

In Conclusion

The People

If you describe a person's whole being, for example: never judges others, plays the saxophone, always greets you with a smile, enjoys country western music, loves to sing & dance, is a strong advocate, etc., and then include their disability, you see each person as they are and their disability is just a small sliver of their whole being. There are some amazing people in RI who just happen to have a disability.

The definition of quality of life is as diverse as all people. In addition, the definition of safety, enjoyment, good health, activity level, clean home, how to brush your teeth and what a friend is, etc. differs widely. The key to finding a person's definition of quality of life is to truly listen to a person's dreams and wishes and find ways to support them in their journey.

We meet individuals, staff and families who sometimes have different gifts and expectations about what's possible for the person visited. It is also true that a person's satisfaction is based on their experiences, which may be very limited. The people who provide support to a person have a large impact on the experiences and opportunities a person has. For instance, yes, they like where they work, but is it the only place they have ever worked? There are themes shown in the data and/or are observed on our visits that indicate we do see wonderful, individualized supports for many, but there are areas where this can be significantly better. **The definition of quality and happiness must be defined by the people we visit and then supported by families and staff.**

Families

As we move into adulthood we have preconceived notions of what being an adult means. Often it revolves around finding a loving partner, living on our own, having family & friends, doing meaningful things and working at a job that provides enough resources to be healthy, have the basics (food, shelter, etc.) and a little extra to do things we love.

Parents love their children but never expected to have a child with a disability. They worry about their adult child's safety because they understand their child's vulnerability. They worry about people outside of their family caring for their child. They read the papers and hear the possibilities of abuse, and they understand the issues of subtle neglect. A mother at one visit said, "I shouldn't say this but I hope my child dies before me so I can die in peace."

Our Project

In summary, the past 9 years have afforded our Visitors the opportunity to meet, talk to and appreciate the diverse talents, dreams and goals of people with disabilities. Through this project, we have been able to offer specific information to provider agencies about what the people say about the quality of their lives. Over the past 9 years, we have attempted to follow up on approximately 2600 expressed issues and by building this follow-up process we tried to help strengthen their voices in the hopes of effecting change in their lives.

The project has afforded us the ability to outreach to families whose sons/daughters are still living at home, and provide them with information as well as offer opportunities to learn about best practices.

To date, we have prepared a number of reports: our 2001 Trends Report, the 2004 trends report, an annual "Three Wishes" Report for agencies comparing a person's 3 wishes to their goals and now this final 2008 trends report, Quality of Life- The Definition Is as Diverse as We Are.

Agencies

Agencies were often started by people who truly love people with disabilities and leveraged their own assets to start their agency. There are so many wonderful people providing supports in RI. When you visit, it is a wonderful feeling when you see, hear, and feel respect and integrity.

Presently, it is a huge challenge for all agencies to provide support to Rhode Islanders with developmental disabilities. Every person thinks, hears, feels differently and there are constraints that limit the funding for individualized support services and for direct support professionals. There are agencies that have a creative, person centered focus on each individual's dream. Even with the challenges, they listen well and support every person in their own journey. Paid supports, as good as they can be, often provide group vs. individualized supports because of low funding levels, insurance costs, etc. Often, parents and family members want to have an agency of support for their adult children, so that when the parents can no longer care for their child, they know the adult child has someone to turn to for the basics of care, respect and an ear that truly listens.

The Division of Developmental Disabilities

MHRH and the Division of Developmental Disabilities have gone through significant challenges in the past 4 years. Leadership changed with varied styles and intent. At times the reorganization meant no DDD Director and no real leadership. The huge deficit in the federal and RI budgets has impacted the most vulnerable in our communities. Our state system must be responsible for people who are often defenseless to mistreatment and neglect so oversight is critical. Since all must have assistance throughout their life journey and since many have difficulty having their voices heard, we must become good listeners, understand their message and respond. How does change provide the best of supports which do not diminish independence but increase it and keep it affordable? How do we offer new opportunities for residential and day supports with less money and keep the existing opportunities for the people who are happy? This dilemma has been ongoing and now is enormous due to the fiscal climate.

In Summary

A person's satisfaction is based on what they know. What they know is based on the number of positive and negative experiences they have had. How can a person say they want something different if they don't know it exists or know it is possible? People's experiences are affected by the breadth of the supports they receive whether from a parent, sibling, family member, staff, foster parent, friends or someone else in a person's life. If the people around us truly listen, foster respect and find ways to make things happen with, or without money, the quality of our lives is improved. It seems simple but our system has challenges in providing individual supports based on each person's dreams. Listen, figure it out and then do it. That is all it takes.

*I like the dreams of the future
better than the history of the past.
Patrick Henry*

This report was prepared by listening to people, their support agencies and families. Thank you to all who participated and we hope we have represented you well. We understand no data is perfect; however we did our best to gather the knowledge and insight from you and express what we heard.

Thank you to our QLI visitors Al Tomko, Connie Gomes & Deanne Gagne; the computer knowledge and steadfast work of Kerran Ascoli; the encouragement of Anne Frank and Ken Renaud; and to Doreen McConaghy, for her strength and in depth understanding and knowledge of what is and what can be.

-Barbara McCrae