

The Rural Institute **E-News** Transition Projects

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A Quarterly Newsletter Produced by the Rural Institute Transition Projects

Special Edition: Emerging Leader Showcase







MT-TIRC, the Montana Transition Training, Information and Resource Center, is committed to developing and disseminating information that improves the transition outcomes for youth with developmental disabilities. Our project focuses particularly on inclusive transition outcomes (in the community, alongside same-aged peers without disabilities) in the areas of education, employment, housing, and recreation.

Each year we work with a minimum of ten youth and their families to assist in planning for the transition from school to community and adult life. The initial step in transition planning is to determine what the student wants her life to look like the day after graduation. Where will she live? What will she do for fun during the day? Where will she work? Will she take classes or pursue a degree? What help will she need to do these things and who can help her?

The Emerging Leader Showcase was developed to help youth, families, and schools create a vision for what life in the community could look like for young adults who have ongoing support needs. We are continuing to recruit stories of young people with developmental disabilities who live, play, learn, or work in their communities. We especially want to hear about youth and families who are self-directing their supports and creatively blending resources. Although the Administration on Developmental Disabilities defines "emerging leaders" as young adults ages 18-30, we have expanded our showcase to include stories about youth (under age 18) and adults over 30 as well.

Emerging Leader Showcase stories will be shared in our electronic newsletters, posted on the Transition Projects web site (http:// ruralinstitute.umt.edu/transition), and added to the Online Transition Tool Box (http://sites.google.com/a/PLUK.org/transition-toolbox) so youth, families and schools can use the stories as resources.

If you want to nominate an emerging leader, please download the nomination form from our web site at http://ruralinstitute.umt.edu/ transition/EmergingLeaders.asp. You may also contact Connie Lewis by email at cjlewis@ruralinstitute.umt.edu or by phone at 1-800-732-0323 for the form.

Resources

University of Montana's Rural Institute Transition Projects: http://ruralinstitute.umt.edu/ transition/

Online Transition Toolbox: Information on agencies, services and resources that schools, youth and families might need to access as they plan for life after high school. The materials and information can be printed, copied and shared with students and families as part of their curriculum or in preparation for Transition discussions at IEP meetings http://sites.google.com/a/ pluk.org/transition-toolbox/

We have moved! Our new address is: 700 SW Higgins, Suite 250 Missoula, MT 59803

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EMERGING LEADER SHOWCASE

Bodhi Interviewed by Ellen Condon

Bodhi is twenty-seven years old and graduated from Sentinel High School in 2002. Today, he lives in his own apartment in Missoula with supports. When I visited Bodhi and his mom, Deanna, at Bodhi's apartment he greeted me at the door, invited me in and asked me to take my shoes off at the door. I was struck by how clean and tidy his apartment was. As Bodhi gave me the tour it is clear that this is "his" home, and everything is in its place just as he likes it. His exercise bike is in the living room facing the TV. He has family and friend photos displayed in his bedroom. He also has posted sticky notes and signs on his walls where he can look at them.

He chose the paint colors on the walls: olive green in the bath, sky blue in the living room, and a pale yellow in the kitchen. The artwork on his walls was collected on trips he has taken with his family and also includes other items that he enjoys. On his refrigerator he displays a large calendar where he records how much he exercises daily. Currently, he either goes for a walk or rides his stationary bike 10 miles every day. He also records how often he waters the lawn (he receives \$2 for watering).

So what is so unique about Bodhi's story? His home sounds like many of our homes - what is the big deal? Bodhi is a young man with a developmental disability. He has significant support needs regarding his seizures, supervision in the community, safety, and managing his behavior. Currently, he has someone supporting him 24 hours a day. Many times people with Bodhi's needs are served in a group setting if they are lucky enough to receive adult Developmental Disabilities (DD) funding after exiting high school. Bodhi and his family knew that he did best in settings where he was his own boss and where he had a lot of choices, where supports revolved around what worked for him and the supports were flexible based on what he wanted and needed. In a group setting where Bodhi would be



expected to adapt to a routine and live with people he didn't choose and maybe didn't enjoy, the family feared he would be more agitated and experience increased behavioral issues.

When Bodhi's family began thinking about what his life would look like after high school, Deanna said she referenced what other young adults without disabilities who were Bodhi's age were doing. Their neighbor and Bodhi's friend, Eddie, was planning on moving out of his parent's home and into his own apartment after he graduated. That became the vision for Bodhi, too.

The challenge for Bodhi was that he would still need someone with him to assist with daily chores and activities, and to make sure he stayed safe. Bodhi needed help with activities such as cooking, grocery shopping, daily outings and keeping up his apartment. His support staff needed to provide medical support when Bodhi had seizures and needed to help ensure Bodhi stayed safe in the community. He was on the DD waiting list for adult services (supported living and supported employment), but no one knew how long it would take to get these services. Luckily, Bodhi still had child and family DD services that provided some support through a habilitation aide and respite in his home while he waited for adult services.

(Continued on page 3)

Bodhi, cont.

Bodhi's mom put his name on the wait list for subsidized housing through the Missoula Housing Authority. The summer he graduated he became eligible for a reduced rent apartment. After visiting the available units, Bodhi chose one near where he had grown up as a kid. It had two bedrooms and a yard, and was on a quiet street within walking distance to downtown Missoula and the University.

The family envisioned a gradual transition from Bodhi living with them to him living in his own apartment. They began having Bodhi visit the apartment with his habilitation aide and occasionally spend the night, again with the aide providing supports. Very quickly Bodhi was ready to move out of his parents' and into his own place.



supports him on weekends so he can get together with a friend from high school. His mom provides transportation and they touch base by cell phone when he needs a ride or help. This lets Bodhi be more independent during the activities.

One of the most important things to Bodhi about his apartment is that he is his own boss. He chooses if he wants to exercise, what he wants to buy at the

> grocery store, whether or not the stereo is on and what movie to watch on the TV. If he wants to lay on his couch and watch TV, he does. (When he was shopping for his couch, he tried them all out in the stores by removing his shoes and laying on them to make sure he found the right one.)

Deanna encourages other families to set the bar high for their children and identify the supports that are needed to reach each goal. Think big!

The family pools together

available resources to pay for the supports Bodhi's needs to live in his own apartment. He began receiving Supplemental Security Income (SSI) when he turned 18, which they use to pay some of his support expenses. Initially they also used the respite and habilitation aide funding and began accessing personal care attendant (PCA) services. Later on Bodhi started receiving 10 hours per week of DD funding instead of the habilitation aide supports and this was added to the mix to fund support staff. This funding was recently increased to 20 hours a week. Bodhi has support from 3:30 in the afternoon until 9:00 the following morning, six days a week. On Saturdays, he stays over at his parents' house. On weekdays, he attends a day program for people with disabilities that the family originally paid for out of their pocket but that now is funded by Vocational Rehabilitation.

Bodhi and his family recruit, interview, train and do payroll for all of his support staff themselves. Bodhi always has the final say in who is hired to work with him. He has chosen to have different people every day as he likes variety. No staff person stays with him more than two nights a week. Bodhi also chooses what they will do for fun such as going to the University of Montana to play air hockey or foosball, hiking or walking, going to sporting events, or browsing at Barnes and Noble. Bodhi's family also Look at what other young adults their age without disabilities are doing and consider the same thing for your child. Continue to set goals about what they can learn and do in the community for themselves. Talk with your child early on about what life can look like after high school. EXPLORE ALL THE OPTIONS. If what you and your child want for their future doesn't exist, create it and pool together resources to fund it. Listen to your child about what works and doesn't work for them. Make a plan and prioritize skills that the young adult may need to learn. Identify friends and/or family who might be able to help. Identify resources and get on any waiting list that may exist for those resources. Start small and celebrate the little things. Watch for your child to let you know they are ready and seize the moment when it is presented. Keep reassessing what is working and what is not, and then continue to add or take away support to help your child reach his or her goals.

So what are the next steps for Bodhi? Bodhi has begun thinking about buying his first home. He and his mom go to open houses to see what is available and to help Bodhi envision what he wants – so far he wants a house with two bedrooms and one with a garage to store his lawn mower. Knowing Bodhi and Deanna, he'll be a homeowner before long!





INTRODUCTION

Maclaen graduated with honors from Polson High School in 2002. He was told he was ineligible for Developmental Disabilities Program (DDP) Community Supports funding because his needs were too high. Due to the impacts of his disability (Prader-Willi Syndrome), professionals doubted he could live on his own. Instead of becoming discouraged and giving up, Maclaen and his family set out to prove the experts wrong. Today Maclaen rents a trailer in Polson, works two jobs, enjoys time with friends and family, and finds all kinds of ways to relax and have fun when he isn't working.

EMPLOYMENT

It took years of dedication and hard work for Maclaen to get where he is today. In the spring of 2000, Maclaen's special education teacher, Don Dubuque (now retired) and Ellen Condon (Project Director) invited Maclaen to participate in Project WISER through the University of Montana's Rural Institute. WISER's mission was "to develop an innovative model of transition planning in the Bitterroot and Mission Valleys which promotes individualized customized employment for students with severe disabilities and ongoing support needs."

As part of WISER, a Vocational Profile was developed for Maclaen. The Profile identified characteristics of an ideal job...this information was initially used to create work experiences and later to negotiate paid jobs using a Representational Portfolio. (Please refer to the Transition Projects web site for more information about these tools.) During his participation in WISER, Maclaen worked at the Polson City Library, St. Joseph Assisted Living, Mainsail Video, Top 40 Video, Odyssey Glass, various offices in the county courthouse, and Linderman School, and he chose to volunteer at the local humane society to explore whether or not he would like to pursue this line of work and possibly start his own dog boarding business. In addition to giving Maclaen more information he could use to make career choices, all these experiences helped him make invaluable connections to people in his community.

Before Maclaen graduated, Mr. Dubuque developed a job for him based on his interests, contributions, and support needs. Vocational Rehabilitation funded his initial wages while he learned the job, and a PASS plan (Plan for Achieving Self Support) was approved by Social Security to fund follow-along supports and transportation starting the day after graduation. (Maclaen had been referred to DDP for supported employment services but he was on the waiting list. Without follow-along supports from another source, it was feared that Maclaen would lose his job while he waited for his name to reach the top of the list.)

Maclaen was eventually approved for Developmental Disability (DD) services. He worked with two different provider agencies but was not satisfied with their services. He said the agencies were not very organized and gave him jobs he didn't like at all. They cut his wages even though he was focusing on the task at hand and accused him of things he hadn't done. Most critically, Maclaen said they weren't listening to his wants, needs, and interests but were just going with what was convenient in terms of finding him employment.

Training Calendar

The Transition Projects hosted six Youth Track Web-based conferences during the 2008/2009 project year. These 90-minute sessions were designed for young people with disabilities, their families, and those who provide services to these youth and families. Audio recordings, PowerPoint slideshows and handouts from the sessions may be downloaded from the Rural Institute Transition Projects Web site: http:// ruralinstitute.umt.edu/transition

The available archived training sessions include:

- 10/6/08: Disability History
- 12/1/08: Transition and
- Personal Care Services
- 2/2/09: Adult Developmental Disability Service Providers – Who are they and what do they do?
- 4/6/09: After Graduation Ideas for Rich, Full Days
- 6/1/09: Creative Housing Options
- 8/3/09: Self-Awareness, Self-Advocacy and Self-Determination

The 2009/2010 training calendar is currently in development. It will be sent to Montana Transition Listserv members and included in newsletters as soon as it is finalized. To join the Montana Transition Listserv, go to the Transition Projects Home Page and enter your email address in the box provided. Fliers may also be downloaded from the Transition Projects Web site as they become available.

We value your opinion. To provide feedback to us about this newsletter and our other products, please take our quick online survey at: http://www.surveygizmo.com/ s/58441/transition-projectsfeedback

Maclaen, cont.

His parents decided they could provide better supports and in July 2009 started their own business, Zeda LLC. His mom and dad are his job coaches, charged with finding Maclaen more work and more hours. In addition, they have meetings scheduled with Maclaen's current employers to discuss essential supports that weren't built in when Maclaen was hired. Maclaen's mom Valerie explains that outside provider agencies often don't know the person they are representing well enough to adequately explain necessary supports to employers. Parents, on the other hand, have years and years of experience with what works and doesn't work for their child. She suggests that DD service providers make sure they establish and maintain good communication with the people who know their client best. Valerie has been able to talk one-on-one with employers and others in the community to alter their preconceived ideas about hiring people with disabilities. She has used Maclaen's Portfolio to tell people about his abilities and strengths...to portray him as an asset and not a liability.

Today Maclaen works ten hours per week as a Courtesy Clerk at Safeway and five hours per week as a Library Assistant at the Polson City Library. At Safeway, Maclaen bags groceries, does carry-outs and go-backs, completes price checks, corrals the carts, sweeps the walks, and picks up the floors to prevent injuries to customers or employees. As a Library Assistant, he shelves books and videos, sorts through the recycling paper to find pieces patrons can use for photocopies and scratch paper, organizes and puts away plastic bags and free materials (catalogues, puzzles, calendars, etc.), organizes and straightens the shelves to make them flush and neat, picks up garbage inside and outside to make the library look nice so patrons will want to come back, and runs errands (to City Hall, the post office, the print shop, etc.). At both his jobs, Maclaen says he works as a team with his outstanding bosses and coworkers. He is grateful that the work experiences he had in high school helped prepare him for work and for life as an adult.

HOUSING

Even in high school, Maclaen knew he would rent his own place after graduation. He wanted to be independent, to make his own choices, and to "live just like all adults." Maclaen feels strongly that "no one can expect to live for free or be dependent forever on other people."

When choosing his future housing situation, Maclaen had to consider two important factors. First, he didn't have much money. With only Supplemental Security Income (SSI) and limited wages, Maclaen couldn't afford most of the rentals in the Polson area. Second, he wanted to be near family members so they could help him with home maintenance chores, meal times, and other areas where he needed a hand. Maclaen's grandfather had the perfect option – an affordable trailer for rent three houses down from his parents and right next door to his aunts.

Maclaen's trailer has a big living room where he watches television, listens to music, plays on his Playstation II, types documents and plays games on his



computer, and spends times with his two cats. He has a bedroom and a bathroom, as well as a porch where he can have picnics or just relax outside. In his kitchen, his refrigerator contains only cat food (to keep it fresh and cool), and

meals if his parents are out of town. The rest of the time, Maclaen eats his meals with his parents. This is the strategy Maclaen and his family developed to deal with the disordered eating that is part of his disability.

For fun, Maclaen also likes to swim, go for walks, shop, read books (he participates in a reading program that offers prizes), go out to eat and spend time with friends, meet new people, attend sporting events, exercise, make picture collages, take trips (shopping or vacation trips), help with planting and harvesting food from the garden, and complete projects (both inside and outside).

Having his family close by is important to Maclaen. He can easily visit them (they enjoy getting together to play games) and give or receive assistance as needed. Maclaen has two phones at home...he likes to call and chat with friends but also has the phones in case of an emergency.

To live on his own, Maclaen had to learn many new skills including how to pay rent using his SSI check and wages, outfit his home with the basic necessities (smoke alarm, fire extinguisher, phone, dishes, microwave, bed clothes, etc.), take care of his belongings, and keep his trailer clean. His parents and school teacher taught him how to pay rent before he graduated; the other skills he learned both by people telling him what needed to be done and by observing other people in their homes to see how they furnished and cared for their places. (Continued on page 6)

Maclaen, cont.

Maclaen lists all sorts of benefits to living on his own, including:

- I have my own computer so I can play games and type things;
- I have a Play Station II for video games;
- I can watch satellite television whenever I want (and I can watch whatever I want!);
- I can visit with my friends and family on the phone;
- I can have company over to visit;
- I don't have to share a room with my brother anymore;
- I don't have to abide by my parent's rules (in my home, my parents have to respect my rules and my feelings, which they do);
- I have two cats;
- And I share a dog with my mom.

HELP ALONG THE WAY

Maclaen credits his family and his current Opportunity Resources Incorporated (ORI) DD Case Manager with helping him obtain the supports he needs to live and work in Polson. (He went through several years of constantly changing case managers and feels that the inconsistency made the case management service much less effective.) His case manager spends time with him and works with Zeda to help him find work. arrange transportation to and from work, and ensure he has fun things to do in his spare time. Zeda provides Maclaen with the following DDP-funded services: supported employment, supported living, day services, and transportation. Maclaen also receives natural support from coworkers and supervisors who are willing to help out and explain things as needed at his jobs.

Maclaen explains that it was critical to have people who believed in him and who believed he could live on his own. They looked at the things he couldn't do and figured out ways to get those things done. Maclaen says it wasn't very hard for him, but it was really hard work for his parents. They had to search for resources, try different agencies, ask others for ideas, and ultimately form their own DD provider agency. Valerie adds that she and Maclaen's dad also had to learn how to "let go" and treat Maclaen like their other children. They had to accept that he might sometimes fail...that's how we all learn and grow.

FUTURE PLANS

When asked about his future goals, Maclaen said he plans to keep his trailer in good care and condition. He hopes to live there as long as possible but is concerned that as his parents get older, he may need to move closer to his brother and sisters so they can provide the supports he needs. Maclaen also strives to be happy and healthy, and to try to find some more work and additional hobbies. His mom said they may write another PASS plan next year so Maclaen can start his own business. To achieve these goals, he will continue to work as a team with his case manager and the staff at Zeda (his parents). He wants to help his team members get to know him better... even his parents have something to learn because as Maclaen explains, the parent/child relationship changes once the child becomes an adult.

FINAL THOUGHTS

Maclaen has many words of wisdom to share with other young people who want to live on their own and work in the community:

- Believe in yourself and what you want to do. Never give up. Keep trying. Try new things. Anything is possible. Your dreams will most likely come true.
- Be friendly, kind, courteous and work as a team with your parents and the people who provide services to you. Believe in others.
- When things go wrong, talk it out as a team and don't hold it inside.
- Learn from the examples of other people. Learn from your friends. (Someone can be a really good friend even if they're too busy to hang out with you.)
- The only thing you can count on is change everywhere, all the time and in all places.
- Believe in God and pray. Help others and He will help you with anything you need. God will never give us a challenge beyond our ability as long as we do the best we can.
- There will be challenges, trials, and roadblocks in your life. Everything that happens is for you and others to learn from. God cares about us, loves us, and always wants to help.
- If you have Prader-Willi Syndrome, know that you can live on your own, do your own thing, have your own place and not have to be watched 24/7. It's extremely rare and unordinary, but you can do it. For me, it's possible because I like to do lots of different things and I found lots of things I can do to stay busy. Have your parents and others help you monitor what you eat, help you figure out things to do for fun, and help you find work. It totally is possible, but it depends on you. You need to be willing to put forth the effort yourself. You have to be part of the team and play a role.







Lissie "Melissa" is a 33-year-old businesswoman. She is the proud owner of Lissie's Luv Yums, a gourmet dog biscuit business, which she has been running for 10 years. What

originally began as a dog walking business venture quickly changed into making dog biscuits when Lissie began giving homemade dog treats for Christmas and birthdays to the owners of the pets she walked. The owners kept clamoring to be able to buy more of the biscuits and a new business idea was born. Lissie uses her business to educate others about Fetal Alcohol Syndrome (FAS), which Lissie was diagnosed with as a baby.

In order to start the business Lissie and her foster mom, Sister Johnelle, obtained a grant from the Rural Institute on Disabilities partnered with the Montana Job Training Partnerships Act. With this grant money they were able to buy equipment for making the dog biscuits, made a TV commercial and ran a newspaper advertisement. Later, Vocational Rehabilitation (VR) provided funding for more development.

When I arrived for my interview with Lissie and Sister Johnelle, they were in the midst of mixing up and

preparing a batch of the dog biscuits to be baked. Lissie was rolling out the dough and using dog bone shaped cookie cutters to create the biscuits while Sister Johnelle was removing the biscuits from the cookie cutters and placing them on the baking sheet. Then Lissie painted the signature heart with beet juice on each biscuit.

Although Sister Johnelle and Lissie work together to make the

biscuits each morning, Lissie knows how to complete all the tasks associated with her business from mixing ingredients to baking the biscuits. She is in charge of all the packaging and has developed all the skills necessary for keeping her business records.

Because of the demands of the business, Lissie has learned how to use fractions and multiplication, two skills she had been told as a youth she would never be able to learn. She sells her biscuits from her home, online, and at the local farmers' market. Lissie has had to learn how to make change correctly and has developed a list of the cost of different amounts of her products to refer to, which helps her to make change more quickly.

Lissie's business has expanded to the point where she hires others to bake the biscuits after she and Sister Johnelle provide them with the dry ingredients. She is able to pay them through the money she makes in her business. However, they have a difficult time keeping bakers since it is only part time work and doesn't pay a lot. This means constantly training new bakers.

Lissie's business has become self-sustaining, but she and Sister Johnelle stay in touch with the Montana Department of Commerce, Small Business Development Center, and Made in Montana Program for ideas and support in sustaining a small business in Montana. At one point Lissie and Sister Johnelle started to create a PASS Plan, but were not able to utilize it. They are considering pursuing this option again, with the idea of expanding Lissie's business.

When answering the question, "How do you know what supports you need when looking into employment options for someone with a developmental disability?", Sister Johnelle said that it is difficult to know because each persons' skills, needs, and challenges are different. One important aspect is that you need someone who knows the person and their challenges and can be an advocate for them and teach them to be an advocate for themselves. You must spend adequate time at this point in development to be sure

> you are on the right track and must not short change this step. Also, it is important that the advocate be able to read the signs of the person to tell when they may be overwhelmed or when something is not working well for them. Sometimes people with disabilities are not able to tell you what they need for supports on their own.

Lissie has many interests outside of her business. She uses

Community Support funds and case management through the Montana Developmental Disabilities Program to help her pursue these interests. She uses her funds to go to a local gym three times

(Continued on page 8)

Lissie, cont.

a week with a support person from Quality Life Concepts. Some of the other activities that Lissie has enjoyed in the past or is still active in include bowling, attending powwows, yoga and reflexology, swimming, biking, learning Sign Language by taking classes at the Montana School for the Deaf and Blind, reading, completing word search puzzles, and doing a penny fundraiser for housing and counseling for at-risk young adults.

Lissie is also an active member in several associations. She is an associate member of the Sisters of Humility of Davenport, Iowa. She is also a member of the Substance Abuse and Mental Health Services Administration (SAMHSA) Nationwide Fetal Alcohol Spectrum Disorders (FASD) panel (she is the American Indian expert member) and has been a member of the Montana Council on Developmental Disabilities for 5-6 years (she was the Vice-Chairperson for two of those years). Lissie uses the contacts she makes through these organizations and through her business to be an advocate for people with FAS and to get the message out about the harmful effects of drinking while pregnant. She has spoken at conferences, has done radio interviews and her story was recently featured in the winter edition of the magazine *Apostrophe'* and on the PBS show *Business: Made in Montana*.

Lissie has lots of advice for others who are looking to start their own business. Take time out of your day for your own time and to relax. Don't give up on your dreams, but don't get pressured into doing too much too soon. Also, don't get pressured into a particular job. If you can't do a 9-5 job, look into starting your own business. You can set your own time and tasks for the day. It is more flexible and you have more control of what you do and when you do things. Lissie also says when you have your own business, you may not always like everything you need to do, but to keep the business going you need to do those things you don't like. However, the more you do these things the easier they become. Lissie is not limiting her future plans to the dog biscuit business. She plans on keeping her business operating but also wants to pursue a career as an interpreter for the deaf. She believes it is important to keep her heart and mind open for whatever possibilities lie ahead.







Danielle is an outgoing 19-year-old college student in Columbia Falls, Montana. In high school, she was part of the Recycling Club, Special Olympics, the

Wildcat Warehouse Club (a student store), Key Club and cross country. These activities helped her learn to advocate for herself – to let people know what she wants and needs, to understand what works for her and what doesn't, and to speak up when she's not being treated fairly. They also helped her learn the value of hard work and dedication to the pursuit of one's dreams.

In 2007, Danielle participated in the Montana Youth Leadership Forum where she says she decided what

she wanted to do with her life – teach children. Danielle graduated from Columbia Falls High School in 2008 and started researching how she could earn a teaching degree. While visiting the Flathead Valley Community College (FVCC) web site, she discovered that she could take her initial classes in nearby Kalispell. Danielle contacted a FVCC guidance counselor through the web site and the counselor told her about the option of taking a few classes to "test the waters" before applying for admission. Danielle started with computer classes last year. She enjoyed them enough that she applied for admission (with the guidance counselor's assistance) and was accepted.

This fall (2009), Danielle is enrolled for six credits. Her classes include sign language and basic math. Once she brings her math and other skills up to the college level, she will transfer to the University of Montana in Missoula and pursue her teaching degree.

Danielle's college guidance counselor helps her arrange tutors for her classes. Danielle is expected to request any classroom accommodations she might need. She generally waits to start the classes before requesting anything – Danielle says she has to learn more about the teacher and the class expectations before she knows what accommodations she'll require. (Continued on page 9)

Danielle, cont.

Last year Danielle paid for her courses out of a savings account. She had been receiving Supplemental Security Income (SSI) as a child and had saved enough money to pay for her first year of school. However, when she turned 18, she lost SSI because Social Security said she didn't meet the adult disability requirements. She had to reapply for benefits and was just approved this summer. (Note – refer to the Rural Institute Fact Sheet "<u>SSI and Children Turning 18</u>" for helpful hints about the eligibility redetermination Social Security conducts when SSI recipients reach adulthood.) In the meantime, Danielle applied for and was awarded student financial aid to help meet her college expenses.

Danielle says that going to college was "scary at first, like being a freshman at high school. It was a big school and I didn't know everybody." She immersed herself in FVCC activities so she could meet other students. For example, Danielle is active in Circle K, a group that does volunteer work in the community. She is also working with a counselor to start an Alliance for Students with Disabilities at the college. This will be an extension of the club from the University of Montana. Danielle hasn't decided yet exactly with the alliance will do, but she wants one of its primary missions to be outreaching to other students with disabilities at FVCC.

In addition to handling her college homework load, Danielle works for the Child Development Center in Columbia Falls as a Habilitation Aide for children with disabilities. She teaches the kids to play games and spends time with them in their homes and in the community. This summer she worked with one child from 9:30-12:00 one day per week. Danielle has held this job since right after she graduated.

Danielle is passionate about helping other young people with disabilities. She is an active member of the Montana Transition Training, Information and Resource Center (MT-TIRC) Advisory Board and also part of the Emerging Leader work group. Danielle was one of four board members selected to represent MT-TIRC at the Montana Association for Rehabilitation/Youth Transition Conference October 7th-9th in Butte.

For fun, Danielle likes to spend time on her computer (she is an avid email and Facebook user), ride her bike, and hang out with friends. She has been a Special Olympics athlete for ten years, competing in basketball, skiing, and track and field events.

Danielle lives with her parents and will soon start paying them rent. She rides to and from school with her brother (also a student at FVCC), and her mom provides transportation for work. Eventually Danielle hopes to get her driver's license.

Danielle has received assistance from several agencies over the years. As previously mentioned, she had SSI benefits as a child and will continue to receive them as an adult. A Vocational Rehabilitation (VR) counselor helped her get her job at CDC and she still meets with her VR job coach from time to time to talk about other jobs she might like and how she can get her driver's license.

The Montana Developmental Disabilities Program (DDP) has also provided services to Danielle and her family since the time she was born. Her current case manager helped her to reapply for SSI and is available to meet whenever she has questions. (One of her former DDP service providers is now a co-worker at CDC!)

In order to succeed at college and her job, Danielle says she had to learn to get prepared for whatever was scheduled for that day (school, work or both). For example, for school, this would include packing her books, pens, pencils, and paper so she'd be ready for class. She also had to learn to speak up for herself, like to ask for classroom accommodations or to tell a rude peer to leave her alone. Danielle said all her hard work has been worth it. She has a great job where she gets to work with kids, and she attends college where she can meet other young people and take classes that will help her reach her career goals.

Danielle advises other young people to work hard, both at their jobs and at school. She also stresses the importance of learning to stick up for oneself. "It can be scary when you first start doing it, but it gets easier with practice. Speak up for what you want and don't want! In the long run, your hard work will pay off. It takes time, patience and encouragement but you can do it!"







JD was nominated for the Emerging Leader Showcase by one of his former Jefferson High School teachers in Boulder, Montana. She expressed admiration for how hard he works at his Helena Industries job; for his active involvement in community celebrations,

church and other activities; and for the initiative he showed when he chose to move from the home he and his dad shared in Boulder and rent from his boss in Helena.

First, a little history. JD used to live in Boulder and commute to Helena every day for work. He took pride in his 32 1/2-hour-per-week job preparing mass mailings, making pallets, cleaning, and stocking supplies. In the winter, though, he frequently found himself stranded at home due to snow-packed or icy roads.

Initially, the plan was for JD to move into an Eagles Manor apartment in Helena. However, there were problems finding the accommodations he needed and this plan fell through. To help him get to work year-round and on time, JD's boss, Ro, offered to let him move into her house and he accepted the offer. Now JD uses his Social Security and SSI checks to pay his monthly rent to Ro, and Ro transports him to and from work every day. Ro and JD have known each other since he was 18, so it was a comfortable arrangement for both of them. As an adult, JD didn't need permission from anyone to make the move – he just informed his Development Disabilities Program (DDP) Case Manager, Kathy.

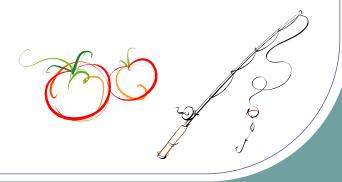
JD does a variety of things for fun, including going to movies, watching television, taking care of his tomato plants, playing with Ro's cat and two dogs, going shopping, hanging out with friends, hunting and fishing with Ro, and listening to his police scanner. (He is saving his wages to buy a new digital scanner.) He also occasionally attends church in Boulder or in Jefferson City with his friend Jacob. JD says he really likes Helena and didn't find the move from Boulder difficult at all.

In terms of supports, JD receives transportation, housing, recreation and shopping assistance from Ro. Jacob has a paid staff person who drives the young men to church in Jefferson City. John Barragato from Alliance Outreach Services in Boulder provides staff to transport JD to Boulder so he can spend some weekends there with his friends and his dad. Kathy from the DDP performs case management duties on JD's behalf. JD's dad maintains a bank account for his Social Security and SSI checks, which are used for rent and other basic living expenses. (JD cashes his own paychecks at local stores.) He recently applied to the Montana Independent Living Project for personal care and habilitation help and is waiting for his application to be processed.

JD hopes to be a licensed driver some day. Several years ago, he had a learner's permit but he did not take the driver's exam before the permit expired. JD said he found driving hard...he needs to practice staying focused and being responsible behind the wheel.

JD's primary goal right now is to apply for and get a job at Home Depot. He wants to cut and stack lumber and help customers. (Note: because he has Social Security and wages that decrease his SSI check, JD might be a good candidate for a Plan for Achieving Self-Support, or PASS Plan. He could use this plan to shelter income and save toward his vocational goal. For more information about PASS plans, visit: http:// ruralinstitute.umt.edu/transition/SSAworkincent.asp)

When asked what was most important for readers to know about him, JD replied that he is "nice, smart, a hard worker, focused on his job, and happy." His advice to other young people with disabilities is to "work hard, be good to your friends, learn to cook, respect your elders, be responsible, don't call people names, don't fight, and be happy." And we'd like to add a piece of advice - follow JD's example. When challenges arise, be creative...design a solution (like renting from a boss) that works for YOU.







Michael is an integral member of the Polson community. He is a homeowner, a taxpayer, a driver, and a valued employee at his two jobs. And according to Michael and his mother, he's done this without the assistance of government agencies. (He used to receive SSI and Medicaid, but hasn't had either benefit in years.)

About eight years ago,

Michael decided he wanted to buy a house. He talked to a realtor, who told him how much money he needed to save for a down payment and suggested he attend First Time Homebuyers' classes. Michael started putting money into the bank and completed the classes so he could learn the essentials of buying a house. His grandmother taught him how to cook, clean, pay bills, and do the other things he would need to do as a homeowner.

Michael had about \$800 saved. One Sunday at church, a man from Just Because Ministry called him to the front of the congregation and presented him with a check for the rest of the down payment. (The man was a neighbor of Michael's grandmother. Clearly the connection was a helpful one for Michael!) Michael was able to secure a mortgage and buy his house. He

now makes his monthly mortgage payments of \$300 by buying money orders.

To pay his bills, Michael has two jobs. He says, "You need a second job if you live in Montana!" He works 40 hours per week at Safeway, where he has been a Courtesy Clerk for 14 years. He got the job on his own by completing an application and an interview. Since he

works full time. he receives benefits such as health insurance and vacation and sick leave. His favorite part of the job is bagging groceries.

Michael works at Pizza Hut as a dishwasher nine hours per week.



He's been there almost three years and also got this job by applying and interviewing.

Michael drives himself to and from work. He has had his driver's license since he was 18 or 19. (He is 33 now.) Michael attended driver's education classes in high school, studied the driver's manual and then had his grandmother help him practice for the exam. He took the exam orally.

For fun, Michael hangs out with his family and friends, walks his dog, swims at the lake, works in the garden, and mows his lawn.

His future goals include to keep working at his jobs and to eventually move into a bigger house. Michael's advice to young people with disabilities who are getting ready to graduate and begin their adult lives is to work hard ... "you have to work hard in order to have your own house and the other things you want and need."

Emerging Generation by Darren Larson, MT-TIRC Advisory Board Member

Disability culture is diverse and widespread, including people of all ages, races, and religions. Male or female, the possibility of experiencing disability is without question. Birth, unforeseen circumstances, or just the process of aging brings disability to nearly everybody, causing one to think the largest minority group in the world would have benefited from a strong unified voice. Yet we know this has not been the case in years past. Civil Rights legislation made its way through Congress in the 60s without much concern to the civil rights of those with disabilities. Those with disabilities tended to relate more to others who shared the same disability. but not as much to the disability culture as a whole. These "pockets of strength" acted more as self-serving entities. Instead of seeing the big picture and realizing what benefited one type of disability probably benefited all people with disabilities, disability groups narrowly focused on addressing barriers they thought affected just their disability. Only within the last 40 years has the disability community made the conscious effort to come together to offer one voice, which culminated with the passing of the Americans with Disabilities Act in 1990. This comprehensive piece of legislation addressed many concerns affecting Americans with all types of disabilities. (Continued on page 12)

Emerging Generation, cont.

There are a number of reasons why it took some time for people to relate to a broader disability culture, most notably the lasting stigmas of the old paradigm or the medical model. This way of thought provided the understanding that people with disabilities could be fixed and that there was something inherently wrong with them. In the mildest of forms, this way of thinking isolated and segregated those with disabilities by exemplifying their differences and giving them the status of third rate citizens. In its most extreme form, experimentation, forced sterilization, and even the killing of people with disabilities occurred throughout the world. Hitler's T4 project to generate the perfect race is most prominent in historical writings. What is talked of less is the forced sterilization of 60,000 Americans with disabilities in the early to mid-1900s and that Hitler actually sent doctors to America to learn those techniques. It's not easy to admit, but it's the past we come from and can learn from.

The switch came with the emergence of the new paradigm or the Independent Living movement in the 1960s. This new way of thinking brought about the understanding that disability is a natural part of life and instead of looking to fix the person, the barriers of society were the new focus. Now people with disabilities were beginning to be seen as having control of their own lives and were more readily accepted in social norms. During this period a number of leaders began advocating for themselves and for others. Ed Roberts who was denied admission into UC Berkeley and was told by his Vocational Rehabilitation counselor, "You're too crippled to work," graduated from Berkeley and later became the State Vocational Rehabilitation Director for California. Judy Huemann led a sit-in of a federal building in San Francisco in 1977 that lasted for 26 days until 504 regulations were approved and endorsed by the Health, Education and Welfare Department. It was the longest such take-over of any federal building. Wade Blank formed a national advocacy group known as ADAPT which advocates non-violent direct action to bring attention to disability rights and abuses. Justin Dart and his wife Yoshiko travelled to all 50 states collecting stories from people with disabilities that proved to be instrumental in the drafting and passage of the Americans with Disabilities Act. All these leaders, plus countless others, found it necessary to live their lives in the manner they chose to and in doing so came together to offer one, unified voice.

Looking ahead, it's exciting to think what our generation will emerge as. We have the opportunity to transcend the ability/disability distinction and take a step further in realizing everyone is a person first. Like other minority groups, our goal is to achieve equality and respectability. We need to be conscious of this. As we learned from the past, our voice is much stronger when we talk from a broader perspective. Our generation must improve on reaching out to other minority groups to embrace our similarities and expand upon our ability to accept one another. Acceptance is always in direct conflict with difference and the more we are comfortable with our differences, the more we will progress towards equality and respectability. This will prove to be the next chapter in our historical pursuit to achieve a more perfect union.

For further insight read, The Road to Independent Living in the USA: An Historical Perspective and Contemporary Challenges by Kathy Martinez.

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