
Section VII: Training, Monitoring and Evaluation

DDS Department of Developmental Services
"Building Partnerships, Supporting Choices"

Affordable Housing

Affordable housing is a cornerstone to individuals with developmental disabilities residing in their local communities. Due to the high cost of housing in California, many individuals served by the regional centers require deep subsidies in order to make housing affordable. DDS is actively pursuing projects that will increase capacity and precipitate the construction of new affordable housing.

This site provides information about affordable housing projects in which DDS is involved. The site also links users to public and private agencies that can assist individuals with developmental disabilities in finding affordable housing.

DDS Projects:

- [DDS Affordable Housing \(DDS-AH\)](#)
- [DDS Rental \(DDS-R\) \(PDF\)](#)
- [2002 Housing Legislative Report \(PDF\)](#)

AFFORDABLE HOUSING LINKS AND INFORMATION:

- [Affordable Housing Coalitions and Agencies](#)
- [Affordable Housing Resources](#)
- [Affordable Housing Links](#)
- [Housing Element](#)
- [Housing Funding Resources](#)

http://www.dds.cahwnet.gov/AH/AH_Home.cfm

Section VII:

Training, Monitoring and Evaluation

Training

Proper staff training is of vital importance in SLS. This is an area that cannot be compromised. The best of plans and intentions can fall apart when personalized training is not implemented. The additional hours paid to support staff for training hours is money well-spent.

At the beginning, the initial orientation and training described in the SLS Regulations (Article 6, Section 58651) needs to take place within the first two weeks of employment. This was described in Section IV of the manual. When starting up a supported living arrangement, training ideally begins even before SLS officially begins, if possible; this is an issue to discuss with the regional center. Thereafter, when new employees are hired, this training must occur within the first two weeks of their employment. The consumer and members of the circle of support, as well as others spending time with the consumer, should also have this orientation and ongoing training. There is a specific requirement for the consumer and circle/unpaid support to have certain trainings that are identified in the SLS Regulations (Article 6, Section 58653). If you have a person who helps you oversee the SLS arrangement, such as a manager or facilitator, that person would be ideal to deliver this training.

Of course, initial training should primarily focus on the consumer and how to best meet his or her individual goals, desires and needs, as well as the values and philosophies of SLS, consumer rights, mandatory reporter and special incidence reporting, and the regional center fair hearing process. The content of the two-week orientation training is intended to provide a solid foundation from which to continue learning about the person and supported living. When hiring someone who has “experience” in SLS, take care to ensure that they are properly trained in the basic values and philosophies of SLS. Previous employment in another SLS arrangement or agency providing SLS does not necessarily guarantee that the person has participated in good, solid SLS training.

First aid and CPR are offered through a variety of sources, including the American Red Cross. Keeping these certifications current are also legitimate training or health

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& safety expenditures. Your human resources records should detail the dates of employees' certifications for first aid and CPR, and your tracking system should be such that you can easily see who is due for re-certification.

Ongoing training

Ongoing training should include topics that are most relevant to the person being supported, and should include some training provided by the consumer, with support. It is important for personal attendants and others to remember that we have much to learn from each person we support. In fact, people using supported living services are the best trainers we could ask for; our most important lessons are taught by them.

A sample list of ongoing training topics is included in the Forms and Samples section of this manual. The SLS Regulations (Article 6, Section 58652) do outline continuing training requirements that vendors must meet. These are basic, and should be a minimum of the types of training that should occur.

Ongoing training is just as important as the initial training. Once employees know the consumer better, and become more familiar with the daily workings of SLS, they may hear and perceive information with more depth, and they will have more direct experience and feeling to draw from when hearing important information.

One of the best things about supported living is that training is specific to one individual and does not have to be generalized across a group. This is much more effective, interesting, and is likely to produce much more immediately useful results.

Staff interested in professional development should be encouraged to attend additional trainings and conferences whenever schedules and budget allow. Offering support staff opportunities to attend conferences, seminars and trainings will benefit everyone, and it can be a great eye-opener to see how others function in similar roles. Trainings, workshops and seminars attended by staff should be thoroughly documented.

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House meetings offer excellent opportunities for informal training. These meetings should be mandatory for all employees. They should be scheduled in advance and held weekly in the beginning, and no less than twice each month after that. Of course, if the consumer feels a need for more or less meetings, this topic should be discussed openly with the vendor and circle of support so a comfortable agreement can be met.

At house meetings, everyone should have input, and an agenda and meeting notes should be generated and kept on file. The minutes, or notes, and agendas are helpful for the vendor as documentation and for the consumer and staff for communication, as well as having a place to go to for recollection about a certain topic of conversation.

A portion of one meeting each month should be dedicated to a training topic. This is a great opportunity to go over consumer satisfaction and standards, bookkeeping and record keeping, IPP goals, health and safety issues, and staff concerns, as well as any changes in policies. Always start the meeting out with a focus on “What’s working/what isn’t?” and remember to dwell on the progress!

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These go hand in hand, and are critical to ensuring quality services and supports that are fluid and responsive to the person receiving support. Ask, watch and listen. Pay attention to behavior changes, in the consumer and in support staff, and be available and approachable when someone needs technical assistance, or just a hug.

Living with a person every day, whether you sleep there or not, is a tough job - both for the support person and for the person being supported. We all get on each others’ nerves sometimes, and often all we need is a bit of a break. Try to stay sensitive to the unspoken issues as well as those that you hear loud and clear. They are all important. Handling a small thing today can keep it from being huge tomorrow.

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Several examples of consumer satisfaction and evaluation tools are included in the Forms and Samples section of this manual. The basic evaluation that needs to happen includes:

- Consumer satisfaction with individual employees
- Consumer satisfaction with the vendor and his or her supported living services
- Vendor evaluation of employees

Circle of support members can be valuable assets in the processes of regular monitoring and periodic, more formal, evaluation. It's important that someone other than the vendor or an employee facilitate the consumer satisfaction survey regarding the vendor and the person's services. This is, of course, a way of helping to ensure that the consumer is not unduly influenced and feels free to fully express his or her thoughts.

Evaluations are important feedback for everyone in the process. Some people want to evaluate their circles of support as well. Constructive sharing of ideas and feelings helps each person know better how to provide supports and friendship in the most meaningful and personalized ways.

Regional centers have various ways of monitoring services. Fiscal audits are one way that the regional center judges if you are doing your job as the vendor. Quality assurance monitoring assists them in meeting their responsibilities to the consumer, as well as their mandated responsibilities for monitoring compliance. Some regional centers require monthly reports, others require quarterly, six month or annual reports. Ask if your regional center uses a particular monitoring tool for quality assurance; if they use one, ask for a copy. This will give you a better idea of the regional center's expectations of you as a vendor, and of the SLS arrangement as a whole. You will find that some things are specific to SLS agencies serving many individual consumers and will not be applicable to individual vendors. Contact your regional center for clarification and assistance.

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And In Conclusion...

Supported living services are exciting and challenging. Being an individual vendor is one of the most rewarding, fun and exhausting jobs many people have ever had. And, they wouldn't trade the richness of the experience for anything. The most important things we can do are to keep focusing on the person we are supporting, keep caring, keep learning, keep growing, keep listening and keep being available for truly meaningful relationships with this family we call a circle of support.



Deron's Dream

After frustrating experiences with group homes for her son, Joan Schmidt helped create a place that helps mentally disabled people

**By David Barton and Bruce Dancis -- Bee Staff Writers
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It may not look like much, this tiny house set behind a low cyclone fence in a low-income Sacramento neighborhood south of City

College, but it is a dream home

It was a dream without a dreamer. Or so some thought.

For years, this home was hidden inside the mind of a man who, for most of his life, wasn't acknowledged even to have a mind worth noticing, let alone dreams worth pursuing.

And yet, as Deron Schmidt, the home's owner, wanders the grassy lot on a sunny November morning, there is a palpable sense of contentment. He is in near-constant motion, from his bedroom to the kitchen to the trampoline in the front yard.

The contentment is there in his relaxed but energetic demeanor, in his soft, dark eyes. Or is it?

To look into Deron's eyes is as much to wonder as to know. Even those closest to him have a tenuous connection with his inner world, even as they see his life improve as they pursue their stilted, but fruitful, dialogue with him.

Schmidt, 29, is autistic. Like many with this poorly understood developmental disability, he has never spoken a word, and until the past few years, he was prone to violent outbursts that made him difficult to handle, even to house.

"About 10 years ago, he was getting pretty violent," says his mother, Joan Schmidt. "We couldn't have him at home, and at

the group home, they were afraid he'd hurt somebody. I could see that the only remaining option for him was Sonoma State (a developmental center that is the hospital-like home for those who are unable to cope in private or group homes). I'd visited hospitals, and that just wasn't an option for us. So I said, 'What if we took the same money to maintain someone in a hospital and set him up in a supported, independent-living situation?'"

Behind Joan's thinking was the notion that Deron's outbursts were based on something real: frustration and anger that he had no control over his life.

“I don’t know about you, but my worst nightmare would be to have my mother in charge of what I wore and did every day,” says Joan, a robust mother of four adults whose lifelong work as a trainer and organizer in various business capacities, as well as her role raising an autistic son, has made her an appealing combination of authority and diplomacy, of kindness and resolve.

“Everyone is entitled to their decisions and choices,” she says. “Everyone has an idea of what they want. When you see people who are very developmentally disabled, I think much of that glazed look is just that they’ve shut down because they aren’t a part of what’s going on.

“But when people get a chance to make their own choices, we see them come alive and wake up, because we ask them what they want to do and where they want to go.”

With that in mind, Joan and her friend Kathi Campbell, who is also the mother of an autistic adult, have formed a nonprofit company, Creative Living Options, that aims to give people like Deron a chance to live their own lives.

Launched in March, the company is already serving four individuals -- not including Deron, for whom his mother is what is called a “parent vendor” -- and has a long waiting list. It is one of a dozen or so such agencies in the state Department of Developmental Services’ Alta California area, which covers 10 Northern California counties, including Sacramento County.

Julia Mullen is the manager of the community development branch of DDS, which has an annual budget of \$2.1 billion to serve some 170,000 people in California with serious developmental disabilities.

Of those 170,000 people, she says, 67 percent live at home with a parent, even through adulthood, and 16 percent live in licensed care facilities (or group homes). Only 9 percent live in their own homes. The other 8 percent live in state hospitals or skilled nursing facilities.

But, she says, “Supported independent living is the fastest-growing living arrangement in the developmental disabilities service system. It’s because our society has come to a greater appreciation of the fact that people with developmental disabilities are citizens, too, and that inclusion in the community is important for them and for the community at large.

“We all grow from their presence.”

Deron moved into the community, into his own apartment, 10 years ago and became a homeowner in August of this year. He still needs around-the-clock assistance, but what has changed is his behavior and, those close to him believe, his sense of having his own life.

In the past few years, his violent outbursts have decreased from hundreds in a day to a few, if any, per month.

But since Deron doesn’t speak, how did his mother know he even wanted his own home?

“He told us,” she says.

The key to talking to Deron has been “facilitated communication,” by which a question is

asked and the answer is given by the disabled person using a keyboard.

“When we sat down with Deron, we asked, what does he like?” she says. “He likes to go for walks, he likes jewelry, he has a great appreciation for art, and so you start building his life and how to make the supports. He doesn’t like crowded places, so let’s not put him in a place with a lot of people. It’s just as you and I would do it: How do you want to structure your life?”

But facilitated communication is a controversial approach. Because many autistic people have poor motor control and therefore cannot type, their hands must be held in some fashion by a “facilitator.” And this has led to accusations that it is the facilitator, not the autistic person, who is responding.

But Mark Grassinger, Deron’s friend of 12 years and the house manager for his home, has no doubt about the usefulness of facilitated communication. The proof, he says, is in Deron’s life.

“He was so aggressive and unhappy when we met,” says Grassinger. “He had no voice, and through facilitated communication, we were able to find a voice, and through that he was able to start living.

“I understand the skepticism (about facilitated communication), I really do,” says Grassinger, 37. “Society has taught us that if you don’t speak the same as everyone else, you must not be all there. Speech is the communication people are willing to accept as a sign of intellect. And Deron has never formally learned to read, though he reads magazines all the time.

“But I know that FC works with Deron, because when Deron makes choices, they are sound choices,” he says. He offers a couple of examples.

“When we go out to breakfast, and he types out what he wants, and then he demolishes it, he’s made the choice he wanted,” he says. “When he picks out a pair of shoes in the morning, he’ll keep them on, whereas if they’re the ones I choose, he’ll take them off.

“I can tell by his actions that he is happy with his choices. The validation of his expression is truth enough for me.”

Grassinger has been with Deron for 12 years, and the trust that they’ve developed is the key to not just the facilitated communication but to Deron’s sense of being an individual, and an adult.

But adult responsibilities can chafe as much as they liberate.

“When we start doing things for him, he loses the desire and the ability to do things for himself,” says Grassinger, who directs the household and keeps Deron on track. “So he needs to take responsibility for himself, and he does. He gets himself up now. He shaves, showers, he’s fully included in his life -- and he has self-esteem now, he derives great pleasure from being able to accomplish things.

“I treat Deron as I treat anyone else,” he adds. “In many ways, I don’t treat him any differently from my other friends. I don’t let my other friends hit me, and I don’t let him.

It's like, 'Dude, if you want to hang, this is the way it is. Don't hit me.' And he gets that.

"If I went in and said, 'I'm just here to take care of him, love and nurture him,' Deron wouldn't have gotten where he is today."

And since Deron has 24-hour assistance, he has three roommate/helpers, each on an eight-hour shift, led by Grassinger. One is Joseph Sampaio, who, during his eight hours daily with Deron, takes him to his apartment complex to do some light weight training.

"He feels better if he looks well," says Sampaio. "He doesn't like to do it at times, but he feels good about himself."

Another helper is Gabe Jimenez, who has a relationship with Deron that's quite different from Grassinger's, Sampaio's or Joan Schmidt's.

Jimenez is a stocky, muscular man who, when not with Deron or his own family, is a professional wrestler known as Big Ugly. And part of his unique contribution to Deron's life is the way he avoids the common caregiver's trap of treating the charges like children. Jimenez doesn't buy that.

"He's a man, even though he's got a disability," Jimenez, 28, says as he and Deron make a fifth walking lap around the track at Hughes Stadium, where Deron works out three days a week. "He wants to be in control, but he also wants things done for him. So he has to learn that being in control means work."

And Jimenez is not a hugger or a hand-holder. He prefers instead to indulge Deron's predilection for giving high-fives, figuring that if Deron's going to become a part of society, he has to observe its social constraints.

"The general public doesn't want some 29-year-old man to walk up to them and give them a hug," says Jimenez. "Same way it's not OK for him to walk up to someone when they're eating and take food off their plate."

But while Deron is learning the most basic social rules and undertaking the mastery of activities most people don't even think about, he is also teaching those around him.

"Deron has been one of my greatest supports and continues to be," says Grassinger. "I see the struggles and challenges that he has, and it puts my own trivial problems into perspective. I derive great strength from Deron."

"And Deron has shown me that I have this ability to work with people with disabilities," he says. "You can go your whole life without knowing what you're going to do, and Deron has shown me what I have to do."

To that end, Grassinger has undertaken a social-work degree at Sacramento City College. As for Joan Schmidt, knowing that Deron is on his way to his own life has freed her to help those who may not know about their options to choose supported living.

"My thing isn't Deron now," she says. "I don't worry about what will happen to him if I drive off a cliff tomorrow. I want my kids to live to the highest sense of their desires rather than just keep them safe at home in bed. With someone with developmental disabilities, it

doesn't always happen that they ever get to grow up.

"And everyone deserves the chance to grow up and have his own life."

Deron agrees. Sitting down on the day before Thanksgiving to talk through his keyboard, he's not in as sunny a mood as he was the previous week. Some of the head-slapping behavior that was once the norm has returned, and his responses to questions are punctuated by yelps and cries and the random head movements that are a common feature of autism.

And yet he recognizes a visitor and, unprompted, types "Yim glad bto see you."

Asked how he likes his new house, he types, "it feelsright."

Writing like this, with Mark holding his wavering arm, is always difficult for Deron, but it his link with a world that otherwise would have no idea who he really is inside.

So, despite his pained expression and struggle to control his head and arms, he volunteers a closing comment.

"I have becomen real happy since i have received help yliving on myu own."

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Journey of Life

By Kathleen Campbell

The following article was originally published in 1999, updated in 2000 and again, with the Epilogue, in 2001.
Previously published as *Is There Life After Special Ed?*

Having a person with disabilities in your family changes your life forever. Moms, dads, siblings, grandparents, extended family and friends learn to adjust, adapt and regroup



Mike Bryson (left) and Jason Coon (right), 1998

from the time a child with disabilities enters the picture. Parents, especially, learn the intricacies of laws that we never knew - or ever wanted to know - existed. Terms like "IFSP", "IEP," "early intervention," "IPP", "fair hearing, please", and an impressive host of diagnoses roll off our tongues like a second language. We learn how to advocate for services; find small bits of support for ourselves; study behavior modification strategies -- for us, if not for the kids; and, learn to be resourceful beyond anything we ever dreamed we could be.

As the years go by, we are sure that we've pretty much heard it all, seen it all, and know it all. We've read the books, watched the videos, gone to the meetings, been devastated by the insensitive pediatrician or neurologist, talked to and cried with other parents, fielded the guarded phone calls from well-meaning professionals, brought flowers, cookies or both to the most intimidating administrator so she would like our child better, filled six binders with documentation, figured out special education, identified the difference between a "policy" and "the law", and learned our rights. This is, after all, survival of the ... well, OK ... most informed, articulate (the polite term), and well-known at school and the doctor's office. Nothing can surprise us anymore.

And then it happens. It happened to us over ten years ago. Just when we thought we knew all of the answers, they changed the questions. Suddenly - amazingly - our son, Jason, who has developmental disabilities, became an adult according to the laws

of nature and the State of California. It crept up on us through transition plans and discussions of “work experience”. Slowly the reality dawned that soon we wouldn’t have special ed to kick around anymore. We were entering the Twilight Zone of Adult Services! Overnight, the rules changed, and the familiar terrain that we were used to negotiating was dramatically different. New issues cropped up: agencies with different, and sometimes conflicting, rules; “supported employment,” “day programs” and SSI; reliance on regional center services and Medi-Cal; college classes (what are the laws about modifications THERE??); conservatorship or not; “consumer choice” (Who is making the decisions? Yikes!); and, perhaps the most basic of concerns - lifestyle, housing and meeting daily needs. If I was not there with Jason every day, who would handle everything? Our own mortality loomed. What will happen to him when I die? Who will advocate and negotiate for him? Who will be his “squeaky wheel”? How can he be most safe and secure? The questions were endless, and decisions that needed to be made seemed overwhelming!

In Jason’s case, our decision was to tackle housing before he left special education at the age of 22. This way, he wouldn’t have to make all of the big transitions at once. For over a year, we traveled the California countryside seeking out every possible adult placement. All of the options were group residences of one size or another; the nicest ones had waiting lists. None of the choices had room for Jason and his friend, Mike, and the guys had developed a great friendship - a first for each of them. Although very limited in their communication skills at that time (now both can use facilitated communication, a method of typing), they let us know that they wanted to live together. Finally, as is often necessary in group or congregate living situations, there was a lot of talk about daily “programs”. We knew that road; Jason and Mike were already living in a group situation with other kids at St. Vincent, a licensed children’s facility in Santa Barbara. The more we looked and talked, we and Mike’s parents realized that what Jason and Mike wanted - and what we wanted for them - was not a good residential program, but a good life.

“Supported living,” a new concept to California when we began our planning in 1991, was the answer for Jason and Mike. This is an option where people live in a home they have chosen (or apartment, condo, etc.) to rent or buy, with or without roommates or housemates, and are provided the supports and services they need at home and in the community to create a lifestyle specific to them. The person’s own wishes, dreams, strengths, needs and choices provide the foundation for planning the supports and services, including who will actually provide the training and assistance that is needed. The paid supports are funded through the California Department of Developmental Services (DDS) through local regional centers, as well as In-Home Supportive Services (IHSS), a county-based program of the California Department of Social Services. The person’s own income, even if it is only SSI, is used for personal expenses such as housing, clothing, groceries, utilities and other typical monthly personal expenses. Actually, the option of supported living was never offered to Jason and Mike. In fact, several key people pronounced them “too severely disabled” to ever live in their

own homes. Undaunted, we created a proposal to work with the regional center in helping Jason and Mike develop a plan. And since we were already pushing the envelope, we decided to function as the agency, or “parent vendor.” When you’re breaking new ground, you might as well go all the way! Thanks to Jason and Mike’s tenacity (“Move! Move!”), a forward thinking regional center director, and our unmitigated audacity, Jason and Mike are currently enjoying yet one more wonderful year in their own home in Santa Barbara.

They live in a four bedroom, 3-bath home near the beach. Several shopping centers, many restaurants and bus stops are within walking distance. The downtown area and City College are minutes away. They have jobs and go to classes. Two housemates live with them and are paid to provide support. All four share the rent, utilities and groceries, with Jason’s and Mike’s shares coming out of their SSI and sometimes some other small wages. On weekends, housemates or other friends provide paid support. Through the variety of people providing support and the friends that they introduce to Jason and Mike, as well as their unlimited opportunities to participate in the community, there is an ever-expanding circle of friends.

It is now impossible to go to any busy area of Santa Barbara or Goleta with Jason without someone saying “hi” or stopping to chat. No one is hired or fired without Jason’s and/or Mike’s approval. They participate, at varying individual levels based on their interest, in interviews, weekly meetings, evaluations and other typical daily decisions. They have gained experience in making choices, and have become active self-advocates. The people supporting them have also become advocates. Of course, there are still difficult days, excessive laundry and lots of coordination to make things come together. And Mike’s mom and I must constantly resist the impulse to hang kitchen curtains and re-fold the towels.

But, most importantly, it isn’t a program. While it is not a perfect life, it is, by Jason’s typed account, “... a life with peace. It is good.”

Here are a few key points that help define supported living:

- Everyone is “ready”. This is different from traditional services such as independent living, where a person has to prove his readiness to live in his own home. Even people with what are considered the most severe disabilities, challenges or reputations can succeed in their own homes with the right supports, services and training. No one can be denied supported living services by the regional center based solely on the nature or severity of their disability. Through appropriate planning, implementation and flexibility of support, we make the services meet the person’s needs and wishes instead of fitting the person into someone’s pre-determined program goals. People don’t fail at living in their own homes; we fail to provide the appropriate types and levels of support at the right times.

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- Individual choices drive services and supports. The person receiving services should be supported and encouraged to make, or be significantly involved in making, the choices and decisions about his or her life, supports and services. Each supported living arrangement should be different from the next, by design. Circles of support, including families, often play an important role in assisting the person in making decisions and supporting those decisions.
 - Separate housing from provision of services. In group situations, for example, the housing and services are often, if not usually, provided by one entity. When irresolvable problems arise with a consumer's services or her needs change, typically she is asked to move to another placement. In supported living, she stays in her own home and familiar surroundings, and the services change as necessary. In fact, by regulation, the provider of services (the regional center "vendor" or agency) cannot control the home of a person they are supporting in a supported living arrangement.
 - No licensing. The person's home is just that -- his home. There is no community care licensing in supported living. Not having to deal with licensing gives more freedom in planning supports (for example, learning to spend time alone, if that is a goal), and more time to spend on developing and utilizing true measures of the person's satisfaction with his life.
 - Services and supports evolve and change as the person's wishes and needs change. Flexibility in supports and services is key in supported living arrangements. Hopefully, the person's desires and needs will evolve and change in many areas of life as that person experiences growth and gains self-confidence. None of us want lives that are stagnant. Supported living services must be adaptable and responsive to each individual.
 - More opportunities for independence and individualized support. Even though Jason and Mike live together, we specifically planned for them to have individual supports. This maximizes their learning to make choices and decisions, their senses of independence and self-confidence, and their ability to have the differing types of support they want, need and have a right to receive.

As with other services, some service coordinators are better informed than others and some regional centers are more supportive than others, but all must follow the law and regulations. If you are interested in supported living, call your service coordinator to request information and to schedule a meeting to discuss supported living or add it to your IPP as a goal. Make sure you include an estimated timeline for moving in; you can change this if you need to later, but it helps everyone to know what your expectations and wishes are. It may take some work to get there, but having a home to call your own is worth it. For Jason, it is freedom, independence and opportunity. For me, it is the

security of knowing that he has a place to call home, that he is growing and achieving new things each day and that he is happy. And seeing Jason's pride as we celebrate special times, such as Thanksgiving, with him as our host.

The numbers of people choosing supported living as a lifestyle option are increasing. We now know many individuals who experience a degree of opportunity and independence that no one would have predicted before they were receiving supported living services. This is especially true for some of our friends with, shall we say, "severe reputations" in regards to behavior. Remember, supported living is an option available statewide to regional center clients; its availability is not dependent upon the whim, training or opinion of anyone professional.

Our next great adventure is home ownership for Jason and Mike, and others with developmental disabilities. Many programs are becoming available to provide purchase and/or down payment assistance just for this purpose, and we have been spending quite a lot of time tracking down these resources. What better way to ensure your

place in the community than become a homeowner? Besides, we can always use more "adventure" in our lives.

We all feel fortunate to be a part of Jason's and Mike's lives. It is our hope that we will, together, be able to continue supporting them as they determine their life directions and achieve their hopes and dreams.



Vanessa (left), Jason and Susan (right)
have been sharing a house for several years in Santa Barbara, CA.

Epilogue

On August 19, 2000, just one day after Jason's birthday, his dear friend and housemate, Mike, lapsed into a coma and died. There was no warning, no good-bye. He was 29 years old and we all miss him every day. For Jason, he has lost a soul mate with whom he shared his life and home for over thirteen years, first as roommates at St. Vincent's, a group facility ("home") for children with developmental disabilities in Santa Barbara, and later as just two cool guys living in their own place near the beach. For us, we have lost part of our family, as sure as if Mike were our own son.

There has been much grieving over these past years by many people in Mike's life, including the other friends that shared his daily life and, often, his home – the people providing support to him each day. They were there when Mike collapsed. They stayed with him, talking, reassuring, making him laugh, holding his hand, advocating for him with the medical staff. They were the last people he saw, gracing them with one of his typical "Mike" smiles before he slipped into the coma. They comforted and cried with Mike's other friends and family, and they carried on for Jason and our family when all of our hearts were breaking. Indeed, they are much more than "support people", "personal attendants", or "staff." These young people were truly a part of Mike's family. He was their friend, their equal ... they loved him, challenged him, respected him, and they still grieve for him. Mike taught them lessons they would never have learned without him. He has changed their lives.

Jason tells us through his typing that, "Mike stayed as long as he could... Mike's gift to us was what he taught us about love and family. Now his lessons will shine through us. He loved us all and wants us to love each other." In death, as in life, their connection with each other is strong. "Mike will always be my best friend. He watches over us."

We have weathered cleaning out Mike's room, grief counseling, and memorial celebrations where we gathered to remember the wonderful, funny and not-so-funny moments of his life with us. Life does go on. But for all of us, Mike will stay in our hearts. Mike has made his mark on this world and it is indelible. He was one of the pioneers, a successful example of unexpected independence, a valued member of his community. He has helped to pave the way for others who will come after him. I am grateful for the honor of having known and loved him. Our lives are certainly richer for being a part of his life.



Some lessons are hard to learn. Letting go is hard. Finding out that we cannot protect our children from all the hurt in the world – although we knew it all along – is hard. But as difficult as real life can be, it would be worse to be isolated from the experiences and, yes, risks that provide us the freedom and opportunity to grow. This is part of the circle of life. Disability, or marching to the beat of a drummer no one else has ever heard, should not be a barrier to these powerful experiences that enrich and deepen our lives.

Mike did not miss any of life. He had the chance to make his own decisions, chart his own course. Thank goodness we didn't wait until someone, somewhere thought he was "ready" to live in his own home and in his own community. He might have still been waiting for a life when his came to an end. We never know what tomorrow will bring.

Michael Jackson's music has always been a favorite of Mike's and Jason's. He sings a song, "Gone Too Soon" that will always remind us of Mike. "...Shiny and sparkly, and splendidly bright, here one day, gone one night. Like the loss of sunlight on a cloudy afternoon, gone too soon." Gone too soon ...

Examples and Forms

