



NRS SELF ADVOCACY NEWS

Luke Taylor—Making Connections

“I achieved my goal”

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Luke Taylor is a young man who is using technology to help navigate his world more independently. It started when he obtained an I-Pad for his job. Luke has a job with a lot of different assignments in many different locations. Luke and his staff have used a software program called Pictello to create visual storyboards for each of his tasks. Luke is a visual learner. He can use Pictello to show him pictures of himself performing the various steps of each task. Pictello can also show him the sequence and locations of each task that he has to do. Now, Luke doesn't need staff to tell him where to go and what to do. He can use the I-Pad to figure it out for himself.

Luke has started using the pictello application for household activities too. He has worked with interns from the Urban Youth Collaborative Program to create Pictello Storyboards for a variety of day to day activities. There is even an application that shows him a picture of each staff member, with a recording of their voice greeting him. This helps him to learn to say everyone's name.

Luke sometimes has some difficulty in expressing his emotions and in recognizing emotions in others. The I-Pad is helping him with that too. There is an application which helps to match the expression on people's faces with feelings such as sadness, happiness, anger, etc.

Luke's vocabulary is increasing too. There is an app for typing words to match with pictures. Luke is learning to use those words. Luke's speech therapist is working with him with to use language to express broader concepts and to make comments about what he likes and doesn't like. This is a great leap for Luke. His frustration level has gone way down, and he is much better able to manage his own behavior.

Luke's father Ed Taylor had this to say about the benefits of working with the I-Pad; "Luke is very visual. This is the best visual machine around for a kid who is short on language. It has text, words, visual images. It is a window into Luke."

Ed went on to explain that "Luke is a lot more independent. The I-Pad works for Luke because it provides structure for him. He can know how long a task will take, how many steps are involved, how far along he is in the process. This helps him to stay engaged in what he is doing" The iPad provides a way to present Luke with choices. Luke is making more decisions about his life. He is becoming more independent, more in control. He is connecting with his world.

NRS is dedicated to working with the individuals and families we support to enhance their lives by realizing their dreams and achieving their goals

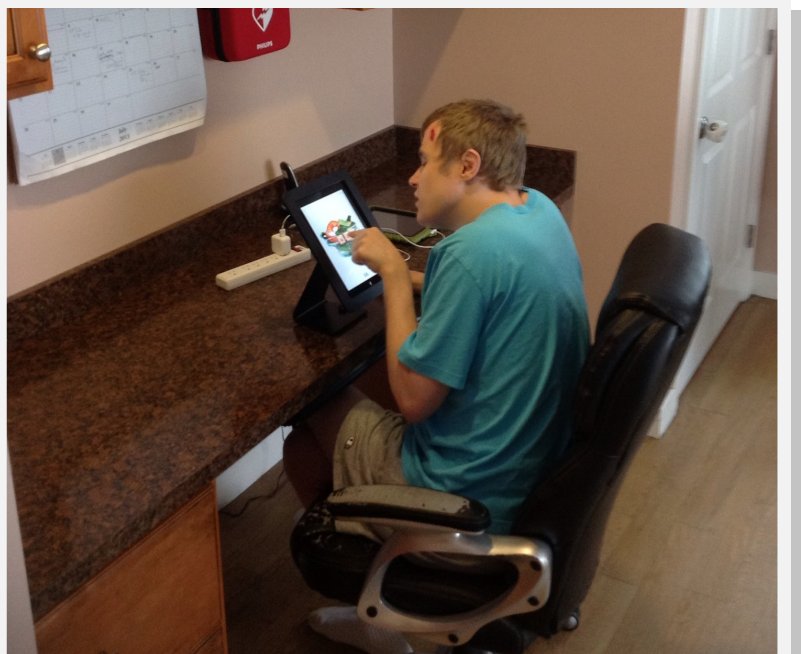
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Scott Gilson—Born to Ski

You cannot judge a book by its cover. Scott Gilson is 49 years old. He is a bit round around the middle. He spent most of his life at the Templeton Developmental Center. He is deaf. He has a long and full beard that makes you think he plays guitar for the rock group ZZ Top. Yet Scott Gilson is an athlete.



Scott is an avid skier. He has been skiing all of his life. "I used to ski with my family when I was young. My Mother taught me how to ski when I was 5."

Scott moved into his new NRS home this past July. Upon coming in to the house, he told the staff that he wanted keep playing sports; soccer, softball, basketball, and of course, skiing. Scott is a downhill racer Most of his teammates are "twenty somethings", but Scott has no trouble in keeping up. "I like to go fast", he tells me, and he has the awards to prove it. "Most Fearless Skier" and "Most Inspirational athlete" are two of his most recent ones. I asked him if he ever falls down, and he told me "I have fallen down, but I get back up and keep going. I go very fast". One of the staff at his home tells a story of going skiing with Scott. "I went down the mountain with Scott and was waiting at the bottom for him to finish, but I didn't see him. Then I looked over to the ski lift, and Scott was on his way back up the mountain already. He had beaten me down the ski trail, and was getting ready for his next run!" Scott skis at Nashoba, Gunstock, Wachusetts, and Blandford mountains, but his favorite is Sunapee.

When Scott is not busy skiing, he works out at least twice a week at Planet Fitness, where he is a member. He runs, and lifts weights. Scott plays centerfield for his softball team, which includes some of his old friends from Templeton. He enjoys shooting baskets and has a basketball rim set up in his back yard. Scott is very competitive and can beat most of the staff in basketball. He has a very good outside shot.

Scott has made lots of friends through his athletics. The ski team gets together for cookouts and parties, and Scott enjoys his friends, Melissa and Bob. Scott is active in his community; raising money for walkathons. He recently collected \$200 for Mass Advocates Standing Strong's walkathon, and has also participated in the Jingle Bell Walk for Special Olympics.

According to Scott, "Skiing is great fun, everyone should try it". He also says "I am happy that I moved here. I like it here. My roommates are nice and I like the staff". When asked about his beard, he says "I love my beard and will not cut it". Scott is doing well in other areas of his life as well. He participates in community based supported employment through the PLUS company. Scott earns a good paycheck by bundling wires for a company in Haverhill called APEM. Scott told me, "I want to keep playing sports for a long time". **I am certain that he will, because Scott is an athlete.**

Daysiree Perez—Showing the Way

Daysiree Perez is a resident in a home who is supported by NRS staff. She is also a trainer, who teaches NRS staff. This is because Daysiree is not the type of person who sits around and watches her life go by. She is someone who gets involved, speaks up, and takes charge of her life.

Daysiree came to live at her home in Danvers several years ago. She joined the local self advocacy group. She became trained to be a fire safety officer and a human rights officer. When Mass Advocates Standing Strong were developing their "Awareness in Action" training program, they asked Daysiree to give feedback and suggestions about how to make the training better.

In 2012, DDS formed a partnership with a private agency, Triangle Inc. to develop and promote a new training for individuals and staff called IMPACT-ability. Daysiree was asked to be a member of a committee to figure out how to implement it statewide. Daysiree made important contributions. She wrote up an account of a personal experience that was posted on the DDS website. Daysiree says, "When they saw my story, they loved it. It was very heartfelt. They wanted somebody who had known about abuse to tell what it is about."

Daysiree completed an 8 week IMPACT-ability course which included self defense techniques that individuals could use if they were being attacked or abused. Daysiree explains, "I learned self defense for people in wheelchairs. I was very proud to graduate. I invited my foster Mom. She loved it. She could not believe that I could defend myself in a wheelchair"

Daysiree was asked if she would like to be a trainer. Part of the IMPACT-ability program includes a training for staff members. Daysiree, "I am teaching NRS staff. I like doing it. I don't feel shy to do it. I'm teaching them how it is on the other side. How it feels to be abused. I'm not just throwing my business out there, I am teaching them".

As if that was not enough to keep her busy, Daysiree was approached by Mass Advocates Standing Strong to be a trainer for the Awareness in Action classes. "They saw my story on the website and they loved it. They asked if I want to be a trainer. I went to the DPPC offices in Burlington and learned how to be a trainer for Awareness in Action"

Daysiree is paid for both of these training programs. Her advice to others is "speak up for yourself. Speak up for others who cannot speak for themselves. Keep on trying".

Thanks Daysiree for showing us how.



Michael Mahon—Half the Man I used to Be



Ten years ago, Michael Mahon was a big man; 450 pounds is a heavy weight for anybody to carry. Fast forward to April 2013 and Michael has just cracked the 200 pound barrier – he now weighs 199 pounds. He has lost more than half of his weight – a 250 pound loss. Michael lost so much weight that he had to have surgery to remove the excess skin around his midsection.

Many of us would like to lose a little weight, some of us would like to lose a lot of weight. It is no easy thing. Yet Michael Mahon has done it. I asked Michael about the secret

of his success. "I do a lot of moving, exercise. I use a treadmill, I bicycle, go swimming, and walking." Michael went on to say "I keep in the habit of doing exercise every day. It is part of my routine". "The best thing is to keep the weight off for as long as I have. I want to keep on achieving."

Michael also makes smart choices about eating. He asks for rice cakes for snacks. He enjoys eating fruit and fish, and usually stays away from sweets. Once in a while he will have a piece of cake to celebrate a birthday or special occasion, but he doesn't like to do it too often.

Michael has made some other smart choices around eating too. Michael likes to visit his family, but he knows that when he used to live with them, he had a hard time in controlling his eating. Now, Michael visits them on the weekend afternoons, after lunch and before dinner, so that he is not tempted to stray from his good eating habits.

I asked Michael what he likes the most about losing all of that weight. "I feel like a new man. I can play basketball and I can run. I had to get all new clothes, the old ones don't fit anymore. I am down to a 34 inch waist line." I asked him how his family feels about his achievement. He said "they were very surprised and very happy. I did something for myself. I achieved a goal that I set for myself. I set a goal and I achieved it"

Michael went on to tell me that, "I don't want to go back to the way I was. I make good choices now". He told me that he was planning to go out for dinner this weekend at "Chipotles" He told me that it is a good choice, because they offer healthy food.

I asked Michael how he got the confidence to try and achieve his goal of weight loss. He said "I didn't know how I was going to do it. I just put my mind to it and did it. I try to do the best that I can, and I just did it." His advice to others; "Keep believing you can do it. Try really hard to do the best you can."

Tom Silva—Taking Charge

Tom Silva is a young man who recently moved into a community residence in Burlington. He is a very active fellow who has a wide range of interests and activities, including music, movies, bowling, swimming, going out for coffee and meals, taking walks, and shopping at the mall.

When he is at home, he likes to relax and listen to music on my walkman. Music is a real passion for Tom, and he spends a lot of time listening to it. His favorite artists are Kenny Rogers, Michael Jackson and Tim McGraw. There was only one problem. The walkman was running through batteries at an alarming rate. It was costing Tom \$20 a week, and Tom didn't want to use all of his spending money on batteries. Tom would sometimes get worried about the batteries, whether he had enough of them. This was causing stress in his life.

Tom and his staff talked about how to solve this problem. They hit upon the idea of getting a battery charger and rechargeable batteries. Staff helped Tom to purchase the right one and showed him how to safely charge his batteries. Now Tom can charge his own batteries independently and he has access to a constant supply of them. The only time that Tom needs staff assistance is when he needs to purchase new rechargeable batteries.

Tom feels great about being able to take care of his batteries by himself. He is more independent. Tom is working with his staff on taking charge of other aspects of his life.



Roy Pearson—It's Never Too Late

When Roy Pearson moved into his new home on Main Street in Woburn, he was quite, shy, and didn't like to go out much. Now Roy is a performer in a singing group, entertaining audiences in auditoriums and hotel ballrooms.

Roy moved into his new home in the community two years ago from the Monson Developmental Center. He certainly seemed to like his new home, but he did not want to go out and explore his new community. Roy declined to attend a day program, preferring to stay in the house. He spent most of his time relaxing by himself, not socializing much with his house mates. But Roy did show an interest in music.

Staff at the home learned that a singing group out of Lexington was going to be holding auditions. To everyone's surprise, Roy agreed to go. Well, he loved it. He also won a spot with the group. Now, the "stay at home guy" was going out to rehearsals every week. Then he started to find some places in the community that he liked to go to; his favorite restaurant and coffee shop, even shopping for clothes.

Roy began to make friends with other members of the group. They sing the old standards, songs like "Let Me Call You Sweetheart" and "Young at Heart" and "You've Got to Have Heart". On the evenings that Roy is not rehearsing with the group, he practices at home. The group provides him with CD's of the songs that they are going to be performing. Roy is currently in rehearsal for a performance at the Sheraton Hotel for a conference of the Mass. Association of Occupational Therapists.

When I recently spoke with Roy, he told me "I like to sing songs. I get to sing with my friends. I am a good singer". Roy is only 70 years old. He is living proof that it is never too late to try something new.





Self Advocacy Cookout

Chef Jim Oldford cooked up a batch of burgers, dogs, and chicken-kebobs for our summer meeting, while Bill Goodwin looks on. The cookout was the idea of Richard Ramig, seen enjoying the results.....



If you would like your achievement story to be published in the NRS self advocacy newsletter, please send the following information to Rich Santucci at the NRS offices.

I Achieved My Goal

Name:

The goal that I achieved is:

Things that I did to achieve my goal are: