

T's STORY by Matthew Nguyen

Sometimes someone comes into your life and takes you to the edge teaching you things you never realized were there to learn. Sometimes this happens in the field of human services. We met someone who challenged our thinking about how things **should** be done vs. how they were being done. This person also challenged the system which was designed to support him. The person described shall be called T. T. struggles with an intellectual disability, neurodevelopmental disability and a mental health disorder. This story embraces the fact that none of these disabilities should ever overshadow the fact that we are all human beings who have needs. We hurt the same, we anger the same, we become frustrated the same when our needs are not met. T. was no different.

T. was a young man in his early twenties living in a group home. He was unhappy with his life and seemed to have no direction. He was angry and showed his anger by breaking out windows in his home and threatening his neighbors when he became stressed.

In 2012, Keystone Human Services agreed to offer residential services to T. At first, he did well. He seemed to settle into his new neighborhood – even developing friends in the neighborhood. Soon after he moved in, the neighbors became concerned about T's anger. This increased his anxiety which in turn increased his anger. T. continuously worried about his future. He began to feel rejected, frustrated and confused.

He was feeling a number of pressures. He was concerned about his relationship with his mother. He looked forward to her visits and often did not understand the situations that occurred that would cause visits to be cancelled and rescheduled. The mother/son relationship was frequently misinterpreted and misunderstood by T. This caused much anxiety and sometimes severe emotional distress.

During this time, T. obtained a new cell phone and was learning new ways to reach out to others as well as access new information. This "new information" also challenged T. in regard to his inability to process abstract ideas. The very nature of the never ending information available to him through the internet, social media and texts were abstract and over stimulating. Due to the new activities challenging his understanding and judgment, the unsafe situations created, resulted in restrictions. These restrictions were to assist in keeping T. living and learning safely in the community.

T. did not see or understand these restrictions to be a matter of safety, but a stripping of his rights to full access of technology. He rebelled against these decisions. The more rebellion, the more escalated the situation would become. Then a traumatic situation occurred with his family and things quickly spiraled even further out of control in T.'s life.

Feelings of anger and hurt overtook T. His rebellious actions resulted in broken windows and light bulbs. He threw bricks through car windows and at other people. Numerous times police had to be called and upon their arrival, he taunted them and refused to cooperate. Also during this emotional spiral, T. got in the pattern of using psychiatric facilities as a place to get a break and see "friends". T. realized he could commit an aggressive act and he would get a "respite" at the local hospital or inpatient unit – sometimes 2-3 times a night. Within the agency, this resulted in moving to other homes and neighborhoods. Within the home, roommates and staff were also constantly changing.

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As staff tried to be consistent, he pressed harder, resisting traditional behavioral strategies. While T. was meeting his needs for power and control over his life this was not achieved in a safe way. People were hurt and property damage and loss were financially mounting. Neighbors were concerned for their own safety and the safety of their families. Eventually, T. began to harm himself which left Keystone no choice but to hospitalize him. T. was trying to “have a voice”, but it was all so confusing and happening so fast no one really knew what he was trying to say. Reactivity and crisis took over.

At this point, Keystone Human Services knew they could no longer effectively serve T. despite endless effort. A 30 day termination letter addressed to the County was sent stating that T. could no longer be served safely.

While a 30 day notice means at the end of 30 days T. would go to a different provider, there were no other providers who would take him. T. continued to raise the level of danger to self and others. Everyone knew he did this to have his needs met, however support staff had no idea what his needs were. The team's dilemma became, “Should long term inpatient care be sought, a state center, a state hospital?” “Is he going to end up incarcerated?” All members of the team realized for T. these were not options. If his life was going to improve, it would be up to them to make it happen. The “team” became very large, including collaboration and participation from all of Keystone, county, outside consultants and dual diagnosis support.

The team members made a number of changes but it was the “grass roots” front line team that executed the plan and T. who made the difference. The following is a list of the changes that were made.

- 1) **“Out of the box thinking”** had to occur. A realization that not every need falls within a “service definition” and if T. is going to have a life, he needed the coordinated resources and collaborative efforts of the intellectual and developmental disability system, the mental health system and natural supports.
- 2) His **medical and psychiatric** needs were met.
- 3) The team changed how they listened to T. Staff realized that T. was searching for a life of meaning. Their role in helping him find this meaningful life, was critical.
- 4) T. had a diagnosis of **Fetal Alcohol Spectrum Disorder**. The team learned how this disorder affects learning and understanding. They learned to balance their expectations, understanding what was realistic for T. to obtain.
- 5) The team **opened their minds** to learn different approaches and learned that due to T's diagnosis he could not manage such things as abstract ideas. Everything would need presented in a concrete clear manner.
- 6) They realized and **accepted** that some things needed to stay the same and that was OK. That was progress.
- 7) **Communication was a MUST**. The team began to meet weekly to tighten accountability. This resulted in tasks being accomplished in a timely manner.

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- 8) A sense of **“we are in this together”** among all team members developed. Regular emails and team meetings served as a way to keep everyone on the same page and up to date on action steps.
- 9) Staff recognized **“teachable moments”**. T. is supported and encouraged to participate in “everyday experiences” with staff to guide and support him.
- 10) “Staff” became **guiders, mentors, and coaches**. This approach assisted in T. feeling in control over his life.
- 11) It was realized that a **regular routine and framework of support** is necessary for success. It was also realized that it is important to have a **robust team** - not relying solely on the direct line staff to provide all the necessary supports.
- 12) It was recognized that **each member of the team brings talents to the table**. Monopolize on those natural gifts. They lead to honest connections.
- 13) **The team changed their thinking so that T. could change his**. When all of these things occurred T.'s life changed.

What is T.'s life like now? Pretty darn nice. T. has a full and meaningful life in his community. He works with a job coach for employment and habilitation staff doing meaningful activities in his community. He plays soccer and soft ball for Special Olympics, has season passes to Hershey Park, and a membership to the local community center. He had a garden in his back yard and he maintained it. Stopping by to visit T. over this past summer meant receiving a handful of tomatoes or cucumbers to take home to the family.

He looks different. Not only does he smile and joke around, he takes pride in how he dresses and how he makes friends. He is fond of the person with whom he lives. He helps his housemate get ready to walk out the door for work each morning. Most importantly, T. trusts his own judgment and has control over his own life. One thing that happened to help was a new plan that included and considered his strengths and needs in regard to his Fetal Alcohol Spectrum Disorder. One of the motivating strategies for T. is earning money for the days he did not exhibit target behaviors. This is important to him at least until he finds a job. This strategy was important as it enables him to no longer rely on his mother or staff to give him money. He earns it honestly and controls what he earns. He has learned to save and has even taken his mother out to dinner. He has learned that a meal out with your mom can cost up to \$30.00! He is learning through **natural experiences**.

He has learned **reciprocity**. He shares his concerns with his family and the professionals in his life. He also cares how they feel. He has learned to **accept feedback** and to **problem solve**. Most importantly, T. realizes he has important people in his life that he can count on. He is even figuring out how hard it is to ask a girl out on a date....he's still working on that one!

Although T. will always have his struggles as everyone does, his feelings about himself have changed. He is learning and growing. This creates contentment and finding contentment can make all the difference in the world!

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This story is dedicated to T. who worked so very hard to find himself. It is also dedicated to the committed, dedicated team at Keystone Human Services who never gave up, who opened themselves to new learning and opened themselves up to the idea that discovering and accepting a person's true needs is immeasurable.

A special thank you goes to T. for allowing his story to be told and to Matthew Nguyen who without his countless hours of leadership and the time taken to write this story, T.s story may not have been told. Many now can be touched and guided by this new way of thinking. **Change** needs to be received and embraced by we who work in this system; then and only then can it be embraced by the people we serve every day. Thank you T. for teaching us this invaluable lesson.

Respectfully submitted,

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T's Story was written by Matthew Nguyen and read by Robin VanEerden.