A Smith-Magenis Guidebook

JUNE 2016

Exploring Adult Residential Living

prisms

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

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Parents and Researchers Interested
in Smith-Magenis Syndrome

Founded in 1993, Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) is a non-profit 501 (c) 3 organization dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS). PRISMS supports research and fosters partnerships with professionals worldwide to increase awareness and understanding of SMS.

PRISMS is governed by a ten-member Board of Directors, each of whom has a child with SMS, allowing for a unique perspective and understanding of living with Smith-Magenis Syndrome. A multidisciplinary Professional Advisory Board supports the work of PRISMS by providing medical guidance for families, as well as reviewing and sharing information about the most up-to-date research.

Donate, Join and Volunteer With PRISMS

This non-profit organization depends upon contributions to continue its work. PRISMS hosts a biennial international conference, publishes resources on critical topics of interest to the SMS community, and sponsors research initiatives with the purpose of advancing progress for this rare population. Join PRISMS, make a contribution and network with other families about SMS. With your support, PRISMS can continue its mission.

There are many opportunities to become involved and work with others across the country and internationally on issues important to the SMS community. Join us by becoming a member. Send your tax-deductible contribution so PRISMS can continue to disseminate valuable information to support families. Many people give their time, resources and talents to benefit people with SMS. Volunteer positions are available to serve on advocacy, fund raising and advisory committees as well as on the Board of Directors.

If you have time talents or resources to share, please contact us at info@prisms.org. To learn more about PRISMS and our work, visit www.prisms.org.

A donation, no matter how small, helps PRISMS achieve our mission. Contributions can be made online through our website (http://www.prisms.org/us/how-to-help/make-donation) or mailed to:

PRISMS, Inc
PO Box 206528
Dallas, TX 75230-6528

PRISMS, Inc.

Since 1993, Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) has been a valuable resource for families and professionals when they first learn about Smith-Magenis Syndrome and every step thereafter.

OUR MISSION

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS.

OUR VISION

As the leader of the worldwide Smith-Magenis Syndrome community, PRISMS engages, inspires and empowers families, physicians, educators, researchers and others so they can support and improve the lives of everyone affected by SMS.

OUR VALUES

Compassionate—We are a compassionate organization that cares deeply about the well-being and the needs of each and every individual within the SMS community.

Empowering—We empower families with the knowledge they need to make the best decisions for their family's needs.

Conscientious—We conscientiously ensure that all of our actions and practices serve the needs of the SMS community.

Inclusive—We encourage and seek participation from all those interested in advocating for and creating a positive impact for the SMS community.

Excellence—We focus on quality, conducting our work to the highest ethical and professional standards and striving for excellence in all that we do.

OUR PROGRAMS & SERVICES

- Newly Diagnosed Information Packet
- Regional Representative Program
- International Partnership Program
- PRISMS Building Bridges of Hope Conference
- PRISMS SMS Research Symposium
- Telephone and email support for families and professionals seeking more information on SMS
- PRISMS website, www.prisms.org, providing the latest information and support for the SMS community
- Database of registered SMS families
- Spectrum Journal, a quarterly newsletter offering insight, perspective and updates on all things SMS
- Awareness items including SMS brochures, bookmarks, wristbands
- "On The Road to Success with SMS: A Guidebook for Schools" resource
- And more!

To learn more about PRISMS, visit: www.prisms.org

To address questions or comments about this resource, please contact PRISMS at info@prisms.org.

Acknowledgements

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Special thanks to the project's lead writer, Deborah Wehrlen. With her years of professional experience developing residential services for people with disabilities, she played a critical role in creating this resource guide.

Most importantly, PRISMS thanks and appreciates the families who shared their personal experiences in seeking residential services for their children with SMS.

About this Residential Resource Guide

To the SMS Community,

In 2015, the Board of Directors, staff and volunteers of PRISMS formed an Adult Residential Setting Workgroup to develop a document that focuses on the needs of adult children and their families as they transition from an educational setting to skills for daily living as an adult. This guide explores the process of identifying and understanding residential services and supports for adults with SMS.

The transition from childhood to adulthood requires careful planning and review on the part of the families. One important challenge is to secure housing and residential supports for adults with SMS. We hope this guide provides the information necessary to promote a successful transition toward living more independently. By creating this resource, PRISMS intends to provide families with the information needed to understand housing options. We hope to make this complicated journey as simple and successful as possible for you.

PRISMS is honored to offer this resource guide on adult residential settings for individuals with Smith-Magenis Syndrome. We hope this publication is useful as you begin your exploration into residential options.

Sincerely,

PRISMS Adult Residential Setting Workgroup

A Note From the Workgroup About Our Process, Our Voice and Being Inclusive

The goal of this residential guidebook is to provide information on adult living opportunities for those with Smith-Magenis Syndrome. The target audience includes the individual with SMS and their families including parents, siblings, relatives, guardians, support staff, professionals and any other interested parties.

This project was conceived, coordinated and written by parents and professionals, all of whom brought their personal style, voice and perspective to the development of the text. Our intent is to provide useful and practical information to families considering residential options for those with SMS as they become adults. As a result, there is variation in the way we refer to those with SMS and their support person/people. You will find a variety of terms throughout the text including family member, loved one, son or daughter. Similarly, it is not possible to anticipate every scenario and label each one accordingly.

We believe that given the proper supports, there is no limit to what is possible for someone with SMS. Each family and every living situation is different. Capacity and resources vary greatly across the country. We offer the information without judgment and with the hope that each reader finds something of value that might help when considering residential opportunities for your child/loved one/son/daughter/charge with SMS. Finding the residential setting that best meets the need of the individual with SMS is a personal decision best left for each family to explore.

Many types of residential options are included in this guide for your information. PRISMS did not vet service providers nor do we endorse any particular model. In most instances we identified individuals with SMS who live in these settings and included them in our case studies. There are a few models where we are not aware of people with SMS being served. This guide will be a “living resource” that will be updated as families provide us with their experiences.

— *The PRISMS Adult Residential Settings Workgroup*

With Heartfelt Appreciation

Funding for the production of this guidebook for SMS residential living is made possible through the generous gift of Betty and Ira Dyer, the grandparents of Charley Mayer. On behalf of the entire community of families, we are grateful for your support!

What is Smith-Magenis Syndrome (SMS)?

Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a recognizable pattern of physical, behavioral and developmental features. Common characteristics include variable levels of intellectual disability, developmental delay, early speech/language delay, distinctive facial features, low muscle tone, middle ear problems, skeletal anomalies and decreased sensitivity to pain. The syndrome includes a distinct pattern of neurobehavioral features characterized by chronic sleep disturbances, arm hugging/hand squeezing, hyperactivity and attention problems, prolonged tantrums, sudden mood changes and/or explosive outbursts and self-injurious behaviors.

Despite these challenges, people with SMS respond well to educational, behavioral and environmental supports designed to meet their needs. Many individuals with SMS have engaging and endearing personalities, along with a well-developed sense of humor. They generally appreciate attention and respond well to positive reinforcement. Adults with SMS have been described as eager to please, communicative and affectionate. Most adapt readily to structure and routine.

Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 15,000 births. SMS is under-diagnosed, and as awareness grows, the number of people identified increases yearly.

Planning and Preparing for the Future

Every parent of a child with a disability ponders that nagging question "What will happen if I can no longer take care of my child?"

Children diagnosed with Smith-Magenis Syndrome (SMS) typically have their educational needs addressed and funded by their local school system, as rights to a free and appropriate education are an entitlement guaranteed by Federal Law. To ensure educational needs are met, an Individual Education Plan (IEP) is developed with the student, family, child study team and teachers.

As the child becomes an adult, the process of securing residential and adult services is a different matter. Long-term care is funded through a combination of federal and state Medicaid funding. Few states offer residential services as a legal entitlement for adults. Resources are limited. Services and options vary greatly from state to state.

Advance planning is critical in order to best support a person with SMS. This guide provides descriptions of residential living arrangements, options and examples in use by some SMS families. Included are planning documents, tool kits and other resources to assist families through the process of developing a residential plan.

Developing a Residential Plan

Parents work hard to plan and provide for their children. Many individuals with SMS live at home and there may not be an immediate need for the person to live elsewhere. In-home support services can include respite care, home health aides, vocational or day habilitation services, travel training and more. As children with SMS get older and their needs, interests and abilities change, it may be time to consider a residential housing option outside of the family home. The process of determining what is available and assessing what meets the person's needs is ongoing. It is never too early to begin researching and planning for the future.

When a student with SMS enters the teenage years, it is important that the educational team begin working with the child and family toward a long-term vision of life beyond school. Parents are often shocked to realize how different the adult services world is from the educational system they have learned to navigate. The sooner they begin thinking about adult services the better as the learning curve is steep and waiting lists are long. In addition, too much unstructured time for a young adult with SMS can result in significant regression and behavioral outbursts.

As there may be lengthy waiting lists for adult services, plans should be in place for the school-aged student transitioning into adulthood. No one can predict the future, but by the early teens, the educational team should have a good sense of the supports that a student with SMS is likely to need in adulthood. Understanding the student's and family's aspirations within the context of those needs allows the team to focus the remaining school years on achieving desired long-term goals.

Many residential models exist. Parents and guardians should determine what is available and what model can best meet the needs of their family member. Securing the resources to pay for residential services and gaining access to services can be complicated. Professional advice from advocates or legal experts might be useful when navigating the system. It is not uncommon for families to rely on a team of community members to help develop a plan. The state may assign a service coordinator, transition specialist or case manager as a resource. In some instances, families employ a consultant to advise them.

CASE STUDY

LAURA'S MOVE

Prepared by Mary, Laura's mom


Laura

Our daughter, Laura, (currently age 31) lived at home with us until she was 27; a year after her name finally reached the top of the interest list for our state's HSC Medicaid Waiver. (It was an 8.5-year wait, so I hope that others apply when their child is much younger). Because we had talked about it for years, and because her younger sister had already moved out, we thought that Laura was ready to move too. But that decision did not happen overnight.

When Laura was still in junior high school our school district's Transition Specialist urged us to think about the future. She said, "Students spend far more years as an adult than they do as students and we need to plan for that part of their life span." She also reminded us that typical children mature and move towards independence incrementally, starting with play-dates and sleepovers with friends, as well as with camps or school trips. Laura had done none of those things; I never thought she could handle it or they could handle her. But it was time to find ways to make this happen. We began to let other people care for her occasionally, and found a special needs overnight camp.

We made these changes very gradually, over several years. I was so overwhelmed with caregiving, therapy, doctor appointments and school issues that I thought I could not begin to think ahead. I knew I should, but it *was one more thing. In addition, at the time, we were in one of those stages where I was Laura's "preferred parent." She was constantly with me and I did not have energy for anything else.*

My husband, Randy, took over the job of acting on information that we had learned.

Here are some of the steps we took:

- *Called our state agency to put Laura's name on Medicaid Waiver Waiting Lists*
- *Applied for SSI when Laura was age 18*
- *Attended city-wide information fairs about Disability Services for Adults*
- *Met with a financial counselor about Special Needs Trusts and adult living options*
- *Made a will that incorporated disability planning*
- *Learned about guardianship pros and cons and made a decision that it was best in our case to apply for guardianship once Laura was 18*
- *Visited a variety of residential settings (mostly without Laura for our first visit)*
- *Attended "adult issues" workshops at PRISMS conferences*
- *Networked with friends whose children were older to ask what did and did not work for them**

*[*One especially helpful suggestion was to try to plan the move around a "natural" transition time, such as when the other siblings are leaving home too.]*

We had many questions about the future. We wondered what was best for Laura, her sister and us. What were the options she had to be safe and happy? Who could do our job when we die? Of course, we did not have all of the answers, but just talking about it kept us focused. At one of our periodic Person-Centered-Planning meetings, Laura surprised us by saying she wanted to move out someday. Then a few years later when her little sister left for graduate school, Laura said, "What about me? When can I move?"

If you had asked me when we first started talking about her moving, I would have said it was impossible. But I was wrong.

We considered a variety of living situations, including Independent Living Centers and campus based group homes but eventually chose a community-based group home that we all were excited about. After putting Laura's name on the waiting list for one of their group homes, we enrolled her in the agency's day habilitation program. She attended the program for one year, getting to know the staff and other clients, and letting us know (and vet) them. This really helped with Laura's eventual transition. We discussed very openly that Laura would one day be able to move into one of their houses. We also made our own home a little less inviting. When she would ask to go somewhere or play games or something, I would say, "Oh, we are old here, we don't like to do as much as young people do". When a room became available, they asked Laura, "Would you like to move in with some of your friends?" That was a great approach; she was very excited and kept saying she was going to be "independent" from us.

Now that Laura is an adult, I am very happy that we started to think about her adult life while she was still young. Laura and our hopes and dreams have changed from what we thought we wanted when we first started planning. We found good options that we did not know existed, and other options we realized that would not work for our family.

So is Laura living in the ideal place for her? We do not know, but it is the best we have found. One of our surprises was how much she enjoys the structure and predictability of group living. She is pretty happy there, not happier than when she lived with us, but not less happy either. We do not know the future, but we do know that we will not be around forever. We are happy with the plans we made for her.

Submitted by Mary Beall.

Preparing for More Self-Reliance

There is a lot of preparation involved for individuals with SMS to live productive lives with some degree of self-reliance, and planning is key. Assessments of abilities can identify strengths, interests and needs. It is important to begin teaching activities of daily living (ADLs) as early as possible so that young adults with SMS become prepared for living with some degree of supported independence. Some important and valuable skills to learn are managing personal care and becoming as self-sufficient as possible, learning household responsibilities such as light cooking, cleaning, laundry and handling money. Another important skill set is safety; recognizing danger, keeping safe and responding to emergencies. The use of technology such as texting and e-mailing on a smart phone or computer are valuable tools to increase communication. Emergency call buttons can summon someone in the event of an emergency. Stoves can be equipped with a device to shut off automatically if unattended. Many devices exist to promote safety and support self-sufficiency.

As skills are attained, further advancements can be made. Breaking down goals into smaller objectives enhances success in skill acquisition. For example, meal preparation skills can begin with sandwich making and advance to microwave cooking. Individuals learn at their own pace. People gain confidence and self-esteem while acquiring these independent living skills. With support, each person can develop abilities in preparation for living more independently outside of the family home.

Checklist When Developing a Residential Plan

The following outline offers steps to consider for residential planning with a commentary provided by parents.

- ***Gather Information***

✓ ***Learn about different types of residential programs****.*

Tips from Parents

Attend advocacy group meetings to learn about residential opportunities in your area. Try to keep an open mind about your future options. You may not be able to imagine ever letting your child live away from you, but your circumstances, options and desires can change as you and your child get older.

✓ ***Research, read, participate in webinars, attend lectures and conferences, talk to experts and network with others. Find out what has worked for people with SMS.***

Tips from Parents

Join groups like PRISMS to learn more about the specific needs of people with SMS. Connect with other parents who have similar experiences.

✓ ***Research your options via the internet. The information available pertains to people with developmental disabilities in general. It can be adapted to suit a person with SMS.***

Tips from Parents

Many on-line disability-related resources are available at the local, state and national levels such as:

University Centers for Excellence

http://www.acl.gov/Programs/AIDD/Programs/UCEDD/Contacts.aspx

State Councils on Developmental Disabilities

http://www.nasddds.org/state-agencies/

The Arc

http://www.thearc.org

Autism Speaks

http://www.autismspeaks.org

▪ *Apply for Government (or Public) Benefits*

✓ ***Locate the state agency in your area that serves people with developmental disabilities and determine what resources are available.***

Tips from parents

Contact your state disability services agency and add your child's name to the waiting list for residential services. Keep track of the people you talk to and develop a relationship with them. Help them get to know your child.

✓ ***Apply for Social Security and Medicaid benefits.***

Tips from Parents

Apply for federal funds before your child turns 18. Get connected to "the system" as soon as possible even if you are unsure if you will be accessing these services in the future. Apply for everything. When a name gets to the top of the waiting list, the program will call to see if you are still interested. If you are not, you can always turn it down when offered. You do not have to prove the child's level of disability to be on the list, so apply even if you think your child is too high functioning for that program.

✓ ***Review the types of resources and regulations regarding governmental benefits***

Find more information at:

http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/long-term-services-and- supports.html

Tips from Parents

There are "means-tested" funds and services, such as SSI, that are based on income and assets. After age 18, this "means test" is based on the individual's personal income, not the family's, so the child can become eligible regardless of family income.

*If the family income is low, it is possible that a child with developmental or intellectual disability qualifies for services at an earlier age. Be sure to apply as soon as possible.

▪ *Develop a Vision and a Plan*

✓ ***Assess the strengths and weaknesses of the person with SMS to determine what residential settings best meet their needs. Consider what challenges might present themselves and how to address them. Certain residential models or a blending of their features might be best suited to meet their requirements.***

Tips from Parents

Assess your child's needs. Ask yourself questions like:

- What is the level of need?
- What kind of support do they need with physical tasks and daily living activities?
- What are their sleep patterns? Can good sleep hygiene be supported?
- What behavioral supports are effective?
- What behavioral challenges can be expected? How often? How extreme?
- What interventions work? What interventions are least effective?

✓ ***Write a description of the person including positive qualities and a personal history, and describe their needs, preferences and dislikes***

Tips from Parents

Compile a summary of "what works with my child" to be shared with other caregivers. Individuals with SMS have very specific behavioral difficulties and emotional reactions. Often techniques and regulations that work well with a majority of people with intellectual and developmental disabilities are not effective for those who have SMS. Living situations will need to be tailored to their needs, staff will require specific training on what helps, and what are the triggers that can potentially make things worse. A written list or summary about your child can be helpful to caregivers.

✓ ***Secure funding to implement the plan. If resources are not readily available, advocate for additional resources with state officials and legislators.***

Tips from Parents

Work with your state agency to ensure they know your child and understand the complexities of SMS. Securing adequate funding may take time. Be prepared to advocate. Keep hold of your vision, do not get frustrated and do not accept “no” for an answer. Some families may choose to privately fund their program and avoid public systems.

▪ *Locate Services and Vendors To Implement the Plan*

✓ ***Research local vendor agencies and confirm the quality of their services. Speak with other families regarding their experiences with this provider. Evaluate their ability to address behavioral support needs.***

Tips from Parents

Given their complex behavioral needs, adults with SMS often require a higher level of adult support and individualized program than other adults with intellectual and/or developmental disability. Not all service providers are equipped to meet these needs.

Determine if the agency or program accepts individuals with behavioral challenges and evaluate their protocols.

(Many, especially private programs, do not.) Have your list of questions prepared in advance including:

- How are caregivers trained?
- Are positive behavioral supports utilized?
- Is the staffing level flexible to accommodate emergency needs due to behavior? For example, can additional staff be brought in quickly?
- Is the agency open to receiving people with SMS specifically?
- Do they believe that this genetic syndrome drives the behavior of the individual?
- Are the residential routines individualized so that a person with SMS can utilize their strengths while receiving help with their weaknesses?

✓ ***Visit residential programs to determine how effective the setting is to meet the needs of someone with SMS.***

Tips from Parents

Learn about staffing ratios and specialists that work with the agency such as psychiatrist, behaviorists, physician, nursing staff and support personnel. Inquire about their availability and if these are full or part time staff.

Make a list of your concerns before the visit and ask many questions.

✓ ***Select a service provider that meets high standards of quality. Verify your choice with input and assistance from other sources like case managers, support coordinators or consultants, and our personal network.***

Tips from Parents

The residential setting must be capable of providing the behavioral supports and implementing a plan of action. If they cannot, it is not the right place.

▪ *Monitor the Program*

✓ ***Review quality measures and continually assess quality of life once services are provided. Continue to advocate. It is important to monitor continually the quality of services being provided.***

Tips from Parents

Maintain a relationship with the vendor. Confirm that staff show interest and willingness to learn about the behavioral and learning characteristics of people with SMS. Do they utilize strategies to support positive behavior in people with SMS? Be able to offer any new insight you are learning about SMS.

Keep a list of contacts and know who is involved.

- Who is the program manager? Are you able to contact them?
- Who is available to substitute and how available is that person?
- What is the contingency plan if the caregiver becomes sick or is no longer available?

✓ ***Assess and revise the plan as needed. The plan may not work exactly as initially envisioned.***

Tips from Parents

All settings will require someone to monitor, evaluate and solve problems. Be prepared to meet with managers or the team and assess how things are going. Be thinking of annual goals and keep people involved in the big picture and looking to the future.

▪ *Prepare for the Future*

✓ ***Establish plans for the future regarding special needs trusts, wills and guardianship***

Tips from Parents

Learn about options for saving for your child's future. It is likely they will need public services at some point. A savings account in their name can make them ineligible for funding, so do not start a fund without learning about Social Security eligibility, special needs trusts, or the ABLE account, etc. You can learn about these issues through meetings with special needs estate planners, at workshops and on the internet.

✓ ***Form a Circle of Support enlisting assistance from family, friends, advocates and professionals.***

Tips from Parents

Envision a day when you will not be available to provide oversight or support. Start a process to develop a network of people who are comfortable and willing to serve as advocates.

Resources and Funding

Mainstream resources such as food stamps, rental and utility subsidies can help to stretch the budget for people with low income.

There are two components to the expenses of residential living:

1) Living expenses (rent, food, utilities, recreation and clothing)

2) Support services (e.g. staff, transportation, behavioral supports, therapies and vocational/day activities)

Public funding to cover the two components of expenses of residential living might be provided in total or partially by different agencies or sources. Most of the personal income (which likely will come from SSI benefits) will be spent on living expenses including food, clothing, utilities and rent. Securing subsidized housing vouchers will assist in paying rental expenses. Mainstream resources such as food stamps, rental and utility subsidies can help to stretch the budget for people with low income.

Supportive services (residential support staff, transportation, vocational and day habilitation services, therapies, behavioral support and more) are typically funded by Medicaid Home and Community-Based Services (HCBS) Waivers and are approved through a state agency. When determining the type of residential model, it is important to consider how much supervision, training and care the person needs. The cost of staffing is the single and most significant ongoing item in the budget and can exceed $100,000 annually. Some people can safely spend some time on their own while others cannot. These factors are taken into consideration when an individual budget is determined.

Public Support

Social Security Benefits

At age 18, people with developmental disabilities who are not earning a living that is self-sustaining can apply for benefits through the Social Security Administration. Most commonly, individuals apply for and receive Supplemental Social Income (SSI). Medicaid health care is included with these cash benefits. Other benefits such as long-term care require separate applications. (Go to http://www.ssa.gov for detailed information about these benefits and eligibility requirements) In most instances, sustaining Medicaid eligibility is a requirement in order to receive waiver support through the state agency for individuals with disabilities. Call your local Social Security office to find the best time to begin the enrollment process; it is usually six months prior to turning 18.

DEFINITION OF REPRESENTATIVE PAYEE

Representative payee is a person or an organization who manages the benefits of a person who cannot. The payee uses the SSI benefits the individual receives to pay for the current needs of the beneficiary.
A representative payee must keep records of expenses and provide yearly reports. For more information go to: https://www.ssa.gov/payee/faqrep.htm#&a0=0.

Home and Community-Based Services (HCBS) Waivers

Through the 1970s, the primary residential option for people with developmental disabilities was institutional placement. In the 1980s, the federal government permitted funding for states to offer alternatives to institutional care and funded residential placements in the community. States obtain "Waivers" of federal Home and Community-Based Services (HCBS) funding to supply services for persons with disabilities to live in community settings. Each state submits plans to the Centers for Medicaid and Medicare Services (CMS) regarding the types of supports and eligibility requirements. Such service options may include individual supports, training in independent living, therapeutic services, behavioral and crisis intervention, transportation, supported employment, vocational/day habilitation services, environmental modifications and other supports. When a state distributes all of its designated funding, it can establish a waiting list for people identified “in need” but not presently funded. For information regarding CMS waivers, go to http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/By-State.html.

As an alternative to receiving an out-of-home placement like a group home, a person with SMS may obtain intensive services within a variety of settings including a licensed community residence, one's own home or the family home. With supports delivered in flexible ways, the person has more control to self-direct and use the funds to pay for the services most needed. Typically, when a person is eligible for supports through the state's Medicaid Waiver, an individual budget is developed based upon an assessment of abilities and the needs identified in the service plan. The person can then select supports from a menu of options and a list of qualified providers. Apply as early as possible because waiting lists for residential services can be very long.

When moving to a different state keep in mind that each state has its own rules and regulations regarding waivers with no reciprocal arrangements.

Medicaid State Plan Services

In addition to waivers, each state identifies "state plan services" which are specific benefits to which a Medicaid recipient is entitled. Examples of state plan benefits through Medicaid might include prescription, behavioral health, personal care assistance, nursing care, occupational, physical and speech therapies. To locate the governmental agency for disabilities services in your state, go to http://www.nasddds.org/state-agencies/.

Subsidized Housing, Rental Assistance Vouchers and Mainstream Resources

There are sources of public funding that help offset and supplement living expenses for those with low incomes. These mainstream benefits are generally available to people who rely upon social security and/or earn low wages as their primary sources of income. People with developmental disabilities may qualify for financial assistance programs such as subsidized housing, rental and utility subsidies, prescription assistance and SNAP (Supplemental Nutrition Assistance Program) formerly known as Food Stamps.

Subsidies in the form of rental assistance vouchers may also be available. With affordable housing, an individual meeting financial guidelines pays 30% of their income toward the rent. Rental assistance subsidizes the difference between the tenant's contribution and the actual rent. The US Department of Housing and Urban Development (HUD) publishes a list of Fair Market Rates (FMR) for geographic areas across the country. Subsidized rents must be at or below the FMR for the region. Affordable housing developments may have "project-based subsidies" or a person can apply for a "tenant-based subsidy" that stays with the person when they move from place to place.

Go to http://portal.hud.gov/hudportal/HUD?src=/topics/rental_assistance for more information.

Private Resources

Special Needs Trusts

Special needs trusts are frequently established for individuals with disabilities who receive an inheritance or insurance settlement. When established correctly, special needs trusts permit the person with a disability to have funds available and still qualify for Medicaid and SSI benefits. The funds must be utilized for the sole benefit of the individual with a disability. Each state has its own regulations pertaining to such trusts. Seeking advice from an attorney or a financial advisor who specializes in special needs trusts is recommended so as not to jeopardize governmental programs with means-tested benefits that include income and asset limitations. For information on the basics of establishing a special needs trusts go to http://www.americanbar.org/content/dam/aba/publishing/rpte_ereport/te_lewis.authcheckdam.pdf. For information regarding Social Security benefit requirements related to trusts, go to https://www.ssa.gov/ssi/spotlights/spot-trusts.htm.

The Achieving a Better Life Experience Act (Able)

Enacted into law by Congress in 2014, the ABLE Act permits the investment of funds for the benefit of a person with a disability. Similar to a 529 plan, an ABLE account grows tax-free and can be used for qualified expenses including housing, education, transportation, health care, employment supports, therapies and other similar expenses. There are limits to the amount of annual contributions with a maximum accumulation of $300,000. The ABLE account does not jeopardize Medicaid eligibility but may affect Social Security benefits after exceeding a ceiling of $100,000. Each state must pass enabling legislation defining guidelines, benefits and limitation of ABLE accounts.

When correctly administered, an ABLE account or special needs trust provide additional ways to invest funds to benefit an individual with a disability without risking Medicaid eligibility. It is important that families understand the state and federal regulations and their impact before establishing these funds. Coordination of a comprehensive plan is required. It is advisable to consult with a financial advisor and/or attorney with expertise in these laws and regulations. Go to https://www.federalregister.gov/articles/2015/06/22/2015-15280/guidance-under-section-529a-qualified-able-programs for more information.

Private Payment

Many residential facilities accept private payment for services. Families may not be eligible for public support and choose to cover the cost of services privately, or to supplement services provided through public sources. Check with service providers regarding their ability to accept private placement. It is important to confirm the use of any private funds will not jeopardize eligibility for public benefits such as Medicaid or Social Security benefits.

Parent or Family Established Services

Families may pool resources and raise funds to establish their own residential services. Many might think they will be all set if they raise the money to buy a house. Raising the funds and purchasing a house is just the beginning. It is important to consider that running an independent house and program are time consuming and costly. Hiring highly qualified staff and maintaining staff coverage are challenging tasks for this housing option. Not all families are in a position to supply the ongoing administration and financial burden of sustaining such a residential program.

Guardianship

Adult guardianship is the legal process by which an individual assumes the role of decision-maker for an adult who is unable to make such decisions for him- or herself. There are several types of guardianship including limited guardianship, guardian of the person or guardian of the property.

When people who have the diagnosis of Smith-Magenis Syndrome become 18 years of age, they will likely need assistance managing their affairs, requiring assistance and guidance from family, friends or a legal guardian. If guardianship is necessary, it should be tailored to the person's needs. Strict monitoring must be in place to protect the best interests and preferences of each person. For more information on guardianship go to http://www.friendshipcircle.org/blog/2012/10/16/when-your-child-turns-18-a-guide-to-special-needs-guardianship/ and

http://www.thearc.org/who-we-are/position-statements/rights/guardianship.

Elements of Best Practices

> *Adults with SMS tend to do best with a varied schedule of high interest activities that include a mix of work as well as social and recreational experiences.*

When researching or developing residential models, families should become familiar with current, best practices in order to assure the quality of their plans and the happiness of their family member. Best practices components of quality in residential housing and supports incorporate several elements listed in this section.

Individualized Planning and Design for the Person

Specific person-centered planning based upon the individual's dreams, needs and abilities can be incorporated into the development of a residential plan. Housing design considerations might be necessary to accommodate the specific characteristics of the person with SMS. To create full accessibility, the housing design and living environments must include elements that assure safety, physical accessibility and technology in support of independent living.

Adults with SMS tend to do best with a varied schedule of high interest activities that include a mix of work as well as social and recreational experiences. Such an individualized schedule can sometimes pose a challenge for adult service provider agencies because of the need to arrange transportation and staff support. Ultimately, however, careful attention to setting up and maintaining a well-structured schedule within the day and residential settings can decrease the need for intensive and costly behavioral supports for the person with SMS. (See the bibliography for helpful resources regarding these issues.).

Choice of Where and With Whom To Live

The setting and model of residential services should be determined based upon what best suits the individual, their lifestyle and their family. It is important that the individual has input in deciding where to live and with whom.

Opportunities for Inclusion and Integration Promote the Development of Relationships Among People With and Without Disabilities in the Community

Residential and housing models should promote opportunities for full integration of individuals with and without disabilities into the neighborhoods and communities where they live.

Centers for Medicare and Medicaid Services (CMS) Final Rule on State Transition Plans

In 1999, based upon the Americans with Disabilities Act, the Supreme Court rendered a decision in Olmstead v. L.C. mandating a shift in the way services and supports are provided to people with disabilities. Since that time, states are required to deliver services in the most integrated settings appropriate to meet the person's needs. People with disabilities have a right to live in community settings rather than being isolated in institutions.

The National Council on Disability (NCD) reports that research outcomes over the past fifteen years find that smaller more dispersed and individualized community settings further integration and positive outcomes for individuals with disabilities.

Specifically, greater individual choice, satisfaction, housing stability and higher levels of adaptive behavior and community participation are associated with living in residential settings of smaller size. These findings support the Centers for Medicare and Medicaid Services (CMS) final rule regulations establishing that only settings of limited size and with certain characteristics will be entitled to receive federal Home and Community-Based Services waiver funding http://www.ncd.gov/publications/2015/02242015.

Quality Monitoring

It is never too early to begin researching and planning for the future.

As parents or guardians of children with developmental disabilities, what are the expectations in terms of quality? How can success in a residential situation be measured? These difficult questions might be overlooked in the midst of the daily challenge of coping, lobbying for support, attending meetings, or working to establish a program structure. It is important to step back and consider how things are going from the perspective of the person receiving services.

Quality Monitoring Tools

The following list of criteria or Personal Outcome Measures was developed by The Council on Quality and Leadership in 1993 as a way to evaluate the quality of life for people in supported situations. The list is not prioritized and may include some criteria that are not valid at all times for all families. Yet many of the criteria are basic qualities that most of us take for granted. Using the checklist as a tool for review or evaluation can reveal aspects of a program or residential situation that may need adjustment or modification.

Personal Outcome Measures:

- People are connected to natural support networks
- People have intimate relationships
- People are safe
- People have the best possible health
- People exercise rights
- People are treated fairly
- People are free from abuse and neglect
- People experience continuity and security
- People decide when to share personal information
- People choose where and with whom they live
- People choose where they work
- People use their environments
- People live in integrated environments

- People interact with other members of the community
- People perform different social roles
- People choose services
- People choose personal goals
- People realize personal goals
- People participate in the life of the community
- People have friends
- People are respected

For more than 40 years, The Council on Quality and Leadership has been a leader in working with human service organizations and systems to continuously define, measure and improve the quality of life for all people. CQL offers training, accreditation, consultation and certification services to organizations and systems.

For more information or additional reading go to The Council on Quality and Leadership at http://www.c-q-l.org

Personal Outcome Measures at http://www.c-q-l.org/the-cql-difference/personal-outcome-measures

Essentials for Residential Living

For a person with SMS, quality staff supports are essential for safety and well-being. Having direct supports provided by people who know and understand the person makes a difference in quality of life.

Adults with SMS can pose intense behavioral challenges. They are often quick to recognize inconsistent approaches between one setting and another, as well as differences from one staff or family member to another. They can be quite skilled at “dividing and conquering” by exploiting inconsistencies by behaving one way in one setting for one person and a different way in another setting for another person. For this reason, good communication among staff, the family home, residential living option and additional service providers is crucial for behavior support to be successful.

In order to be effective, support staff must be well-trained, compassionate and consistent. Using the specialized services of a behaviorist to prepare, train and oversee implementation of a behavioral support plan may be needed. All caregivers will need to have training on positive behavioral support.

For a person with SMS, opportunities to socialize are also very important. Having friends within the same household can be a great experience. Other individuals might be disrupted by having many people living together. They may prefer living alone or with one or two people. Choosing the right mix and number of people living together makes a difference.

Privacy is essential. Each person living in a residential setting needs his or her own bedroom Construction or renovations of the home could include accommodations for comfortable lighting, noise attenuation, unbreakable glass and a barrier-free universal design.

Residential supports can be located in a variety of settings. When deciding on housing options, consider what is important to the adult with SMS. Is there easy access to stores, restaurants, banks, places of worship? Is the house in a neighborhood where they have friends, family or employment? What hobbies or recreational activities are available?

Residential Models

Family Living
Individual Models
Congregate Housing in the Community
Intentional Communities
Institutional Settings
Other Housing Options

Overview of Residential Models With Housing and Supportive Services

Many models exist with different levels of staff supports, as supported housing is not a one size fits all proposition. Each can be adapted to meet the needs of people with all levels of ability and support needs. Models described in this guide can be established in any location within a variety of housing structures such as houses, apartments, condominiums, and accessory apartments. Elements of various models can be blended with others to establish customized supports. It is best to select a model based upon who the individual wants to live with and the level of staff assistance required. Over time, an individual's needs might change requiring more or less support. For instance, a person might develop skills and advance to a level where staff is less involved in their lives. Someone else might try one model and find that it does not suit him/her. Conversely, as a person ages or develops a health condition, he/she could require more structured care.

Elements of various models can be blended with others to establish customized supports. It is best to select a model based upon who the individual wants to live with and the level of staff assistance required.

What Are Typical Residential Support Needs of a Person With SMS?

For a person with SMS, opportunities to socialize are very important. Having friends within the same household can be a great experience. Other individuals might be disrupted by having many people living together. They may prefer living with one or two people. Choosing the right mix and number of people living together makes a difference.

Privacy is essential and each person living in a residential setting needs his or her own bedroom with space to be alone. The construction or renovations of the home could include accommodations for comfortable lighting, noise attenuation, unbreakable glass and a barrier-free universal design.

Staffs providing supports must be well trained and consistent to be effective. Specialized services like a behaviorist to prepare, train and oversee implementation of a behavioral support plan may be needed. All caregivers will need to have training on positive behavioral support.

The location where a person chooses to live takes into consideration the things that he or she like to do. Is it important to be able to walk to stores, restaurants, banks, places of worship? Does he want to live in a neighborhood where he/she has friends and family or employment? What are hobbies or recreational activities located that he/she enjoys? Residential services can be located in all types of settings based upon personal preferences.

FAMILY LIVING

Residential programs within family-based settings

Living in the Family Home with In-Home Supports

In-Home Supports are services for individuals who continue to live at home with their family members.

Definition and description:

Individuals with developmental and intellectual disabilities often live with their families or relatives for much if not all of their lives. Government funding may be available for the person to continue to live at home. Through Medicaid Waivers and state plan services, the state agency for disability services may offer a variety of in-home supports including respite, family support, personal care assistance, therapies and behavioral support to eligible recipients. Every state has different services and different eligibility requirements for the programs they offer.

Respite caregivers or in-home staffing can ease the daily load of family members. Additional services can be provided to supplement or enhance the program. Parents and caregivers can receive training on how to utilize positive behavioral supports. Upon graduation from one's educational entitlement, services such as day habilitation, vocational training, job coaching and placement are available through each state's vocational rehabilitation and/or disability services organizations.

Considerations:

Supporting your family member as they continue to live within the home has many advantages. The family can choose resources that are most essential and have them delivered in the home. In some states, relatives can receive remuneration for the personal care they provide. Parents feel secure knowing that they can oversee the level of care their child receives. The person with a disability continues to develop within the comfort of his or her loving family. Supportive services can help ease the caregiving responsibilities of the parents.

When designing this option, contingency plans should be made in the event that this plan is no longer feasible due to aging parents, demands on siblings or increased need for supportive services.

The person with SMS might benefit from living more independently and having to assume more responsibility for him- or herself.

For more information go to:

https://www.disability.gov/resources-parents-caregivers-child-disability/ and

Supporting families- http://supportstofamilies.org/

CASE STUDY

Two case studies are presented below representing two different approaches to a family living setting. Jacqueline lives in the family home as she always has. Paul's family has built a new house large enough to include extended family members. The situations are different, but in each case the family is closely involved in the daily life of their child with SMS living within their home.

CASE STUDY: JACQUELINE'S HOME

Jacqueline was initially diagnosed with SMS at age 13 after numerous incorrect diagnosis throughout her life secondary to various medical issues and developmental delays. Her diagnosis, and our subsequent relationship with PRISMS, was truly a watershed event in our lives. Jacqueline is currently 25 and lives at home with her parents. She is our only daughter of four children, two older brothers, ages 38 and 40 years, and a younger brother, age 23. Her younger brother is currently at home as he transitions to a career after recently graduating from college. This has established a brother-sister bond that was not as strong when younger because Jacqueline required so much more attention with her medical and physical needs than her younger brother. In fact, she sweet-talks him into playing a game of cards with her every night before she goes to bed.

Jacqueline lives in a small town in southeast Missouri with a population of around 40,000. Our home is a 4-bedroom home in a quiet suburban neighborhood with limited traffic and wonderful neighbors who watch out for her. Each day after work she goes to a local gym to exercise, and more importantly, to bond and socialize with her personal trainer, other exercisers, and all staff at the fitness center. Jacqueline also has a small dog, Chevy, who is her constant companion when she travels to our family farm and around her home. During the warmer months, she also rides her 3-wheel-bike in the neighborhood with her dog in the basket on the bike. Even though she loves Chevy dearly, she is already requesting a cat for her next pet.

Jacqueline attended public schools until the age of 21. Through that process she "interned" at a sheltered workshop, VIP, where she continues to work full time days since her high school, graduation. This job situation provides transportation to and from work each day of the week picking her up at 7:45 am and bringing her home at 3:45 pm. At the sheltered workshop she performs light "industrial type" tasks and she is trained in all types of safety programs. She receives a small wage, but more importantly her work gives her a purpose in life and allows her to have a separate work set of friends and acquaintances. The staff is very conscientious of her mannerisms and habits, and they know how to work with her to control any outbursts. In addition, they have social outings and Jacqueline participates in bowling for Special Olympics with most of her co-workers too.

Obviously, Jacqueline is happy with her setting and environment and she likes having mom and dad around. I guess we have always envisioned this would be her adult home or "placement" and we have seldom considered anything else. Jacqueline is independent in many ways and the possibility of other settings is not out of the realm of possibility, but it would have to be carefully scrutinized and need to provide much flexibility. The necessity of watching her diet closely and insuring her medications are taken timely are huge concerns each and every day.

Like other children with SMS, Jacqueline is very social. She functions well in and around adults better than her own peers do, and she is able to go out with us, paid sitters, or mom's adult friends to spend time socially without much incident. We usually purchase her gift cards for her birthdays and holidays for area restaurants so that she can assist with paying for her dinner and then she uses her spending money for the tip.

Meltdowns are far fewer as she has matured and sleep disorders have essentially disappeared. She is able to spend time at home unsupervised for several hours if necessary. This is made partly possible through her proficient use and knowledge of I-phones and I-pads, and her ability to communicate using them as well by texting or emailing on them. For the most part she has taught herself how to work on technology gadgets without training. However, she is very dependent on them and she is not happy without them, especially with dead batteries and no internet access. Jacqueline constantly works on word search in Grade 3 or Grade 4 workbooks while she is watching a video or conversing with a friend on her techno-gadgets.

There are no documents necessarily pertinent to our situation. We did set up a conservatorship for Jacqueline before she turned 18 in order to be "in control" of her affairs, which has proven very beneficial. We are currently completing work on a Special Needs Trust for her as well, which we are convinced is in her best interest. The conservatorship requires us to file a three page written question and answer report annually with the courts, which is very easy to do.

At this point, we seem content with Jacqueline residing at home for the foreseeable future because of the control it provides us, and the fact that she is very comfortable with the arrangement. Obviously, it is not the perfect scenario for us, in our late 50s as we move towards retirement, and there are things we simply cannot do with the requirements of having a young adult with SMS at home. In addition, we have six grandchildren, whom request us to attend their birthday parties and sports activities, and Jacqueline is not always content with these additional plans. Because Jacqueline loves structure in her day-to-day life, these added situations need to be discussed with her well in advance of the scheduled event to prevent a meltdown. This is the life we choose for now and not necessarily the path for all parents to take. Each child's circumstances, requirements and surroundings, and economic factors will require different decisions on a family-by-family basis.

Submitted by Jacqueline and her family.

CASE STUDY: PAUL'S HOME

Paul, now age 47, lives in his single-family home with his parents in Oregon. Also living in the home are Paul's only sister, her husband and teen-age daughter. We do not live in separate apartments inside the family home, but all together as extended family.

Before 2001, we lived and worked in Arizona. Throughout his childhood and early adult years, Paul grew up in a suburban neighborhood with his sister and parents. During a period of three years from ages 15-18, Paul resided in a startup home for troubled teens with two or three other individuals and house parents. This placement was about two hours from our family home, which was difficult for all of us.

Paul is no longer in a residential program. It did not meet his needs. Fortunately, Paul does not utilize any additional staffing support other than caregiving by family members. His mother and family members are paid to provide supports through the provider agency that serves Paul. Since Paul cannot drive, she provides for his transportation needs as well. Paul's weekly routine includes two days per week in a day recreation program, which involves community service, church attendance every Sunday, and other regularly scheduled social events sponsored by the local recreation district and Special Olympics.

Paul also receives two monthly checks from the Social Security Administration. His sister—who is also his legal guardian—is the representative payee for his Social Security and manages his individual funding needs.

Paul is very content living with his family and he does not want to live independently. Within the home, he consistently carries out simple chores such as providing assistance with laundry, dishes and handling the daily mail. Each of the family members sees him as helpful, caring, responsible and cooperative. Both Paul's needs and those of other family members are being met, and there are many benefits to his continued living at home.

Paul's week is now much less structured than when he lived in a group home or foster home setting since his daily schedule is integrated only within the family's routine, not those of other adult clients. He enjoys attending church services regularly. In his former group home, whether or not he could attend church was dependent upon sufficient staffing. In addition, Paul values his "alone" time, and often prefers to enjoy time in his room with television programs, game shows and video games at his fingertips.

As with all SMS parents who arrive at the day when their child becomes an adult, we had to make a decision regarding his future residential placement. Paul's residential setting had taken him far away from us to Nevada for the final years of high school. It came to an abrupt end upon his graduation because of staff issues outside of our control. Would he now live at home or would he live in a group/foster home close by? This decision was not difficult for us mainly because of Paul's personal preference: he wanted to live at home with his family and as a large extended family, we were able to meet his needs.

We faced no significant roadblocks in order to accommodate Paul's coming home from the residential program. There were adjustments made to family schedules and routines. For example, instead of working outside the home, I developed a typing service directly from our home that enabled me to care for Paul and his needs at the same time. Later, when my husband had *an opportunity to take a night position at work, this enabled me to begin teaching during the day. We alternated shifts in caring for Paul.*

We also needed to create Paul's daily workplace setting. After some months of exploring possibilities including Vocational Rehabilitation, which did not work well for him, we succeeded in placing Paul into a sheltered workshop in our hometown.

Submitted by Paul and his family.

It may be helpful for families to know about the resource that is available to them entitled ALL ABOUT ME! One Family's Experience with Smith-Magenis Syndrome.

(It can be ordered from PRISMS website).

When families need to transition their adult with SMS into a residential setting, it is important to consider these questions carefully:

Readiness

- Is your adult with SMS eager or hesitant to move out of the family home?
- Is he/she interested in self-determination?
- What level of self-sufficiency does he or she seek?
- Can the level of independence sought become a reality for his or her future?

Responsibilities

- Who will assume primary responsibility for the person's daily support?
- Who will manage medical appointments and activities?
- What will be the financial impact and/or liabilities involved with the adult living outside the family home?
- Who will be responsible for the management of income and expenditures and deal with Social Security Administration, insurance companies and other legal entities?

Considerations

- What is the likelihood of healthy continuity in the newly considered residential setting?
- Will the staffing of the potential new placement be sufficient?
- What type of emotional and physical security does the new setting provide?
- Will the needs of the individual including health, spiritual, social, psychological and emotional needs be met?

Satisfaction

- Are the existing parents and their children satisfied with this setting?
- Will the person be able to maintain his or her personal interests such as hobbies, friendships and pastimes after the move has been made?
- What, if any, restrictions will the facility place on the person and the family?
- How compatible will the person be with other members of the home?

Host Homes, Support Families, Foster Care or Teaching Family Homes

Support families are paid to provide supports in their homes for people with disabilities.

Definition and description:

Terms such as host homes, teaching family homes, specialized home care and foster care families describe families who open their homes and share their lives with a person or persons with developmental disabilities. The host family receives compensation as well as training. The biological family can continue to play a vital role in the life of their family member. Unlike traditional foster care, support families operate under the auspices of a professional agency that offers respite, training, crisis intervention, therapeutic supports and supervision. Most states set their own standards and regulate these homes through a licensure process.

Considerations:

This model works well for those who enjoy being part of a family unit. It is a cost-effective model embraced by many states. When well matched to a caring family or individual, the person with a disability can enjoy the consistency of supportive family members and develop wonderful lifelong relationships. It is important that caregivers in this model receive the training and support necessary to meet the needs of a person requiring specialized care. Relationships between the natural and support families must be cultivated to assure the best outcome for their loved one.

In this model if the host family does not succeed in supporting the person with SMS, he or she must be moved to another home and make another adjustment.

For more information:

The Mentor Network at
http://thementornetwork.com/program/host-home/

CASE STUDY

ALI'S HOME

Ali, our 28 year old daughter lives in a "Host Home" with her provider, Robin, another client and two dogs. It is a typical suburban home on a quiet street with a beautiful back yard. This is the nearest Ali has lived to us since she went away to school as a young teenager. Living closer to her family has made a huge difference in both our lives and hers.

Our situation was, and is, unique in that we live on a farm in a very rural area of Southwest Colorado and the scope of services is limited. The remoteness of our environment and our decision not to relocate to a more urban area has shaped many of our decisions regarding Ali. Her placement in a residential setting outside of our home began well before she became an adult. At the age of 14, we decided that Ali needed more than what our family and school could provide in our small town in Western Colorado. We had family on the East Coast and were familiar with Camphill Communities. And so, she began her freshman year of high school at a Camphill's residential school in Pennsylvania called Beaver Run.

At the age of 21, her state funding in Colorado through a Medicaid waiver became available. We moved her to Loveland, Colorado where we had begun the initiative of forming a "life sharing" community based on the intentional communities of Camphill Villages. After many struggles, we had to abandon this initiative and Ali moved into a nearby host home. In April of last year, we *finally moved Ali into her current host home in a city of about 50,000 on Colorado's Western Slope, about a two and one-half hour drive from our home.*

The process of finding a host home provider is a fairly simple one. The trick is finding the right one. When Ali decided she wanted to move closer to us, an RFP (request for placement) was sent to the providers in our area. We were lucky in that there were a number of potential host homes to choose from (this is not always the case). Ali's new case manager helped set up appointments for us to meet the various families. Ali was able to spend an extended amount of time with her two top choices, and once she had chosen Robin, an overnight was planned to test their compatibility. Luckily, our choice was Ali's as well. Robin is similar to our family in values and lifestyle. We communicate well and consider each other friends. Our relationship with Robin is crucial to Ali's success.

Ali's current "team" consists of Ali, her parents, her host home provider (HHP), her residential case manager, a behavioral therapist, her day program manager and numerous other individuals. The amount and quality of her services is directly related to how aggressively we advocate for her and what we ask for.

Ali's placement is funded through a Medicaid waiver with the State of Colorado. This provides the bulk of the funds needed to cover Robin's host home, day program, behavioral services, medical equipment and supplies such as hearing aids and non-medical transportation. Ali also receives a monthly SSI check to cover her food, clothing and shelter as well as a small allowance for personal spending needs such as a movie or Starbucks. We often pay for "extras" such as sports equipment and vacations.

Living in a host home is a lot like living with a family. There is no "staff" in a host home and the provider is responsible for most of a resident's care. Obviously, respite care is an important part of the picture and Robin has numerous individuals she can call on to step in when she needs to be away.

Ali likes the family setting of a host home. She likes being part of a community of typically "abled" people, and in general does not do as well in settings with other disabled individuals. There are no "shifts" in a host home setting and the continuum of care provides stability and predictability in Ali's life. The downside of this model is the tendency of a provider to become overwhelmed and eventually "burn out" when faced with the behavioral challenges of caring for an individual with SMS. It is vital, when choosing this model, that the host home provider have previous experience in caring for individuals similar to Ali. They also must be well supported within the developmental disabilities community with respite providers and other support staff. This is the fifth host home Ali has had in the last *six years. We are hoping this one will last well past the "honeymoon period" and beyond. Finding the right individuals to live with Ali has been our biggest roadblock.*

We believe that we are the experts when it comes to our children. As parents, we are often the best resource for those unfamiliar with SMS. Any training and leadership that we can offer to those involved in our child's life is crucial.

I like to think Ali is more like other young women than different. She wants independence, a job and to be her own boss. Unfortunately, her emotional age and impulsive behavior makes this challenging. But it is not impossible. We have great hopes for Ali's life and her future.

Submitted by Ali and her family.

INDIVIDUAL MODELS

Supports tailored to meet individual needs within different types of residential settings.

Lifesharing or Shared Living

An individual shares their home with others who provide care and supervision.

Definition and description:

Lifesharing is defined in Pennsylvania as "Living with and sharing life experiences with supportive persons who form a caring household. The mission of Lifesharing is to enrich the lives of people with disabilities by matching them with a compatible family or an individual who chooses to open their homes and hearts http://www.palifesharing.com/Home_Page.php." In Shared Living, also known as Lifesharing or Shared Housing, two or more unrelated individuals share a home. This model involves people, with or without disabilities, who agree to share housing, expenses and household responsibilities. Typically, each person has his or her own room and shares common areas such as kitchen, living and dining rooms.

Persons of many different lifestyles seek opportunities to share housing. College students, young adults, families and senior citizens pursue this as an option. In some instances, a housemate can receive compensation to provide needed supervision and support for the person with a disability. Other services such as transportation, vocational/employment and additional direct staff support may be required. Usually, living expenses for food, utilities and rent are shared among the occupants.

Considerations:

This setting could provide excellent opportunities to develop close relationships with housemates and inclusion within the community. The success of this model is predicated upon a relationship of mutual respect among the people sharing this lifestyle.

The person with a disability and/or their advocate must be fairly independent and assertive to assure full rights and equality within the household. Strong lifelong relationships can form as a result of sharing a home and lifestyle. Written agreements delineating the financial and operational responsibilities are essential for the success of this housing model. A lease or home ownership defines the stability of housing when housemates change.

In this model, there might be a high rate of roommate turnover.

For more information:

The National Association of State Directors of Developmental Disabilities Services publishes the

Shared Living Guide specifically for people with disabilities that can be found at https://www.nasddds.org/publications/nasddds-titles-for-purchase/shared-living-guide/.

ANCOR offers a sample written agreement for people with disabilities intending to share housing at http://www.ancor.org/resources/best-practices.

The National Shared Housing offers generic resources to home providers and home seekers at

http://nationalsharedhousing.org/.

Supportive Housing Including Supervised Apartments, Supportive Living and Independent Living

Individuals live in their own homes or apartments and receive support from paid staff or companions.

Definition and description:

The terminology, degree of staff support and specific regulations differ from state to state in these supported models. Supervised apartments and supportive living refer to options for those who can live with some independence with paid staff support assistance as needed.

In some models, staff lives on the premises and provides support and assistance as needed. Residents receive supervision, training and assistance in areas of need including cooking, money management, activities of daily living (ADLs), coordination of medical care needs and other areas as determined to be needed and based upon the state's funding.

On-call procedures are in place in the event of an emergency. Housing rental vouchers can be secured to assist with the cost of rent.

Considerations:

In these homes, individuals with different abilities can live alone or choose to share their house or apartment with another person. Occupants control their housing through a signed lease to maintain their legal right of occupancy when caregivers change.

For more information:

Contact the Supportive Housing Association or Independent Living Centers in your state.

CASE STUDY

CHARLEY'S HOME

Charley is 31 years old and lives in his own home – sometimes called "a home of your own" - in southern New Hampshire. This small, single-family house was purchased by his family in 2007. Currently, Charley shares his house with two live-in companions who are employed by a vendor agency. They provide full-time support for Charley, 24 hours a day, 7 days a week.

When planning for his adult life, we envisioned Charley living in a neighborhood setting with supportive companions, and being part of the community where he was raised and developed many relationships. We believed that owning his home would create a more stable residential placement, and there would be less of a chance that Charley would move from place to place.

We developed our vision for this program from a variety of sources. We attended many conferences and workshops offered by family support groups and other organizations such as the NH Institute on Disabilities (the "University Center of Excellence") in New Hampshire at http://www.iod.unh.edu or for a CoE in your state visit http://www.aucd.org. We joined family-

based networks of support and learned from others who were exploring options for their families. And before he turned 18, we connected with the NH Department of Health and Human Services and staff who guided us through the process of building a program for Charley.

It took us almost a year to prepare the house, to find a roommate and for Charley to understand what it would mean to live away from his parents. With the help of a program manager, Charley began to spend weekends away from the family and to develop confidence about this new situation.

In 2008 when Charley first moved into his house, the family managed all aspects of his program. The program was a "Consumer Directed Program." We hired and supervised staff and managed all the administrative details. This structure required full involvement from the family – we needed to step in should someone be sick or need a vacation. We provided all reports required by the state, coordinated care for Charley and much more.

The scope of these program responsibilities proved too much for the family, and in 2011, we changed to a "Community Program with a Vendor Provider" and hired a service agency to run the program. The responsibilities for hiring and supervising staff, tending to administrative details, meeting certification requirements transferred to this agency.

Even with a vendor agency, the family is still deeply involved and very connected with Charley. We interact regularly with Charley and his companions – and we also are members of the planning team.

Funding for the program comes from a variety of sources. Charley has a Medicaid waiver through the NH Department of Health and Human Services. This provides the bulk of the funds needed to cover the cost of the vendor services. Charley also receives Supplemental Security Income benefits that are used for residential and daily living expenses. Some operating and upkeep expenses for the house are paid by the family via a special needs trust.

If it sounds complicated – it is. The structure of the program has developed over the years. We have hopes that eventually operations will be routine, the program self-sustaining and direct responsibilities for the family will diminish.

Qualitative information:

It is hard to imagine another type of program for Charley. At different times, we have asked "experts" to conduct a visit and evaluate what is in place. Each time we are encouraged to continue the program.

We believe Charley is mostly happy with this setting – but his happiness is very hard to measure. In this setting, he has many opportunities to engage with others in his community. These interactions motivate him and lead to "natural" and sincere relationships with others. We believe he learns and grows from these experiences. Like most people with SMS, the opportunity to socialize is very important for him. As he matures, he has more and more opportunities to facilitate these relationships on his own.

It took some time to lobby for the funding needed to support him. As a person with SMS who can have extreme behaviors, Charley's need for support was very clear. These needs placed him high on the waiting list for services.

The greatest challenge to building a successful program has been with staffing and finding people who Charley is comfortable with and who enjoy this work. People who work directly with Charley need to establish a sincere and honest relationship with him. There have been moments where Charley has been aggressive and in turmoil – staff need to be positive, to be able to look beyond those moments and remember the bigger picture.

Another challenge is maintaining a clear and shared focus amongst everyone involved in the program. As staff cycle into place - whether they are managers or direct support workers - there is a great risk that they will not understand how and why things are the way they are. It is difficult to keep the necessary documentation current and ensure people are trained, oriented and committed to program goals. Providing training and guidance for staff, and supporting positive relationships within the team is an ongoing process that takes deliberate effort.

Our advice for other families would be to begin now to develop relationships in your community, join and participate with disability groups and ask how others are supporting their family members. Be connected with the disabilities community such as the family support council, disability rights leaders and more. Get to know who is around you, keep notes with names of people you have met or heard about and do not be shy about introducing them to your family.

Submitted by Charley and his family.

CONGREGATE HOUSING IN THE COMMUNITY

Settings where several people with disabilities live and are supported by trained staff.

Residential Living Including Group Homes and Community Residences

Definition and description:

A group home or community residence is a living arrangement where a small group of people with disabilities who need care and supervision live together with supports and services. Homes are established in all types of neighborhoods. A provider agency employs and manages the operations of the home. A state entity regulates and licenses the home. The sizes of group homes vary but tend to be small with four to six residents. Direct support staff are available, often in eight-hour shifts throughout the day, and depending upon the needs of the residents can be as much as 24/7 including overnight awake support. Staff provides training for the individuals with special needs in the skills of daily living and personal care as needed. Residents, with staff support, share responsibilities for cooking and household chores. Ideally, each person has a private room and shares common space including the kitchen, dining, living and recreational areas. Group homes should provide opportunities for the residents to develop friendships and participation in the local community.

Considerations:

With good staff that are well trained, families get a break knowing that their young adult is being cared for around the clock. Staff in group homes are responsible for setting up and bringing the clients to appointments, activities (i.e., art lessons or the gym) on outings (movies, fairs, malls), and food shopping. The residents in group homes have a built-in extended family made up of peers (even if varied in age) and caretakers to provide attention and support.

Compatibility of the individuals living together is significant to one's quality of life; the residents of the home should mutually decide upon rules and shared responsibilities of the household. Ideally, each person should get to select the housemates with whom he or she will live. This is difficult to achieve in a group home model especially because the state agency funding the home is responsible for filling it with residents.

The turnover rates of staff providing direct support in group homes is high. This can disrupt the continuity of services provided within the home causing the potential for unrest in the clients.

For more information:

An on-line directory of available residential housing options throughout the United States can be found at https://www.autismspeaks.org/housing-catalog.

ANCOR is a national non-profit organization representing over 1000 providers of residential services at http://www.ancor.org/.http://www.ancor.org/

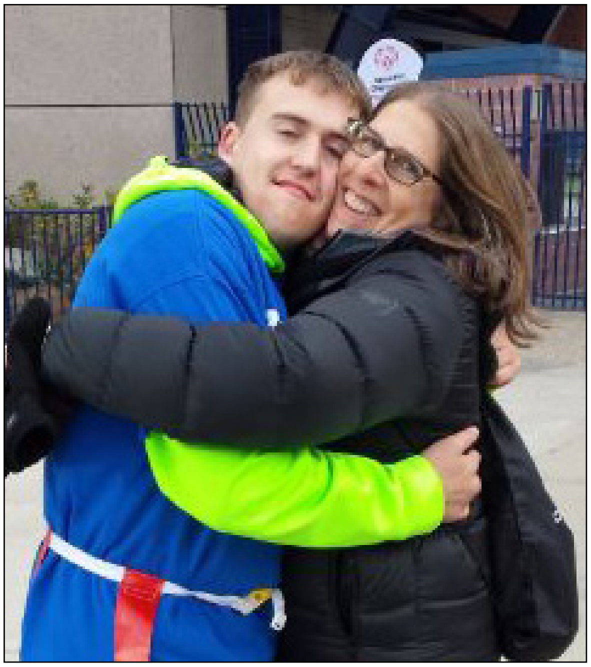
CASE STUDY

ZACH'S GROUP HOME

Zach, age 24, lives in a residential house in our hometown in eastern Massachusetts. It is just three miles down the road from the house where he was raised and where we still live. Zach moved into his new home on the day he turned 22, the state directed time when districts no longer support children in educational settings. It is when your now young adult, who is hopefully under the auspices of an agency such as Department of Developmental Services (DDS), becomes eligible to receive services. For seven years prior to moving into his group home, Zach lived in residential schools in our state that were fully funded by our school district. Because of his behavioral support needs, Zach ranked as priority I for an adult placement. That meant that he was eligible to receive full funding for housing, a day program and transportation fees all to be covered by DDS. Despite Zach's eligibility, it was a lot of work to make everything happen.

Zach's current house is a co-ed with all five young adults turned age 22 within six months of one another. All of Zach's housemates have varying degrees of developmental, intellectual and behavioral issues. The staffing ratio during the day was originally set at two staff to five residents. Because of the unpredictability of Zach's behavior and its domino effect on the other residents, the staffing levels increased to three and sometimes four staff as needed. Staff shifts are 8 hours, 24/7, with staff who are awake overnight, 365 days a year.

As all of the young adults go to day programs, so unless need be, the house is not typically staffed weekdays between 9 a.m. - 3 p.m. An example of need would be when an individual is ill, has an appointment or refuses to go to his or her day program. Staff are responsible for taking the individuals to appointments and activities. Parents are welcome to do so if they choose. The house manager (house specific), the residential coordinator (oversees several houses) and a behaviorist (for the entire agency), as well as the housing agency are available at any time via phone, text or email.



Zach and his mom Leah at Flag Football Special Olympic Games.

All of the services Zach receives are funded through DDS. Additionally, both the housing and day programs get revenue from fundraising and private donations. Zach receives a monthly benefit checks from Social Security Income (SSI) with 75% of that check going to the housing agency. A portion of any money Zach earns is used to pay for food, utilities and transportation. We *are Zach's legal guardians and choose to maintain control over his finances, whereas other families choose to relinquish this responsibility. Each family does what works best for them.*

Zach had been in residential schools since he was 15 years old and he became accustomed to living dormitory style with approximately 10 kids in a staffed setting. This was great because Zach is so social and there is always someone around to engage him. We started working on Zach's post-age 22 plan when he turned 16. At that point, he was acclimated to his residential setting. It became clear to us that as an adult Zach would not be able to live in our home, nor would he be able to live independently. We went to countless workshops, seminars and meetings in an effort to understand how the system worked and learn what we needed to do to ensure support as Zach approached age 22. Because his behavior "off the charts difficult" he was able to maintain his priority 1 status on the waiting list for services. This pretty much guaranteed that he would receive waiver funding for housing and supportive services. In our state they did not let us know until about six months before Zach's 22nd birthday regarding exactly what benefits he would receive.

So how did we work towards getting a residential placement? We started working on it from the moment he was born. Really! From the time Zach was a baby we had regular evaluations, therapies and professional meetings. Most importantly, we made sure to contact and cultivate relationships with the appropriate agencies that would be involved in our lives for the long term. Because we had no idea what Zach's adult needs would be, we wanted to be prepared for and help direct the outcome. Around the time Zach turned 15, we started inviting DDS coordinators to his annual Individualized Education Plan (IEP) and all other school or team meetings. When Zach turned 18, we started planning in earnest with our DDS transition coordinator. We had many conversations about what would best suit both his needs and ours. You have to think about your priorities. For us, we wanted to see Zach in a safe place, with his own room, no more than five young adults and with appropriate staff. Equally important, we wanted Zach to live very near us and on a public transportation route, as he can do some independent travel.

When Zach turned 20, we visited several housing agencies and explored day programs in an effort to see what would be the best fit. Given the behavior issues displayed by individuals with Smith-Magenis, as well as the developmental and intellectual disabilities, our options were quite limited. As Zach was closing in on age 22, we got confirmation that the housing agency we selected would purchase a house in our area, and confirmation as to which day program he would attend. This gave us some time to work with staff in both locations in an effort to prepare them for how to best work with Zach.

We are very satisfied with the housing and day program that Zach attends. Do things need continual tweaking? Yes, they do. Is it critical to stay in close contact with the behaviorist, the residential coordinator and the house manager, all of whom work closely with Zach? Absolutely. Zach alternates between being happy and disgruntled with his setting when he does not get his way and when he cannot control everything. What is important for us is when we walk into Zach's house; we hear laughter, joking and see smiles on the residents and the staff faces. That tells us more than Zach's words. It lets us know he is happy and that we made the right choice, at least for now. Like any setting, there are glitches, staff that do not work out, rules that need to be changed and other issues that need addressing. This *makes having open communication between the program staff and the family imperative.*

It took some time for the house to settle into a good functional routine. Does Zach's housing model continue to be a good fit for him? In short, this is not clear. There has been a lot of staff turnover which makes progress for the residents difficult. For Zach, that meant a loss of independence and skills he had developed in his residential schools. At times it appears as though the kids were ruling the roost. With the other families we worked with the agency's management as they shifted their goals, added new staff and brought in a new manager. They are now on track and things are improving. Communication was key in this effort. Without it, effective change cannot take place.

One of the tools used for accountability and measurement of outcome is an ISP, an Individualized Service Plan. It is the adult version of an IEP. Written in the ISP are a strong vision statement, goals, objectives and interventions unique to each young adult. Zach's ISP was developed by his team including his DHS coordinator, house staff, day program staff, mom and dad and most important, Zach. He has a say in the direction of his life goals and it is our collective job to work towards that end.

Our advice to other families as they begin to transition their young adult with SMS into a residential setting is that there is no one who can tell you what to do. No one size fits all and no right answer. Your child might live with you forever, or your child might need to live in an alternative setting that could start at any age. The decision is yours, based upon what works best for your family and your child. The best thing is to think hard about what quality of life you want for yourself, your family and your child with SMS. Then look around at what opportunities are available to you. Make sure to start when your child is young, cultivate relationships, and most important, keep the lines of communication open and transparent. Also, trust your instincts. You are your child's best advocate and support.

Submitted by Zach and his Family.

INTENTIONAL COMMUNITIES

Settings for People With Disabilities Created by Organizations With a Specialized Interest or Philosophy

Definition and description:

Another concept in congregate living pertains to intentional communities. These living arrangements are often developed around a shared philosophical or religious belief system. These communities are located in a variety of settings that further define their purpose. Those sharing this lifestyle may include multiple generations of people with or without disabilities. In some instances, people without disabilities volunteer or receive a stipend for assuming care-giving responsibilities.

Because people with disabilities have a right to live in most integrated settings, the Centers for Medicaid and Medicare (CMS) have taken a strong position to exclude the use of HCBS Waiver funding within Farmsteads or Gated Communities. Published as a Final Rule, CMS also prohibits waiver funding to be applied to settings where persons with disabilities live and work at the same location. Each state has submitted a transition plan of how they will meet these requirements. This ruling presents a monetary consideration for persons with disabilities who desire to live in a large congregate setting. It is recommended to confer with state officials regarding what can be approved for funding when considering a congregate model.

Considerations:

Members of intentional communities tend to hold strong commitment to supporting people with disabilities.

Federal Medicaid waiver funding may not be available to support intentional communities if settings segregate people with disabilities.

For more information:

As stated on their website, the L'Arche Community was initially founded based upon a Roman Catholic tradition. Today, it is ecumenical and open to people of all lifestyles in 40 locations internationally. The mission involves people with and without disabilities living communally. Their vision is that "People of differing intellectual capacity, religion and culture can come together in unity, faithfulness and reconciliation. L'Arche enables all people to share their lives in communities of faith and friendship. Community members are transformed through relationships of mutuality, respect and companionship as they live, work, pray and play together at http//: www.larcheusa.org."

Camphill Village was established in the 1960s as an alternative to institutional care. It was founded upon a philosophical commitment to provide opportunities for people with disabilities to lead enriched lives within the support of a larger community. "Camphill Village is based on the active affirmation of the dignity, spiritual integrity and valued contribution of each individual http://www.camphillvillage.org/." Operating in several states, people live and work within small family-like homes located within the village. Multi-generational volunteers are recruited internationally to live and work within this campus setting.

Farmsteads, Ranches and Retreats

Settings organized around shared work in a rural environment

Definition and description:

Small businesses like farming, ranching, hydroponic gardening and their associated activities create the need for an integrated workforce to maintain the workflow. Located on larger properties, this model of living has the ability to create small congregate housing on the premises. Farmsteads, as agricultural communities, have existed for decades and are re-emerging as an option for people who enjoy the routine and structure of farming. In rural settings these models can isolate people with disabilities who live and work on the same property.

Considerations:

These settings provide opportunities for those who enjoy the outdoors and an active life.

Working and living at the same location with the same people might limit one's ability to lead a fully integrated lifestyle.

For more information and examples:

Farmstead New England in New Hampshire provides opportunities for a person with autism and other developmental disabilities to lead "a meaningful and satisfying life" as a contributing member in a rural farm community http://farmsteads-ne.org/. Three people with disabilities and one person without live in their own one-bedroom apartments that are interconnected within a cluster.

Established in the 1980s for adults on the autism spectrum, Bittersweet Farms has four sites in Ohio. Their website purports that the farm "provides supportive and well-structured programs that emphasize meaningful activities and work, and an avenue for using special talents and abilities. The goal is to increase autonomy and self-reliance, empower choices, maximize dignity and encourage interaction through vocational, residential, community living, transitional school and recreational programs http://www.bittersweetfarms.org/."

Eric's Ranches and Retreats provide guest rooms for visitors on a ranch in Montana or in a guesthouse in Minnesota http://www.eriksranch.org/index.html. These small businesses create employment opportunities in addition to a place to live. The guesthouse is located in the city. People living on the premises are employed in service positions including giving tours of the historic neighborhoods, in the operation of the bed and breakfast facility.

Pinchbeck Rose Farms employs people to operate their greenhouse in Connecticut where they commercially grow flowers through a business called Roses for Autism http://www.rosesforautism.com/.

Gated Communities, Campuses and Villages

Planned communities for people with developmental disabilities

Definition and description:

Communities have been developed for people with disabilities resembling models utilized by senior citizens. Gated communities offer enhanced safety and security measures. Onsite services such as transportation, recreation and meal preparation are available. Some communities offer a continuum of care options including skilled nursing care to meet a person's needs.

Considerations:

Gated communities, designed for people with disabilities, include enhanced safety features, barrier-free design and other amenities. They can be large and tend to be isolated from the larger community of people without disabilities. Such communities may not qualify for federal funding if located in settings that tend to isolate people with disabilities from the community.

For more information:

For a listing and description of several residential communities go to http://www.downhomeranch.org/resourcesresidential.shtml .

Noah's Landing in Florida is designed for people with developmental disabilities. It resembles a retirement community with individual housing units, security features and on-site amenities http://noahsarkflorida.org/residential-options/the-villages-at-noahs-landing/.

Project Freedom is a non-profit organization that develops and operates barrier-free housing to enable individuals with disabilities to live independently http://www.projectfreedom.org/.).

CASE STUDY

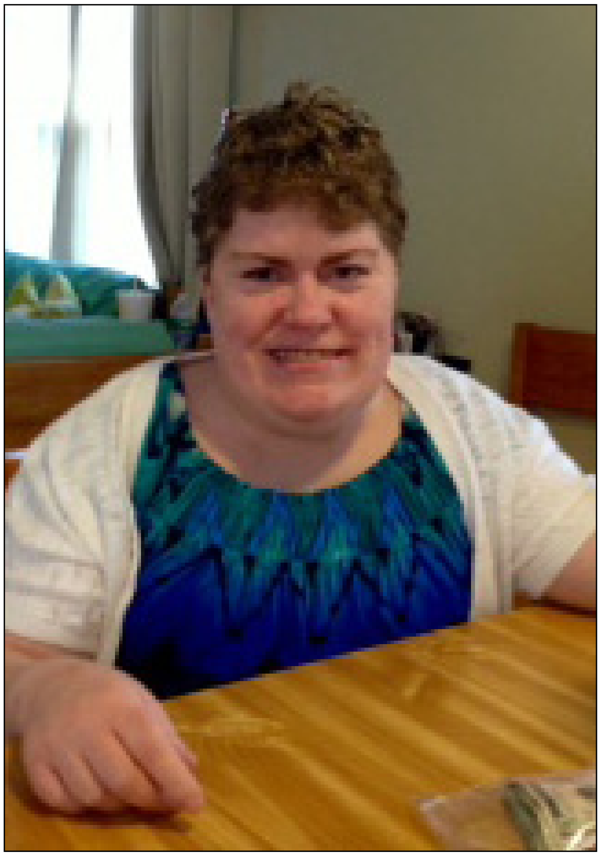
CHRISTY'S HOME

Christy was 17 when she first went to the group home campus settings at Bancroft Neuro Health in New Jersey. At that time her older sisters were in college. Christy accepted the notion that she would be going to Bancroft "Special College". She was going to learn a skill so she could get a job.

At that time, we did not know of her SMS diagnosis. Her teachers from her school attended a conference at Elwyn. They learned about SMS and were sure that the diagnosis fit Christy. They contacted me and encouraged me to have her tested. The blood work confirmed that Christy did indeed have SMS. Christy was 18 at that time.

Bancroft Neuro Health's programs include Elementary/Middle School, High School, Vocational, Post-Secondary and Transition School. Bancroft and Bancroft Neuro- Rehab, as well as their day treatment provides a range of residential, vocational and therapeutic services for children and adults with autism, acquired brain injuries and other intellectual or developmental disabilities. Services include physical, occupational and speech therapy, cognitive rehabilitation, neuropsychological testing, counseling, behavioral supports, vocational training and life-skills instruction. They operate a few group homes on a campus type of setting. Their website is www.bancroft.org.

When Christy graduated at 21, she went to a new group home and vocational center operated by Bancroft Neuro Health. While Christy is bright and capable of working at a job skill, her behaviors have limited her success. She is still very hyperactive and easily distracted. Her



oppositional/defiant behaviors make it difficult for the staff to get her to do anything she does not want to do. They use a token reward system with some success. They are limited in their abilities to harness her skills on a regular basis. Presently at the vocational center, Christy works on making dog treats and beaded bird toys. She excels best however, at sales convincing people to buy these items.

Her group home is in a lovely residential neighborhood. It took a few attempts before finding the best compatibility with housemates. Fortunately, the agency operates several group homes. In her first few group homes, she was placed with all females with various disabilities. They found the competition between the girls was too much for staff and Christy to manage. Christy now resides with three men with autism. Initially, we were resistant. We were fearful for her vulnerability to aggression or advances by the men. This home, however, proved to be a better situation for Christy. The men are non-verbal and somewhat fearful of her. The agency always provides a female staff to assist her. Christy really only seeks the attention of the staff.

Her group home is a split-level with the men upstairs. She has her own bathroom, bedroom and family room downstairs near the staff office. She has a 2:3 ratio of staffing. They implement a token review/reward system to promote positive behaviors. She has several loving caretakers. There have been few turnovers at the group home with many more at the vocational center. Christy has many activities in the community where she goes shopping, bowling, or to the movies. She competes at Special Olympics in track and bowling and sings in their choir, called Joyful Noise.

Christy comes home every other weekend and for extended visits over holidays. She is happiest when she is home, but she is ready to go back at the end of a weekend. Christy is now age 39. We have learned to trust that the staff has her best interest at heart. They have learned to "enter her dance" and I am so very grateful.

Submitted by Christy and her family.

INSTITUTIONAL SETTINGS

Controlled environments with specialized services for individuals who need extensive supports and a high level of care or supervision.

Intermediate Care Facilities (ICF)

Definition and description:

ICF refers to federal funding and regulations within facilities pertaining to the Intermediate Care Facilities. Both large state operated institutions and some smaller community facilities are regulated under these standards. People living in such settings require an institutional or nursing level of care and receive "active treatment" to develop their skills, health and well-being. Each person receiving such services should live within the most integrated social and physical setting as possible while continuing to have their needs met.

Nursing Homes

Definition and description:

Nursing homes exist for those with medical needs that require skilled nursing care. An assessment must indicate that a nursing home level of care is required in order to approve admission to long-term care within such a facility. Nursing homes tend to serve people of advanced age and health care needs that may not be compatible for younger people with disabilities.

Assisted Living

Definition and description:

With assisted living, people live with some independence with supervision from paid caregivers.

Each person has their own space in a small housing unit that is located near others who require similar supports. Meals may be prepared independently or served within a community dining area. Nursing and medical care is available along with monitoring of medication and additional therapies. People residing in this long-term care model can come and go independently if they are capable of doing so.

Considerations:

Institutional models are based upon a medical model serving people in need of skilled nursing care. They tend to serve large numbers of people within each facility with limited opportunities for community involvement.

For more information:

Locate the Department of Health or senior services in each state for a listing of these facilities.

OTHER HOUSING OPTIONS

Unique, innovative and/or specialized housing solutions.

Supportive housing is a combination of housing and a range of consumer-directed supportive services helping people to live productive lives in stable housing with focus upon integration into the community. Go to https://www.en.wikipedia.org/wiki/Supportive_housing for more information.

Hybrid or Reverse Integration

Definition and description:

To strengthen access to community involvement, housing developments can be designed to include apartments that accommodate people with and without disabilities. Developers secure funding to establish complexes of affordable housing units and designate a portion of the apartments for people with disabilities. These settings of integrated housing are referred to as hybrids or reverse integration.

Funding for affordable housing developed through the US Department of Housing and Urban Development as well as Low-Income Housing Tax Credits program require affordable housing developers to set aside a percentage of apartments for people with disabilities or special housing needs.

Considerations:

Opportunities to live among people without disabilities promote the development of relationships and inclusion into the community. Affordable rental rates are determined by federal regulation. There may be opportunities for housing rental assistance within these units of housing.

For more information and examples:

Hope House supports people with disabilities to live in homes/apartments of their own or within integrated housing that the Foundation owns and operates at http://www.hope-house.org).

Cohousing

Definition and description:

"Cohousing is a type of intentional, collaborative housing in which residents actively participate in the design and operation of their neighborhoods. Cohousing provides the privacy we are accustomed to within the community we seek http://www.directory.cohousing.org." Residents of such planned communities share a commitment regarding the value of caring for one another. People of all ages and lifestyles live within these small neighborhoods, and members share a mission whereby all residents assume the responsibility of caring for the members of their neighborhood and of maintaining commonly owned property. Although these communities are not established with intention for people with disabilities, they provide an accepting and caring place to live.

Cohousing designs enhance interaction of residents with common areas including parks and community rooms that enhance socialization while also providing for personal space. Retirees and persons with disabilities can benefit from design considerations built into the housing for comfort, economy and accessibility.

For more information and examples:

Some existing cohousing communities include Tierra Nueva Cohousing in Oceano, California; Sonora Cohousing in Tucson, Arizona; and Sunward Cohousing near Ann Arbor, Michigan. Go to http://www.daybreakcohousing.org/ for more information

Accessory Apartments or Cottages

Small housing units

Definition and description:

Renovations of the family home can create a personal space within a suite, garage, accessory apartment or small cottage. Elder Cottage Housing Opportunity (ECHO) is specifically designed to support an elderly family member on the same property as the extended family. This concept can be applied to persons with disabilities. An ECHO home is a temporary structure and when living requirements change, the ECHO Cottage can be removed. Such housing offers a safe place in close proximity to family with more independence and privacy.

Similarly, Tiny Houses are very compact housing units that are mobile and can be installed on the property of extended family to provide a personal space for a loved one. Such physical housing options may include ECHO Cottages, Granny Flats, Elder Cottages and Tiny Homes that can be located on property adjacent to the family home.

Considerations:

These housing options may not be readily available in all areas. Check with local regulations before establishing such housing units as zoning regulations may restrict development of accessory housing.

For more information:

ECHO Cottages at http://www.echocottages.com/

Elder Cottages at http://eldercottages.com/

Tiny Homes at http://thetinylife.com/what-is-the-tiny-house-movement/

Home Ownership

Homes owned by a person with a disability

Definition and description:

First-time homeowner mortgages are available for a person with a disability to purchase a home.

Considerations:

Ongoing maintenance and expenses involved with home ownership must be taken into consideration with this plan of living. The advantages of home ownership involve stability, security, building equity and creating a home design that meets personal requirements.

For more information:

Contact your state's Housing Mortgage Finance Agency or local banks regarding first-time homeowner's mortgages or financing programs for people with disabilities.

Co-Operative Ventures

Housing developed by an organization of families and/or developers

Definition and description:

Co-Operative Ventures is one where families pool their resources to develop a residence. The organizers of such a venture must consider the model, size, complexity and their level of commitment to the project. Grants to establish affordable housing are available. Parents developing residential services of their own must contemplate who will own and who will be responsible for administering the residential program. There are several options including forming a legal entity to own the project. A parent run organization can also sponsor the development of housing through a for-profit or not-for-profit corporation. Another alternative is to establish the home ownership, lease the housing and employ a provider to administer the services.

Considerations:

In developing and administering such a venture, the leadership maintains close control over the quality of the housing and services. The responsibility and commitment of time to administer such a residential program cannot be underestimated including hiring and supervising personnel. There are numerous regulations in place to address issues such as zoning, building code requirements and licensure. The provider assumes responsibility for the lives and well-being of the residents. Emergencies can occur with frequencies that require administrative attention. The founders must determine a contingency plan in the event that they are no longer able to lend time and/or resources to this cooperative venture.

For more information:

Go to http://specializedhousing.org/ for information about a co-operative venture in MA.

HUD has informative materials regarding home ownership and mortgages for first-time homebuyers at http://portal.hud.gov/hudportal/HUD?src=/topics/buying_a_home.

The National Capital Bank publishes a guide called Home Base: The Playbook for Cooperative Development that thoroughly describes the generic concepts and development of cooperatives at http://www.uwcc.wisc.edu/pdf/Home%20BaseBook.pdf.

Note: The services referenced in this document are for illustration purposes only. They have not been vetted or endorsed by PRISMS.

Promote the Work of PRISMS

We hope that this publication proves to be a valuable resource for families in the SMS Community.

As we continue to grow and improve programming for the SMS community, PRISMS depends on generous gifts and contributions from people like you. With your support, PRISMS can continue its mission.

There are many opportunities to become involved and work with others across the country and internationally on issues important to the SMS community.

- Join us by becoming a member.
- Send your tax-deductible contribution so PRISMS can continue to disseminate valuable information to support families. A donation, no matter how small, helps PRISMS achieve our mission. Contributions can be made online through our website (http://www.prisms.org/us/how-to-help/make-donation) or mailed to:

  PRISMS, Inc
  PO Box 206528
  Dallas, TX 75230-6528

- Volunteer positions are available to serve on advocacy, fund raising and advisory committees as well as on the Board of Directors.

Many people give their time, resources and talents to benefit people with SMS. If you have time, talents or resources to share, contact PRISMS at info@prisms.org.

DEFINITION OF TERMS

Consumer-Directed or Self-Directed Options

Most states offer consumers and their families the option to direct their own services or to select a service provider(s) to supply the residential supports. With a self- or consumer-directed model, the consumer/family assumes responsibility for coordinating the service they will receive. For example, they interview and hire the direct support staff. The consumer/family assumes responsibility for coordination of the services that they receive from one or more providers. Typically, a fiscal intermediary pays the expenses once the consumer approves the expenditure.

With provider agency driven services, the individual, with their family, selects the entity who delivers the package of services. The decision regarding self-direction is a personal choice largely based upon the commitment of time and energy available. The decision to self-direct is flexible and can change as circumstances warrant.

Positive Behavior Support is defined as the integration of rigorous, science-based knowledge with applied expertise driven by stakeholder preferences, values and goals within natural communities of support. Go to http://www.apbs.org/evidence-based-practice.html for more information.

Fiscal Intermediary is an entity responsible for the fiscal administration of a person's self-directed budget. The fiscal intermediary pays the bills after the consumer authorizes that the expense was incurred. In some instances, the intermediary serves as the employer of record assuming responsibility for insurances, taxes and withholding expenses for the direct support staff hired by the consumer.

Gentle Teaching is a technique for working with children with difficult behaviors that has evolved into a philosophy to support persons with all types of disabilities. Gentle Teaching helps individuals feel safe and affirmed, so in return they affirm others and develop and maintain meaningful relationships. For more information go to http://www.gentleteaching.com

Guardianship - Adult guardianship is the legal process by which an individual assumes the role of decision-maker for an adult who is unable to make such decisions for him- or herself. There are several types of guardianship including limited guardianship, guardian of the person or guardian of the property.

When people with the diagnosis of Smith-Magenis Syndrome become 18 years of age, they will likely need assistance managing their affairs, requiring assistance and guidance from family, friends, or a legal guardian. If guardianship is necessary, it should be tailored to the person's needs. Strict monitoring must be in place to protect the best interests and preferences of each person. For more information, go to http://www.friendshipcircle.org/blog/2012/10/16/when-your-child-turns-18-a-guide-to-special-needs-guardianship/ and http://www.thearc.org/who-we-are/position-statements/rights/guardianship.

Microboards - John Shea writes of his experiences and definition as "A microboard is a non-profit society of family and friends committed to knowing a person, supporting that person and having a volunteer (unpaid), reciprocal relationship with that person. Some microboards become the entity through which paid services and supports are provided. Involvement, caring and standing by the person are valued over technical expertise." Go to http://www.dimagine.com/page19.html, http://www.allenshea.com/ and http://www.communityworks.info/articles/microboard.htm for more information.

Personalized assessment assists planning for the level and types of supportive services required. The Supports Intensity Scale at http://www.aaidd.org is a standardized measure utilized in many states to identify the intensity and scope of supports that a person needs to live as independently as possible. It is used in person centered planning to identify preferences, skills and life goals.

Person Centered Planning is an individual planning procedure that centers upon individual's gifts, talents, inclinations and achievements. In the case of an individual with a growth-related handicap, stress is placed on the individual, their relatives and the reinforcements required allowing the individual to make selections, engage in the community and attain dignity. Go to http://psychologydictionary.org/person-centered-planning/ for more information.

Positive behavioral support is a behavior management system used to understand what maintains an individual's challenging behavior. People's inappropriate behaviors are difficult to change because they are functional and serve a purpose. These behaviors are supported by reinforcement in the environment. For more information, go to https://en.wikipedia.org/wiki/Positive_behavior_support.

Representative payee is a person or an organization who manages the benefits of a person who cannot. A payee uses the benefits to pay for the current and future needs of the beneficiary. A payee must also keep records of expenses. For more information, go to https://www.ssa.gov/payee/faqrep.htm#&a0=0.

Service plans also referred to as an Individual Service Plan (ISP), Individual Habilitation Plan (IHP) or Individual Educational Plan (IEP) are goals and objectives to meet the person's needs established through an interdisciplinary team process.

Supportive housing is a combination of housing and a range of consumer-directed supportive services helping people to live productive lives in stable housing with focus upon integration into the community. Go to https://en.wikipedia.org/wiki/Supportive_housing for more information.

Bibliography and Reference Materials

The following resources provide additional information on the subjects discussed in this document.

I. SPECIFIC INFORMATION ABOUT SMITH-MAGENIS SYNDROME:

WEBSITES

Parents and Researchers Interested in Smith-Magenis Syndrome, Inc. (PRISMS)

PRISMS is a not-for-profit membership organization dedicated to providing information and support to families with SMS by increasing awareness, education and research of SMS. The site offers specific tips and information to aid educators. Learn more at: http://www.prisms.org/

Genetic Home Reference provides a general definition of SMS.
Learn more at: http://ghr.nlm.nih.gov/condition/smith-magenis-syndrome

BOOKS

Dechaine, Shirley, *ALL ABOUT ME! One Family's Experience with Smith-Magenis Syndrome*, Mountain Creek Publishing, 2005.

Hass-Givler, Barbara & Finucane, Brenda, *On the Road to Success with SMS - a Smith-Magenis Guidebook for Schools*, PRISMS Publications, 2014.

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Dykens, E.M., Finucane, B.M. & Gayley, C. (1997).Cognitive and behavioral profiles in persons with Smith-Magenis Syndrome. Journal of Autism and Developmental Disorders, 27: 203–11.

Dykens, E.M. & Smith, A.C.M. (1998). Distinctiveness and correlates of maladaptive behaviour in children and adolescents with Smith-Magenis Syndrome. Journal of Intellectual Disability Research, 42: 481–9.

Udwin O., Webber C., & Horn I. Abilities and attainment in Smith-Magenis Syndrome. Dev Med Child Neurol. 2001;43:823Y828.

II. INFORMATION ABOUT HOUSING AND RESIDENTIAL PROGRAMS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES:

WEB RESOURCES AND TOOLKITS

PLANNING

The Arc provides an online publication on future planning.
Learn more at: https://www.futureplanning.thearc.org/where-to-start

Autism Speaks publishes a Housing and Residential Supports Tool Kit.
Learn more at: http://www.autismspeaks.org/sites/default/files/housing_tool_kit_web2.pdf

Neighbours International offers books, videos and toolkits helpful for planning to live more independently.
Learn more at: http://www.neighbours-international.com/our-books.html

Housing in Florida published by the Florida Counsel on Developmental Disabilities.
Learn more at: http://www.fddc.org/sites/default/files/file/Housing%20Guide.pdf

Research and Training Center on Community Living (RRTC) “Through Asking the Right Questions…You Can Reach Your Destination” is one resource developed by the Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota and Developmental Disabilities Division, Hennepin County Social Services. The publication offers questions to ask providers when making decisions about residential supports for family members with disabilities.
Learn more at: http://rtc.umn.edu/questions/index.html

Supported Housing Association of New Jersey publishes The Journey to Community Housing with Supports - A Road Map for Individuals and Their Families in New Jersey that can be downloaded at their website.
Learn more at: http://autismnj.org/Housing/SHAGuide

The National Fragile X Foundation publishes a guide entitled Independent Living: Summary of Guidelines for Establishing a Private Home, by Marcia Braden, PhD.
Learn more at: https://fragilex.org/wp-content/uploads/2012/01/adolescent_and_adult_project_03_living_settings.pdf

Housing Design

“Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders” The Opening Doors report is a collaborative study regarding building design to support housing for people with autism and other related disabilities.
Learn more at: http://www.autismcenter.org/sites/default/files/files/openingdoors_print_042610_001.pdf

BOOKS

Krouk-Gordon, D. and Jackins, B. Moving Out: A Family Guide to Residential Planning for Adults with Disabilities. Bethesda, MD: Woodbine House, 2013.

Lovett, Herb, Learning to Listen; Positive Approaches and People with Difficult Behavior, Baltimore: Paul H. Brooks Publishing, 1996.

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Emerson, E. (2004). Cluster housing for people with intellectual disabilities. Journal of Intellectual Disability and Developmental Disability, 29(3), 187–197. doi: 10.1080/13668250412331285208.

Racino, J. A. (1995). Community living for adults with developmental disabilities: A housing and support approach. Journal of the Association for Persons with Severe Handicaps, 20(4), 300–310.

Wong, Y. I., and Stanhope, V. (2009). Conceptualizing community: A comparison of neighbourhood characteristics of supportive housing for persons with psychiatric and developmental disabilities. Social Science and Medicine, 68, 1376-1387. doi:10.1016/j.socscimed.2009.01.046.

Udwin, O., Howlin, P., Davies, M. & Mannion, E. (1998). Community care for adults with Williams Syndrome: How families cope and the availability of support networks. Journal of Intellectual Disability Research, 42: 238–45.

Michael J. Kendrick PhD, "Natural Authority of Families," The Compass, 2000. "The Choice Between a Real Home and a Program," Progress, Vol. 2, Issue 1, Commonwealth of Mass., Dept. of Mental Retardation, 1993.

Wolf Wolfensberger, Susan Thomas and Guy Caruso, "Some of the Universal 'Good Things of Life' Which the Implementation of Social Role Valorization Can Be Expected to Make More Accessible to Devalued People," Social Role Valorization, Autumn, 1996.

III. OTHER GENERAL WEBSITES

Autism Housing Network -- an online resource regarding existing and emerging housing resources nationwide.
Learn more at: http://www.autismhousingnetwork.org/

Belonging Matters, Inc. – an Australian advocacy group focused on inclusion and community living.
Learn more at: http://www.belongingmatters.org/#!free-resources/c12dz

Community Resource Alliance – a North Carolina consulting company – more information about five-star services.
Learn more at: http://www.craconferences.com/fivestar.html

Community Resources Unit, Inc. – an Australian social services support and advocacy organization.
Learn more at: http://www.cru.org.au/

Disability is Natural – an online resource organized to change the way people think about disabilities.
Learn more at: http://www.disabilityisnatural.com

IHC - In Your Home – a New Zealand service and support organization.
Learn more at: https://www.ihc.mykoha.co.nz/cgi-bin/koha/opac-main.pl

Jean Vanier - is a Canadian Catholic philosopher, theologian and humanitarian. He is the founder of L'Arche, an international federation of communities for people with developmental disabilities and those who assist them.
Learn more at: http://www.jean-vanier.org/en/home

Marc Gold - Marc Gold & Associates (MG&A) is a network of training consultants who are disability professionals specializing in the area of employment and community participation for persons with significant disabilities.
Learn more at: http://www.marcgold.com/

Social Role Valorization – resources and conference information. Social Role Valorization (SRV) is a set of approaches designed to enable devalued people in society to experience the Good Life. (Conference June 10 – 12, 2015 Providence, RI).
Learn more at: http://www.socialrolevalorization.com

Social Role Valorization Implementation Project – a Worcester, MA – based organization that offers consultations and workshops.
Learn more at: http://www.srvip.org/index.php