

Journey of Life

By Kathleen Campbell

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

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 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 in 1991. 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.
- ***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 adults receiving regional center services; its availability is not dependent upon the whim, training or opinion of any one professional. Just as with other goals and regional center services, it should be a decision led by the person, and determined with input from the person's circle of support (team).

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 ...