

TRENT

Living Independently

by Jackie Altman Marquette



HOW YOU CAN HELP ME: CREATE MY ENVIRONMENT

- Create a structured, ordered environment.

If the environment is inviting it will provide me the opportunity for building success and trust.

- Create an environment that meets my sensory needs.

Demonstrate to others who are around me ways to talk to me and help me when I become confused or experience change.

- Create an environment where the expectations are clear to me.

- Create an environment that encourages me to become independent.

I am learning to become less dependent on others. When I learn steps toward helping myself, I am becoming more independent.

- Create an environment where all staff work together as a team.

RECREATION

I enjoy bowling. My community coach and friend David takes me different places on Saturdays. I like to bowl on the bowling team at Easter Seals. I have made new friends. Belonging to a team makes

me feel accepted.

I may not always participate fully in an activity as others do. Please do not keep that from inviting me to be with others. Because once I am in a situation with others, I enjoy being part of a group.

HELP ME ADAPT TO A NEW SITUATION

I often refuse to go new places or do new activities and tasks. I am unsure because I don't know what to expect. Sometimes a lot of new people, sounds, and movement occur in a situation. At times I become agitated or frustrated. So I many need to get used to the environment slowly. As I become more familiar with the task or environment, I usually accept the environment.

It helps me when you prepare me for new things and places by using one of these methods:

- Help me write a social story about the new situation.
- Use pictures
- Take me in the car to do a drive-by to the new place you want me to visit. The first time please do not require that I get out and go in

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Trent is a 25-year old man with autism. At age 23 he started living independently, with the help of a job coach, a community coach, a roommate and a respite worker. Trent's verbal skills are limited and he does not have the ability to express himself that well. Therefore, his mother, Jackie, wrote a collection of pieces, some of which are included here, to help the people in Trent's life better understand him. Touching upon topics as diverse as getting up in the morning, to being part of the community, Jackie wanted Trent's caregivers to not just understand autism, but to have a real feel for how Trent reacted to his environment, his individual needs, and how he could participate more fully in all life has to offer.



WAITING IS SOMETIMES DIFFICULT FOR ME

Sometimes I have to wait. I am ready to go to work. I am waiting for the Tarc 3 bus. Sometimes I have to wait even when I do not want to. I am learning that there are items that the bus will be late. I am choosing to wait calmly. What can you do to help me? As I sit patiently, remind me that I am waiting patiently. Help me understand that the bus may be late sometimes and when I accept leaving late, tell me how well I accepted this change.

FEELING TIRED

When I feel tired I may get agitated or grumpy. I may begin making noises (vocalizations) that may indicate one of several possibilities. I may be overloaded by all the sensations around me, I may be fascinated and interested by the sensations of the environment, or I may just be tired. These noises are a sign to others that I am having difficulty coping. If I become tired or need help, I am learning to tell the person I am with how I feel. For example, I can say "I feel tired" or I could point to this picture of a bed. Sometimes I make noises (vocalizations) and withdraw from my environment. I usually withdraw only when I am at home and when I am transferring from one activity to the next. I usually need only 15 minutes. I have learned that when I withdraw, the time is helpful for me to get ready for the next activity. So if you see me withdrawing into my own world for a short time and if it is not important I participate, don't try to stop me. Please allow me this time.

UNDERSTANDING MY FEELINGS

Help me understand my feelings by helping me label my feelings. I also have great difficulty understanding your feelings and I have great difficulty expressing my feelings. Others supporting me can help me label feelings in natural situations.

If you can place a name of the feeling along with a possible reason for why I may be having the feeling, then it may help me understand feelings better.

Some Examples:

"I'm mad. Travis is wearing my shirt."

"I'm happy. I am watching Jeopardy."

"Buying a new Nike shirt at Footlocker makes me happy."

"Dad is not home this weekend. I cannot go to his house. I feel sad about not visiting my dad."

WAKING UP IN THE MORNING

It is hard for me because I do not want to get up early.

One of my goals is to get up with an alarm clock and without being called.

Before I lived independently it helped when mom called upstairs and said "You have 5 more minutes." When I was given 5 more minutes, I had time to process the information. After the 5 minutes were up, I was prepared to get up. Now I have two alarm clocks, because my roommate lives with me.

I am being reminded by others that when I get up by myself, I am becoming more and more independent. I am working on becoming more independent.

if I am feeling unsure. I will go in the next time we visit.

For Example:

When my mother got married, I walked her down the aisle during the ceremony. Three days before the wedding, my community coach, my mother and I visited the chapel. I listened to the music, practiced walking my mother down the aisle, sat in the church pew, looked around the chapel and got used to the surroundings. When the big night came, I was ready to walk mom down the aisle even with all the people watching me. My brothers were proud of me as I participated in mom's wedding.

Please try these strategies when you are introducing me to new environments and I cannot have a short first visit.

- Use pictures or a written checklist to explain to me what will happen.
- When I am out in the new environment and you notice I am beginning to get upset, please take me out of the situation briefly. I do not want to get upset in front of other people. I could leave shortly and then come back later. I may just need a little time to get used to the new situation.
- When I have the appropriate behavior in the new environment, please tell me I have handled the situation well.

A Message from Jackie

Everyday throughout the day when my family catches me doing an activity or chore by myself they remind me how well I am doing. They often say to me, "Trent you are becoming more and more independent everyday." I have also learned to remind myself, "I am independent." Sometimes when other people point out my independent behavior, it helps me recognize what independence looks like, even in small meaningful activities.



I wrote *Independence Bound* to share personal stories of how my son Trent and I overcame obstacles during his transition to independent living, a victorious, life-long dream we had shared. We forged ahead with our dream but nearly gave up because of several family crises: divorce, financial loss, cancer, unemployment, and a move to a new residence.

After Trent graduated, we both experienced grief. I grieved while our family faced major life changes while Trent grieved the ending of his secure, familiar life. I found ways that helped me manage my life through the transition phase and moved forward to new discoveries and independent living for both of us. I eventually began to see the gift I gave to Trent by allowing him to live independently, even though I was so terribly afraid. I found meaningful self-evaluation questions and developed checklists that helped lead me through the process of managing these endings and moving into our new life. My hope is that these checklists and methods may help families who also want independent living for their adult with a disability.

Jackie Marquette is a Transition Consultant for families of adults with disabilities. For more information, visit www.independencebound.com or email Jackie at Jam4independence@aol.com, if you are interested in having her talk to your group about her book.

WITHOUT WORDS

When I sing and rock to the beat, I appreciate the language of music.

When I exhibit reverence in church, I respect spirituality.

When I join a group, I may only partially participate, but I like belonging.

When I earn money at my job or for a chore and choose to spend my money on a new shirt, I am developing my self-determination.

When I choose a movie to attend, I enjoy recreation just as others do.

When I leave my house eagerly for work, I seek a reason to get up everyday.

When I walk with a spring at my job, I am exhibiting pride and value work.

When I enjoy visits and family get-togethers, I feel connected and safe. My quality of life is dependent upon you.

As you extend your patience and effort to help me belong to a world I have difficulty understanding,

you affect my happiness,
you affect my life.

Please do not give up on me.

