You're Not the Boss of Me

By Sam Durbin

with Mary Shannon

Stories of
Self-Determination
For Determined Adults

"Determination and perseverance move the world; thinking that others will do it for you is a sure way to fail." — *Marva Collins*

Once homeless and alone, author Sam Durbin managed to find a lifeline of support and acceptance at Integrity House, a program for people with disabilities in Santa Ana, California. He served on the Board of Directors of Regional Center of Orange County for six years, and currently serves on the Consumer Advisory Committee for the Department of Developmental Services in Sacramento. Sam is a public speaker and powerful advocate for people with disabilities and has championed self-determination throughout California and the United States. Sam currently lives in Costa Mesa, California with Tashie, his beloved Husky.

Advance praise for:
You're Not the Boss of Me: Stories of Self-Determination for Determined Adults

"This book will help all of us better understand the importance of consumer choice and our role in supporting these choices. Sam's real life stories underscore the value of working as a team to assist others in achieving their dreams."

— *Terri Delgadillo, Director, California Department of Developmental Services*

"This book is for everyone, but mostly for Sam's peers who don't believe they can succeed and are often told they won't. Sam has provided a blueprint, not for what you should do, but for how you should look at yourself as a valued person and share yourself with others."

— *Carol J. Risley, Chief, Office of Human Rights and Advocacy Services, California Department of Developmental Services*

"This book was very informative! It was refreshing to read, was written in a friendly manner, and included concepts that are so important to persons with developmental disabilities. Finally, an easy-to-read book on everything one needs to know about Self-Determination."

—*Larry Landauer, Director, Consumer and Community Resources, Regional Center of Orange County*

"I (being a member of the disabled population) know for a fact that we have love to give. . . .Sam's feelings were poured into this book, just as she pours her loving feelings upon others. This book is an excellent depiction of her grace and integrity." —*Owen Stark, member of Integrity House*

"This book is filled with very touching stories about the successes and challenges that people with disabilities face in everyday life. It is thought-provoking and really makes you think of people with disabilities differently."

— *Dave Giglio, Associate Vice President, Grubb & Ellis and member, Board of Directors, Alliance of Abilities*

"There is much to learn from [Sam's] successes so far, and I hope that many readers will take advantage of this book and become even better humans than they were before reading it. I certainly know I am a better one for having known Sam. I hope you will be too." — *Dr. John Flowers, Sam's friendly shrink.*

"Sam has a true gift to see a person for who he is, and possesses the compassion to inspire a person to become his very best. Many have been blessed with Sam's touch, but now this book will reach countless others, and hopefully inspire them to become their very best." — *Mark Antenucci, Director of Development at Independent Options*

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Chapter 1
How It All Began

In 1993 I was homeless once again and on the streets. I had nowhere to go and not one friend. I was totally out of control and my anger had pushed away everyone who might have helped me. I had no one to listen to me or make my misery bearable. All I had were social workers telling me what to do or where to go and I hated them and their rules. I thought I would never find a place to just be myself and live a meaningful life.

Finally, one helpful social worker found out about this place that helped people like me find roommates. It was something called a Clubhouse and when I got there they gave me a tour. I couldn't believe my eyes. *The members were running it*!

I was totally amazed. Mike was answering the phones in the clerical unit and had a friendly smile for everyone. Here was someone I could become good friends with. Robyn was typing up the attendance in the clerical unit. Woody, who has cerebral palsy and not much use of his arms or legs, was peeling potatoes and carrots in the kitchen helping to make the daily lunch for everyone in the clubhouse. Joe and Terry were

running the snack bar selling chips and coffee and soda. Chad, who is blind and works in the horticulture unit, was watering the plants.

I saw members with disabilities cleaning the tons of albums and CD's for sale in the business unit. Others were busy getting ready to buy other things for the clubhouse with the money they earned, like exercise equipment and a pool table, stereo, and a TV.

When I saw all of these members working and helping each other alongside staff I knew in my heart I belonged here. I wanted to be a part of it so much I almost cried. It soon became a reality and these hard-working, dedicated Clubhouse members became my true family.

This was the most amazing place I had ever imagined. All these people told me that the Clubhouse was theirs, and the only way it could continue to run was if everyone pulled together and did what had to be done.

I walked up to the director, Cathy DeMello, and said, "I need a friend." She didn't laugh or ask a lot of questions or tell me all the rules I would have to follow or kick me out. All she said was, "Great. We need help. When can you start?"

That's when my whole life changed. I totally got into the Clubhouse model where everything was based on peer support and helping each other out. Everyone there believed in this idea called "self-determination." It was hard to accept at first. I had been told what to do, where to go, and had rebelled against rules for so long, it took a while to realize that I really could make decisions for myself, and that I was a valuable part of the team at Integrity House. The staff and

members worked side by side. We were all equal. There was a lot of work to be done, and whoever could do it, did it.

I also had a lot of trouble accepting the fact that I was worthy of being loved or that I belonged. I couldn't love myself enough to feel I deserved anything, so the staff and members loved me until I could. This changed my life. Now the most important job I have is to love the members until they can love themselves. Integrity House is all about supporting each other.

I am unbelievably lucky to have so many friends and now I write this book so that all people with disabilities can have their dreams come true like mine have at Integrity House. Because of the unconditional love I found here, I have accomplished a lot of things. I have found out that I am a great speaker when I talk about self-determination. I also have found out that my opinion is respected as a member of the board of directors for Alliance of Abilities, the non-profit that oversees Integrity House. I have become a cheerleader for people with disabilities in their quest for a life they get to create for themselves.

I wrote this book in three parts. The first part is about taking a stand on what we want to do with our lives, like where to work, where to live, who to live with, who we hang out with and love, and where we want to go for fun. It is our choice, and as adults, we get to make decisions that affect the most important and basic parts of our lives.

The second part is about the practical ways that we can get through the consequences of making our own decisions. I write about family and medical matters, and just what our responsibilities are when

it comes to legal, medical and other parts of our lives. This part also helps you to find out where you can create your own circle of support so that you can make decisions about your life and your goals.

The last part is the appendix. I didn't know what an appendix was, except that I had to have an operation to get mine taken out when I was a kid. But I now know it is the extra stuff at the end of a book that you can look back on or use as a guide for your own journey to self-determination. My favorite part of this section is the "Helpful Hints" because the members of Integrity House wrote it. Everyone was encouraged to offer their ideas and we wrote them down. I think you will find some excellent advice here.

More than anything, I want you, wherever you are, whatever your disability is, to have control over your life and your dreams. And my dream is that you read my book and embrace it and know that your life is important and that you are a beautiful human being, totally deserving of love and support, and you can decide—for yourself—what will make you happy. I am so lucky to have you and all my friends in my life.

Dignity

The fire of anger burns in me
My eyes are closed, I cannot see
The colors are red and yellow and green
The colors that live inside of me
I awake and the fight is on
To be treated as equal as everyone
My friends and I have dignity
It's your eyes that see the disability
My friends might fall and I reach my hand
I will not pick them up
But I'll help them stand
You can love and support us
And stand by us til the end
But don't baby us or shelter us
And treat us less than
Listen to us, and hear us and try to understand
This is our life, we live it every day
The challenge is upon us, but we are okay
The fire that burns inside of me
Is the anger that fights for our dignity.

Sam I Am, October 2000

Chapter 2
You Can't Tell Me Where to Work

About 10 years ago, I was told by my regional center that I needed to be in a work program because my behavior was too bad to work in the community. I was prone to yelling, screaming, using foul language, and throwing fits of rage. In other words, I had to be in a workshop setting, and be supervised all the time. Arrangements were made for a job coach to pick me up every day and take me to a job that they thought was suitable for me. Of course, they didn't ask me what I wanted to do. I guess they assumed that it didn't matter to me.

First of all, they needed to see how I worked at a large toy chain. I stocked shelves and put toys away. Two feet behind me was my job coach, watching everything I did. I was totally embarrassed when customers came by. But what bothered me the most was when my boss wanted to talk to me, my job coach would get right in the middle of it. My boss would ask me to do another job, like clean the bathrooms or welcome customers, and my job coach would interfere, saying, "I don't think that's a very good idea."

I looked at my boss and said, "I can do it—give me a chance."

Going outside and pushing carts wasn't that hard, but the more my job coach would watch me, the angrier I got. I finally told him to give me some space. "I don't need a babysitter. Go have a cup of coffee. I am doing good!" Then he grabbed me by the arm and pulled me to the side.

"I know what you can and can't do. I read your chart."

I looked him straight in the eye and said, "Yeah, you may know my chart, but do you know me?" And I walked away.

I worked for this toy store for twenty-one days. I wanted to prove that I could work in the community and do a good job. Finally, the time came to get our paychecks. I was so excited. I had never worked before and received a paycheck. They handed me my envelope and I walked off by myself with excitement and opened it. My heart dropped. The check was for $11.24. For 21 days. I kept looking at the check and thinking that they either made a big mistake, or they think I am less than the other workers. But it was no mistake, and that made me really angry.

I went straight upstairs to the executive director's office and went in without knocking. "What kind of place are you running—are you saying we are less than?

"Now Sam, why would we be saying that?"

I threw my paycheck on his desk. "If you are paying me that, you must be paying everybody else the same, and if not, then you think people like me and all the hard work we do are worth less. This is a slap in the face."

As I walked out he said, "Sam, I can fire you for misconduct."

I said, “You can’t fire me, I quit.”

I did fight this and I won. They had to pay me minimum wage for the 21 days and the training. They wanted me to come back, but I never did. I wanted to have a job that I liked, and not have someone looking over my shoulder and thinking that they know me because of my chart.

I have a friend Charles that was part of a work share program like mine. For years Charles would say to his job coach, “I want to work at McDonald’s” and every day she would say, “You have to come to work at Pizza Hut.” He never wanted to work at Pizza Hut. He wanted to work at McDonald’s.

Pretty soon Charles got tired of working where he didn’t want and stopped showing up and started to get in trouble. His coach came up with a behavior mod thing to force him to keep working where he didn’t want. She made a deal that if Charles came to work every day, they would give him a dollar so he could buy a soda, and he loved his soda.

Charles was my friend, and when I heard this I was outraged. They were just bribing him to do what they wanted. Why couldn’t he just work at McDonald’s? That’s where he wants to be.

The bribery worked for a while, but then he stopped showing up again. Instead, he sat at McDonald’s and drank soda and just hung out there all day. Charles made some friends at that McDonald’s and left an impression on everyone, so when he asked for a job they gave him one. He was doing really well at first, but he kept going over to the soda machine all day long to get soda. They talked to him about how this was

inappropriate, but he had a hard time understanding, so they had to let him go.

Charles was devastated. He couldn't understand. He worked hard and he showed up to work every day. Why did he get fired? His circle of support had to be straight with him. "Because, Charles, you kept going to the soda machine when you were working, even when they told you not to."

"But when I showed up to work at my other job, I got to have soda and if I work I should have soda." Charles lost his job because of the manipulation of his job coach.

In the real world, you shouldn't have to bribe people to go to a job they don't want. Help them find a job they do want. Ask them what they want you to do and then help with their goals to achieve it. Charles had to learn the hard way about how the real world works. He still wants to work at McDonald's.

People with disabilities are human beings, not a piece of paper with a name on it, and not less than. We have a right to work where we want and to get paid what we are worth, and it should not be less than minimum wage. We need to be treated as equal human beings in society and our communities. We do not need to hear, "This is what you need" anymore. We need to hear, "What would you like to do?" And then pay us what we are worth. And we are worth a lot.

There are a lot of companies that hire people with disabilities and treat them very well. Everybody wins then. The businesses get hardworking and loyal employees, and the workers with disabilities get

paid what they are worth and feel like they are independent and self-reliant.

Chapter 3
You Can't Tell Me Where To Live Or Who To Live With

It used to be that if a family had a child with a disability, most doctors would tell the parents to institutionalize the child. That means put them in a big cold hospital that smells bad and is full of locks and keys and rules. It was supposed to be safer there, away from the rest of society, so nobody would ever see the "mistake" that was made. Hardly anybody ever thought it was a real person that was being put away. It was more like taking an unwanted puppy to the pound.

Many, but not all, parents did what they were told was "best" and abandoned their kids to a state hospital. That is where the child with a disability would stay most of his or her life, without a family, without anything normal that kid's need. I spent a lot of my adult life in an institution and, believe me my friends, that's not where you want to be. You have no choices, you have no freedom, you aren't a person. They take away your dignity and your freedom and sometimes your soul.

Life got a little better for people with disabilities when we were sent to board and care homes. With board and care I had a little more freedom. Not much, but a little more. When I got out of the institution I was relieved. I thought that finally my life would be like a "normal"

person's. That's all I have ever wanted, to be treated like a normal person, with the same consideration and freedom.

But some of the board and care rules were worse than the institution, like you had to be in bed by 8:00 p.m. Even at the institution it was lights out at 10:00 p.m. At the board and cares I was at there never seemed to be enough food or towels or toilet paper. I would always have to ask permission to use the phone and me and the other residents were never allowed to be in the living room where the TV was.

What got me really upset was the staff of one home I lived in was eating steak and chicken, and we were eating hot dogs and pizza and drinking Kool-aid. We would get a glass of milk once in a blue moon.

After a while when the staff told me to go to bed at 8:00 and I didn't want to, I would climb out the window and hang out at Carl's Jr. until I was tired. It felt good to have that freedom, even if I was "disobeying" the rules.

Then I started going in the refrigerator to get a glass of milk, just like a normal person. So then they locked the fridge door. When they caught me climbing out the window, they called my service coordinator at Regional Center and told him I was "non-compliant." For going to Carl's Jr. and getting a glass of milk. Imagine that.

My service coordinator came and talked with me about these things. I asked him why I had to go to bed at 8:00, and why couldn't I go in the fridge when we wanted a glass of milk?

"Don't you pay for them to have these things for us?"

"Yes, we do," he said. "We only want to keep you safe. Don't you understand that?"

"How dangerous is getting a glass of milk?" He couldn't answer that, so he told me he would talk with the "caretakers" and it was good for a while. But it didn't last long. It was hard for the people "caring" for me to understand that I was an adult, not a child. I started climbing out the window again and getting into the fridge to get what I wanted.

They called my coordinator at Regional Center again and told him they were giving me a thirty-day notice to leave. They said I was a bad influence on the other "consumers" because they started climbing out the windows and getting into the fridge, too. We weren't real people to them. We were "consumers," like widgets in a factory. And the widgets were getting too uppity.

At that time I heard of a new program called supported living. The idea was that people with disabilities would live in their own apartment, but with staff members to help them. I was very excited. I was ready to start to live my own life on my own terms, but with help.

I love supported living, even though having staff there 24-7 is much more than I want. Nobody telling me that I should do this and I shouldn't do that. Nobody telling me what I can and can't have in my own refrigerator. Nobody telling me I have to go to bed when I'm not sleepy.

I have been living in my own apartment for the last twelve years and I love every bit of it. I am the boss of me. I get to choose my roommates, and I get to go to bed when I'm ready to. Nobody makes

the choices for me. I've always said, "you can tell me were to go, but you can't tell me what to do!"

This is a scary thing for some people to hear. They might think that people with disabilities are going to light themselves on fire, or go crazy and run around naked, climbing trees, throwing rotten tomatoes at "normal" people, or forget to eat food and die. This doesn't happen. We manage to take showers, wash clothes, cook breakfast without setting anything on fire, take a bus, get to our job or other daily activities, and make time to be with friends. Sometimes we need help with these things, but only as much as we need and no more.

The biggest need the members of Integrity House have is for affordable housing. Some people might think that because we have disabilities, the government gives us a lot of money and services and anything we need. Not true. We do get money to help us pay rent and buy food and go to the doctor. But only enough to barely survive and live our lives.

Integrity House is in Orange County, California where most of the houses cost almost a million dollars. Rent for a one-bedroom apartment is at least $900.00, and a two bedroom is over $1,300. And that's if you can find a nice place. Most of the members get $850.00 a month from Supplemental Social Security (SSI), and if we share a bedroom with someone, the rent still takes a big chunk our income. Finding a place is really tough for us.

The Department of Housing and Urban Development (HUD) has a waiting list of seven years in Orange County right now for housing

subsidies. Almost one third of the members of Integrity House are on that waiting list and another third have HUD housing. The rest either live with their family or in board and care homes.

Every time a new member comes to Integrity House, they ask about independent housing, and every time we scramble and shuffle to find them something that will help them with their goal of self-determination.

We recently got a call from a community service worker. One of her consumers asked her to call adult protective services for him because his dad was taking his whole SSI check and not buying any food. She wanted us to find him a place to live where he could be in control of his own money and his own life. Another consumer was living with his mother, who has a mental illness. His father was in jail. When his mother went into the hospital, he had nowhere to go.

The need for housing is often desperate, and Integrity House does whatever it can to help people with disabilities find funding for housing, or roommates, or apartments, or anything that will help those who don't know where else to go find a place to call home.

Integrity House has a reputation in Orange County for offering this kind of support to anyone who has a need, regardless of their ability to pay for the services they offer. They also offer a clubhouse run by other members just like them to meet friends, have lunch, and work hard keeping the place running. If you run out of money for food, Integrity House has a pantry full of donated food. If you have a problem with a roommate, the circle of support at Integrity House will help you

work things out. Integrity House lives up to its name: integrity. This means when we say we will do something, we do it. It also means that people come first here.

My friend Isabelle came to Integrity House from a board and care home. She wanted to live independently and she loved the Clubhouse. She formed a great circle of support with people who cared about her.

Isabelle had a bad habit of stealing. Because she learned this from her family, she had a hard time understanding why it was wrong. When she lived with me, she stole my change and special food that I bought. She took things she wanted from her friends and people she didn't know.

Her circle of support finally had to sit her down and tell her straight out: "Stop stealing from us. It hurts our feelings and it makes us feel bad about you. If you want something, we will try to get it for you. All you have to do is ask." She cried and told us she was going to try and could we help her. It took a while, but she stopped completely, and now we can trust Isabelle.

Isabelle has seizures and needed help to live independently, but when she went to her mom's house for visits, she would forget to take her medication and her mother would never remember to tell her. This made her seizures worse. Her circle of support told Isabelle that if she went to her mom's, no one would remind her to take her meds and she would get sick. But a lot of times she would still go. She felt torn between wanting to be with her mother and living in her own

apartment. She always had the right and the choice to come and go, but it was important to know the consequences of visiting her mom.

At one point, Isabelle's mom wanted her to come back home for good. Isabelle thought this meant that her mom loved her, which was something she wanted more than anything. She thought her mother had changed and would help her with her meds and everything would be wonderful. But very soon, Isabelle started to call the Clubhouse all the time, saying that she missed us so much and that she loved all her friends. Her mom then found out that Isabelle's support money stopped when she moved in, and so her mom told her to move back to her apartment. Isabelle was very hurt and cried. Her circle of support tried to help, but Isabelle did not realize how difficult it would be to get her independence back.

Isabelle was having seizures left and right. On top of that, her mom was trying to get money from her that she didn't have, and she was hitting Isabelle. Isabelle didn't understand why she just couldn't come back. Her circle of support got together again to plan how to help her. She wanted to live independently, but because her seizures were not under control, she needed to be in a board and care home before she could go into supported living.

A board and care home was found, but Isabelle is not very happy there. She continues to go to her mom's house and doesn't take her meds regularly. She still comes to the Clubhouse because we will always be her circle of support, but we also support her choices, whatever they

may be. Unfortunately, sometimes they are the wrong choices. But that is our right, too, as independent adults

Sometimes, family or friends don't always tell us the truth. Sometimes they are not interested in our independence or what is best for us. Isabelle lost her independence when she made a bad choice and will have to slowly work her way back to where she was before. I think Isabelle paid the price of somebody else's greed. She thought her mom was acting out of love, but she is learning each day how to take better care of herself, independently with the help of her circle of support. Now all she talks about is when can she live independently. We know she'll make it.

About seventy percent of the members of Integrity House are on a member scholarship. The rest have funding for the day program either through Regional Center or other programs for people with disabilities. No one is ever turned away because they can't pay for any of the services. Integrity House is more like a family, with responsibilities and loving care for each and every member.

Feeling safe and secure in a home, having friends and support for living your life the way you want, are all possible. Sometimes it takes hard work and lots of looking, but that's what Integrity House is all about.

All we ask is that nobody put us down for wanting the same things that anyone else wants. Don't be blinded by the disability, but see the abilities that we do have and accept us for the great things that we do,

like living on our own, and choosing who we want to live with and where we want to live.

Chapter 4
You Can't Tell Me Who To Love

There was a time when boyfriends and girlfriends who had disabilities couldn't live together, even if they were husband and wife. One would live in one board and care and the other would live in another board and care. I couldn't understand it. "They got married! They want to live together!"

But the rule-makers say, "They can't because people with disabilities can't live together because they might have sex and get pregnant." When I first heard this, my heart stopped. I couldn't believe what they were saying. I thought to myself, they really see us as "retarded" or "defective" and less than. Who has the right to tell us we can't live together or love each other? Just what will it take to open people's eyes to the fact that we are the same as everyone else?

Most people in our society don't have a clue about people with disabilities. They think we need to be taken care of, sometimes like little children, in every piece of our lives. From what clothes we should wear to how we cut our hair, from what movies we can go see, to who our friends should be, many people see us as not only not having a brain to

think with, but also not having a heart to love with. Some think that having a disability means we are not capable of loving someone.

The real truth is that the one thing we do better than anyone else is love. Even when "normal" people treat us as "less than," we love unconditionally, no strings attached. When you have grown up with others thinking that you are not smart enough to be a part of the world around you, or when you have had an illness or accident that limits what others think you can do, that doesn't mean that your heart has been turned off.

I want to say it very clearly here: People with disabilities fall in love, have boyfriends and girlfriends, kiss, hug, and even have sex and get married! Just like everybody else. It is normal, natural, and a wonderful part of anyone's life.

When I first met Melissa at Integrity House about two years ago, she was wild, out of control, and unhappy. She lived with her family but she wanted to live independently but at that time she was not ready and she even admitted it. She cried all of the time.

About seven months after she came to the Clubhouse, we got a new member named Jimmy. He had kind of a chip on his shoulder and seemed unhappy, too. When the two of them met, fireworks went off. They said they were just friends, but in a couple of months we began to see a big change in Melissa. She wasn't as wild anymore. She was in love. In spite of their disabilities, they loved each other unconditionally and began to help each other out. They fell so much in love, on

Valentine's Day Jimmy proposed to Melissa. They both were so excited to get married.

Melissa wasn't crying much anymore and she was definitely not unhappy. Jimmy's attitude changed completely because Melissa helped him see what a great and loving guy he could be. At one point she told Jimmy, "I am not going to marry you if you act like that." Jimmy got real scared because he didn't want to lose Melissa, so he worked very hard to be a better person.

Jimmy and Melissa got married on April 13, 2006. I know we never would have seen such a change in Melissa if Jimmy hadn't come into her life. Or such a big change in Jimmy. Despite what others said to try to keep them apart, their love was much stronger because it was what they wanted—to be together forever. The members and staff of Integrity House threw the happy couple a wonderful wedding reception after they were married at the courthouse.

It's amazing what love can do. When Rob joined Integrity House he was nineteen years old and just didn't care about life at all. He would spend his days outside smoking his life away. He just existed. Then Elena came to Integrity House. It was love at first sight. They were inseparable and I took a lot of joy in watching Rob grow. Rob began helping out at Integrity House, and pretty soon he and Elena got an apartment together. With extra support, they were doing very well together. Rob took loving care of Elena.

When Elena got pregnant they were very excited and happy. Elena gave birth to a 10 pound, 9 ounce baby girl. Because of Elena's

background and the severity of her disability, she needed a great deal of support. Rob didn't want a lot of staff in the apartment after he got the hang of taking care of his daughter, Emma, but this put a lot of responsibility on his shoulders. He was taking care of Emma and Elena, and this was very difficult for a young man with a disability.

Rob had to decide what he wanted to do. Although committed to both of them, he really needed to focus on the baby. Rob and Elena separated with the agreement that Elena could see Emma any time that she wanted. They have both moved on with their lives, and Elena continues to see her daughter on a regular basis. Rob is grateful for the way that Elena's love saved his life and gave him his beautiful daughter. Emma is almost seven years old and bright and healthy.

Some people may not agree with this. They may think that people with disabilities are like little children who need to be sheltered and kept like babies all their lives. They are wrong! They may say, "You can't have sex! You can't get married! You don't know what love is and you can't make that decision on your own. We'll make it for you. And the decision is: you can never love someone 'that way!'"

This is insulting. When two adults decide that they want to be together or get married, they only want to be like every other human being. They want to love someone and be loved in return. They want to have someone there for them all the time. Someone who will support their dreams and hold their hand when things get tough. Someone to cuddle with and laugh with and cry with and eat dinner with. Even have a baby together. Is that so hard to understand?

Many years ago, people with disabilities had no choice when it came to having a child. It used to be that right away, as soon as they hit puberty, girls had their tubes tied and boys were given vasectomies so they could never have children. Some people might think being sterilized is a good thing, that having a baby is a big responsibility and a person with disabilities could never understand that. Or that people with disabilities will, of course, have babies with disabilities. Or even worse, that sterilization will somehow save a baby from "defective" parents.

Doctors are no longer allowed to just steal the ability to have babies from adults with disabilities. They have to give them an informed choice. And more and more people have started to realize that with support and lots of love, many people with disabilities make great parents and their children grow up happy and healthy.

Having a child is probably one of the biggest responsibilities in anyone's life. I believe that the decision to have a child should be based on love and what is best for a baby. Most people with disabilities have more love in them than anyone could ever realize. Everything else, like bathing, changing, clothing, and keeping a baby safe and out of harm's way, can be learned.

Just like any other new parents, people with disabilities can learn, too. Sometimes it takes us a little longer to understand things, and sometimes we need a little more support than at other times, but don't tell us we don't have a right to look into our baby's eyes and find happiness. Don't tell us we are not good enough to teach our baby to

walk or read or sing or take care of her or himself. Sure, there are times when some parents just aren't able to understand how to take care of a child, or circumstances or health mean we can't live together. But just like anyone else who can't take care of his or her child, no one can tell us we can't have a baby.

That's why it's important to hear me out. We don't have a problem loving our babies. We have a problem learning to take care of them. We can learn and we have learned.

I teach sexuality classes. There is a big interest in this topic, and everyone is free to ask any question they want. No questions are off limits. But I had to think twice one time when one of the staff members at a program told me, "You guys should never have children. What if you have a child with a disability?" I was outraged, but I bit my tongue.

"First of all," I told her, "it's obvious to me that you see a *disability*, not a *person*. And second, who better to raise a child with a disability than someone with a disability?" Sometimes it takes a while to turn your thinking all the way around so you come back to see the truth in something as simple as: We are regular people. We want to have babies sometimes.

Let me tell you about my good friends from Integrity House who have been married for twenty-six years. When they first got married, doctors and other staff members they worked with told them they should never have children. But they loved each other very much, and they wanted to have children. They just ignored the advice, decided to run their own lives, and have raised three very normal children and now

they have two beautiful grandchildren. They insisted on having support from the very beginning, they were open to ideas and suggestions, they learned all they could, and they had the family they always wanted.

Another close friend, Connie, decided to have a child. Connie has cerebral palsy and uses a wheelchair. She knew all the difficulties and challenges along with the responsibilities involved. She still wanted her child. Connie had a baby girl and has grown to be a wonderful and creative mother. She discovered unique ways to raise Michaela on her own as a single mom. She has support when she needs it and asks for it, and Michaela is happy and healthy and growing more beautiful every day.

My friend Maria has two children. Maria wanted to be a good mother, and tried her very best, but she could not care for her babies. This didn't stop her from loving them, though. She didn't have the concentration and the learning skills to keep them. Maria knows this and accepts it. She loved being pregnant and she is a beautiful mother. Her babies are living in loving families and she gets to see them whenever she wants. They know her and love to be around their special Mom.

I myself am a parent. I have a son twenty-four years old and just out of the Navy. When he was two, I lost him because I didn't think I had any right to be his Mom. I wish I knew then what I know now, but at that time in my life, I had no support, no one to tell me I could do it, that all I needed was to love him with all my heart and learn to take care of him with support. But today, my son and I have the best relationship.

I am proud of him because he knows who I am and respects me and loves me still the same, even with my disability. I am his Mom, and always will be.

This is an important message for anyone who thinks people with disabilities are less than anyone else. If we believe everyone is equal and we mean what we say, and we believe in freedom and freedom stands for equal rights for all, then we have to realize that nowhere in the Constitution does it say we are all equal "except for people with disabilities." We all have the right to choose what we do with our lives and we all have the right to have the American Dream.

All people with disabilities want is to be allowed to make our own choices. We are adults. Don't judge us because you see a disability. Don't say we can't love a baby and raise him or her to be a good person. Try to see what I see when I look in a mirror: someone who wants to live my own dream.

We should not be treated as less than. And certainly not as children. We are adults, wanting the same things everyone else on the planet wants. As the adults we are, we should make our own choices, even if some of them are mistakes. But we are responsible for these mistakes, so we also pay the consequences of our actions, just like people without disabilities.

Having a disability doesn't mean that we don't have feelings. We laugh, we cry, we get angry, we get our hearts broken, and we fall in love. So we really aren't that different after all. No one should tell us who to love, or put up walls to stop us and treat us as less than. No one should

assume that we can't feel or that we aren't capable of loving or be afraid that we are going to make a mistake. We will feel deeply and fall in love and make mistakes, just like everyone else.

What we need is respect. We need our wings so that we can fly. And then we can love and be loved by another. Just like everybody else.

Chapter 5
You Can't Tell Me Where To Go To Have Fun

My friends and I from Integrity House have lots of places we go for fun. One place in particular is a local street fair. It's held every week on Thursday. They have great food, interesting things to buy, and rockin' music. Most of all we love being in our community with all of the people.

We also like to go out to eat. We have a great restaurant near us called Heroes. We go there to watch football games or baseball games. We especially like it during the basketball playoffs or the Super Bowl. It gets pretty loud, but we are as loud as the rest and we love it. Everyone at Heroes accepts us and everyone has a good time.

We have another hangout place called Ciro's Pizza. They have party-size pizzas, and with our group we need it! Sometimes there are eight, ten, or more members of Integrity House laughing, talking, listening to the jukebox, and just hanging out. They have karaoke a few nights a week and a few of us get up and sing.

We also like to dance, and for those who like country music, we like to go to In-Cahoots to listen and line dance. Some of us like to go fishing at a lake. Most of the time we don't catch anything, but it's great

to hang out. We go to movies, to Disneyland, Knott's Berry Farm, baseball games, swimming, the beach, and many other places. A lot of times we just hang out at someone's house and watch movies. But most of the time we are out and about in our community. It gives us a sense of belonging. Our community has learned about us just by our being there and they accept us. They don't get embarrassed around us any more. They treat us like any other adult.

It wasn't always like that.

There was a pizza place we liked to go to watch playoff games. One time everyone got really into the game, yelling and cheering and having a good time. Well, the manager came up to us and said that we were too noisy and that we would have to leave. We were shocked. My friends started to get up. I told them, "Sit down!"

I went up and told the other customers—in a loud voice—that the manager told us that we had to leave because we were too loud. "Can we stay and watch the game with you?" I asked.

They were great. They said, "Sure! Sit down with us. You're not any louder than we are!" They bought us a pitcher of beer. We made some great buddies.

When I went up to pay our tab, the manager apologized to me. I told him that he needed to apologize to all of my friends because he singled us out. I told him that that was discrimination and that we belonged here like everyone else.

Now we are really good friends with this manager and his doors are always open to us because we stood up to him. All he really needed

was to be educated. He soon saw that we were good customers and good people.

That's how we get accepted, by educating. If we want to be a part of a community, we need to be out in the community and show people that we like to laugh and eat pizza and have a good time. If we want to be accepted, we have to educate the public.

Most people are not deep-down mean. They are just ignorant. They may not have ever seen someone, or known someone, who has a disability. They see us as outsiders, or others, or less than. The best way to educate them is to stand up for ourselves, politely or loudly, whichever works! No one can tell you where you can have fun and where you can't, as long as you respect others and demand they respect you.

Chapter 6
But I Will Consider Family Issues

We all need advice and ideas about how to deal with situations that are overwhelming or scary or complicated. Some people go to their parents. Some go to their friends or other family members. People with disabilities, especially those of us at Integrity House, are very lucky. We have what we call a "Circle of Support." We might have family, friends, caseworkers, social workers, doctors, or therapists. But the most important support of all is our peer support.

The people at Integrity House are called members for a reason. We are not "clients," or "consumers," or "residents," or any other word for someone who has to be taken care of or who is less than. We are members—which means we all pull our own weight to the best of our ability and what we contribute to our clubhouse and the members is what we get out of it.

Let's say that a married couple with disabilities has a child, and there is a real concern about the needs of their child. What if the child needs daily medication or a ride to a physical therapist or a baby-safe house? Do we just take the child away from her parents? Move her to a

foster home? Give her away to somebody who could never love her the way her own parents can? No, we don't. We call in our circle of support.

The couple gets together with anyone and everyone they think will have good ideas to solve the situation. We then come up with as many different ideas as it takes to make it work. We pull from everyone at the table and discuss it. Then we come up with a plan of support that helps the couple take care of their child.

Maybe all they need is reassurance that what they already are doing is just fine. Or maybe they need someone to come to their home to help. Whatever it is that will work for them is discussed, not to order them around and tell them what to do, but to help them make the decision that will work for them as a complete family.

But the final decision is theirs to make. They choose what kind of support they need and what will work best for their family. That's where it should stand.

However, sometimes people with disabilities don't see things logically. Because of their disability, they might not see that it is a bigger problem than they can handle alone, or that they need more help than they will admit to. But again, their circle of support is able to help them see that they do need some help. The members are not there to yell at them and say they are bad people. They are there to express concerns and help with ideas. And when it becomes a family matter, we listen to individuals carefully and take all their concerns and ideas and hopes and dreams into account. This is their life to live, and the circle of support is there to help them do just that.

Every time I talk about going back where my mother lives, all my friends, especially Cathy, start freaking out. I have family there but the reason for going is always to see my son, Andy, and my five nieces. Every time I go there, I lose all my control. I give them all my money and fall back into the craziness I swear I left forever. When I go there it takes five or six months just to get back to where I was before I left.

But I'm like a little kid every time, hoping they will finally love me and accept me just the way I am. But they are just not capable of doing that. Being the stubborn-headed fool I am, I always think I can try one more time and I don't listen to nobody.

My last trip to see my son is when I wrote this book. There were times back there that I found myself in situations that I could not control and I just wanted to come home. I would ask myself, "If this is my family, why do they judge me and make me feel so bad?"

Then I remembered what Cathy always told me, "Just because they are your biological family doesn't mean they are your true family." And that kept me focused on what I needed to do. I needed to go home to my true family.

So late at night I packed up and headed home. I made it back in two days, driving almost straight through, and fell into the arms of all of my friends and family at Integrity House. I was a mess physically, emotionally and mentally, and my spirit was broken once again. The next day I slipped out of reality and ended up in the hospital. It has taken almost a year for me to get back to my normal self. The good thing is that I finished my book.

But because I didn't listen to my true family, my circle of support, I paid a price that I cannot afford to pay anymore. Even though the decision to go was always mine, I didn't want to listen to the advise of my circle of support, and the consequences I paid nearly killed me.

I want to tell you a story about my friend, Mikey. When Mikey was seventeen he got sick, very sick. He had a very rare disease called MELAS Syndrome that caused him to have several strokes that left him brain injured. It also meant that he would die soon. I met Mikey at the clubhouse when he was twenty-one years old. I think that he weighed about ninety-eight pounds. He had long hair that was braided, and he was full of piss and vinegar. Mikey had a strong personality and never backed down.

Mikey had two beautiful parents who, though divorced, were very dedicated to him. He lived with his dad, but saw his mom often. Mikey was home alone a lot, so, one day, he came to Cathy and me and said that he wanted to live in his own apartment and hang out with his friends. He wanted what any young man would want. Even though he knew that he was dying, he told his parents he wanted to experience independent living. They were against it at first, but Mikey stuck to his guns and said that this was what he wanted before he died. So they agreed.

A big planning meeting was held. Mikey's entire circle of support was there to help him plan. He needed to find an apartment, a roommate, and staff. It took some time but Mikey never gave up. I

would see him in Cathy's office asking, "What can I do to make this happen? What's next?"

One morning Mikey came up to me, looked me straight in the eye, and with tears in his own eyes said, "Sam, I want you to be my roommate. Please, Sam." I got scared knowing that Mikey was going to die and I wasn't sure what I would do. It felt like a big responsibility. I told him to give me fifteen minutes and I would be right back and we would talk about it.

I ran into Cathy's office and told her. She got that smile on her face. "Sam, you would be great with him."

"Cathy, he's going to die, and I'm scared. Do you think Mikey's scared, too?"

"Well, if he is, he isn't showing it. He's taking the risk of moving out into independent living to hang out with his friends. And he chose you. What an honor." She was right; it was an honor.

Mikey lived with me the last eight months of his life, and he was never alone. Those last eight months he lived life to the fullest. One of Mikey's dreams was to go to Cancun, Mexico and watch the sunset, and this was his last dream to come true. Cathy and her sister, Mary, took him to Cancun where he passed away the day after he saw the sun set. His parents didn't want him to go into independent living. They were scared for him, and I was scared about him living with me, but it wasn't our choice, it was Mikey's choice. He wanted those last months to be spent with his friends and to have some freedom. He never backed down. He knew what he wanted. If anyone deserves a medal for

self-determination it would have to go to Mikey. He was my teacher on self-determination.

Many people with disabilities don't have as much of this special kind of support as we do. I have heard others outside Integrity House say they wish they had that kind of support. But I am here to tell you, when it comes to support, we all have it! Sometimes it takes lots of standing up for yourself and a clear idea that you are a human being, an adult, and you have rights. You are an independent person who can make decisions about your life. There is nothing wrong with asking for help when you need it, but decisions about your life should be yours and yours alone.

Our society needs more places like Integrity House. With the support and love of friends and staff, and a philosophy of self-determination driving all the work that we do here, we are able to help each member be as independent and productive in our community as possible. We are lucky that when we consider family matters, we will listen to those around us, but the final decision is ours.

Chapter 7
But I Will Consider Medical Issues

I have a friend at Integrity House. She got very sick, but she never complained or said it hurt or that she was feeling bad. She was scared and confused. She wasn't sure what to do about it, or what was wrong. Well, it turns out that she had an infection that got into her blood stream and she almost lost her life. But because she had friends and a large circle of support, someone saw she wasn't feeling well, someone else took her to a doctor, someone else made sure she took her medicine, and we all took turns bringing her good food and making sure she ate it.

She is fine now. Part of being a member of Integrity House means that we look out for each other, and when things like that happen everyone pulls together to look after everyone else.

My friend had her mom and dad, her caseworker from the local regional center, her staff from Integrity House, two nurses, her boyfriend, and all her friends. She had been successfully living independently for a long time, and she usually doesn't like to listen to anyone. She has a mind of her own and lets everyone know it. But this time she was totally involved in working with her circle of support to develop a plan for her future health.

She made a decision to temporarily trade her independent living for a supported living plan. She is getting more support but she is still living in her own apartment with her boyfriend. She still comes to Integrity House every day and tells me that she is getting better so she can go back to independent living. Knowing her, I am sure that day is coming soon, but supportive living is a great way to help her out as long as she needs it. But she made this decision herself, based on all the information and support around her.

About three years ago, I was in the same position. I had a medical issue and I never saw it coming. Because I am a diabetic, I need to watch out for things like my feet. Well, I had an ingrown toenail, and I had to go to the hospital to have the doctors take it out. They put me on antibiotics. One day I was putting on my socks and I noticed that the toe looked black. I went to Integrity House and one of the staff said to go to the doctor right away. I asked why and she told me that there was something wrong. My toe didn't look good.

She took me to the doctor, and we were totally unaware that it was anything serious. I thought it was stupid to waste time going, but my circle of support insisted, and I didn't want to let them down.

I just assumed they would give me medicine and we would go home. I didn't have any idea what was about to happen. The doctor came in and looked at my toe. She told me to go down to x-ray and come back right away. I still didn't have a clue. We took the x-ray back and the doctor looked at it, left to make a phone call, and came back and

said I had a bed at the hospital, and I needed to go right away. The word hospital hit me like a ton of bricks.

"What for? No way am I going to the hospital! Forget it!" The doctor told me that if I didn't go, I could lose my toe. I was shocked. I had no idea that the infection was in my toe or what that really meant. If I had been by myself, I would have just left, just got up and walked right out of that place. But the staff member reminded me how important I was, and how serious this was. I wasn't happy about it, but I trusted her, so I stayed.

The next eight weeks were hell. Even with IV medication twice a day, I still lost my toe, but I could have lost my foot or even my whole leg. I never saw it coming, I never knew it was a problem, and even when they said it could happen, I didn't believe them.

When they said that they needed to remove my toe, I cried like a baby, but my circle of support was right there, helping me with decisions I needed to make, and supporting me without question. My friends and supporters sat with me, cried with me, laughed with me, and helped me feel that it wasn't the end of the world. Just the end of my toe.

You see, we definitely need to have a circle of support, especially when the decisions are so hard to make, and we don't see or understand what is happening. When I foolishly told the doctors that nobody was going to cut off my toe, they told me, "If you wait, your foot will be next, then your leg. The infection is spreading fast."

My circle of support was there to help me to understand the seriousness of the situation. But the final decision was still mine to

make. With the help and support of my friends, I was able to make the right medical decision. I told the doctors it was time to take off the toe.

When we face a difficulty in life, it is always better to share it with someone who is on our side. This is true for everyone, including those with disabilities. Especially those with disabilities. Just because someone has a disability does not mean that someone else gets to make the tough decisions in life for them. With a circle of support, these decisions can be made with a clear head and a helpful hand.

Chapter 8
But I Will Consider Legal Issues

Legal issues are very important for people with disabilities to learn and know about. Even more, it is important that they get a strong circle of support to help them get through any legal issues. If I would have known about legal matters and the court system I don't think I would have lost custody of my son. I had no clue what my rights were and I never understood all the paperwork. It was so far over my head I just couldn't get it. At that time I didn't have the support that I have today.

I would like to tell you the story of my son, Andy. I was five and one-half months pregnant when I had my son, Andy. He was born on December 28, 1981 at 11:42 a.m. He weighed only one pound. He was so tiny and was so very sick. Andy had heart surgery when he was just six days old. He also had a tube in his belly that I had to feed him through because he couldn't eat and then he got a tracheotomy tube because he couldn't breathe right. I never left his side for six months.

He was the joy of my life and he melted my heart. I loved him so much. While Andy was in the hospital I was there putting my hands in the incubator, touching every toe and finger, his back, his hands, letting him know I was there. I also went to every class to learn how to feed

him with the tube in his belly and take care of his trach. You only have to go to the class two times, but I went to every class to make sure I knew how to do it.

Andy grew and at six months old he was ready to go home. I was so proud and ready to take care of my son, the joy of my life. Andy and I lived with my parents. They were both very controlling. I didn't have a job, just SSI. When Andy turned 11 months old, he got the tube out and then when he turned one year, he got his trach out. The hospital taught me well how to take care of Andy and now it paid off.

He was fine for the next two years. Andy and I were very happy together. I loved watching him learn to walk and talk, dancing around with him, singing, and laughing. Putting him to bed at night was the best. Even though I couldn't read, he would get a book and I would look at the pictures and make up the story for him and every night he would put his arms around me and kiss me and say, "I love you more," and I would say, "But I loved you first." That was every night.

One day I got very sick and was hospitalized. I was in the hospital two weeks. When I got out my whole world was turned upside down. My parents said that they went down and got custody of my son and that I lost all rights and control over my Andy. I still lived in their home, but I couldn't have very much contact with him.

I would sneak in his room at night and just touch his hair and rub his back, anything to feel close to him at that time. I knew nothing about the legal world. I didn't know how to fight back, and I was lost. I kept

asking how this could happen? I am a good mom and I love him. How could this be?

Six years later, my father died and I ran from there and never returned. But I always had contact with Andy. I wanted to see him more and have visits with him, but the only times I would dare to go over there were when I knew my mother would be gone.

Finally, when Andy was twelve years old, Dr. Flowers told me to have somebody over at the courts find out what the judgment on me was, so that I could have visitation rights with Andy.

So we did, and what I found out that day was heartbreaking. My parents had lied to me. They never got custody of Andy. I got really angry, running out of there crazy, hurting, crying, going right to my mother's house and taking him home with me. I remember Dr. Flowers telling me, "Sam, you can't do this." But I kept saying, "They stole all those years from me! How could they? He's my son!"

I sat down and cried hard, harder than I have ever cried. Well, I began to have visits with Andy alone, and that was so great for both of us. But then I got word that my mother wanted to move out of state with Andy and I was nervous.

We had a big meeting because I wanted Andy to live with me. But I needed to do it in the right way, because he had always lived with her. I didn't want him to feel pressured or feel bad about what he would like to do, knowing what the outcome could be. I was hoping that he would choose me, and I thought I had a pretty good chance.

So, we all sat down and I told Andy that whatever the decision was that he chose, I would never be angry at him. I just wanted him to have the choice to live with me. He looked at me with tears in his eyes and said, “I don’t want to hurt you, Mom.” And this big twelve-year-old boy came and sat in my lap and said, “I want to move with Grandma.”

With a big lump in my throat, I kissed him and said, “Okay, Buddy, no worries. And Andy, I’m very proud of you. I know this is hard.”

As Andy was leaving with his grandmother, he turned back around and came running into my arms and said, “I love you, Mom. I know who gave me life, Mom.” And then he said, “I love you more, Mom.” And I said, “I loved you first.”

If I would have known the legal system and had known what to do and had my circle of support I know I would never have lost my son to a lie. But I am grateful now that I can help others see and learn how to keep their children. My son Andy is now 24 years old and just got out of the Navy. He returned to live with his grandmother, but he knows I am always right here.

About him being one pound when he was born: he is now 6 feet tall and weighs 265 pounds. He has turned out to be a remarkable young man. I loved you first, Andy, but I also love you infinity. You are still the joy of my life and you still melt my heart.

There are a lot of reasons people with disabilities need help and support when it comes to legal matters. We need someone to help explain apartment leases, for instance. When it is hard to read or

understand all the legal terminology, it is easy to get cheated or tricked. It is important to know what our rights are and how to protect them.

If people with disabilities get into legal trouble for something they have done, they need to face the consequences of their actions. But they should also have the same chance to defend themselves as anyone else. Our court system needs to be aware of the difficulty some people with disabilities have in reading, understanding, and responding to any legal charges they have to face. This doesn't mean that they can't make decisions for themselves. If a person with a disability is an adult, they have many rights and responsibilities. They may just need more help in understanding them.

When I lived in Fullerton, California I was very lucky to know several Fullerton police officers. They were very good with all the members and very compassionate. They received training in how to treat people with disabilities. They would often just stop by the Clubhouse to say hello and visit. But there are many police departments that still need training. Bad things can happen if there is a lack of understanding and awareness of just what it is to live with a disability.

I would like to ask that every person with a disability take the time to ask their local police department if they train their officers in respectful ways to deal with people with disabilities. If not, ask them not why, but WHEN will they start? I know how important this training is because of what happened to me.

Two years ago, on the way home from Cathy's house I stopped to buy a soda. As I was driving in my truck my soda fell over and I reached

down to pick it up and I swerved. There was a motorcycle policeman behind me and two more in a car behind him.

They pulled me over and I felt they had a right to because I swerved. One police officer asked me if I had been drinking and I told him, "No." I told him that I spilled my drink and when I reached for it I accidentally swerved. I told him I don't drink, except for maybe a beer every once in a great while.

The first police officer said, "Right. Get out of the truck and stand over by the other police officer." They were going to test me to see if I had been drinking. It is called a sobriety test. I agreed because I wasn't worried. I knew I would pass, as I hadn't been drinking. While I was standing and waiting, I put my hands in my pockets. That's what I do. The police officer yelled, "Get your hands out of your f**** pockets!"

I said, "Okay. I'm sorry." I was trying to be polite, but I started to get a little scared. The police officer gave all the tests to me and I passed every one of them. The last test was where I blew into this machine and it told you what percentage of drinking you had done, and mine came back 00.0%.

When he was done he told me to go stand over by the other officer and the two of them checked inside my truck. Then one officer checked my pockets for weapons. They didn't find anything in my truck except my medications. They asked what are they were for and I told them. So they asked if I had a disability. I told them yes, and I have a card in my wallet that my regional center gave to me if something like this

happened. The card had a number to call for someone to explain about my disability. It also had Cathy's number

Cathy's house was right up the street. I gave them the card, but one officer said, "We don't need this," and ripped it up right in front of me. I was really getting scared, but I kept just standing, hoping and waiting to go home. I forgot and put my hands in my pockets again and the officer standing next to me took his boot and kicked me in the back and knocked me down. I got back up quickly, both scared and angry.

He said, "I told you not to put your hands in your pockets." The next thing I knew they handcuffed me.

I said, "What are you doing?"

"Just stand there," and I saw a tow truck come for my truck.

"What are you doing? What's going on? Why are you towing my truck?" I was really upset. I told them that Cathy was right up the street. She can come get it for me. "Please don't tow my truck away, please!"

The police officer yelled in my face, "Shut the f*** up!"

I was so scared and so angry I yelled, "You shut the f*** up!" and when I did they knocked me to the ground, smashed my face into the street, and the other cop put his boot into the back of my neck. When they yanked me up by my arms, I was so scared I didn't know what to do. I was all alone and couldn't get to my circle of support.

Then they told me, "You're under arrest."

I said, "What for? A DUI? But you know I passed the test. Why are you doing this?" They didn't even answer me or look at me. They took me to the police station and drew blood out of my arm and booked

me. I gave them Cathy's number, but they chose not to call her. They called my friends, my peers, Michelle and Holly to come pick me up. I was so confused, but I was very happy when I knew they were on their way, thirty minutes at the max. I said to myself, just hold on. It will be okay. My friends are coming.

Just then another officer came in and said, "Come with me. You have to wait in a holding tank." I followed him and this is where I lost it. No windows. Locked door. Scary smell. The room was as small as a small closet that you put jackets in and it was dark. I begged him not to put me in there. I begged him on my knees, but he threw me in there anyway. I screamed and yelled and punched the walls until my hands bled. I freaked out and I lost complete touch with reality.

It took Michelle about an hour to get there, but the police officer kept me an extra hour because I freaked out. When he finally let me out, I couldn't even walk. I was crawling on my knees. He grabbed me by my arms and pulled me up, but my legs kept shaking and wobbling. He said, "You act right or I'll put you back in there for the night." I couldn't even talk.

He opened the door and I started to wobble when I felt my knees give out. Michelle and Holly were there to lift me up and help me to the car.

That night I couldn't sleep. I just stayed in my bed all night shaking. The next morning Cathy came over but part of me felt I had suffered so much I just couldn't go on and I had slit my wrists. The pain of the isolation and humiliation and fear had sent me off the deep end.

Cathy called 911 and more police came into the house. But I recognized these police. These were my friends; these were people that had never treated me badly. They were very caring and compassionate and saw me as a worthy human being, not some animal to be locked up in a cage. The difference was that they had been trained.

That's why it is so important that police departments have training to teach their officers that just because we have disabilities doesn't mean we can be treated like animals. Sure, we do stupid and sometimes dangerous things and need to be held accountable for our actions. But to be treated the way I was treated, just because I "look" a certain way, is not right, no way.

I was glad I was able to pull myself back together and move on, with the help and support of my doctors and my circle of support. But this horrible thing that happened to me makes me mad enough to want to never see it happen again. We need to have mandatory sensitivity training for so-called macho police officers to change how they treat people with disabilities. Everyone has a right to be respected and law enforcement should be an example for the rest of the community.

This department never filed charges against me. They knew I hadn't been drinking, but they saw that I was just a little bit different and I didn't act in the perfect way for them, and they overreacted. The only way this can be okay with me is if it never again happens to another person with a disability.

A friend of mine has Asperger's autism syndrome and lived with his mother until she died. After the funeral a judge told him that he was

going to be sent to an institution, without asking him or offering him choices. He got scared, and he ran away to Mexico. Even though he struggled down there and got all his money stolen, when he came back six months later he felt stronger and more independent. He never did have to go to an institution. He came to Integrity House where he found a powerful circle of support to help him. He now lives in his own home and is doing great. His experience with self-determination helped him become a very strong advocate for people with disabilities, especially with legal issues.

It is important to know what is happening when it comes to legal matters. Sometimes police officers, judges, and social workers will ask us questions that we don't understand. Sometimes we get confused and just say "yes" to get over with whatever it is. This is usually a very bad idea and we end up somewhere we don't want to be because we didn't understand.

Being an adult means taking responsibility for yourself when you choose to live independently in a house or apartment, with roommates or without. You have the responsibility to do your part. You have to pay the rent, you have to pay for the lights and water and gas and you have to pay for food, phone, and cable.

Living on a limited income as we do is not easy, so it is very important to learn to budget our money so that we can have a roof over our head, lights to see, gas to cook our food, and hot water to shower so we don't smell. We need all of these things to stay independent.

I have a friend who was just learning these lessons. She took an entire month's check and went and blew it on new clothes and a bike and a new stereo and TV. She had just moved into her own apartment and wouldn't listen to anyone's advice about budgeting. When she couldn't pay the rent or any of the utilities or even buy food, she ended up homeless.

When she arrived at Integrity House, she still wanted control over her money because she always bought whatever she wanted, even when it got her in trouble. But her new friends and circle of support helped her see that she had to make a decision. If she wanted to go into a homeless shelter, she could continue making bad choices. If she went into a board and care, she would lose her independence.

But if she wanted to find a roommate and move back into an apartment, she would have to give up control of her money until she learned to be more responsible with it. She made the decision to let Integrity House help her keep her independence by teaching her how to budget her money.

It was very hard for her, especially when her check came the next month. But understanding that she would be out on the streets if she blew it all again, she decided to stick with having someone help her budget her money. She even managed to pay back all the money Integrity House had loaned her, which made her feel good about herself.

Being responsible isn't always easy, but if we want to live as adults, we have to do it in order to live life the way we want, like every other

human being. Winston Churchill said it best, " With responsibility comes greatness." We can all be great. Like my friend Sarah.

I met Sarah at the hospital after she had a baby girl on the bathroom floor of the board and care home where she lived. She never knew she was pregnant and neither did the board and care people. They said Sarah had no idea how to take care of a baby and they called Child Protective Services. Sarah told them she wanted to keep her baby and learn how to take care of her. Sarah's service coordinator called the Clubhouse and Cathy and I came to the hospital and worked many hours over three days with Sarah to help her learn to feed her baby. But three days to learn everything it takes to be a good mom was just not enough time so Social Services took Sarah's baby away from her.

Sarah became very sad and wanted to get her baby back. She went to parenting classes. She went to all her visits with her baby. She went to all of her court dates and she went to classes to learn how to take care of her little girl. She did everything possible to keep her child, but her baby got very sick from a disease transmitted by the father. He had lived near Sarah and took advantage of her. She never knew that having sex could cause her to have a baby. The baby would have this disease for the rest of her life, but Sarah still fought for her baby for two years.

Even though she fought hard, and even though she did everything they asked, social services still came to the final decision that Sarah could never have her baby back, that she was incapable of taking care of her child. The reason was that Sarah should have known that having sex could cause her to get pregnant. They also said she never should have

had the baby on the bathroom floor because that showed she was irresponsible.

Sarah paid the price of losing a baby because our society failed her. In our school system if you have a disability the school doesn't give you sex education. They think that they would have too many problems with the parents and they don't want to risk being sued.

But how can people with disabilities have any kind of normal life if they don't know what they need to protect themselves. From pregnancy, from disease, from being taken advantage of.

Don't isolate us from the rest of the world. We are not things that have no feelings. We are good-hearted people with wants and needs and we need to be educated. When you isolate us you make us feel unworthy, like we don't belong. I promise that if our society helps and doesn't isolate us, all they will see is true beauty and growth to live the life that we truly deserve.

I love my friends enough to say life is so sweet, that when you grow and love and laugh, it only gets better. I want my friends to take charge of their lives—all parts of it, including sex education.

Sarah never gave up. She just got stronger and more determined. She is married now and lives with her husband and now has a little boy who is two years old. She is a great mother and a good person. You did it, Sarah!

It is so important to have a circle of friends and supportive people help us make informed decisions. The legal rights and responsibilities of adults with disabilities are no different from anyone else. All we need

is patience and understanding, something everyone could use sometimes.

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Chapter 9
Finding Resources

I believe in self-determination and I believe in being independent and I believe in the power of friendship. This doesn't mean I won't get knocked down. The real meaning of self-determination is that I just get back up and keep on making decisions for my own life. There are so many resources out there that can help us become more independent and fight for our own rights, and help us become more self-determined so we can make good decisions about the quality of our lives.

I was one of the lucky ones who stumbled onto Integrity House when I thought no one or no place would ever help me. But I now have a chance to give back what I found here. I can help you find just what it is you want to do with your life, who you want to hang out with, and where you want to go. You can do it. All you have to do is be determined!

You can find these resources and you can choose those you want to use and those you don't want to use. There are many self-advocacy groups. We need these resources. We need to learn about other people becoming self-determined and living their dreams as a way of realizing that we, too, can make the decisions that lead us to independence.

You might hear that self-determination costs a lot of money for different programs. But self-determination is not a product, or a service,

or a place. It is something that doesn't cost one penny. It is freedom to have our dreams come true.

Self-determination is not a program. Self-determination is what lives inside our hearts, our souls, our lives, and our dreams. It is something that no one can take away or give to us. It is something that we all have to discover for ourselves.

What I call self-determination may mean something completely different to you. Self-determination might mean having an apartment to call your own with your own bed and curtains you picked out all by yourself.

Or it might mean having spaghetti for dinner instead of meatloaf. It is something every person should decide for him or herself. It is the power to say, "This is my life and this is how I want to live it!"

All people with disabilities have a circle of support, but sometimes you have to look hard and be persistent and make sure those supporting you want what is best for you, not for their program or what they think you need. Most of us have regional centers and IPP's (individual program plans), and IEP's (individual education plans) to make it clear what we want. It is important to be clear about what you want—and don't want—in your life. Make sure it is written in your IPP. The people who are paid to help you should cheerfully make it easier for you to become independent, happy, and able to determine for yourself just what it is you want for your life.

What happens when a member of Integrity House goes over the line? Or when they become a danger to themselves? What happens

when they make a bad choice to turn their back on their circle of support?

Bill came to the Clubhouse with a real anger problem. He had been arrested several times and got into fistfights regularly. But he wanted to be accepted so badly, to be loved and cared about, he worked hard to control his outbursts. He saw Integrity House as the last resort, the one place that he could finally be accepted.

One particularly bad day, something small set him off and he exploded. He kicked a huge hole in a door and attacked a staff member, punching him in the face. Many of the members were frightened and hid from Bill as his rampage went on. Some were crying, because they considered themselves his friend and would have done anything for him.

Finally, he was persuaded to go home. A meeting was held with all the members, and it was decided that Bill would be suspended from the Clubhouse for seven days…a whole week with no contact with the staff, members, or services. He could only return after that time if he apologized to everyone and promised to control his anger. Otherwise, he faced getting kicked out permanently.

This was devastating to him. He could have turned his back on all his friends and his circle of support. He could have given into the rages that overtook him. The week without the Clubhouse was one of the worst in his life. He cried every day. Many of the members also missed him terribly.

At the end of the week, Bill returned and realized that the only way to survive in the world was to be a part of something greater than himself, and that was his circle of support at the Clubhouse. He apologized from the bottom of his heart, and since that time, whenever he feels that anger start to surge up in his gut, he remembers what is really important in life, and he asks for help. He always gets it.

We all need to find where we belong in the world, and it may not be easy to admit that we need help sometimes, but the rewards are worth it. There is a lot of love out there. It's up to you to accept it.

I have tried to gather as much good information as I can to help you become as independent as you want to be. All of us have goals, and all of us should be able to work towards them. Look at the end of this book for some help with finding resources for goal setting, helpful hints, and gathering a circle of support.

Living with a disability does not mean you have to do what others tell you to do all the time. It just means you need more help sometimes to live the life you want, one that you have planned for all by yourself.

Be determined! Look out for yourself! Find that power in your heart to live life to the fullest. You deserve it!

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Chapter 10
Finding Your Way In the World

When I was on the Board of Directors at Regional Center of Orange County, it quickly became very clear to me that the focus there was on children with disabilities and the services that they need. The adults were just kind of left in the background. Kids do need a lot of help, but what many people seem to forget is that the kids grow up and become adults and aren't so cute anymore. It seems as though services start to dry up for them.

How can teenagers with disabilities successfully move into the adult world when they've been treated as children for so many years? Once they hit adulthood, the attitude seems to be to throw them out into this great big world and tell them, "You're an adult now, be independent." Where do they go and what do they do now that they are supposed to somehow be taking care of themselves?

Like lots of other people who suddenly find out that they are no longer little children, we are scared to death. But it's worse for us. We often have no clue about how to be independent and self-sufficient. For eighteen years, all the focus was on what we couldn't do or how much we needed to be taken care of, or worst of all, how "brave" we were. How

many “cowardly” people with disabilities have you ever heard of? We’re all supposed to be brave and plucky, and meanwhile, nobody is teaching us how to find a job, or balance our checkbook, or use the bus, or find someone to love.

My friend Joe came to Integrity House a couple of years ago. He has Down Syndrome. His father died and his mother got very sick and was put into a nursing home. Joe is 63 years old and had always lived with his parents.

He lived with his brother while Regional Center looked for a place for him to live. At first they wanted him to live in a board and care home, but Joe wanted more. He wanted to live in his own apartment and was very excited about it.

So he first moved into a HUD building by himself with supported living. Joe’s mom had taught him how to cook and he really enjoys cooking. He did well for a while, but soon he became very lonely and Joe decided that what he wanted was to have somebody take care of him, because that was what he was most comfortable with.

Joe still wanted to live independently, but with roommates. He wanted to go into Integrity House’s independent living program. At first it was very difficult for Joe. He still didn’t grasp what it meant to take care of himself because his parents never taught him how to be independent.

Joe still refused to live in a board and care and so our circle of support got together to help Joe understand what independent living

really is. Joe is working very hard and doing much better, but it will still be a long process.

Joe's parents loved him very much, but they didn't really prepare him for when they couldn't take care of him any more. This is a very big problem for other adults with disabilities. Parents need to help their children get ready to be independent in case something happens, or their child decides that they want to live their own lives when they are adults.

There has to be a change in how people with disabilities are treated in our society. By the time we get to high school, it is getting pretty late to learn how to navigate the world. Communities, schools, and regional centers should offer lots of classes, starting with job training. We need to know how to act in an interview, what to wear, and how to fill out an application. If we can't read or write, then we need to learn to find ways to apply anyway. We should also have the choice about what job we would like to have. We are not all one person, "disabled." We are individuals with different talents and likes and abilities. Someone should ask us just what we think we would be good at and help us get a job doing it.

Another class for high-school-age people, with or without disabilities, should be living independently. These classes would emphasize safety first in things like cooking and trusting people. They need to learn how to clean, pay rent, grocery shop, and get along with a roommate. And if someone wants to live alone and can afford it, that should be an option, too. But it should be the person's decision, not

someone telling them what to do or who to live with. Other adults have choices. That's all we want.

Learning to use the bus system would be another big help in feeling independent. Depending on other people to go to the movies or to meet friends or get to work is humiliating. Using the bus system can be a great skill that will go a long way to helping new adults feel independent.

Too much time is spent focusing on what kids with disabilities can't do and not working on the good qualities and talents they do have. There should be lots more effort put into getting them ready to become adults. If I haven't learned to tie my shoes by high school, give it up! There's Velcro and slip-ons, for goodness sake!

Instead teach me how to say "No!" to creepy people and "Yes!" to friends. Teach me what kinds of nutritious foods to buy. Teach me how to express my frustration in healthy ways. Teach me how to get someplace on time so I can be a dependable worker.

At my regional center they have a children's camp, Camp TLC. Well, I think they should have a camp for adults, called "Camp Independence" which would be a place to practice independent living skills. Regional Center could also have a special apartment where teenagers with disabilities can spend a week or two to get the feel of being independent and actually have them practice all the things they have learned.

People with disabilities really aren't that different from anyone else. We want to work and have friends and go out to eat sometimes.

We have good hearts and beauty inside and want to share our talents with the world. Sometimes we need help with being independent, but give us a chance. We might surprise you...and ourselves!

Chapter 11
Peer Support: My Love, My Life, My Friends

In my heart and deep down in my soul, my friends, past, present, and future, are the true reason I am writing this book. My friends, you are my love and my life. You saved me when I thought I was beyond saving. You picked me up and took me into your hearts without any prejudice or judgment. You loved me when all I really needed was to be loved.

This doesn't mean that staff members or professionals who work with people with disabilities can't be my friends, because lots of them are. Dear friends, and cherished. They have helped me find a place to live, a job to do, and a life with meaning. But they go home at the end of the workday. They go to their lives and their friends. But when I go home, I get to spend time with the people who understand me, who live the same life as me. We are there for each other day or night, weekends and holidays, no strings attached. This is pure, unconditional love.

My friends and I don't see disabilities; we see each other. We see friendship. We see love. And we see life. We see beautiful human beings. If it wasn't for my peer support I wouldn't be where I am today. They have given me courage and understanding to make it through each day. They accept me for who I am. I might get cranky, or blow up about

something. I might be so sad sometimes I don't want to get out of bed or face the day.

It's my friends who come over and knock me off the pity-pot. They don't let me forget how important I am to them and how important they are to me. We all depend on each other. They see me for the person I am and the love I have in my heart. They don't see a disability.

For some reason, lots of people are afraid of peer support. Peer support is powerful medicine, and it's free. Maybe some professionals and staff members who work with people with disabilities think they might lose their jobs. Or they worry that somehow people with disabilities getting together will make all of them a little crazier.

But that's not the way it works. We will always need some kind of support, and we will always be grateful for the professionals who are there to help us with our daily needs.

And what about getting a little crazier? If laughing and joking and dancing and singing out loud and having a great time when we are out together is crazy, well, I guess we do get a little crazy sometimes! Doesn't everybody?

Christmas can be a tough time for many people. Usually it's because they have no family and nowhere to go. Sadly, that includes lots of people with disabilities. I was one of those people before I met all of the members at the Clubhouse.

Being home alone on the holidays was one of the hardest things for me to endure until that first Christmas after I came to Integrity

House and I found myself surrounded by all of my friends. That day, I vowed never to be alone on Christmas or any other holiday again.

Now, I start two months before Christmas to get ready and start taking down names of the members who have no family or nowhere to go. There are usually about eight to ten members. A few of the members help me put stockings together for everyone. We put candy, pens, make-up for the ladies, and baseball hats for the guys and apples and oranges and any other treats I can find. Then I go out and buy each of them a gift, something I know that they will like. Members and staff help everyone buy a gift for everyone who will come to the party.

Then we go out and get the Christmas tree. Everyone crams into my apartment on Christmas Eve and we decorate the tree. I usually have all of the lights up already. We make hot cocoa and sit around the fireplace and talk, then everyone goes to sleep.

After everyone is asleep, the fun starts. I fill the stockings and bring out the gifts, just like Santa Claus. In the morning, everybody acts like a little kid, even me. The surprise on their faces—that's the glory of it all. We have so much fun and I have fun watching them. Then we put on a huge feast, either a ham or turkey with all the trimmings. Everyone goes home tired, but happy and content. We have spent a holiday with those we love and who love us.

Spending holidays with my friends has enriched my life in ways I never thought possible. My friends give me warmth within myself that makes me feel as if I do belong here on earth, that I am special, just like them.

When I am having doubts and feel like just pulling the blankets over my head for the next month, my friends are the ones who show me how far I have come. I am honored and proud to be part of their lives, for they are my chosen family.

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Chapter 12
Where Do I Go From Here?

After reading the stories here in my book, you might think my life is all perfect and wonderful and one party after another.

Not true.

My life has ups and downs, just like anybody else's. I get discouraged and sometimes I get so mad (usually at the way me or one of my friends is being treated) I act out and push people away. But I have learned ways to help me cope with these problems.

The biggest difference in my life now compared to my life before Integrity House is that I have discovered my purpose for being on this planet. Every day I wake up and I think: what can I do today to help every person with a disability know they have control over their own life? How can I spread the word about self-determination to everyone who needs to hear it? How can I reach out and give back just a small piece of what I got from my friends at Integrity House?

I now know that I'm not just a piece of shit. I'm someone who is unique and special. I know this because my friends tell me all the time. These friends care about me and I care about them. We depend on each other.

I also have a place that depends on me. It's not that Integrity House would fall apart without me, because I know it wouldn't. But

when I go there, there is so much work to be done, I just have to stop thinking about small things that may be bothering me and pitch in and get the big things done. And if I don't do them, who else would?

I still have lots of dreams I want to come true. I want to travel more, especially if I get to speak to groups of new friends with disabilities. This is something that makes me very happy. My friend, Mark Antenucci, said that he's never seen a person light up so many other people. But it's really the other way around. I'm the one that comes alive when I speak to a crowd, especially one that truly understands just where I'm coming from.

People respond to what I say because I speak from experience and I speak from my heart. All the love I feel comes out when I help others take hold of a dream and go for it.

I have other dreams, too. I want to own my own home where Tashie and me can live in peace. I want a garden to take care of and a big TV room where all my friends can come over for dinner and watch a ball game or shoot some pool. I want a place that no one can ever kick me out of again.

I want all my friends, both those I already know and those I haven't met yet, to have a safe and nice place to live, too. Everyone deserves to call a place home. One of the biggest needs for people with disabilities is housing, so I would like to stop worrying about *where* they are going to live independently, and concentrate on *when*.

I have smaller, personal dreams, too. I would like to spend more time fishing and camping. These things clear my head and give me a

sense that the world really can be a great place to be. I'm at peace when I'm out in the woods or holding a fishing pole.

Most of all, though, I want everyone who has ever had to struggle with bad times and heartache and troubles to gather a circle of friends and find their path to the dreams at the center of their hearts.

If I could do it, you can too.

Appendix A
Resources

If you are just discovering that you have a right to determine what happens to you in where you live, what you do, and whom you have as friends, it might feel overwhelming trying to find people and places to help. Many of the resources in this section are found on the Internet. If you don't have a computer or Internet access, you can ask someone to help you, or go to the library and use the computers there (the librarians will help), or ask a caregiver to get some phone numbers so you can call.

It may take lots of determination to form a circle of support and get your message of independence across, but don't give up! You and your dreams are worth it!

Integrity House **www.integrity-house.org**
This is the official web site for Integrity House in Santa Ana, California. Alliance of Abilities is the non-profit that administers the programs at Integrity House. You will find the latest newsletter, information on members, programs and services.
Look for the link to: *You're Not the Boss of Me.*

Disability is Natural
http://www.disabilityisnatural.com.htm
A source for thought-provoking articles, products to promote new ways of thinking, and more! People with disabilities constitute our nation's largest minority group. It is also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, socioeconomic levels, and ethnicities are represented. Lots of information about changing the public's perception of people with disabilities.

MicroBoards
http://www.communityworks.info/articles/microboard.htm
A MicroBoard is a formal way of organizing your own circle of support. This site seems to be geared towards social workers and those who work with people with disabilities, but it might spark some good ideas for your own path to independent living.

"A Microboard is formed when a small (micro) group of committed family and friends join together with a person who lives with challenges to create a non-profit society (board). Together this small group of people addresses the person's planning and support needs in an empowering and customized fashion. A Microboard comes out of the person centered planning philosophy and is therefore created for the sole support of one individual." *adapted from Vela Microboard Association's website*

Project Civic Access
www.ada.gov/civiccommonprobs.htm
This website is put out by the Department of Justice. It suggests lots of ways that people with disabilities should be able to become full participants in community life. It mostly has to do with construction and planning, but has a good attitude about inclusion.

ACT Advocating Change Together
http://www.selfadvocacy.com/index.htm
Advocating Change Together (ACT) is a grassroots disability rights organization run by and for people with developmental and other disabilities. ACT's mission is to help people with all kinds of disabilities to see themselves as part of a larger disability-rights movement and make connections to other civil and human rights struggles.

California Department of Developmental Services
http://www.dds.ca.gov
The Department of Developmental Services is a great resource for people with disabilities, especially those in California. DDS has many publications available, including:

From Conversations to Actions: Using the IPP
This has many stories of how people with disabilities have used the Individual Program Plan to live their dreams.

More Than A Meeting, A Pocket Guide To The Person-Centered Individual Program Plan

A Consumer's Guide to the Lanterman Act

Community Conversations With People With Developmental Disabilities In California

Person-Centered Planning, Building Partnerships And Supporting Choices

And, from Minnesota:
It's My Choice From The Governor's Council On Developmental Disabilities
This is a practical workbook that is very easy to use.

Appendix B
Helpful Hints Written By Members Of Integrity House

"Don't give up."
Chris *lives with his parents*

"Nice people, I like it here."
Herman *lives with his family*

"Always strive to be better."
Jimmy *lives with his wife, Melissa*

"Keep going, even if someone says you can't do something—do it anyway." **Scotty** *lives with family*

"Do a WEB page so people can contact us."
Brad *lives with his girlfriend*

"Don't hate, contemplate. Don't step back, always go forward."
Melissa *lives with her husband, Jimmy*

"Show you are responsible.".
Nykkole *lives independently*

"Don't give up and let other people push you around."
Joel *lives with family*

"Respect people, enjoy people, love them a lot, make sure they don't treat you badly."
Annie *lives independently*

"I learned how to manage my money and I learned how to cook."
Joseph *lives independently*

"Pay your own bills and save money, then do what you want to do."

John *lives independently*

"Get a job."
Eddie *lives with his parents*

"Learn how to clean your own place."
Jamie *lives independently*

"Even if people are against you—do what you want."
John and Matilda, *married for 27 years, 3 daughters, 2 grandsons*

"I moved out of Fairview [Developmental Center] in 1981 because I was good."
David *lived at Fairview for 21 years, and now lives in a board and care*

[Living independently means] "being held accountable for your actions."

Owen *lives independently*

"I was in a board and care and it is much better living by yourself."
Joe *lives independently*

"Get out on your own and be independent—it's wonderful."
Robyn *lives independently*

"I told my mom I wanted to be on my own."
Marianna *who lives on her own*

"Remember to take your meds so you won't have seizures."
Maria *who lived on her own but is back in a board and care because of seizures*

"Make sure you don't get taken advantage of."
Brooke *who lived on her own, but is living with her parents now*

"Look for someone to support your decisions."
Ana *who was once homeless, but now lives independently*

"Don't be afraid."
Nathan *lives in a board and care, but is moving towards living independently*

About the Cover

Growing up I didn't have anyone to listen to me, understand me or to protect me and I never had a friend. All I had was an old pepper tree in our back yard. That old pepper tree heard all of my deepest secrets, saw all my pain inside and out, and saw me at my worst and at my best. Most important of all, though, is when that pepper tree showed me that a friend doesn't have to talk, they can just listen.

One time when I was about eight years old, my life was about as awful as it ever would be. I hadn't eaten in several days and I was getting weak. I leaned up against that tree and thought, "I wish I could just die. I wish I could close my eyes and never wake up." Just then a little gust of wind swept by and shook all of these little round red peppers out of the tree onto my face and arms. It felt like the tree was crying, and when I stood up he creaked, like he was hurting, too.

No one had ever cried because of me. No one had ever cared what happened to me. Feeling this great, loving kindness from this tree gave me strength. I put my arms around him and I hugged him, saying, "Don't worry, I didn't mean it. I won't leave you. I promise, I am going to get stronger." And I did.

Ever since then, whenever I was scared, tired, cold, or hungry, all I needed to do was climb into the old pepper tree and the wind and its branches would sway back and forth with the wind like a lullaby. This

old pepper tree gave me a reason to live. It showed me that it was possible to be loved and cared about. I learned compassion and determination from that old tree. I kept that strength buried deep inside of my soul, through lots of troubles and pain. But I held on. I knew that if that pepper tree could be strong and caring, I could too.