

The importance of everyone

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Onondaga Community Living is an organization in Syracuse, New York, USA that supports people with intellectual disabilities. Each person's service is designed based upon what a person wants and needs. OCL has moved towards helping people in their home, with jobs of their choice, and with volunteer positions all in their community. OCL also assists people with their social life and their valued role as an accepted citizen. OCL works to support people with their family lives and also with the academic pursuits. The agency has opened its arms to helping people to have typical relationships with community members. Every person service is self designed.

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This is a story about a set of people: a family who wanted a normal life for a daughter who was labeled with a disability, a service provider that had to listen, understand and allow life to unfold naturally and community members that had to believe and join in, to make the circle complete.

A circle is just that, it is round. Think of a bicycle wheel. There is a hub, a center point. In this story you will find that to be Kristen. There are spokes all radiating from the hub, all equidistant and all with equal strength. You will find them to be two sets of families, community members, friends, an agency and staff supporters. You will then find the wheel, which holds the spokes intact, which is the dream and value that comes to the life of Kristen that each spoke upholds. The tire on the outside is how it runs against the world and cushions the ride when bumps are hit. Life is never perfect and even though the ride may get harder and the tire may need to be re-inflated or replaced, as long as the spokes are equidistant and with equal strength and there is new air to replace the lost air, the journey will go on.

An introduction

Our agency (Onondaga Community Living – OCL) met Kristen when her family heard of the college service we had. Kristen's family had always felt that Kristen had a lot of potential but they found it as a big let down when she entered into the adult service world. Traditional day programs and grouped vocational programs were plentiful but not at all what Kristen and her family were looking for. Wait lists for any volunteer or work programs were huge.

But, what about this college service? They had an opening. The application and information was on line. It seemed like a normal progression for their daughter. Kristen

was accepted into the Access College service at OCL in August of 07. The transition from the high school setting to that of a University can be challenging for any student with a disability, but with the right supports there is success. Kristen was supported with a college mentor that works with her in a 1:1 relationship. The mentor attends class and aids in whatever area Kristen may need support in from completing assignments to navigating through the campus. She has taken a variety of courses with the help of her mentor. Kristen has chosen now to work with the elderly so her classes are concentrated with that in mind. Kristen meets with an advisor for the University who discusses each class and how it best fits in with her eventual goal of employment.

In the beginning Kristen was shy and did not have adequate study skills but as she became more comfortable with her new life and surroundings, she began to blossom. She began to be more outgoing and entered into class discussions. She began to identify with her new peers and began to enjoy some of the social aspects of going to college. Her family was amazed with the growth they saw in her as she began to expand not only her knowledge but her experiences.

Ready to move and nowhere to go... or is there?

Kristen continued to live at home with her parents as she got the support she needed to take some classes at the local university. As she became more comfortable in her student role, she began to think about what it would be like to get her own place and no longer live with mom and dad. But once again, mom and dad's survey of the adult service world was not what they hoped for. Kristen's mom states,

“Other agencies that we spoke to regarding a

place for Kristen to live were looking at the group home model. The options discussed were either an established home that had a vacancy, or developing one with other families who were also looking for a place for their daughter(s) to live. Kristen prefers to spend time with a variety of people and we were concerned that she would be limited to spending time only with peers with disabilities and “staff.” We had heard from other families that staff turnover rates are high and change is difficult for Kristen. Kristen likes a schedule, but this was also a concern because she can get too dependent on a schedule and become very upset when something happens to change the schedule. We were worried that in a group home Kristen’s level of ability would be compromised. She is very high functioning and if she lived with others who needed more support she would not be expected to work to her competence.”

Our College Coordinator knew that Kristen was looking to have her own place and thought that it might be good for Kristen and her family to begin meeting with people at OCL. A meeting was set up and slowly discussions arose about what Kristen was looking for. As OCL has no openings or beds to fill, the people at the organization had the opportunity to tailor what Kristen and her family wanted. There was no hurry to fill a vacancy. There was a slow, yet targeted discussion to get to know Kristen, her wants, her personal routines and desires while also getting to know the family and the role that they currently had or wished to have in her future life. Kristen’s mom states,

“Working with OCL was completely different. There were several meetings of discussions about what Kristen (and her family) thought would be the best living situation for her. These Circle Meetings were a process of getting to know Kristen as an individual rather than as “another person with a disability.” We discussed the things that were important to her and things that made her uncomfortable. For example she wanted a cat so we made sure that was a priority in finding an apartment. Kristen, and her sister and I, and sometimes others, met monthly for about a year to discuss and plan for the move.”

There was much to know and find out about. She had many interesting things going on in her life with her art, her studies, her community and her family life. There was much to learn about her family and Kristen’s role as a daughter, a sister and an aunt. There was much to learn about how to keep her safe, while also allowing her to grow.

Planning

At first it seemed logical that living in the university area might make sense as she was really identifying with the student population. She even would have a connection with her sister and her sister’s family living in the neighborhood. It would probably be easy to find



Kristen Webb and Erin Edwards

college housing and support her within it. Kristen at first thought that to be the best plan. But as meetings went on Kristen became more and more quiet, and eventually, thought she did not want to move.

As we explored more to find what her hesitations were all about, we found that she really identified with her home community and its comfort and was worried about all she would lose if she moved from there and had a completely fresh start in another neighborhood.

As we abandoned the idea of college housing, we asked Kristen what she then wanted.

“...An apartment with a cat, where I grew up, where I can go to see my family, have Sunday dinner with them, continue to work at the YMCA, meet with my art teacher and take my classes....”

Kristen had a life with meaning currently and did not want to lose it. As we figured out the support needs that Kristen had, we folded into the equation everything that she currently had in her life, along with what else could be done to enable her to grow.

The parents were worried about her safety and security, as they felt that Kristen could be vulnerable. They also wanted good role models available for their daughter. The group met monthly for about a year to discuss and plan for the move. Time was taken to explore her needs and desires. As the support needs and weekly routine were agreed upon, goals were determined:

1. Find an apartment in a location that both the family and Kristen were comfortable with.
2. Find the right person to live with Kristen that could share her new home and be a companion and support to her.
3. Ensure we had the right plans in place.

As Kristen and her family knew the home town neighborhood far better than the agency, it made sense for them to do the apartment hunt. The agency gave them some parameters about rental amounts and did little else.

Kristen and her mom then began talking with landlords and rental people in their neighborhood about apartments and visiting them. They eventually found a two bedroom apartment with good space that they were both satisfied with, that also had security, accepted cats and was within the rental amount. The family passed the lease to the agency for another opinion, everything seemed to fit. Kristen then signed her first lease to her own home.

As we began to think about who would live with Kristen, she wanted someone her own age going through similar life changes. So we put an advertisement together.

Young woman with a disability, going to a local college and moving out of her parent's home for the first time, looks for someone to share her home. Free rent in return for companion and some support. Call xxx-xxxx

Everyone in Kristen's circle was encouraged to talk with people they knew. An ad was placed in the local newspaper, the Sunday paper and on line at Craigslist. The majority of people who contacted us were young women going to college, looking to move out of their parent's home. The agency sorted through the applicants and did initial interviews. After several interviews, a person was decided on, Erin. Erin stated:

"The biggest thing in the ad that grabbed my attention the most is that I would be helping someone and moving in with them. My parent's thought I was not responsible enough to move out and I wanted to prove them wrong."

Kristen, Erin and both of their families went out to a favorite restaurant of Kristen's for their first meeting. Erin and Kristen got along well from the start. Then about a week later, Kristen and her family went over to Erin's home and met with Erin's family again. It was about the two families uniting on behalf of their daughters in their strong desire to have each of them have a successful life and home.

Living life

Once the decision was made that Kristen and Erin would live together, each woman, with their families, began gathering what they would each need to live in their new place. They both were so excited to be moving out and sharing a home together. Both sets of parents helped to move their daughters into their new home and threw a wonderful housewarming party that brought family, friends and agency staff together in celebration of their new home and life together.

Kristen's mother states, "Kristen now lives happily in the apartment with the roommate. She comes for a family dinner every Sunday, sometimes bringing her roommate with her. We continue to be involved in her day to day life, but from a distance. We meet to discuss how things are going, help to monitor her finances and help with doctor's appointments. We see tremendous growth in Kristen's independence. She now plans meals, cleans her apartment, shops and does her

laundry sometimes with minimal assistance. She balks when we act too much like parents and don't treat her as an adult."

Kristen and Erin have a great relationship and enjoy poking fun at one another. They enjoy each others company and are very fond of one another. They do allot together. Erin often goes with Kristen to Kristen's family gatherings or for Sunday dinner. Erin stated that, "Kristen's mom is a great cook!" Kristen often goes with Erin to Erin's family gatherings and birthday celebrations. Erin says her mom loves Kristen and Kristen also loves her mom. Both women feel that they now have an extended family. They both love living together and say they are learning more and more from each other every day.

Life goes on

Everyone feels that this situation went beyond what was originally expected. Kristen has fun with her staff and because she enjoys them is better able to do the work around her home. Her mother says, "When someone other than a parent is the one offering guidance, she takes it so much better." She seems to have fun while living up to her responsibilities.

It is a big step for any person to start out on their own and when it is your child with a disability, it can be very scary. It is scary when you want something but only find closed doors. It is easy to become shoe horned into taking something that does not fit and then give up so much control to an organization.

Having an organization take the time to discuss all aspects of the dreams and desires of the individual, as well as the family, not only helps to alleviate the worries, but it also helps the organization to understand the story and their role within it. Too many times organizations come up with standardized answers before they even know the questions... and the tire goes flat. When you let the story unfold, an organization may find that there may not be much from them that is actually needed, beyond cooperation and filling in the gaps...and new air inflates the tire to make the ride comfortable again.

Having a solid circle of people around you working towards the common good makes life's harder times more bearable. And not having the answers before the planning is done is the key. It is not about residential support. It is about helping Kristen to have the life of her choice given in a way that helps her to mature and grow over time.

Kristen is very much the hub of a very solid wheel that keeps turning with relative ease because she has so many equal and strong spokes in her wheel that help to keep moving in the right direction.