

Learning to Listen: The Key to Supported Living

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"Supported Living is a simple concept which enables... a person with a developmental disability who requires long term, publicly funded, organised assistance to join with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own." (John O'Brien, 1993)

Supported living is a service, which provides as much support as a person needs, as often as they need it. It is one of the fastest growing services for persons with developmental disabilities. One important reason for this growth is that Supported Living Services are empowering people with disabilities and their families to make the decisions about what types and how much support is needed, and how those supports will be implemented. Self-determination and person-centered planning are the cornerstones of Supported Living Services.

For those of us who provide community living services, how can we ensure that we are truly listening to the people we support and their families? How can we avoid "placing" people, "assigning staff support," or assuming that we, as professionals, know what's best for people? How can we become better listeners?

Cheryl Mayfield offers us a glimpse into her transition to supported living: "When I lived in a facility, I didn't have a future's plan. I was told what I would be doing in the future. I didn't have a circle of support; I had a service coordinator, agency director, home manager and direct care staff. I didn't have a choice. I had a schedule. I was a job to some, a burden to some, and a friend to a few. I have discovered the power of my story and opinions.

Most people in my situation (people who have a lot of personal care and assistance needs and people with other developmental disabilities who require supports), often receive basic "custodial" care in large, segregated facilities. The quality of care, the degree of choice, ownership and self-determination is much less in a facility than it is when you live in your own home or apartment. People in facilities are in a 'program,' and are told what their needs are and what goals they should have.

I have lived in these situations in the past, but now live in my own home where I hire, supervise, train and schedule my own staff. I am in control of my life and have the resources I need to live the life I want. In order to help others to be able to realise their dreams, I spend time advocating for services, systems change and self-reliance. I support higher wages for people who assist me with daily living needs, as well as people who

assist with meeting my goals and helping me dream of the future. I support the rights of people who are limited by 'systems' to challenge the system. I hope to inspire administrators, staff, and people like me to reach for dreams and jump hurdles that are imposed by 'regulations'."

| MYTH | FACT |
|---|--|
| Only people who are "independent" can live in their own homes. | All needed support services can be provided to someone in their own homes and in the community. |
| People who need 24-hour care are not eligible | People can receive 24 hour care, 365 days a year, as needed, to be safe in their own homes |
| People with medical challenges can't receive necessary services and life supports in their own homes through Supported Living Services. | Even people with respirators and other intensive medical support needs can receive these necessary supports through Supported Living Services. |
| People who display problem behaviors won't be successful living in their own place. | It is generally easier and more successful to support individuals with behavior challenges to live in their own homes. Many behavioural issues actually arise because the person is living in a facility with other people with behavior |
| You will need to live with another person with a disability. | Regardless of whether or not you need 24 hour support, you should NOT be required to live with another person with a disability unless you want to. |

If you want or need to live with someone else (sometimes you can't afford the rent without sharing the cost with someone; or you may need someone available to support you 24 hours a day), you should be able to choose your roommate(s).

Some quality indicators of Supported Living Services are:

How support is provided:

On an individual basis.

Based on matching interests of support provider and the person receiving the support.

How staff is chosen:

By interviewing with the person.

By spending time with the person on multiple occasions so the person receiving support and the person he/she is hiring have opportunities to get to know each other.

The person receiving support communicates his/her preference of staff through typical communication or augmented communication which may include behaviors and affect.

How staff relates to people to whom they provide supports:

Similar interests

Develop trusting relationships over time

Sometimes friendships develop

How people being supported let staff (and others) know what they need:

Self-advocacy

By acting/behaving in certain ways (behavior IS communication)

Team communication and collaboration

Cheryl offers some helpful guidelines to support personnel when they first meet the person they may be supporting.

Talk directly to the person you will be supporting, rather than agency support staff or other third party.

Ask for safe and easy ways to support and/or assist each individual (especially in areas of lifting, preparing and eating meals, any adaptive tools or strategies, or specific learning style that is easiest for the person to understand). No question is a stupid question; don't be afraid or embarrassed to ask.

See what you and each person you interview with may have in common.

Support staff and the people they support should approach the relationship from a position of mutual respect.

Everyone is happier when all parties involved work together as a team!

Supported living services are generally funded by each state with funds that are used for other residential and community living services. Other generic community resources are also utilized to provide an umbrella of available resources. Discounts for phone, utilities, housing and other services are also available to persons with disabilities who rent or own their own homes.

Some of the best resources related to Supported Living Services can be found on the web at: Connections for Information and Resources on Community Living (CIRCL), <http://www.allenshea.com/CIRCL/CIRCL.html>

Cheryl Mayfield is the co-author of the children's book, "Way," a board member of Avenues Supported Living Services, and a recent homeowner.

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Quality Indicators in Community Living Supports

| WHAT WORKS | WHAT PROMOTES CHALLENGES |
|--|--|
| Having your own room | Sharing your room |
| You make the rules | "Facility" makes the rules |
| You hire and fire support staff | You have limited or no choice in selecting support staff |
| Circle or team meetings are based on your issues and needs | Schedule based on "group" needs |
| Having a variety of support staff | Staff meetings based on agency and/or group needs |
| Developing support strategies | Having the same staff be with you 40 hours/week |
| Hiring a new agency to support you in your home if services aren't working | Making a behaviour program |
| Developing services based on your unique needs | Moving to another facility if services aren't working |
| Getting connected to new people, hobbies, and community activities | "Fitting in" to a model or program |
| | Being alone and isolated |



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