

James, Joe and Risa's House

*by John Shea, Parent Advocate
Allen, Shea & Associates*

Three years ago, I was involved in the creation of a living arrangement for my son Joe, and two friends, Risa and James (JRJ). Joe is tall, handsome, and if one is not seeking a conversationalist, a soul-mate. Risa and Joe were an "item" at the time. They remain affectionate friends. Risa has another guy (or two) in her life. Joe, incidentally, is dating Risa's ex-roommate. James has a great smile and loves to be with his Mom and Dad. He also enjoys riding a tandem bicycle, shooting hoops, riding horses, dancing, and dates two local girls he went to school with. Joe likes to jog, and enjoys bicycling as well.

We were attracted to several supported living principles. Our regional center, however, wanted the place to be licensed. So, we set out to personalize the living arrangement within rules of Community-Care Licensing and the Department of Developmental Services. We are proud of several innovations that we put into place:

- Extensive, up-front use of person-centered planning;
- Separation of housing from services;
- Ownership of the home by interested family members;
- Individual lease agreements with sharing of utilities;
- Greater control by JRJ of their own financial affairs;
- Establishment of a microboard, a non-profit society of family and friends;
- James, Joe, and Risa being employers of those who provide paid support;
- Involvement of volunteers; and
- Use of quality-of-life mapping.

Early on, we had three separate planning meetings, one for each person, using PATH (Planning Alternative Tomorrows with Hope). Our goal was simply to see how the lives of the three might continue to intersect. They had been playing on the same baseball team for two years. Each wanted or needed a different living arrangement. In the process, we discovered common aspirations as well as unique needs. The possibility (indeed, desirability) of JRJ living together evolved from those gatherings.

James and Joe's fathers talked with our local housing authority, but Section 8 Rental Assistance was ruled out, because our housing authority doesn't use the "shared housing" option for unrelated adults. We learned more about preferences (e.g., "life in the neighborhood"; adequate backyard) as we looked at homes and apartments. Ultimately, for investment, life planning, stability, and other reasons, six of us decided to buy a suitable house. The Willis Drive Partnership was formed to hold the property, with one of the mothers agreeing to collect rents and perform other property management functions (e.g., repairs, end-of-year accounting for tax purposes, etc.).

While Options3, Inc., our microboard, holds the license on the house, and our Treasurer (Joe's aunt) deposits and writes checks, we decided to recycle some of the money. Each month, the Treasurer sends each of the three a check for \$500. James, Joe, and Risa deposit their checks in their checking accounts at a local bank, and each month they pay their rent (\$275 each) and split utilities (PG&E, garbage, cable TV, and the common telephone) four ways with their paid housemate.

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Options3, Inc., pays \$325 in rent on behalf of the paid housemate. Estimated utilities are \$75 per month each. If JRJ are careful (e.g., turning off lights, setting the thermostat low), they have about \$150 per month each for discretionary outlays. Food at home is funded separately to encourage family-style main meals.

The microboard concept is growing in popularity in British Columbia and elsewhere, where Individual Funding (i.e., personal budgets) and service brokerage have taken hold. A microboard is like an incorporated Circle of Friends, a group of people who agree to stand beside and support each other. As a group, we commit to James, Joe, and Risa, wherever life takes each of them, whether Options3, Inc. is the service delivery vehicle or not. Our microboard is a newly-formed, California, non-profit, public benefit corporation. It holds the residential license. We asked Risa to be President. She declined, but accepted the vice-presidency.

A critically important feature of the home is having JRJ as employers of the people who provide paid support. Risa speaks for herself. James and Joe have limited conservators-of-the-person, who function as Personal Advocates, assisting James and Joe in making employment decisions. Family and friends screen applicants, who are always interviewed by JRJ and their support team.

Licensed homes for three are financially tricky. JRJ's home has a designated service level of 4G, which means that it must provide 55 hours a week of a second person on-duty. For those hours, the effective staff ratio is 2:1 or 1:1, and this permits considerable individualization. It works financially, only because seven family members and friends, as volunteers, have divvied up various administrative and coordinative functions. Because biking (and, for Joe, running) are favorite activities, we sought a "paid volunteer" to share those interests. We found a wonderful young man through a health club in town. He runs (or bikes) with the guys fifteen times a month, and receives a small stipend to cover mileage and other expenses.

In Level 4 homes that are licensed, it is traditional to "take data," and to file quarterly reports with the regional center. At an early planning meeting, James's mother asked why, if her son were the employer, he would ask an employee to "take data." Good point. We suggested, and our regional center approved, an alternative called quality-of-life mapping. The

individual, family, and friends identify "success indicators" and get together in small groups to plot on a ten-point scale where the person would be if everything were going well, and where he/she actually is. If these two diverge by much, the group brainstorms ways to bringing the two scores closer together. In my son's case, he quickly put on 35 pounds when he moved into his own home. The recruitment of a paid volunteer, beyond its social dimension, was part of a plan to redress the balance between calories in and calories out.

Because we were creating a living arrangement from scratch, we had a wonderful opportunity to be creative. It was, of course, a lot of work. We don't believe in models (or templates), but would encourage anyone to take from our experience anything that makes sense for those they love and support.

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Marlin Minkin, M.S.
Psychologist

Marlin Minkin's work with families and professionals struggling with issues surrounding raising and educating children who are deaf-blind or multiply disabled promotes parent/professional collaboration, while being sensitive to the unique support needs specific to each group. The format of this workshop reflects that sensitivity by featuring two strands: one for professionals and one for family members.

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Watch for Registration Information!

Bayberry's Residential Transitional Service

by Tony Anderson, M.A.
Executive Director, Bayberry, Inc.

[The following is a description of an innovative program in northern California that provides an important service for people with significant disabilities.]

In the spring of 1997 the North Bay Regional Center (NBRC) approached its vendor community with a very special "Request For Proposal" to help them meet their community placement emergency plan related to Coffelt. NBRC's charge was to find a way of preventing extended crisis center stays, supporting clients and their providers during times of strained relations, re-unifying when possible, and finding a new appropriate community living arrangement when a change was needed. After winning the contract and beginning the work of designing such a program, we quickly learned that our regional center was more interested in developing an ideal therapeutically beneficial service than simply meeting its legal requirements. I soon realized that we were entering into a very special and unique partnership project with our local regional center.

During the initial research we found a couple of models for crisis oriented transitional services. The first model was institution-based 60 to 90 day programs that served many people at a given time. The other predominant community model was crisis services in a community care home serving 6 people at a time. We felt these approaches would not meet clients' needs for a number of reasons: 1) the institution model was counter productive to their mandate from the Coffelt settlement to increase community based services; 2) the time period of two to three plus months gave professionals in the system a disincentive towards transitioning people timely to a more stable living arrangement; and 3) having six people living together in the process of a life crisis or major life change may create-in and of itself-a stressful living environment. The following is a description of the program we designed, and a few of the lessons we learned.

The Program Design

The goal and purpose of this program is to create designated short-term housing, intensive planning, and therapeutic transitional programming for psychiatric, behavioral, or other emergency services which require

less interventions than normally provided by psychiatric hospitals, crisis centers, developmental centers, community hospitals, police, or other crisis response services available to the general public. While we do retain the services of nurses and other medical professionals as needed, we wanted to make sure that no generic agency or community service would view this program as a replacement or equal alternative resource. If someone really needed the services from any of the above resources we felt it would be a disservice to that person if their access would be affected because they had a qualifying diagnosis for our program.

We are a community care licensed transition home on the grounds of the Sonoma Developmental Center, and serve individuals who cannot remain in their current living environments and for whom alternatives are not available. The transition home serves no more than two people at one time and most individuals have not exceeded the goal of no more than 21 days. In some situations, clients have stayed longer than 21 days; this is usually due either to medical needs, or to the reputation a client might have related to challenging behavior, which makes it especially difficult to locate a new community living provider.

The Bayberry Residential Transitional Service has served only adults thus far. However, due to the intent of the Coffelt requirements related to comprehensive and exhaustive emergency crisis services, we have arranged for a standing process to request an age exception from licensing to serve children or the elderly. The issue of compatibility is obviously critical to each person's successful transition from one stressed situation to a more stable situation, and therefore our intent is to not typically serve minors and adults simultaneously.

Transitional Intervention and Preservation Team (TIP Team)

The purpose of this team is to intervene in the current situation requiring change, preserve the person's family unit or residential placement if possible, and either transition back to their original placement or to a new living arrangement. In some cases a full admission to the facility has been avoided and we have been able to

send the necessary professional staff needed to keep the individual stable in their current living arrangement. This intervention can include direct paraprofessional, medical, and assessment personnel who act not as experts in other people's homes or facilities, but rather as additional and necessary supports needed for investigating complex human questions.

In the Beginning

After our Residential Transitional Service program is contacted, we usually meet with the Regional Center's Wellness Team, and an immediate plan of action is established that lists goals of temporary placement, the psycho-social needs, psychiatric needs, medical/dental needs, and the clients current wants and desires. Following this, the coordinator: organizes a comprehensive interdisciplinary team; arranges for staffing; goes out to assess and see the client, care provider, family, etc.; transports or arranges for transportation; and assures that the individual has all their questions about the program answered. We want to ensure that client's understand the purpose for their stay, and have any other information that is necessary to help the person feel comfortable in their new, temporary home.

During the Placement

The TIP Team thoroughly assesses the individual's current situation paying particular attention to health issues (i.e., medications, allergies, special diet considerations, and other organic health conditions), social issues (what's happening in this person's family life, social life, work life, home life, etc.), and behavioral programming. In some instances we develop an Essential Lifestyle Plan, which assists us in helping a new provider in meeting our clients needs or help assess which type of living arrangement is both desired by the individual and is also therapeutically indicated.

Because each client's service program is person centered and highly customized, many services vary depending on needs and skills. (Staff to client ratio range from 1:2 to 2:1 depending on the individual's needs.) When appropriate, clients participate in training sessions related to home maintenance, social integration, behavioral shaping and programming, personal care, money management, stress management, etc. Also, due to the special nature of this program, much of the attention is focused on helping the individual assess

their current living situation and establish a process for preventing future needs for drastic transitional life changes.

The transitional services also include daytime programming when the person's work place or school is not accessible during their temporary placement. Also, as part of the transitional service, we assist the client's caseworker in the placement process. This assistance may include: visiting potential vendors; home visits with family; assistance with the new day program or new school; and facilitating—when necessary—a complete medical evaluation, to assist the client in adjusting to new medications and a medications regimen, and/or the development and monitoring of a nursing care plan. In the event that the individual will need transportation to their day program or school, we provide transportation to and from this day programming.

After the Placement

A thorough analysis and description of the transitional plan is finally developed and the team provides consultation and training to the participants in the person's system of support, including the licensed residential service provider, the supported living provider, in home support staff, day program, and/or the person's family and friends.

What We Have Learned

This program is truly a special approach towards helping individuals in time of personal crisis or major life change. The partnership between the Regional Center and our agency is a fine example of how the locally community based service system should work. Our approach has been purely service oriented, continuously asking clients, parents, providers, case managers, and everyone involved about how to help the person through this difficult time in their life. In every situation the person coming into our program has been significantly more calm and respectful than their intake notes indicated and most clients have completed their program without any disruptive or destructive behaviors. Most importantly, in every case each person stabilized and either returned to their previous living arrangement, found a new similar level service, or changed the type of living situation altogether.



The Manager's Role in Supported Living

by Ruthie Kurpinsky, Santa Rosa, California

The main goal of supported living is a simple one. It is based on the belief that every human being has a right to live in a home of his or her choice. Given that choice, the person becomes part of a community setting that allows them to live their life to the fullest regardless of the severity of their challenges or disability.

As program manager of Joshua's Place, this basic philosophy is what Joshua's parents, the support staff, and I strive for. As manager, I suppose the most challenging job I have is continuing to find support staff as caring and dedicated as the staff who currently work with Joshua. I feel fortunate that when I joined Joshua's Place two years ago there was a solid staff in place.

Joshua has extreme special needs and therefore it is very important that we hire staff that can understand his behaviors and his many modes of communication. Along with the hiring/interviewing process (which Joshua and his support staff are directly involved in) is the immediate need for any new staff to learn tactile sign language. Because Joshua is deaf-blind he needs his support staff to be adept at using his FM system, hearing aids, his picture communication system, and to continually maintain a tactile signing environment. Support staff also receive basic training in orientation and mobility to assist Joshua with cane travel.

Joshua has recently lost his remaining vision and although I am a fluent signer, I have never used sign language with someone who is blind and requires tactile communication. I, along with the staff, received training from California Deaf-Blind Services because we didn't have any knowledge about the use of tactile signs. Joshua adapted quickly to this new mode of communication and it is now a wonderful part of his life. It keeps him in "touch" with all of us.

There are many duties that I have as program manager at Joshua's Place. Joshua requires 24-hour support; I schedule staff to assure that these support needs are met. All new staff are trained to dispense Joshua's medication. Staff also picks up Joshua's prescriptions when needed. There is paperwork that needs to be completed. Support staff are required to provide a thorough, written account of his day. This covers medication dispersed, meals consumed (hopefully low-

fat), any problems Joshua may have had during that shift, and activities that he has participated in.

Because Joshua has had some major health issues recently, the detail of the paperwork is very important. I make sure that all staff is informed of pertinent issues involving Joshua. We have a communication book that usually has daily entries from staff or from me. This book is an important tool because we can share information and be up-to-date regarding changes with Joshua. This book may contain information such as necessary household repairs or information regarding upcoming weekend activities. All staff is required to read and initial the book. A daily time card is required; additionally I must be informed when there are any changes in shifts or if they are traveling out of town with Joshua. We keep a calendar at the house that lets everyone know events that are coming up: Joshua's medical appointments, staff trainings, payday, rent due, Prince concert (or The Artist Formerly Known As Prince), birthdays, etc. There is also a housecleaning/maintenance list and all staff and housemates have specific chores to do at Joshua's Place. I make sure they get done.

An extremely important tool that keeps us in touch daily is the telephone. In this day of fax and e-mail, you may think the telephone is a bit outdated. I live about an hour away from Joshua's Place and I find the telephone an excellent way to keep in touch. When I am not at Joshua's, I'm calling on the phone. During the week, I call daily just to check in. This took the support staff a while to get used to, but I think they understand that it is critical I know what is going on with Joshua on a daily basis. The phone is a quick way to accomplish this. I'm in contact with Joshua's parents regularly, typically several times a week, to exchange information and let them know how and what Joshua's doing. All support staff also have pagers and I have a cell phone for any urgent calls.

Managing all the funds at the house is another duty I have. This includes petty cash, food/toiletries money, and Joshua's personal funds. I also collect rent from Joshua's two housemates and make sure that their share of the utility bills get paid. Twice monthly the employees at Joshua's Place get paid and I coordinate the payroll with our payroll service.

A Typical Day in the Life of Joshua

by Jeremiah Price

The cooperation and mutual support the support staff show each other cannot be underestimated when looking at the success at Joshua's Place. When someone is sick, or there is a shift that is not covered, support staff try their best to make sure it is covered. An ongoing joke at Joshua's Place, in which there is a great deal of truth, is "You can't be sick." It is imperative that support staff are comfortable with Joshua and can communicate with him, and vice-versa; unfortunately this means that it would be very difficult to maintain substitute staff. (Typically, new support people receive a minimum of 30 hours of training before ever being alone with Joshua.) If needed, I work shifts with Joshua. I work eight hours weekly as manager at Joshua's Place and I am employed at two other jobs.

Because Joshua's needs are so specific and his modes of communication complicated, he needs those people with him to have the ability to understand him and communicate with him. It is crucial that Joshua has his communication needs met. All new support staff at Joshua's get a crash course in sign language—specifically Joshua's vocabulary. Ideally, it would be wonderful if the people who applied to support Joshua already knew signed communication, but this is seldom the case. The staff and I work hard to get the new people signing; one job requirement is to enroll in a sign language class and learn Joshua's vocabulary immediately.

One of the most rewarding aspects of working for and with Joshua for support staff and for me is fostering natural supports for him. Josh is an extremely social individual. His active lifestyle is what he wants and needs; he deserves to have it. His world seems so full with friends who love and respect him, acquaintances who enjoy his company, and family who want only the best for him. We have mandatory monthly meetings with all Joshua's staff and support from outside agencies when required. We have these meetings with Joshua's best interest at heart, and are mindful of confidentiality and privacy issues. It is Joshua's right and our responsibility that his supported living environment continues to work well for him. It is our primary goal that Joshua become as independent as he can and with support, establish himself as a contributing member of his community.

[Ruthie can be reached at rkurpinsky@yahoo.com for more information about the manager's role in supported living.]

You wouldn't describe Joshua Avanzino's life as being simplistic in nature. People are often misled that individuals with disabilities—especially cognitive disabilities—lead straightforward and simple lives. If only they had an opportunity to look into a day in the life of Josh.

Josh leads a life that could be considered normal by the standards of most twenty-two year old bachelors. On a typical day he will get up, and depending on how he's feeling, either jump in the shower or fix breakfast with the help of his support staff. Then maybe he'll relax for a while and watch Kathy Lee and Regis or start his daily chores. Depending on how wild his night before was, Josh may start cleaning up the house beginning in the living room, then proceed to the monotonous job of placing dishes in the dishwasher. If there is laundry and vacuuming to be done, Josh may now elect to indulge.

Josh, being the organic connoisseur that he is, will have to eventually tend to the garden he meticulously maintains in the backyard. Josh has enjoyed the benefits of keeping a garden the entire four years that I have known him. Once the garden has been weeded and watered, Josh will usually have worked up an appetite. After lunch, Josh will usually go to the store to select his evening meal that he will later prepare for himself with a friend. Upon returning from the store, Josh generally likes to hang out and watch TV while waiting for his afternoon friend to arrive.

Joshua's friends and supports include individuals with a variety of interests and lifestyles. Some of the people Josh socializes with have families, providing a network of home-cooked meals and family atmosphere. Josh's other friends are single and keep a close eye on the local entertainment scene. The variety of interests of Josh's peers insures that he is given many options to peruse. A typical day for Josh with one of his peers could start with a stroll through the local state park followed by a viewing of the latest independent film. Josh may then want to go check out any new styles at the mall. At the end of the day Josh and his friend would come home and fix dinner together while laughing about the days events and putting the last dish in the dishwasher. It's

A Typical Day (continued from page 6)

important to note that Josh always selects the activities he engages in from an array of options.

Though this may seem like a full day, Josh (being the social animal that he is) will usually attend local music shows with friends and dance the night away. If Josh is too tired to go out on a particular night he may elect to just hang out or rent a movie and watch it over a cup of tea with his roommates.

In the time that I have known Josh, I have had the privilege to become part of a strong circle of friends that Joshua has created. Everyone within that circle has been blessed with the opportunity to see the inner beauties Josh has to offer. With the creation of these bonded relationships, all the individuals within the circle have come to care a great deal for Joshua. I act as a voice for the circle as well as for Joshua when I say that supported living is the best possible option for Josh.

In the two years I have observed and assisted Josh in his living environment, I have seen him overcome many obstacles, resulting in a more independent and happy way of life. Though this is a very exciting thing to be a part of, the real excitement lies in the fact that funding for these kinds of programs remains available and approved.

My friend Joshua, as well as many others, will continue to reap the vast benefits they are entitled to by living the most independent and happy lifestyle possible.

[Jeremiah Price is a member of Joshua's paid support staff.]

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Low Incidence Support Network (LISN)

The mission of the Low-Incidence Support Network (LISN) is to provide person-to-person support, central access to information and resources for families, care providers, and professionals who serve children with low-incidence disabilities. Project LISN is committed to fostering personal connections and easy access to information and resources to enrich the lives of children with low-incidence disabilities and their families.

Low-incidence disabilities are defined as visual impairments, deaf and hard of hearing, severe orthopedic impairments, deaf-blindness, or any combination of the above.

Project LISN was created out of a collaborative effort between the California Department of Education, California Deaf-Blind Services, and the Exceptional Family Resource Center.

For any information or questions regarding Project LISN, please contact JoAnne DeJaco or Nancy Cornelius at the following:

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