

UNITY

SERVICES



Stories of St. Peter's

Self-Determination A Revolution

FREEDOM AUTHORITY SUPPORT RESPONSIBILITY

"Self-determination is a humane and exciting way to humanize managed care in our long-term care systems. It can and should become an essential element in our system of supports for people with disabilities."

C. Everett Koop

*Member, Advisory Board Self-Determination Project,
The Robert Wood Johnson Foundation,
Former Surgeon General*

"Self-determination is the freedom people gain from having the recognized authority to plan a future for themselves and directly negotiate for funds which will assist them in realizing their dreams"

Tom Nerney

*Co-Director National Program
Office on Self-determination*

**"The next step is how
we bring control over
their own lives to people
with disabilities.**

I think that's a revolution,

but it's the right revolution."

Jim Haverman

*Director of the Michigan
Dept. of Community Health.*

A revolution is underway, it's called self-determination and it means giving people with disabilities the opportunity to steer their own boat, to be captains of their own ship. Self-determination is the road to freedom. That's the philosophy of Community Living Services' Self-Determination Initiative.

The initiative is one that is gaining strength and popularity at the national, state and local levels. At Community Living Services, it's become a number one priority ever since inception back in 1996. The Self-Determination Initiative is supported by a grant from the Robert Wood Johnson Foundation, one of the nation's largest health care foundations, and has quickly spread to more than 30 states. Community Living Services is one of four Michigan funded sites and has flourished successfully providing self-determination as a way of life to the people it supports.

Historically, people with disabilities have had virtually no control over their lives. They have been in a system where services were decided for them, not by them. The Self-Determination Initiative changes all that. It begins with a person-centered planning process where dreams and goals are set, services and supports are identified and action plans developed. With self-determination, Community Living Services goes a step further by formulating these plans into a personal budget. The budget allows people to identify and acquire support they need to live a full life. It allows flexibility, the freedom to choose where they want to live and with whom. They choose their own support providers rather than having an agency doing it for them and are able to evaluate and control the quality of their services.

After the budget is set up, support coordinators work closely with the individual in shopping for goods and services. The actual dollars are handled by a fiscal intermediary. The individual authorizes payments and the support coordinator helps keep track of the budget.

When people can determine how to spend money on most of their needs, they do so more efficiently and with better value. A growing number of people are now reporting they are more satisfied with their lives at less public expense.

Self-determination works for everyone. People who need assistance in planning and controlling their budgets are assisted by a circle of support consisting of family and friends.

Giving people control over their own budget is the key to economic and personal freedom in the self-determination

process. Freedom is one of the founding principles of the initiative, others include: authority, support and responsibility.

Freedom allows the person with disabilities to develop a personal life based on their dreams and desires. **Authority** gives individuals control over their personal budgets to make decisions such as who will assist them, what supports need to be purchased, where those supports will come from and when they are needed. **Support** refers to those goods and services that are individually tailored to assist a person in living the life they would like to have. Along with this freedom, every citizen has to take on **Responsibility**. This might include: earning a living, paying taxes, living within a budget and contributing to the community.

Community is another key component of self-determination. Individuals and their families are able to enjoy community participation that most take for granted. Many involved with self-determination at Community Living Services have acquired their own homes and are living in an area

where they've made a strong connection with neighbors. They become part of the community by enlarging circles of friends and contacts who can assist in a supportive network.

The lives you are about to read about in this brochure have been transformed. Dollars previously spent on programs, slots and buildings are now being used in more flexible ways. In fact, in each of these stories, the cost of supports are equal to or less than their previous system driven situations. You will see how individual budgets are being used to achieve goals and fulfill dreams. You'll also share their happiness knowing they have the freedom and opportunities guaranteed to every citizen. The revolution is here, now is the time to be a part of the change.

If you would like more information, call the Community Living Services Office of Self-Determination at 734-467-7600.



"Pure Hell." That's how Janice Parsell describes her life with her adoptive mother. A woman who would hit and punch her young daughter who had cerebral palsy and muscular dystrophy. A woman who said her daughter would be better off dead.

That was Janice Parsell's life for 32 years. Constant mental and physical abuse tore Janice down, ripped her apart, but it also strengthened her, made her a fighter, able to speak her mind. She was going to need it. The next ten years had her in and out of nursing homes where she endured degrading treatment. Then she met her knight in shining armor, Bill Sotell.

Bill also has quite a story to tell. He has been married three times. His third wife had him declared incompetent and committed him to an institution. Everything Bill had was taken away from him. Until he met Janice.

Their sweet love affair began in a group home. Bill would knock on my door and ask if I wanted to go out. It was so cute, says Janice. They saw each other as often as they could, hoping they could somehow be together, making their own decisions. And then Bill moved out. Janice, not knowing if she would see him again, looked for a family to stay with who would help take care of her.

That's when she got the call.

Bill called and told me he had just bought a home. He wanted to know if I wanted to come and live with him! It was the happiest day of my life!

I ask you, how incompetent can I be if I qualified to get my own home and help care for a woman who is in a wheelchair? We've proven all the critics wrong, said Bill.

Pure Hell

Janice and Bill are also very grateful they found Community Living Services. The Self-Determination Initiative has given them a freedom they never thought possible. It has given them the chance to take charge of

their lives. They hire the people they need to help out on a daily basis. People who have become part of their family. Janice and Bill have also found a way to get assistance from their neighbors while helping them out too. They watch children and in exchange, the parents take care of Bill and Janice's yard and anything needing repair around the house.

We love living here. It seems like we have brothers and sisters on every corner. Everyone is very special to us, said Bill.

Self-Determination means you never say I can't, you always say I can. I can. I can. We make our own decisions, said Janice.

Recently Janice was diagnosed with colon cancer, a major blow to most people. To Janice, just another hurdle to overcome.

I always say, don't let anyone or anything discourage you. I have it pretty good. If it weren't for Bill and the Lord, I wouldn't be here. They've kept me going. My life is my life, no one tells me what to do.



She already had the doctor lined up, ready to pull the plug whenever she gave the green light. Not wanting to deal with life in nursing homes anymore, not wanting to deal with people telling her what to do, Lynn Szedlus made up her mind, it was time to check out.

"It's not that I want to end my life," said Szedlus back in 1992. "It's just that I don't want to go on living this way anymore."

When she was 11 years old, Lynn was paralyzed from the neck down while playing touch football at school. She is on a ventilator every minute of every day, not able to move by herself, and according to some, not able to think for herself.

"I have been in and out of nursing homes for so many years. No one cares. You don't know what it's like to lay in a wet bed, on a ventilator and yell for someone to change you. It's humiliating, disgusting and it was a living hell," said Szedlus.

The hell didn't stop there. After being in yet another nursing home, Lynn was moved to a hospital not interested in taking care of a patient on a ventilator. A social worker suggested Lynn be moved to another nursing home, but when she adamantly refused, a judge declared her incompetent. A guardian was appointed over her, someone she had never met, and before she knew it, was hauled back up to the same nursing home she had been in before, four hours away from family and friends.

"I was devastated. It sent me into months of depression. Many, many times, I thought about disconnecting from my ventilator. But I have realized something good will come your way. You have to believe in yourself and keep your spirit alive."

Lynn is thankful she listened to her conscience and never went through with the actual death wish.

"I have such big dreams," Lynn said to a reporter back in 1993. "I want to have my own house. I want to hire my own staff. I prayed everyday these dreams would somehow come true."



In the spring of 1999, while still in the nursing home in Gaylord, Michigan, Lynn met with several people from Community Living Services. A support coordinator asked her a question she had never heard before. "What do YOU want to see happen in your life?" Lynn was overwhelmed, finally someone was listening to her! Soon after, Lynn asked a couple of her friends to be in her support circle. They met with Community Living Services, created a budget and planned her future, complete with her dreams and goals.

Lynn's prayers were answered. Her freedom came in the form of self-determination. She, for the very first time in her life, is calling the shots. She is in control of her life.

After that meeting, Lynn began searching for a home. She quickly realized the first house wasn't meeting her needs, so her support circle started looking at other homes, took pictures and showed them to Lynn. She then chose the house of her dreams.

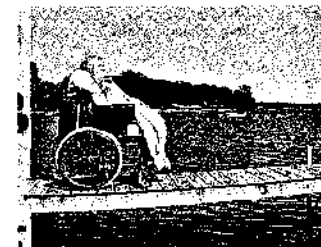
"It has everything I've been looking for. It's on a lake, my bedroom window overlooks the beautiful, water, french doors, lots of space, it's just perfect for me."

Another dream has also come true. She has always wanted to sit in a wheelchair, but because of a neurological disorder, even a slight change in movement or sudden sound makes her wince in pain. But that hasn't stopped her, for the first

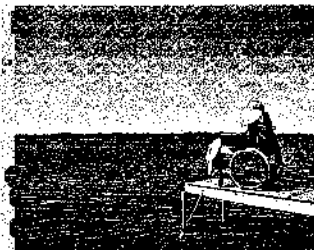
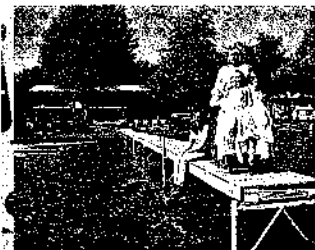
time in 10 years, she sat in a wheelchair, outside on her dock, enjoying the sunshine, delighting in the birds chirping all around her.


Lynn is now in the position to help others, another one of her dreams. "I am strong and can help people who may be going through the same thing. I have been working on my book for the last ten years. I hope my story will encourage and inspire."

"Self-determination has given me complete control. Something I never thought possible. Some people would say I'm a challenge. I think I'm spunky, sassy and strong-spirited. Now with self-determination and Community Living Services on my side, I can finally be heard."



In Control for the Very First Time





*So let me take time to introduce myself,
to let you know that I am in good health.
My name is Tone I say it tall and proud.
And if I had a speaker I would kick it out loud.
I tell you the truth, I am not fibbing bro.
Hard tribulations, still living though.
I took a fight with life and came out a winner.
You messing with a steak, not a TV dinner...*

... lyrics from Tony's CD, Still Livin'

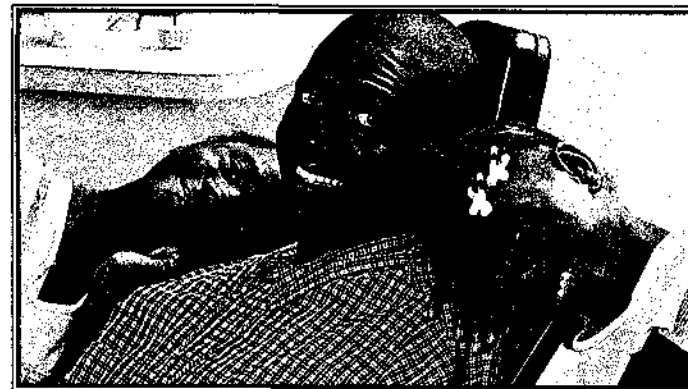
Life was sweet for 18-year-old Tony Alan Banks. He was young, had a decent job, and a brand new home. His life was turning around. It had been a mess for many years. Being a teenage father is no picnic. Tony knew he had to do something to get his act together. It took the premature birth of his second child, who weighed only two pounds, to shock him into reality. He stopped running with the wrong crowd, got a job and was moving his family into a new place.

But all of his dreams vanished in one ear-splitting explosive sound, followed by excruciating pain. Tony had been shot in the back. He was rushed to the hospital and hooked up to every machine possible. Tony asked the Lord to let His will be done. He was watched constantly by medical professionals. They weren't sure if he'd live. Tony wasn't sure if he'd live. His days and nights were bleak, he felt completely alone. No one ever talked to him about his prognosis, his future, his life.

Until one day his nurse walked into his hospital room and said, "Tony, I'd like to introduce you to your wheelchair!" Paralyzed from the neck down, he probably would never walk again. Institutional life had just begun.

Tony was in and out of hospitals, group homes, abandoned housing, living with family members, shuffled around inside and outside "the system." People came and went, no names, different faces, strange, isolated places.

Every day was a struggle but things did seem to get better once a woman named Christine from Community Living Services came into his life. His face lights up every time he says her name. She became Tony's support coordinator and confidant, a person who truly believed in him.



"She told me there was something called self-determination. She said I might be able to rent my own place and get a van. I was beside myself with joy. Someone is finally going to let me make my decisions."

Tony drew up a list of goals, and they talked about much money it would take to move into his own place. How much it would cost to fulfill a lifelong dream, record his first gospel/rap CD with his group MasterPeace.

He applied money ordinarily used for day programs to produce his CD. Tony also borrowed capital for the duplicating and processing from a private foundation. "I learned a lot from the experience. I could never have done it without all of my support. Self-determination is truly a blessing from God."

One of Tony's biggest struggles was relying on expensive transportation services to get him to paying gigs. Thanks to the Self-Determination Initiative, he now enjoys riding around town in his van driven by an assistant he hired himself -- his 22-year-old cousin Robert.

Life is sweet once again for Tony Banks. His career is taking off. A top, Detroit radio personality is helping promote his CD, and he's been interviewed by the local NBC affiliate about his life and his music.

When Tony isn't busy working on new music, he's spending time with his two daughters. Watching movies, playing games and going to fun places together are now a reality -- a dream not possible while living inside the four walls of a nursing home.

"Self-determination is allowing me to achieve all of my dreams. I am planning my second CD and want to learn how to drive. No roadblocks in my way anymore."

Still Livin'



"Johnny loves to swim. If you let him, he would be in this pool all day," said Mary Franti, the twins' sister. "The pool is what sold the house. Johnny was very clear to us in his non-verbal way, that he wanted this house."

When I asked him if he wanted to see another, he took his shoes off and sat down. It was his way of telling me his decision."

Mary has always been involved in raising her brothers. "We have a solid relationship and have a lot of fun together."

For most of their lives, the McGrath brothers lived at home. In 1992, they moved to a group home. It was a very different life for them. Get up at a certain time, do activities at a certain time, charts on the walls, treatment plans that guided every minute of the day. No jumping in the pool whenever you want. Everything was scheduled. John and Michael were just numbers in a program. They wanted out.

"The group home was too regimented. Choosing a snack was the only decision my brothers were allowed to make. They needed to be in control of their own lives and make their own decisions," said Franti. Then, Mary heard about self-determination.

Talk about freedom! Owning your own home with your very own swimming pool! This is the life! The life of twin brothers, Michael and John McGrath. When you walk into their home, John greets you with a smile, Michael with an inquisitive stare. John, is full of energy and is always happy to show you around the house, especially his prized possession - the pool.

"I knew that's what we needed. A way to give them what they deserve, a nice home, a staff they like and choices they can make every day."

With support from Community Living Services, Mary got busy. She talked with her family about how to get Michael and John in their own home.

"We started looking at houses. Both of my brothers were involved with the house hunting. Michael opened every cupboard in every house. The best part

From budgeting to hiring staff, everything they do is a team effort. Mary serves as their advocate and assists them in managing their budget - which they contribute to by working outside the home.

Michael and John also are very involved in the interviewing process. "I ask applicants a list of questions. Then I watch how my brothers react. I watch their body language. I make sure staff know how important it is to view their actions as words."

The neighborhood also has become an integral part of their lives. "Almost everyone knows Johnny and Michael. We have pool parties. Neighbors help with the lawn in the summer and with shoveling in the winter. The guy down at the corner store knows them by their first names," said Franti.

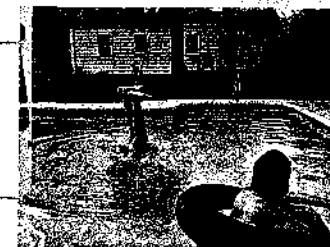
At last, Michael and John have control, power, authority and responsibility over their own lives. Self-determination has been key in achieving these goals. Self-determination works for everyone who needs support. No longer will people be denied rights simply because they need assistance.

This Is The Life!

was at the closing. The realtor handed Johnny the keys and told him he was now a homeowner! It was one of the happiest days of our lives," explained Franti

The Self-Determination Initiative has really worked in these men's lives. They now have the power and authority to make decisions, and it's made quite a difference in their personalities. They are now responsible homeowners and taxpayers.

"They communicate much more effectively now, making it obvious when they disagree with things. They make choices that affect the household. They buy groceries and do housework, even the dirty task of cleaning their own pool is enjoyable to them," said Franti.







"This isn't a story about me helping Jim. It's a story about Jim helping me!" That's exactly how Ginger Smith describes living with Jim Main.

"Jim is always there for me. He's my best friend and he's a great help with my daughters. He takes care of us!"

Jim hired Ginger several years ago as an employee and their relationship quickly blossomed into a deep friendship

But that situation became too restrictive for someone like Jim who wanted to get a job, buy a house and do the things he wanted to do. Then in 1985 a friend told him about Community Living Services. Since then, wonderful opportunities have come his way and something called self-determination changed his life forever.

Ginger is my best friend. She is an inspiration to me. She has helped me set and attain goals. I've been using a wheelchair my whole life and she has given me the courage to learn how to drive a car. I can't wait until I can drive her and the girls to a movie!

Just Getting Started

Jim keeps me together and he is wonderful with my daughters. They love him and have fun with him," said Ginger.

Jim who lived in foster homes since he was 11 years old has a little different story to tell. While in the foster setting, although extremely limited, Jim did have a good role model: his foster mother.

She was very good to him. Ginger remembers Jim telling her, "She was kind and caring and instilled in Jim and his foster brothers morals and values. He was fortunate to have her in his life."

For the first time in my life, I was given a lot more opportunities. I can't say enough about the people and about how much control I have over my life.

Several people from Community Living Services work with Jim and Ginger and set up a budget. Jim then supplements that by working full time at Sam's Club. "I meet all kinds of people. It's very rewarding for me to bring home a paycheck and take Ginger and the girls to dinner or shopping at the mall."



Jim and Ginger have set goals for the future. They've purchased a much larger home which has an additional apartment off the side of the house, giving Jim the privacy he needs. Jim also plans on getting his driver's license soon and would very much like to get married one day.

Jim and I talk about our dreams all the time. I've gone through a divorce. It's not easy being a single mother and raising two daughters, but Jim helps me out so much with taking care of them. He's part of our family. My parents invite him over to dinner all the time. I never would have thought this relationship would've turned into such a wonderful experience.

Goals and dreams are a large part of the Self-Determination philosophy. A philosophy that both Jim and Ginger live by each day. Self-determination has given them freedom to set goals and achieve them. Their dreams are now reachable because they have been given the opportunity and the resources to make things happen.

"We encourage anyone to get involved with the Self-Determination Initiative," said Ginger. "It'll change your life forever."



When you're 17 years old, most teens believe they're invincible. Lauren Baxter was no exception. A vivacious student with a passion for computer games and novels, she felt like the sky was the limit. Lauren dreamed of going after a nursing degree and working in a neonatal unit of a hospital. She also was engaged to a handsome Marine whose ring she wore on her finger.



Lauren was not a typical teenager though in that since she was 8 years old, she suffered from migraine headaches. Some so severe she was bed-ridden for days. One day, a terrible headache developed into something much worse — a stroke, one that paralyzed her and caused her to lose her ability to speak.

For one month after the stroke, Lauren was unable to communicate with anyone. Her mind raced with thoughts she wasn't able to tell anyone. "I'm here, I'm here, look at me, I am scared." But those thoughts were never heard, never communicated.

"We believe the hospital was just waiting for her to die. A lot of people who have strokes are just written off," said Wilma Baxter, Lauren's mom. One day, while Lauren and her mother were in her hospital room, they were visited by a man who changed their lives. A doctor from Australia who could not believe Lauren had never been shown an effective way to communicate. He quickly pulled up a chair and began "spelling with his eyes." Lauren and her mother were amazed.



"This doctor showed us how to talk to Lauren. It takes a bit of practice and a lot of patience but at least she can tell us what she wants. I now teach her staff the technique," said Wilma.

After the stroke and for the next six years, Lauren was in and out of group and nursing homes. Her experiences there were so upsetting, she would rather not discuss them. What got her through those tumultuous years was the faith and prayers of her mother and grandmother.

"We are all very close. We pray a lot and so does Lauren. We have faith."

An answer to those prayers finally came to the Baxters. Lauren was in a nursing home and not doing very well when a social worker told them about self-determination. Swift steps were taken to get her into a more productive, caring environment. She moved into a group home where she lived for over a year. It was there that she and her support circle began planning her life.

"When we were told about self-determination, Lauren and I both looked at each other and said 'Yeah, right! Someone is actually going to give us a budget and help us move into an apartment. We practically laughed in their face. We were so skeptical. We learned after so many years of disappointments to be cautious. For months and months, Lauren's response to self-determination was that she was still waiting for someone to wake her from her dream. She really couldn't believe it was true," said Wilma.

Lauren is now living in her own apartment and in control of her life.

"Lauren hires her own staff. I don't interfere with that," said

Wilma. "I believe she should be as independent as possible. I help her whenever she needs it, and I see her everyday. But I also try to keep my distance and let her make her own decisions."

Lauren is taking classes at a local community college and hopes to someday write a book. She has already written two short stories which have been given high praise by several college professors. When she's not busy studying, she likes to shop, play computer games and play with her cat, Sampson.

"Lauren has really come a long way from the days of nursing homes and group homes," said Wilma. "The future really looks promising. Lauren is finally able to have a voice, finally able to be heard. I would encourage any parent who is considering self-determination for their children to not hesitate. Do it now, get involved, stay close with each other and learn all you can about it. You will never regret it."

Movin' On



Principles

The journey toward self-determination is a process of self-growth, and following are the nine Operating Principles that Community Living Services centers its support around to help people succeed in truly achieving freedom and dignity.

Choice

People have the right to choose how they will live their lives, where and with whom. When people need help, it is friends and family closest to them who assist them in broadening their experiences and exercising their right to choose. It is essential that each person have a circle of support chosen by them.

Relationships

The relationships a person has with others are like precious gems. A relationship must be treasured, nurtured and protected. Those with whom the individual has real relationships provide the strength, assistance, and security which ensure each person's well-being.

Contribution & Community

Everyone has the ability to contribute to his or her community in a meaningful way. Giving of self helps people establish a sense of belonging and identity. Community membership includes having an opportunity to be employed, to own a home, to be truly involved in the routines of the community and to make a difference in the lives of others.

Responsibilities

Individuals, as they take greater control and authority over their lives and resources, assume greater responsibility for their decisions and actions. Professionals and staff work for the individual rather than for the system. Families, friends and staff assist people in creating more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help make dreams come true while never forgetting who is in charge.

Control

People have the power to make decisions and truly control their lives. This includes gaining authority over financial resources and the power to determine what supports are needed, how they will be implemented and by whom. People also have control of hiring those who will provide support.

Dreaming

All people have hopes and dreams which guide the actions they take and are most meaningful to them. A commitment to helping people determine their dreams, respecting those dreams and helping make dreams come true is crucial.

Dignity & Respect

All people have an inherent right to be treated with dignity and to be respected as a whole person. Some of life's greatest lessons are learned by making choices that are later realized to have been mistakes. All people have the right to the dignity of risk. The network of support makes risk possible by weaving a safety net that supports growth.

Fiscal Conservatism

Making things happen does not always require money. It is imperative that alternatives to paid support be found. When support must be purchased, people will get what they need, pay only for what they get, make real investments, spend money more efficiently and make adjustments when they are needed. To find the best quality for the most reasonable price, people are free to purchase in and out of the system.

Whatever It Takes

Those who work in the system become barrier removers. The attitude, "Nothing is impossible, as long as it is legal and causes no harm," is required. "No, we can't" as an answer is replaced by "How can we make this happen?"

If you want more information, please contact the Community Living Services Self-Determination Office at 734/467-7600.



Community Living Services also offers the Center for Self-Determination. A technical assistance and training center for the advancement of the principles of Self-Determination.

The Center will offer administrative support and education for system change.

Topics include:

- Building a Circle of Support
- Transferring Power and Control
- Eliciting the Dream
- Creating and Implementing a Person-Centered Plan
- Building Individual Budgets
- Creating a Voucher System
- Establishing a Fiscal Intermediary

The Center for Self-Determination's training team is led by national self-determination consultant Ellen Cummings.

For more information, please call the Center for Self-Determination at 734-722-6262.

Community Living Services, formerly Wayne Community Living Services, is located at 35425 Michigan Ave. West, Wayne, Michigan 48184-1687.



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