

## ***Sharing the Voices of People We Support***

### ***The Importance of Relationships and Valued Roles***

**Jose Perez, Toby Bazan, and Scott Shepard**

*(from TASH 40th Anniversary Book, 2015)*

TASH has played a huge role in the services we provide to people; influencing our philosophy and mission statements, providing concrete ideas, research driven strategies, discussions with colleagues at conferences, the list goes on and on. Most of all to me, TASH has provided the confidence I needed to pursue my convictions, things that I felt in my gut were the right things to do (commonly referred to as TASH values). TASH gave me the nudge I needed to move forward.

I have the privilege of sharing Jose's and Toby's stories. Jose and Toby are ambassadors for themselves and others who may be labeled with intellectual and developmental disabilities, and who have been labeled with "severe reputations". Every day, whether in the grocery store, at work, in their neighborhoods, and especially when sharing their stories with families and self-advocates, university students, service providers and others; Jose and Toby teach us about the importance of healthy relationships, having valued roles, and self-determination (taking control of your life). Each of them uniquely shares about the often challenging roads they have taken to get respect and live the lives they want. Families, self-advocates and staff who have heard their stories have been encouraged and motivated to seek out inclusive lives for themselves and others they care about. I hope our sharing will do the same for you.



*Jose mowing a lawn in 1996*

### **Jose Perez: Teaching us the Importance of Relationships**

You aren't always happy when you get the things you want. Jose taught me that. When Jose got something without working for it or buying it with his own money, he would become irritable, demand more, and often ended up selling the items that he got. There's more to life than "stuff". Relationships are better than stuff. Jose taught me that too.

I first met Jose and his mom in 1990 when he was referred for day services to a community program I coordinated for a large agency. He wanted to earn money, so we helped him get a job at a pizza place earning minimum wage with a job coach. After a few weeks, he stopped showing up, and when we tracked him down, we found he was hanging out at a gas station, helping out the owner with small jobs in return for a few bucks "under the table". We tried to convince Jose that he would earn more money at the pizza place with his job coach, but he never came back. He wanted the immediacy of getting a few bucks every day (instead of waiting for a pay check), and valued the

relationship he had with the owner (instead of taking directions from a job coach who wasn't his boss).

I reconnected with Jose in 1994, after our local Regional Center shared a story about a gentleman who fired the agency supporting him and had just gotten evicted from his apartment. No other agency would take him due to his behavioral history. I knew who he was from his story and decided that our new, small non-profit supported living agency would try to do a better job of listening to him than others had done previously. I learned that Jose had spent most of his adolescent and adult life bouncing in and out of group homes, never staying at any for longer than a year. He had experiences at great number of schools since he moved so frequently and would be referred to a different school each time he moved. Due to the combination of his presenting irritability and behaviors, and moving every year to different schools and group homes, he didn't have a chance to develop any long term relationships in school or home, and didn't receive much of an education.

The first twelve months we supported Jose (1994 - 1995), Jose moved six times. He was evicted twice, refused to continue living in other places he didn't like, even though we thought those places would be wonderful and supportive for him. I was ready to throw up my hands and give up, but gave Jose the ultimatum that he needed to find his own place that he could afford, which turned out to be a single (studio) apartment close to the bus line that would take him to Universal Studios. For the first time in his adult life, Jose lived in his own home for over a year (actually, over 10 years). We started learning how

to listen to him and his needs better, and to infer meaning to his behaviors. What changed for Jose, was the development of healthy, long term (lasting) relationships.

When Jose was evicted from his first apartment(s), we didn't leave. When Jose fired all his staff but yours truly, we didn't leave. When Jose had meltdowns, we didn't leave.

We stuck with each other. In the early days of supporting Jose, I found that when I took a break to get refreshed at a TASH or Cal-TASH conference, Jose would somehow go into a crisis back home that I would try to deal with over the phone. So Jose began attending and presenting at conferences I went to, as it was easier to have him with me than to trouble shoot issues going on back home. Jose began to get to know people at the TASH booth, where he helped hand out brochures, and at Cal-TASH conferences where he helped sell tickets for the opportunity drawing. The more people he got to know, the less time he wanted or needed to hang out with me.



*Jose with his “honey” Pam*

John O’Brien and Beth Mount remind us that keys to job satisfaction are **building good relationships and making a positive difference**. Two ways they share to keep us focused on this are, *“figure out how to advocate for better lives for yourself and the people you support”*, and *“decide to invest yourself in your work in ways that assist people to become better known to other people as contributing community members”* (O’Brien & Mount, 2005). John and Beth really sum up what we learned from Jose. While we learned that Jose doesn’t like sharing his living space with anyone else, we also learned that he needs to have healthy relationships with people he trusts. When Jose experienced health problems due to his poor dietary choices (high soda intake and

junk food) coupled with diabetes, it took his Endocrinologist to tell him that he was going to stop being Jose's doctor unless he made better dietary choices and got his blood sugar and weight under control. This made such an impact on Jose, that after 15 years, Jose continues to see the same doctor, and his weight and blood sugar are (for the most part) much healthier. Healthy relationships are key for Jose, as they are for all of us. Jose doesn't tolerate being with the same person every day. He gets tired of seeing the same person more than twice a week. We have learned to provide a variety of support staff for him. Jose has known most of his support staff for over 5 years, and many of those for more than 10. Jose's relationships have expanded as a result of his speaking at University classes, and attending conferences like TASH & Cal-TASH. For over 5 years, Jose has had a healthy relationship with his girlfriend Pam; he now keeps his stuff instead of selling it; he hires and fires his own staff; and for the most part, he is comfortable telling his staff to leave when he is mad, so that he can call someone else that he is not mad at, so they can help him to de-escalate over the phone.

***Toby Bazan: Teaching us why we all need Valued Roles***

**Toby Bazan and Scott Shepard**

*(from TASH 40th Anniversary Book, 2015)*



Toby working at Six Flags Magic Mountain

“Valued roles and friendships within the community provide each person with the best opportunity to achieve the good things in life.” (Ramsey, 2007, pg. 9). As family members, friends, service providers and support staff, we can strive to do this “by placing greater emphasis upon the importance of social contribution, intentional relationship facilitation, valued roles, disproving negative stereotypes and introducing a more critical thought base into the process.” (Ramsey, 2007, pg. 6).

Toby was incarcerated at Fairview Developmental Center, a State Hospital in California, from the time he was 15, until 2007, when he was 27 years old. He lived in a locked residential unit and slept under his bed for the entire 13 years he resided there. He had a history of being put in 5 point restraints, where, as Toby describes, “They tie you down by your hands and feet on a box spring, and tie your head down too. Then, they would hit me with a wet towel.” Toby was put in 5 points as recently as 2 weeks before he left the institution in 2007. In the institution, Toby had a few allies, namely Mark, Ken, and Joaquin, who gave him some freedom and space to walk around in open areas inside the fenced facility. When Toby was confined in closed, crowded areas, or when people got in his face, Toby would “get a little nervous”. This would often lead to what Toby calls “issues”, and sometimes the use of 5 point restraints.

Within a month of supporting Toby to move out of the institution in 2007, we identified that Toby had “issues” because of his anxiety. When he felt people were confronting him too much (“getting pushy”), or getting in his face or personal space, this led to issues. We were able to assist Toby to reduce or eliminate several medications, while taking a milder med for anxiety, all of which has helped tremendously. This alone, however, wasn’t enough. After 6 months, Toby was evicted from his first apartment due to some issues with the landlord (Toby has now learned how to be a better tenant and not call the landlord too much and gossip about other tenants). With his second opportunity renting a condominium in Canyon Country, Toby has gotten to know his neighbors and most of the local community; including store owners, the homeless, bus drivers, recycling center staff

and park staff, etc. Toby continues to split the rent and utilities with his roommate, who also provides some of Toby's live-in support.

“Intentional relationship facilitation”, as mentioned earlier (Ramsey, 2007) is important to note, as the process of simply exposing people to social/public situations without facilitation or a plan, is rarely (if ever) a guarantee for the development of long term, healthy relationships. Facilitating relationships by teaching guidelines for building healthy relationships without burning people out has been tremendously helpful for Toby. Without facilitation and support from staff, Toby can, at times, be a bit dominating in a conversation, and may drone on about topics that the other person is not interested in. It is important for Toby to have topics to talk about and to have “status” with the people he meets. When Toby didn't have valued roles, he had less status and was more likely to exaggerate stories about relatives and news stories in order to keep conversations going. As Toby has increased his self-confidence through valued roles he now has in the community, Toby is more connected to others and finds it easier to take charge of his life. Toby is learning how to be a better neighbor, he has become a strong advocate for others less fortunate (people who are homeless), he works at Six Flags Magic Mountain as a Park Attendant (for over 2 years); he was honored through LA County as the Placerita Nature Center Volunteer of the year (2014), he is an advocate for the elimination of the use of restraint & seclusion at regional & state conferences; he is a public speaker; and is well know to his local legislators. Toby built up the confidence to take his first ever plane trip in 2010 to the TASH conference in Denver. Since then, Toby has gone on 10 plane trips.



Toby with County Supervisors at LA County volunteer awards / Toby receiving 2014 LA County Volunteer of the Year, Placerita Nature Center

As Beth Mount shares, “Loneliness is the real disability” (2007). Jose and Toby have taught us that by developing healthy relationships and valued roles in your community, it is much easier to get connected to people, take charge of your life, and avoid the loneliness that is often the root of depression, behaviors and dependence.

#### References

Ramsey, Scott. Roles Based Planning: A thoughtful approach to social inclusion and empowerment. The SRV Journal, 2(1), June, 2007. p 4-12.

Make a difference: A Guidebook for person-centered support. John O’Brien and Beth Mount. 2005 Inclusion Press ISBN 1-895418-62-3