be willing to explore.

- *Which support needs do I think might be met by technology rather than by in-person assistance? Which am I willing to try?*

- *Is the technology I am considering widely available? Am I or do I know someone who is familiar with it?*
- *Can it be used to meet more than one need, or be used for more than one person in the house?*
- *Are there ways this technology can be customized to meet specific need(s)? How would I get this done? How expensive would it be?*

Technology Characteristics & Functions

This checklist can help you think about each option and judge its potential to be a safe, reliable, and effective solution.

- Is the item likely to endure or is it a fad? (Even if it is a fad, it might be right for you. But you need to be sure that you can replace it if it is an integral part of your support system.)
- Does the user tend to be rough on possessions or to break things easily? Are there modifications that can help with this problem (e.g., strong outer cases or a way to hide the technology from curious hands)?
- Does the user lose things frequently? Is there a way to minimize this? Can I buy insurance? Technology is often expensive and cost of replacement must be factored into your estimates. This is especially important in this day of smaller and smaller smart phones and netbooks that have a wealth of helpful features.
- What is the user's level of manual dexterity/visual acuity? Are there adaptive devices that can work with the item you are considering?
- What is the user's level of ability to follow directions? Can the device use audio and/or video to increase its effectiveness?
- Is the system or device you are considering resistant to accidental change or tampering? Can it be locked to prevent this?

- Will this technology be affected by power outages? If so, what backup is needed? Is it automatic? Available on request?
- Who will handle malfunctions of the item or system? Do you need professional help or can your circle of support handle it?
- What is the battery life (if applicable) and how will replacement needs be monitored? Who will actually do the replacement?
- Does the device/system require broadband access, WiFi, or land line phone service? Be sure to factor this into your cost estimates.
- If using wireless technologies, will there be potential frequency interference? If so, what solutions are available?
- In cases of remote camera monitoring, how will privacy of all residents of the house be protected?
- Are there restrictions on who can modify settings or information on this device? How will you protect access? Who will have access?
- Is the function/content easily manageable for the in-home user? Who will review that it is working? How often? Who will modify as needed?
- Who will be responsible for downloading software updates? How often?
- Who will decide when to upgrade or change out the system? Software? Hardware?

Lesson Learned

Technology is constantly changing—it improves or disappears as new things are invented or new applications become available.

Keep your eyes open for new options!

Technological Solutions

The information in this section includes a variety of high and low technical solutions that were considered in the Innovative Independent Living Project. Nothing worked for every participant, but *something* worked for everyone. There are many more items than those listed, and new ones are appearing every day. It will be up to you to think creatively about how various options might be used to enhance safety and independence in your child's home. Some areas to think about include

- Medical Needs
- Communication: Phones & Other
- Remote Monitoring
- Activities of Daily Living
- Cooking
- Community Safety
- Home Security Systems (Wireless or Wired)
- Front Door Access/Security
- Fire & Water Safety
- Computers, smart phones, iPad
- Appliances
- Prompting & calendars
- Training
- Other Technology

Please note the following as you use this list as a reference.

- ✓ This list is not exhaustive. The speed with which new things come to the market is amazing,

especially as businesses develop items for the elderly who need similar solutions. Keep your eyes open for additional things to fit your unique situation.

- ✓ We have not tested all products. Inclusion in the list does not imply firsthand experience or product endorsement. The intent is to provide a sampling of a variety of possible options to stimulate your thoughts and help you begin exploring this area.
- ✓ All items listed below were available as of May 2011. We have attempted to provide links to vendors where available. However, vendors, websites, and prices may have changed, so you should do some web searching on your own.
- ✓ Technologies tested during the pilot project worked differently for each individual, some more successfully than others. There are no guarantees that they will work in the same way for you, but you never will know until you try.
- ✓ **Don't forget to consider low-tech solutions.** Sometimes an item as simple as a white board can meet the same need as a Smartphone. Go for the most effective and affordable solution!!!

Lesson Learned:

LOW tech is always preferable to HIGH tech!
It is usually cheaper, is less likely to need expensive maintenance, and may work just as well!

TECHNOLOGY in CONTEXT

In addition to considering the function and price of technology supports, it is important to think about each solution in the context of how, where, and when it will be used. Will it be used individually or shared? At home or in the community? Monitored or managed on-site or remotely? Used daily or only occasionally?

To the greatest extent possible, technologies should be tested in the same context where they will actually be used. That will provide the most accurate information about the ease of use and effectiveness of the item in your intended situation. A trial period can reveal hidden complications that you might not have predicted.

Personalizing Technology

“High customization is often needed... Each device may need to be customized for a specific individual, and revised on a regular basis as the user’s capabilities change. This customization needs to reflect a number of factors including user priorities, functional deficits, and the environment where the activity is performed, such as home, community, school, and work.”

From: Cole, 1999, in the article “Assistive technology for cognitive rehabilitation: State of the art” - Neuropsychological Rehabilitation, 2004, Vo. 14 (1/2), pp. 5–39.

ESTIMATED PRICE RANGES

(AS OF AUGUST, 2010)

FREE - NO COST

\$ - UNDER \$100

\$\$ - \$100-\$300

\$\$\$ - \$300-\$600

\$\$\$\$ - OVER \$600

+FEE - MONTHLY MAINTENANCE OR SUBSCRIPTION

MEDICAL NEEDS

Wireless Health Monitoring

A wireless monitoring system that uploads data to a computer can allow you to remotely check in on certain aspects of your child’s health status. This is an area that is rapidly expanding and expected to be a huge industry within a few years. The following is one example of such a system.

Life Source Wireless Complete Healthy Monitoring System:

\$\$,T

Includes monitors for weight, blood pressure, and activity level, which may be monitored remotely through Wellness Connected Software. Available at www.sears.com and other stores; other individual monitors are also available for use in the home.



Medication Dispensers

There is a huge variety of aids to help with taking medications on time. They range from simple plastic pill boxes with each day of the week identified to sophisticated telemedicine options. Many are expensive and few of those tested met all the needs of our IILP participants. But because this is one of the areas most needed by our aging population and one of the most expensive to have a caregiver provide, new options are appearing frequently.

The benefits are that there are many that provide reminders (audio and some visual) at constant very specific times each day. Some even upload information about whether the medicine was removed from the holder to a computer or smart phone (monthly additional fees apply). Some are very large, and will need a large part of the counter or table top in the new house; others are very small and could easily be misplaced.

If you are considering using a medication dispenser for reminders or prompting for medications, carefully consider how your child will use the device. Take advantage of trial periods to try them out at home, to ensure that unsupervised use will be effective and safe. Also remember that if your home will have multiple residents, you must insure that only the person for whom the medications are prescribed takes them.

MedReady Automated Medication Dispenser: \$\$,T

Includes audio alert, remote monitoring system, and battery backup. Can remind up to 4 times per day. Available from various Internet sites, like Amazon.com



e-Pill: \$ to \$\$\$\$,T

Offers various medication dispensing and reminder systems (watches, locking dispensers, etc.) Available from <http://www.epill.com/ind.html> or 1-800-549-0095



Low-Tech Alternative: Keep Meds Safe & Cut Costs

*Some more costly pill dispensers include high tech features that restrict access to the correct person, but **low tech solutions can work fine.** Bluerooft Technologies of McKeesport, PA solved the problem by constructing a fiberglass box, vented to keep the pill box reminder tones audible, locked with a combination known only by the user.*

PHONES & COMMUNICATION

Telephone use may be a challenge for your child. Whether you want to increase the ease of placing outgoing calls, restrict incoming calls, or simply monitor telephone activities, a wide variety of actions steps, products and services can help you.

Controlling Incoming Calls

National Do Not Call List: FREE

It is simple and safe to register the house land line and residents' cell phone(s) on the National Do Not Call List.



“The National Do Not Call Registry gives you a choice about whether to receive telemarketing calls at home. Your registration will not expire... Telephone numbers placed on the National Do Not Call Registry will remain on it permanently due to the Do-Not-Call Improvement Act of 2007, which became law in February 2008.”

Call toll-free: 888-382-1222 (TTY: 866-290-4236)
 Online registration is available at
www.donotcall.gov

Options from your land line carrier

Many telephone companies have started offering options to help you avoid answering unwanted calls. The following examples are from AT&T, but you should check with your own carrier to see if they have similar options.

Privacy Manager (AT&T customers only):

\$ **+FEE**

Privacy Manager® is a newer call screening service that works with Caller ID. It stops unidentified callers before your phone rings. For more information, see www.att.com.

MultiRing1 (AT&T customers only):

\$ **+FEE**

MultiRing1 allows you to have two separate phone numbers over one telephone line. Distinctive ring patterns identify which number is being called. *Not available in all areas.* For more information, see www.att.com.

Useful Phones

There are a variety of telephones that have large buttons for dialing, options for pre-programmed numbers (including photos), speakers or audio enhancement, etc. Internet research is especially helpful in this area since it changes so fast. The following is an example of two such phones which have been useful to our participants.

Digital Picture Phone (GE 27956FE1 Dect 6.0 Photo Phone with Photo CID)



This telephone can be programmed to show the picture of the person calling. The resident may feel comfortable answering the telephone when they can see the photo of the person's face. They can also be taught to NOT answer the telephone when there is no picture, which helps with screening unwanted calls.

Amplified Photo Phone: \$

This simple phone allows the user to dial by touching one button with a picture of the person he or she wants to call. Stores up to 9 contacts. Available from many stores and online.



If you want a phone in the home for only limited or emergency use, a “hot line” phone may be just the thing!

Viking Hot Line Dialer - Tone

Programmable: \$

Connect to any land line phone, receives any call; automatically dials one preprogrammed number if receiver is lifted. Available from: <http://www.twacomm.com/>

Allen Tel Courtesy Phone with

Automatic Dialer: \$\$\$

Programmable land line desk phone; dials only one number; activated when handset is lifted; no inbound calls. Available from www.allentelproducts.com

Cell Phones:

Nearly all participants in our project either already had or got individual cell phones during the move transition time frame. In general, these were from regular carriers (e.g., Verizon, AT&T) with typical features.

However, some of the participants discovered how to access the internet, download expensive applications or subscriptions, etc. Others gave out their phone numbers to inappropriate people who called at all hours and became problematic. Working with the carriers, parents were able to turn off certain features and to block specific callers, to make these cheaper telephones work well for all participants. Most of these changes were at no additional cost.

If you have concerns about knowing where your child—or his phone!—is at any specific time, many telephones now have a GPS embedded in them. For an additional monthly fee, you can check whereabouts from any internet connection.

If you want a telephone without all the options and gadgets, the Jitterbug has been designed for simplicity.

Jitterbug: \$-\$\$, +FEE

Offers simplified cell phones and service packages that can include a human operator to respond to a “help” button. Available from <http://www.jitterbug.com/>



Interactive Voice and Video:

Skype:

FREE (TO OTHER SKYPE CUSTOMERS); +FEE (TO LANDLINES/MOBILE)

Voice and video calls through home computer, or conference calls with three or more people; all you need is an internet connection and a webcam.

Available at: <http://www.skype.com/intl/en-us/home>

REMOTE MONITORING

In the Community

***SecuraTrac Guardian Tracking Device:* \$\$, +FEE**

Small GPS device worn by individual, reports location to parent on-demand or automatically; can set SecuraFences to be notified when the carrier leaves an area. Available from www.securatrac.com

***GPS Enabled Phone/PDA:* \$\$, +FEE**

Many handheld phone/PDA devices are equipped with GPS, and services are available for individual tracking and notifications if needed.

At Home

When selecting technologies that will affect the whole household, especially monitoring systems, it is extremely important to consider the protection of individuals' privacy along with the potential safety benefits. Make sure all residents are aware of, and agree to, any outside monitoring by family members or professionals.

The following are examples of the many remote monitoring systems proliferating quickly. The IILP participants have not tested them and we are not recommending any specific program. They are included here simply to give you a place to start your internet and local searches for similar systems if you have a need for one. The companies and services change daily as the demand for such services, primarily for elderly people who need some help to remain in their own homes, skyrockets.

Be sure to check references and compare costs for the exact services you want. You can usually specify requirements and don't need to pay for services that aren't needed.

***Rest Assured Web-based "Telecare":* \$\$-\$\$\$\$, +FEE**

In-home audio and video support from trained caregivers at a remote site on an "as needed" basis. They interact with the user through a touch screen interface much like a television. The subscriber determines the number of hours or specific times the service should check in with the residents. The services available include various sensors such as doors opening or smoke detectors for emergency monitoring. Third parties, such as parents or other caregivers, can also check in and chat face-to-face with the resident from anywhere with an internet connection. Can buy or lease the equipment, which is installed at a single central place in the home. More information (plus other services offered) at <http://restassuredsystem.com/>

***GrandCare System:* \$\$-\$\$\$\$, +FEE**

Central unit is connected to a TV or monitor, and internet source. Provides a continuous display of reminders, etc. to the loved one's TV; wireless sensors monitor activities of daily living; accessed via internet by remote family or caregivers; system can send email, text, or phone call to caregiver(s) if anything is amiss; caregivers can send pictures, etc. to the TV. Available at www.grandcare.com

***AbleLink Technologies:* \$\$\$-\$\$\$\$**

Cognitive support technologies for individuals with intellectual disabilities. A variety of solutions configured for handheld devices and desktop computers, including simplified online connections. These support daily living activities with customized planning, tracking, and prompting, including step-by-step instructions. Available at www.ablelinktech.com

***eNeighbor WiFi Remote Monitoring System:* \$\$-\$\$\$, +FEE**

Automatic detection of need for assistance without the resident activating a device; customized wireless monitors for individual risk factors, such as missed medication; configurable reminder prompts; authorized users can review activities of daily living, or monitor response results on the secure web portal. Available from <http://www.healthsense.com/>

CreateAbilityInc. Prompting system \$\$\$\$ (SOME HAVE MONITORING FEE)

Independence Keeper System, a residential prompting and monitoring system that can be customized to meet individual needs (see detailed description and use in one home at the end of this chapter.)

Webcams: \$-\$\$\$\$ (SOME HAVE FEE)

You can purchase web cams from most electronics stores. There are a wide variety, with prices ranging from \$70 to several hundred. The options include wired and wireless. You can choose options which have lower priced cameras but may charge monthly fees for the internet site access, or somewhat higher priced cameras with no cost for accessing the remote site to view video & audio feeds.

Security Cameras: \$\$-\$\$\$.

The participants in the IILP project chose Panasonic Internet Security Cameras; some are wired and some wireless. The wired cameras have the advantage of two way audio capability, which is unavailable for the wireless option at the time of this writing. Monitoring via the Panasonic web site is free with the camera purchase.

Depending on one's comfort level with technology, these cameras are fairly easy to install without professional help.

HOME AND OUTDOOR SECURITY

Your child and his or her housemates may benefit from technology that acts as extra "eyes and ears" to keep watch over their home and property. Many levels of security systems are available, from simple electronic monitors that notify you when someone is coming up the driveway to sophisticated systems that monitor dozens of things inside and outside the house. Some of these systems are wireless and you can install them yourself; others require professionals to install and monitor. Some have alarms which only sound in the house and yard; others connect directly to a business which calls the fire station and police if they can't reach a person by phone when the alarm is triggered.

You will need to consider the needs of the household, as well as the abilities of the residents to utilize a complex system. For example, if you install a home security system that requires residents to manually set the alarm when they leave or punch in a code to disable an alarm when they come home, you must be sure this can be done consistently and correctly by ALL residents; or you are likely to be disappointed with the effectiveness of this major investment.

Consider the installation costs, monthly fees, and system reliability, as well as the ultimate amount of safety you can achieve. As fully integrated "smart homes" become more common, these costs will come down. At the time of this writing, however, it remains expensive and requires much time to determine what is best for your specific needs.

We have included a few of the options for this type technology below, but the best way to understand what is available is to search the internet for "smart homes" or "home security." Talking to companies in your local area who install home security systems is also very valuable. They are often expanding into areas that include more and more "smart" technology, and can be a valuable resource for you.



Wireless Infrared Driveway Monitor: \$

This type of wireless device uses an infrared sensor to detect motion (human or vehicle) at the entry to your driveway or yard, and sends a signal to a receiver inside the home. It allows the residents to get ready and to have time to think about how you have trained them to respond to visitors. A variety of models are available. Check www.gadgetshack.com/ or www.smarthome.com/

Motion Detector Lights: \$

Can be used to provide outdoor light and to alert residents of the presence of someone approaching the door at night (most will also detect animals, however, so residents will need some training.) Available at home improvement stores or from <http://www.lightingdirect.com/>



Doors/Access Control

Basic Two-Way Intercom: \$-\$

Communicate with visitors without opening the door. Wireless versions are easy to install. Available from www.gadgetshack.com/



Video Intercom: \$\$-\$\$\$

Safely identify and communicate with visitors without having to open the door: When the

doorbell is rung, a picture of the visitor is automatically displayed on the 7-inch color screen. Uses existing doorbell wiring. Can be configured to open door with a touch of a button rather than having person actually go to the door. Available from a variety of internet resources.

Automatic Swing Door Opener (with Key Chain Remote and Electric Strike Plate): \$\$\$

An automatic swing door opener; comes with an Electric strike plate which allows you to lock or

unlock your home or office door with just the click of a button. Available from www.gadgetshack.com and other locations

Keyless Entry: \$-\$\$\$

Many varieties available from Home Depot, Lowe's, locksmiths, or sites such as www.keylesspro.com, www.akmelock.com, www.smarthome.com & www.sdcsecurity.com



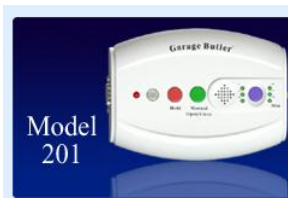
- Mechanical Push-Button Lock: Fully mechanical, no batteries or wiring needed; replaces existing door hardware.



Electronic Touch Pad Deadbolt: Battery operated, permits access with your personalized code or a key; requires no wiring; replaces existing door hardware.

- Fingerprint Biometrics Lock: Fingerprint verification system and lever door lock with deadbolt are combined into one unit; battery operated (2-3 year battery life)
- 3-in-1 Deadbolt: Can open door using key, keypad, or keyfob remote. Battery operated, no wiring necessary.

Garage Butler \$



Don't leave your garage door open overnight again! Operates in conjunction with an existing power garage door opening system. Sensors detect if the door is open or closed. Closes the door after a preset time – between 3 and 60 minutes. Will also close the door when it gets dark. User selected override to keep open as needed. Available at Amazon.com or <http://www.garagecloser.com/index.html>

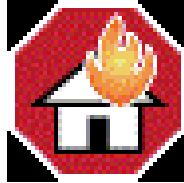
FIRE & WATER SAFETY

Smoke, Carbon Monoxide, & Heat Detectors: §

Programmable “talking” combination devices include a voice that speaks the type and location of danger in your home. Available from: <http://www.detectorsandalarms.com/>

Fire Suppression System: \$\$\$\$

Sprinkler systems must be installed by professionals. Contact your local fire department for contacts for installers in your area. The following document from the American Fire Sprinkler Association outlines considerations for including a residential sprinkler system in your plans for home safety modifications. (first 3 sections are most relevant to you) <http://www.firesprinkler.org/downloads/AFSA-8060.pdf>



Thermostatic Mixing Valves: \$\$-\$\$\$

Regulate water temperatures and protect against certain bacteria; available for various home faucets and pipe configurations. Examples at <http://www.watts.com>

APPLIANCES

Induction Cooktop Stove:

\$\$\$-\$\$\$\$ Can be a stove top range, or countertop cooktop, or even a separate unit similar to a hot plate that sits on your counter. Uses induction heating for cooking. Unlike other forms of cooking, heat is generated directly in the pot or pan as opposed to being generated in the stovetop by electrical coils or burning gas. An induction cooker is faster and more energy-efficient than gas or electric cooking. It allows instant control of cooking energy similar to gas burners. Because induction heats the cooking vessel itself, the possibility of burn injury is significantly less than with other methods; the surface of the cook top is only heated from contact with the vessel. There are no flames or red-hot electric heating elements as found in traditional cooking equipment.



Anti-Scald Devices: §-\$\$\$

These can be shower heads or whole house scald protection mixing valves that can help to maintain safer water temperatures (most can be set to 100*, 110*, or 120*). Configuration varies according to your home’s fixtures. Available from various local stores such as Bed, Bath & Beyond or internet sites such as

www.plumbingsupply.com/scald.html **Enhances safety since burner cannot accidentally be turned on if there is no pan on the stove. Stovetop does not retain heat after pan is removed, except for a very short time period.** Available wherever you buy stoves or ovens.

Front Control Stove/Oven: \$\$\$-\$\$\$\$

Eliminates the need to reach over hot pans with items cooking to change settings or turn oven or stove on or off. Many varieties of front-control stoves are available and may already exist in the home you purchase or rent.

Safe and Efficient Lighting

Good lighting in the new home is a great way to increase your child’s security and comfort. Many types to meet your specific needs are available at your local hardware store, Home Depot, or Lowes; online.

Night Lights: §

Low-wattage night lights can easily be installed in all rooms to ensure that individuals in the home never enter a dark room. They can be activated by a built-in motion detector or by low light conditions.

Sound Sensor Lights: §

These devices are activated by sound and turn off automatically after sound ceases; energy efficient and safe.

Light Timers: §

A variety of programmable timers may be easily attached to indoor or outdoor lighting to save power while the residents are away from home and avoid darkness on the property when they return. They can also be

used to assist with getting individuals who don't like getting up in the dark out of bed in the winter mornings.

Dusk-to-Dawn Light Controls: \$

Uses a light sensor to turn selected lights on at dusk and off at dawn; adaptable to individual lightbulbs or electric outlets. Available at: <http://www.touchandglow.com/> and other sites.

iRobot Roomba Vacuuming Robot \$\$\$-\$\$\$\$

Vacuums your home at the touch of a button. Can be scheduled to clean when you are not at home. Easy to clean and returns automatically to the charger when the battery runs out. Available from numerous sources, including www.amazon.com and www.hammacher.com (who has an unlimited warranty)

iRobot Scooba Floor Washing Robot \$\$\$-\$\$\$\$

Washes tile and linoleum floors at the touch of a button. Some vacuum before they wash. Comes in small or large depending on area to be cleaned. Available from numerous sources, including www.amazon.com and www.hammacher.com (who has an unlimited warranty)

Smart Iron (Oliso TG-1050) \$-\$\$

A steam iron that has digital sensors that lift the iron off the fabric automatically when you let go of the handle and turns off automatically. It helps prevent burning the item being ironed as well as increasing safety for the user. Available from Bed, Bath and Beyond and many internet sites.



Kitchen Garbage Disposal - Batch Feed \$\$\$

Works as a normal kitchen garbage disposal, except will not turn on unless the cover is in place. Greatly increases safety because a person cannot accidentally put their hand in it or drop in a spoon while it is running. Available from most places where you can buy garbage disposals.



Hamilton Beach Smooth Touch Can Opener \$



This easy to use can opener unwraps the seal on a can lid, rather than cutting metal. This leaves a smooth outer edge that can't cut fingers. Available at Bed, Bath & Beyond and similar stores.

PROMPTING

Voice Cue: \$

Discreet (pocket sized, clip-on) auditory cueing device. Record up to five messages (60 seconds total recording time) and set the clock to play back messages at pre-set times. Available from www.enablemart.com and other sites.



StepPAD: \$

Simple pocket-sized cuing device plays recorded voice with prompts/instructions as often as needed. 72 seconds recording time. Available from www.enablemart.com and other sites.



Talking Photo Album: \$

Can record 10-second message per page; memory, task prompting for daily activities, facilitating frequently used social phrases for community interactions, approx 6" x 8"). Available from many internet sites

PowerPoint (Microsoft Office) \$\$

The animation features of this software make it ideal to create customized instructions for almost anything. It is easy to use and has been very useful providing instructions for recipes or making lunches, etc. It is especially effective with a touch computer screen. See Appendix IV for examples.

In-Home

Smartak Audio Wireless Waterproof Shower Speaker With Dock Transmitter- \$

Connect your Radio, Ipod Touch, iPhone, Ipod Classic , Ipods, iPads, Sandisk Sansa, Creative Zen or any MP3 players. Can be programmed with prompts for personal care and safety in the shower and bathroom. Available from www.amazon.com and other sites.



DAILY ACTIVITIES

WeatherCast Wireless 5-Day Forecaster: \$

Streams AccuWeather information free into your home. Available at: www.brookstone.com



Talking Alarm Clock: \$

The Accenda Sunshine Alarm Clock speaks and listens to your commands; can set up to 3 alarms, leave voice memos; other features available at the touch of a button, or voice activated. Available from <http://www.smarthomeusa.com/>



OTHER TECNOLOGY

iPad, iPod, iPhone and similar equipment
 \$\$-\$\$\$\$, +FEE

There has been a phenomenal expansion of portable devices and their software (known as “apps”) that allow communication with and monitoring of technology items – some of which are listed elsewhere in this document. These devices are multifunctional in that they can combine things like telephone, GPS, and computer functions into one device. These flexible devices can not only assist the supporting family and caregivers, but they can also directly aid the individual with developmental disabilities.

These devices can allow, for example, remote camera monitoring by the parents. Or the device might serve as the reminder and prompting device used by the person with developmental disabilities. The device itself can be a location and tracking aid, as described above in the Remote Monitoring section. They can also be used to review or to teach new independent living skills.

In brief, these extremely capable devices should be explored, along with the perpetually expanding software base, to see if they can help meet your needs.

Oven Gloves with non-slip Silicone \$



Gloves offer more dexterity than mitts. These gloves offer heat protection along with silicone pads for a secure non-slip grip. Available at www.Amazon.com or Bed, Bath & Beyond

Orka 17" Silicone Oven Mitt \$



These longer oven mitts give extra protection because they are long enough to protect your arms as well as hands. These are great for safely getting things in and out of hot ovens. Available at <http://www.webstaurantstore.com/>

Flip Video Camera \$

This very simple-to-use video camera has a USB connector so you can upload videos very easily to your computer. It comes with its own software and is a “point & shoot” camera. It can be used for making your own training films (ones which used the residents of the pilot program homes as actors were very successful). The manufacturer of this specific camera has announced that they will no longer produce the camera because there are so many others, including smart phone cameras, which do the same thing. It is included here, however, so you can think about the concept and how it might work for your needs.

***Book: The Complete Guide to Alzheimer's-Proofing Your Home by Mark L. Warner*** \$

Comprehensive practical guide for helping caregivers to evaluate the home environment and to make modifications enhancing safety and function; offers new ideas with the potential to solve some small yet vexing problem; includes overview of how to evaluate the rooms and exterior areas of a typical home and how to formulate a plan that facilitates maximum function. \$38.95. Available from <http://shop.alzstore.com/> or Amazon.com

Touch Screen Computer Monitor \$\$-\$\$\$\$

Many monitors that use a touch screen instead of a mouse are available. Some All-In-One computers also come with a touch screen (e.g. HP TouchSmart). These are useful for those who might have difficulty with fine motor skills or just to help provide a more intuitive interface.

**ADDITIONAL RESOURCES**

New items using technology for support needs come on the market daily. The huge number of baby boomers who require some kind of help to remain in their homes as they age and acquire disabilities has created a large market for the same type of items people with disabilities can use. Your best resource is your computer's search engine because it is the first place companies post new items. However, the IILP found the following to be helpful as well.

ONE EXAMPLE OF AN INDEPENDENT LIVING SYSTEM

Independence Keeper: A Residential Prompting and Remote Monitoring System

The families in the IILP worked with CreateAbility Concepts, Inc., to develop a system which could test whether certain activities of daily living had been done, and would then deliver customized prompts depending on the answer.

As the IILP got underway, the project manager was searching for a partner that was interested in developing a system to enhance the independence of individuals with developmental disabilities. Since 2008, CreateAbility Concepts Inc. has worked with the project to customize a system they already had underway as a result of a prior grant from the U.S. Department of Education.

The following is a description of that system, called the *Independence Builder*. The specific examples come from an installation in use in a home for about three years (since 2008). Throughout that time, many experiments and changes have been done to enhance the effectiveness of the system. This progress has been the result of literally hundreds of hours of work on the part of parents and company personnel. While the results are not perfect, they represent the best solution yet found by the project management for something that can be customized for a broad range of individual needs.

The *Independence Builder* uses a variety of sensor inputs (motion detectors, magnetic contact

switches, etc.) to collect data and send it to the central base station. The transmitted data is automatically compared to preprogrammed conditions (logic tests) to determine if certain tasks have been accomplished. Depending on the results of the test, individualized voice prompts can be sent through “Chumbies” (small audio/visual devices) located throughout the house. All of the sensors and Chumbies have wireless connections to a central base station that controls the system and which allows remote interface via the Internet.

The central base station, or “hub”, is shown below.



The “Chumby” is an important part of the system. Roughly resembling a small clock radio, it consists of a small touch-screen with a leather and plastic exterior. It uses AC power and turns off if unplugged. It is a wireless device that plays the audio and visual prompts generated by the system.

In this test home, there are Chumbies in bedrooms as well as a central location near the kitchen/family room and the basement recreation area. Between transmissions the Chumby displays the time, as shown below.



When the Chumby receives a prompt from the base station, it plays the audio prompt over the built-in speaker and it displays a picture. The user of the system creates the audio and visual cues. A couple of displayed prompts are shown below.



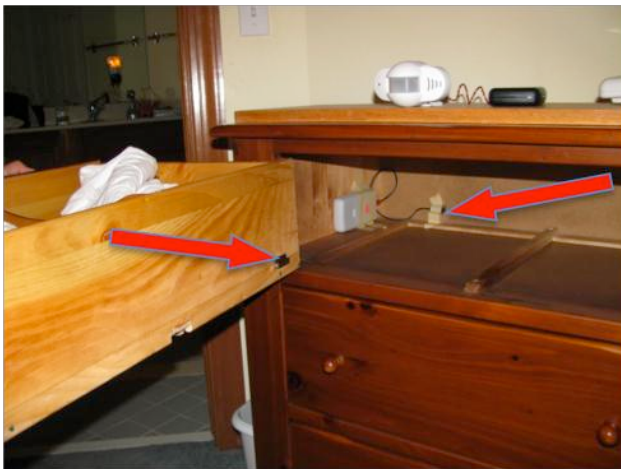
For illustration, the next few photos show some of the sensors that were developed for the project.

The picture below shows an electric razor in its charging holder. A contact switch and sensor head were added which detect when the razor is removed from the holder.



In actual daily use, the system is programmed to test whether or not the person using it has taken the razor off the charger during the time he is expected to shave each morning. "In" or "out" is reported to the base station. If the razor does not report "out," one can assume that he has not shaved. The system is programmed to then send a voice-recorded message to remind the person to shave that is played over the Chumby. It can keep testing and prompting as many times as the parents decide are useful.

The illustration below shows a configuration used to determine when a reminder is needed to change socks or underwear in the morning. The sensor has been positioned to detect when the drawer is opened. A magnet is attached to the back of the drawer and a sensor head is attached to the inside of the chest. These report to the base station whether the drawer has been opened during the time one would expect the resident to be getting dressed. If it has not, a prompt is sent to the Chumby reminding the resident to get his socks and put them on. (Of course, the system doesn't test whether he actually put them on!)



A motion detector sensor is highlighted in the picture below. These sensors are used to detect if there is motion at a particular time of day, i.e., to see if someone has gotten out of bed in the morning. If not, "wake up" prompts will be sent over the Chumby. It was also useful to detect if someone had a "restless" night, especially helpful when evaluating new medication changes.

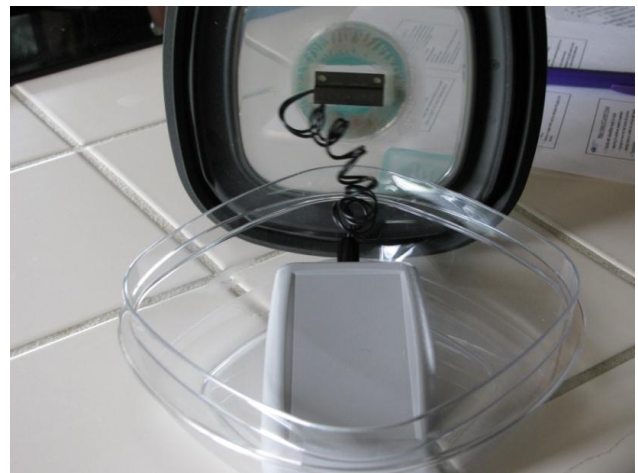


The next two photos show the system set up to monitor whether or not two of the residents took

their medications. Each one has a separate color-coded medication pillbox and sensor, different for morning and evening medications. The pillboxes have a magnet on the bottom and sit upon a customized container, as shown below.



The sensor head is located inside the container and the magnetic contact switch is attached inside the lid, as shown in the photo below.



Parents preload at least a week's worth of pillboxes and deliver them each week to the home. Each evening, the next day's pillboxes are loaded into the container with the sensor. If the pillboxes have not been taken off the container by the time the residents are supposed to have taken their

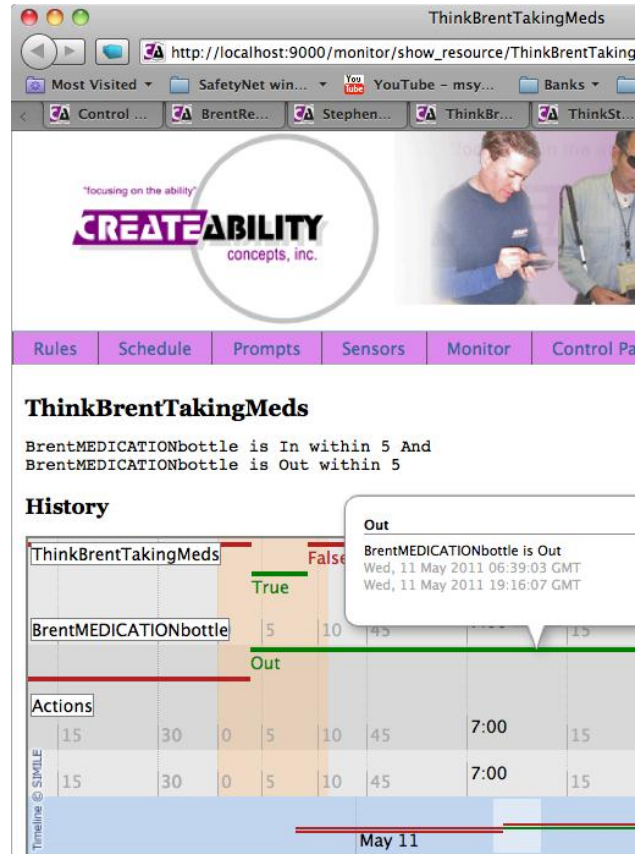
medications, they will get reminders through the Chumbies for as many times as necessary. Note that this system works for these specific residents because they do not resist taking medications; if the containers are removed, they always take the pills. This system would not work for those who actively resist taking medications because there is no one actually monitoring that the pills were swallowed.

There are many more prompts used in this home, and more that could be used if the need is identified. However, they all must be programmed into the computer system that runs the daily tests.

From a parent’s perspective, it takes a lot of careful planning to decide what activities should be part of the system. Figuring out exactly what time frames are best for testing a specific action, how many times to remind about a specific action, recording the actual prompts, verifying that they work as intended, etc., is often confusing and takes a major effort. This is especially true if more than one resident of a home is using the system.

The figures below are samples of the output of the software used for this system. They show the timeline monitoring of sensors and conditions tested along with the resulting prompts. The illustrations are screen prints of the monitor display on the monitoring computer interface. It is accessible from any remote location with a high speed internet connection, and is used by the parents of the pilot test site to monitor activities as needed.

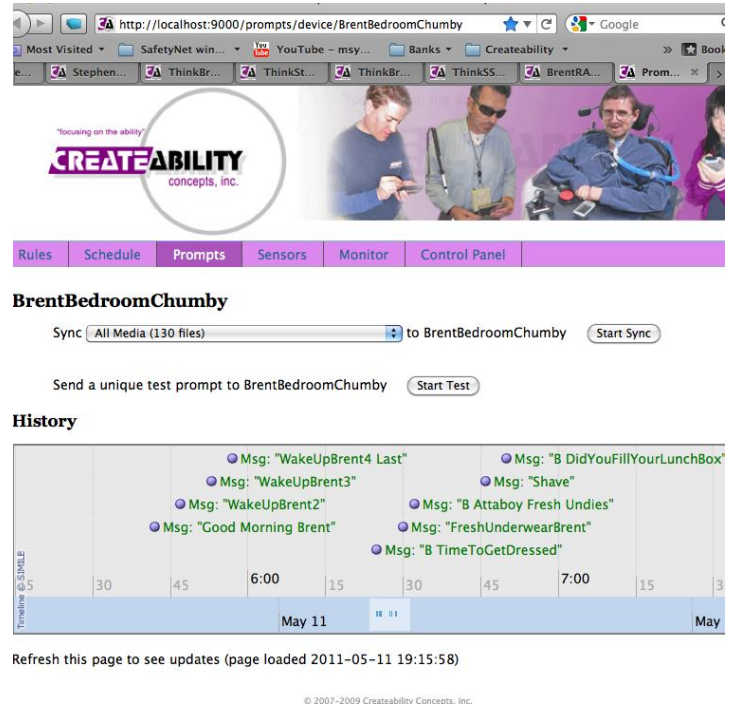
In the illustration below, Brent’s pillbox was removed from its holder at 6:39 AM (the green “Out” line). Also shown, the system logs TRUE for “Think Brent Taking Meds” – that is, Brent gets credit for taking his meds. No reminder prompt was sent, because, in this case the test time for seeing if the container is removed was set to end at 6:40 a.m.– he beat it by one minute.



In the illustration below, you see the output of Brent’s bedroom motion detector. The expanded “balloon window” shows no motion (FALSE) from 11 PM (23:00) the night before until 6:14 AM when he gets out of bed. (Since he often has restless nights, this indicates he had a good night’s sleep and can help predict the kind of day he will have.)



The motion detector output drives some of the prompts, as shown in the following illustration. The prompts came out on the Chumby located in Brent’s bedroom because they relate only to him and he will always be there at this time of morning. The prompt timeline is the same as the motion detector timeline above.



From the BrentBedroomChumby time line above, you can discern the following:

Because Brent did not get up (determined by the motion detector) there were four wakeup prompts sent (the first four purple dots on the left side of the illustration above). The first was at 5:42 a.m., and the last was at close to 6 a.m. The parents know that Brent has difficulty getting out of bed (especially on cold winter mornings!) and have incorporated the “snooze alarm” concept into his routine.

Because the undershirt drawer was not opened (determined by contact sensor described above) a “FreshUnderwear” prompt was generated.

Brent then did open the undershirt drawer after the prompt (and theoretically then put on a clean undershirt), so the Chumby sends a customized “Attaboy” prompt for encouragement.

SUMMARY

As you can see from the details above, this system is fairly sophisticated and requires a lot of work to initially set up the activities for prompting, as well as to figure out what kind of sensors to use for each activity. There are options for window, door, smoke, and other sensors that were not used in the pilot program. Those testing the system used a “trial and error” approach, and made many modifications as they learned more and/or the resident’s habits changed. CreateAbility personnel worked with the parents to modify and improve the system, its reliability and its user friendliness.

It took a significant amount of time to learn how to utilize the system, record the prompts, etc. But once learned, changes could be made quickly. The parents using this system had a fair amount of experience as users of technology, but were not programmers or engineering experts. One needs to be methodical and pay attention to the large amount of detail to get the system working right. One needs to be comfortable using a computer, but there is no requirement to be a computer expert.

The benefits of this system include customized design to meet many individual needs. The detail with which one can specify activities to be monitored is excellent. The users especially liked that the prompting was exception based rather than occurring every day at a certain time whether or not the action had been performed. This helps set the expectation that the person with disabilities can and will do what he should be doing independently, but provides a check and instruction if he does not.

The users also like that they can remotely monitor at least some of the activities happening at their sons’ new house. For example, there is a monitor that shows when the garage door opens or closes. This is helpful for knowing when the residents have arrived home or left for a particular activity (not a necessity, but sometimes useful for the parents’ information.)

One of the most valued benefits of the system from the perspective of the parents is the increase in the residents’ level of independence and improved self-esteem after using it. The young men no longer have their parents telling them what to do each day, and they are proud of their ability to function on their own. Sometimes they even look forward to the regular “interaction” with the Chumby prompts! The parents have a way to monitor that important things are getting done, and can make a decision about when/whether to intervene based on regular data.

For these residents, medications monitoring and prompting was a primary requirement. The CreateAbility system has been very effective in this area. There is still a need to preload the medications containers weekly and for the residents to set the containers upon the sensor on a daily basis. But these have been manageable. The system has been very important to successful independent living in this area.

Ongoing maintenance of the system has been reasonable. Occasionally, CreateAbility will have a software change to upload, and that is coordinated with the parents. About every 2 months, batteries in all the transmitters need to be changed (the system shows battery levels, so the monitoring of this can be done remotely). During the three years that the system has been functional, there have also been several malfunctioning transmitters and Chumbies, which have had to be replaced.

Initial cost of the system is of course dependent on the number of sensors and amount of support needed from CreateAbility personnel. An average initial cost, at the time of this writing (2011) might range from \$2500 to \$4000.

For more information on this system, see <http://ib.createabilityinc.com/> Or contact CreateAbility Concepts
Corporate Square West
5610 Crawfordsville Rd, Suite 2401
Indianapolis, IN 46224
Phone: (317)484-8400 Toll free: (800)484.840

Chapter 11

Support Staff

Support services will play a vital role in the overall sustainable independent living solution in the new home. Your son or daughter will most likely use some in-person staffing support other than family members, even if you maximize use of technology and training to increase independence.

(Note: Chapter 5 of *The Parent Participation Project Manual* is an excellent resource for learning more about how to find and pay for support staff. Only a small part of that information is reprinted here,; see the footnote for information about where to obtain the manual if you are interested in doing so.²

Identify Personal Requirements

Consider the personal characteristics of people you want coming into your home. This might include

² The Parent Participation Project Manual: *Special Housing for Special People*, was written by staff members at Welcome House Inc. and North Coast Community Homes. You can purchase the manual by contacting Welcome House, 440.356.2330, <http://www.welcomehouseinc.org/>.

things such as friendliness, being respectful, honest, caring, prompt, reliable, etc.

Identify other basic factors, including

- **Gender:**
Do you have a preference for male or female staff in the home?
- **Professional or Non-Professional Care:**
Do you require skilled care in the home, or could you hire a family member, friend, or college student?
- Is live-in support an option? Can part or all of this type support be paid by room and board?
- **Turnover vs. consistency of personnel:**
Is it important to you to keep staff turnover to a minimum? If transitions are difficult for your child, seek out staff members or agencies who seem most likely to have long term employees.

Coordinate with your Support Administrator from the County Board

If you are expecting the County Board of Developmental Disabilities to help fund your support in any way, you will need to work closely with your assigned support administrator. Through your Individual Support Plan, you will identify the types of support, number of hours, etc. The correct paperwork must be submitted by the County before your provider (agency or independent) can begin receiving payments.

Finding a Provider for Support

The process of hiring a provider deserves great care and attention. There are many questions to decide on before you even begin interviewing. Here are a few of them:

- Do you have a preference for an agency or independent provider (i.e., one who is certified by the State to act as an independent contractor to provide waiver services)?

- Who will be responsible for gathering information about providers?
- Will the residents of the home be involved?
- Must the residents all *like* the person to be hired?
- What are your minimum requirements?
 - Will they be different for live-in vs. hourly care?
- Will you expect specific prior training?
- Will you require first aid certification?
- How will you plan to negotiate terms/benefits (insurance, time off, etc.) if you contract independently?
- If they will be paid by funding from a waiver, will they be an independent provider or hired through an agency?
 - If you are hiring an independent provider, will you have to help them get certified?
 - How will they be paid during the 2-6 months it takes to get certification?
 - Where will they get the necessary training to become certified?
- Who will ultimately decide on hiring?
- How will the final decision be reached?

Agency or Independent Provider?

There are advantages and disadvantages to each type of provider. The following, which is reprinted from *The Parent Participation Project Manual*³ identifies specific considerations:

“Should you contract with an agency or hire and manage a staff yourself? That answer may depend on your funding source. Some funding requires the use of an agency. Other sources may give individuals and their parents an option to hire individuals directly.

³ The Parent Participation Project Manual: Special Housing for Special People, was written by staff members at Welcome House Inc. and North Coast Community Homes. You can purchase the manual by contacting Welcome House, 440.356.2330, <http://www.welcomehouseinc.org/>

“The rules for Medicaid Home and Community Based Waivers are still being developed in Ohio. Although the proposed rules are stricter in terms of who can provide services, they do not eliminate the option for direct management by families.

“There are advantages and disadvantages to both contracting with an agency for services and directly managing support staff. As with all aspects of housing, you must look at your own situation carefully. But first, consider these pros and cons:

“ADVANTAGES TO CONTRACTING WITH AN AGENCY

- Agencies often have a collective wealth of experience and knowledge.
- Agencies handle employment laws, employment taxes, and employee benefits.
- Many agencies have managers or program staff who can provide additional supervision and oversight.
- Agencies usually provide back-up staffing for vacation and sick days.

“DISADVANTAGES TO CONTRACTING WITH AN AGENCY

- Families have less control over who is hired or fired.
- Agencies tend to have high turnover in staff.

“ADVANTAGES TO DIRECT MANAGEMENT

- You have direct control of who is hired.
- You are involved in training and supervising staff.

“DISADVANTAGES TO DIRECT MANAGEMENT

- It requires a substantially greater investment of time and energy.
- You are responsible for finding backup staff when
- Someone calls in sick or goes on vacation.
- You must handle employee taxes, benefits and employment laws.”

Hiring an Agency Provider

There are many excellent well-established residential provider agencies. Finding the right one for your particular needs may require a lot of effort, but it is one of the most important components of creating a successful housing solution for your loved one with disabilities. *The Parent Participation Project Manual*⁴ has an excellent description of a reasonable process to use in narrowing down the pool of agencies. In summary, they recommend

1. Prioritize your requirements.
2. Have realistic expectations.
3. Make a list of basic questions you need to ask.
4. Telephone a number of agencies and ask these basic questions.
5. Pick 3 agencies for in-person preliminary interviews.
6. Decide which to go back to with in-depth interviews.
7. Request services and work out the details.

The Parent Participation Manual has a comprehensive list of questions included in its Appendix F, pages 44(f) – 60(f).

The areas listed at the end of this chapter will also help you formulate your own questions for both agencies and independent providers.

Hiring an Independent Provider

An Independent Provider is another option for insuring that your child receives the support necessary for his or her safety and comfort. If you plan to pay privately for this support, then you have unlimited options in choosing who will provide the care and how much you will pay them. (Remember that you will likely be considered the legal employer

⁴ [The Parent Participation Project Manual: Special Housing for Special People](http://www.welcomehouseinc.org/), was written by staff members at Welcome House Inc. and North Coast Community Homes. You can purchase the manual by contacting Welcome House, 440.356.2330, <http://www.welcomehouseinc.org/>.

and as such will be responsible for all employer taxes, including Social Security, Medicare, Unemployment, Workers Compensation, etc.)

If you expect to use Medicaid Waiver funds to help pay for the support, you must use a person that has been certified by the state to provide these services. The easiest thing to do is to hire someone already certified. There is a list of such providers on the state Department of Disabilities web site at <https://odmrdd.state.oh.us/providers/search.htm>. It is often frustrating to go through this list and make many calls, only to find that providers are not taking any more clients or are no longer working in this capacity. But it is a place to start.

Another good option to find a certified provider is to use your network of contacts to ask. This network may include disability related organizations, your County Board of Developmental Disabilities, other families already receiving services, etc. In many cases, however, you will want more flexibility in choosing the person to provide support. It is very difficult to find someone with all the personal and professional characteristics you want, and even harder if you are restricted to those already certified.

If you choose to hire someone who is not yet certified, you may need to help them understand what is required to become certified. This is often confusing and it can be very time consuming. Information and the forms to complete can be found at <https://odmrdd.state.oh.us/providers/new.htm>.

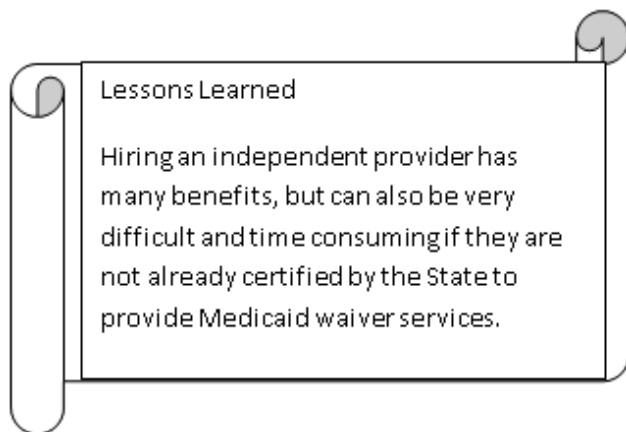
The person who will be the Independent Provider must

- Complete and submit all the forms
- Pass a Bureau of Criminal Identification and Investigation (BCII) test
 - Complete 8 hours of training requirements (can be done online at a cost of \$95 in 2011; <https://odmrdd.state.oh.us/providers/training-info.htm>)
- Submit a current First Aid/CPR certification (available from numerous training sites)
- Pay the required fee (\$50 in 2011 in Ohio)

Once all forms have been submitted, be prepared for a long wait to get approval. In the experience of the

families in the IILP project, the wait has been from 2 to 6 months before approvals have been received and the provider could begin billing. Once approved to bill, the first actual checks for payment have generally not been received for a month or more after bills were sent in.

In addition to the tedious process of getting your provider certified, there are many confusing issues with the actual billing details. An independent provider can choose to do the billing himself, although the State system is not very user friendly. An option in Cuyahoga County is to use the services of S.A.W., Inc., an organization that is affiliated with the Cuyahoga County Board of Developmental Disabilities (http://www.sawinc.org/saw_home.html). They have lots of experience with the system and will do the billing for a percentage of the total amount (3% in 2011).



Support Management and Supervision

The following list of areas to consider was compiled from a variety of resources, and may help you in thinking about what staff can do for your child in his or her new home. Some of these may be longer term goals (e.g., money management or medical issues), but it is worth reviewing the variety of assistance that may be needed so you can make good choices as your child initially transitions.

Communication

- What is the procedure for communication?

- Can I instruct you to do something for my family member?
- Can my family member direct you?
- How often will we communicate?
- Can I call you directly?

Training

- How will staff be initially made aware of individual needs?
- How will staff be educated about technology in the house?
- How will staff be trained about emergency procedures?

Supervision of Daily Staff Activities

- Who manages?
- How often will a supervisor visit the home?

House Rules

- Are there different expectations for staff?
- Is smoking permitted?
- Is using the phone for personal calls allowed?
- Is eating household food/meals included?

Conflicts

- How will disagreements be resolved?
- Who has authority to discipline if needed?
- What kind of corrections is ok? Not ok?
- How will problems generally be resolved?

Time

- How many hours will they be in the home per day?
- What time (early morning, afternoon, dinner, evenings, weekends, overnight)?
- Individual or shared among residents/homes?
- Emergency/situations
 - How to handle backup staffing when scheduled doesn't come?
 - How to handle unexpected days at home (sick, snow, etc.)?

Responsibilities for Assistance

- Personal attention/social interaction
- Meals – Planning/preparation?
- Shopping – assistance with purchase decisions?
 - Food
 - Clothes
 - Gifts

- Cleaning?
 - Common areas
 - Laundry
 - Overseeing use of appliances
- Personal care
 - Selecting clothes
 - Dressing
 - Hygiene assistance
 - Time management – getting ready
 - Sexual activity decisions and interactions
- Communication assistance
 - “Front door” response
 - Phone
 - Mail
 - Banking?
 - Bills?
 - Other paperwork?
 - E-mail/computer
- Medical?
 - Scheduling/taking individual to appt.
 - What access to medical information?
 - Handling medications
 - What is staff liability re: medications?
- Transporting?
 - Who provides vehicle?
 - Schedule - what activities (appointments, social activities)?
 - Religious participation?
- Handle money?
 - Budgets?
 - What expenses?
 - Record keeping?
- Authority/discipline of person with disabilities?
 - In what areas, if any, should staff have total authority?
 - Handling of emergency decisions?
- Activities – how will staff be involved?

Emergencies – house and medical

- How will they be handled?
- What training will we have? For residents? For Staff?

Employment/compensation

- Money
 - Representative payee for government benefits?
 - Banking
 - Power of attorney
- In-kind
 - Room and board?
 - What part of the house will staff occupy?

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Chapter 12

Prepare for a Healthy Transition

Establishing and maintaining a home is an ongoing process. Parents and children can expect to feel very anxious the closer you get to the actual move date.

The goal of your child moving to his own home is to increase his independence and to secure his future for a time when you may no longer be able to—or want to—provide as much care and intervention as you do now. Each family will determine how much support is needed at each stage of the process, and how much they personally will be involved versus having paid supporters do much of the work.

Over time, your child will build new skills for greater daily independence, and other supports will be put in place to provide care that you previously gave to your child. At the same time, you will take on demanding new roles in collaborative management of the home and in long-distance oversight of your child’s activities and well-being. Giving up old roles and adapting to new ones will take time and effort on the part of your whole family.

Time to Grow and Change—for Children AND Parents

Independence grows at a different rate for each individual and each family. Remember that this is

not only a huge transition for your child, but for parents and other family members too.

Your child may surprise you by how much he looks forward to this move. The idea of greater personal independence or being like other adults who have moved away from home is often very motivating. This is not a personal rejection of the life your child has with you, but part of the normal transition most adults go through. For most of the families in this project, there were very mixed feelings of both children and parents. And the closer it got to the actual move date, the harder it was for many of the group.

At many points during the transition, your child may show emotional regression or cling to you. He may be adamant about remaining in your home and not moving. Expect good days and challenging days. Be vigilant about your child’s emotional health throughout the transition, but be careful to avoid over-reacting to the “growing pains.” These are normal as any child prepares to move to an independent situation, but are often much stronger for our children with disabilities.

Parents in Transition

Parents can expect some “growing pains” too. Remember the following as you experience natural emotional ups and downs during the process:

1. *Expect to experience a sense of loss and apprehension as your child makes the transition to a new house.*
2. *Don't feel guilty if you adjust to your child's independence at a different pace than other families. Each parent makes the adjustment in his or her own time.*
3. *Work to keep your emotions positive with the child. Showing your sadness or anxiety may hinder a healthy transition.*

4. *Do not focus conversations on problems or uncertainties. Help your child focus on his or her increasing independence and new goals or activities.*
5. *To the extent possible, limit any other major life changes for now. The transition to a new house is enough for everyone.*
6. *Be aware that other friends and family may not understand how much is still required of you even after your child has moved out. Be prepared to explain your continued involvement, but don't let their opinions discourage you. You know your child best and you must feel comfortable with the new situation.*

Adapted from a publication from the Minnesota Higher Education Services Office, cited in: Ursuline College Parents Guide, Orientation 2005: "Letting Go and Letting Your Student Grow"

Practical steps to promote a healthy and successful transition to the new household.

Consider the dynamics of the whole house, including both parents and residents.

By now you have completed compatibility assessments and grown familiar with each other through shared activities. What special abilities have you noticed? Think about these as strengths for building the new household. Talk about ways to make the most of these relationships. In what ways can housemates help one another within their new home, based on their interests and skills? Be extra aware of the new residents' interactions during the first few days so you can help resolve issues before they become large problems.

Don't stop independent living training now!

Continue training at the new home site, by you or another provider. Spend a few nights there with your child if possible. If you can spend time there before the move getting used to the house and

learning specifics in the future setting, there is less chance of your child being unable to transfer what he has learned. You may want to consider getting someone other than yourself to do this training since your child may respond better during this time of high tension.

Keep up the fun and friendship.

Continue doing activities to create housemate relationships, such as cooking together or making choices or purchases for the home together. Remember that you are creating vital long term connections for your child's support and well-being.

Get professional help if you think it could help.

In Cuyahoga County, the Cuyahoga County Board of Developmental Disabilities may be able to provide psychological consultation for your son or daughter to help lessen the anxiety associated with this major transition. They may work with the entire group of new residents to help them deal with interpersonal issues as well as individual problems. Talk to your Support Administrator to see if this is an option for you.

Helpful hint:

To avoid confusion and the emotional connotations of the word "home," call each house by the name of its location, such as 'Maple Drive' instead of 'old house' or 'new home'.

Chapter 13

The IILP Process – Benefits and Challenges

At the end of the pilot project, informal interviews were conducted with participating families. From their feedback, we identified which aspects of their process were helpful to them, which parts were most challenging in order to make the process better for future families. (That's you!)

BENEFITS

Readiness Assessment Tools

Reflecting back on the positive aspects of the IILP process, many participants expressed appreciation for the early tools provided to help them assess whether this independent living solution was a good match for their family. Having completed thorough assessments of their readiness and resources, many expressed an increased level of comfort, confidence, and direction when moving forward.

The IILP Financial Model

Many identified the Financial Model as an especially helpful element of their preparation. Those who needed to access additional funding appreciated the assistance in locating additional potential sources of funding and in making applications for benefits and funds.

Recognizing If It's Not Right for You Now

Several families discovered through the early assessment process that this housing solution did not fit their current goals, needs, and/or resources. These families appreciated being able to reach a solid decision earlier rather than later to move on to seeking other solutions.

Step-by-Step Guidance and Motivation

One parent expressed that their participation in the project marked a movement “from floundering to reality” for their family, whose previous attempts toward independent living had been stalled by the relative ease of maintaining the status quo. This family asserted that they never would have established the home without the organizational assistance of the program and their collaborators. One family appreciated “being forced to take an incremental approach” to identifying needs and solutions. Breaking the project into small parts provided motivation to take one step at a time to carry out challenging or time-consuming activities to keep the project moving.

The Power of Collaboration

Families also acknowledged the enormous value of being part of a group/collaborative approach. Several parents noted that the frequent meetings and discussions were beneficial and brought up issues that they would not have considered on their own. And the assignments from each meeting kept them focused and moving forward.

CHALLENGES

High Costs – Money, Time, and Energy

Many families found that tasks such as locating housing, identifying housemates, etc., took more time and energy than they initially anticipated. Some families also found the costs of housing and services to be prohibitive and/or a drain on their budgets. Finding resources to help with these areas was also challenging.

Process & Priorities

Many parents found the complexity of the process daunting. Some would have preferred to address the Financial Model later in the process, as it was not their first priority. Several emphasized the desire for more group discussions to directly address the needs of their children.

Ingredients for Success

The following list of “ingredients for success” was compiled from the experiences of families in the pilot project. It is not a “recipe”. Every family brings different needs & resources to the table. However, you can benefit from the lessons they learned, and use these points to focus your efforts in developing your own home.

Ingredient #1: **Accurate Assessment**

What is your current situation? What are your future goals? What do you have and what will you need to reach those goals? Who can partner with you to make it happen?

Good assessments are key in the ongoing (and often overwhelming) process of planning for your child’s home. Throughout this manual you will find tools to help you:

- think through your readiness to move
- accurately identify your resources
- evaluate housing options
- determine specific support needs
- choose compatible housemates

Your solutions will only be as effective as your assessments.

Ingredient #2: **Work for the benefit of ALL residents, not just your own child**

In a household with several people from different families, there are bound to be different ways of doing things. When working with the other families, it is important to think about how each decision affects everyone. It may not always be possible to make everything just right for everyone, but if you all have that as your goal, it will be much easier to deal with the required adaptations.

Ingredient #3: **Knowing Your Resources**

Your family is about to make a large investment. What resources are you prepared to dedicate to the success of the home? Finances, of course, are a major part of your investment, but not the whole of it. Many people will be willing and interested in helping you succeed in this venture, so take advantage of their expertise. Broadening your network of contacts will be very valuable as you move forward.

Homes that really work are also supported by ongoing family and circle of support contributions of:

- ***Time***
 - ***Energy***
 - ***Expertise***
 - ***Skills***
-

Ingredient #4: **Carefully Choosing the Right Housing and Community**

Finding suitable housing in an optimal location is a challenging and time-consuming task. Families in the pilot project reported, however, that it was well worth the patience and effort. Their advice: Hang in there. Don't rush. Keep looking. Once you have carefully investigated communities and thoroughly evaluated housing options and arrangements, you can make a confident investment in a house that will be an excellent long-term living space for your child.

Ingredient #5: **Individualized Independent Living Training**

Independent living training is an exciting component of establishing a home. With thoughtfully selected targets and training, your child will increase his or her level of independence by learning specific skills for activities of daily living. Skills are sustainable – they improve with time and they last a lifetime!

Ingredient #6: Applying & Adapting the Right Technologies

Reducing costly in-person support staff can be done in part by creatively using technology. Sensors and prompting systems, communication devices, specialized software, and much more are available to help your child remain independently healthy and safe. New gadgets and programs show up every day, so it is important that you continue to evaluate what will work best for your child.

Ingredient #7: **Creative Staffing Solutions**

Most homes will require support staffing to some degree. In shared homes, flexible staffing options can allow each individual to receive part-time support as needed without paying individually for full-time support. You may also choose to staff your home with family members or local college students, or by exchanging room and board for hours worked.

Ingredient #8: **Early & Honest Conflict Resolution**

Developing a successful home with multiple families is a collaborative effort. That means that you will roll up your sleeves and get to work, elbow to elbow, with your own family and your partner families. As noted above, the greatest success will come when all families work for the good of ALL the residents, not just their own child.

Conflicts are inevitable in some areas because families have different

- ***Vision and goals for the home***
 - ***Personal values and beliefs***
 - ***Willingness to commit resources***
 - ***Desire to maintain privacy***
 - ***Priorities***
 - ***Personalities***
 - ***Communication styles***
 - ***Ways of handling stress and conflict***
-

The families in the pilot project found that good ways to handle conflict included:

1. Being honest early.

When building a collaborative relationship, it may be tempting to begin by being agreeable and polite, including hold back your real thoughts in order to dodge confrontation. Don't give in to this temptation! It is natural to want to avoid offending potential partner families, and you will always want to communicate respectfully. Sharing your real feelings about personal issues may be very awkward for everyone up front, but honesty is foundational to a successful partnership.

2. Deal with it now.

Whatever issue arises, don't set it aside for tomorrow. Deal with it as soon as possible. Ignore a small irritation and soon it may grow into a major pain!

3. *Remember you are establishing a home for the long term.*

Think consciously about how much the issue you are concerned about will matter in the overall success several years from now. Let that help guide your actions.

Top problems that have derailed other collaborative independent living projects:

- 1. Lack of leadership to focus the group.**
- 2. Lack of clear roles, responsibilities, and accountability among parents.**
- 3. Failure to communicate up-front honestly about issues that later grew into problems.**
- 4. Lack of making the choices that best serve ALL the residents vs. the best choice for one's own family member**