

Introduction to Relationships

One of the four core values of LifeSPAN is *safety and security through relationships*. Relationships make our lives rich and meaningful. Relationships provide safety and security for the future.

Research indicates that an individual's health and safety is directly related to the number and quality of relationships in his/her life.

LifeSPAN facilitates the formation of relationships in the life of an individual with a developmental disability. We do this through the development of a **Personal Support Network**. Personal Support Networks have become the most powerful tool for creating a safe and secure future for our relatives with a disability.

What is a Personal Network?

A Personal Network is a group of committed men and women who are in a relationship with a person with a disability. This person could be isolated and vulnerable by reason of a disability, living arrangements, limited opportunities or society's perception.

A Personal Network is the bridge between living on the edge of community and active inclusion and participation in it.

A Personal Network welcomes and connects people to the heart of community.

Each member of the network voluntarily forms a relationship with the focus person and with every other member of the network. Through their relationship these individuals offer support, advocacy, monitoring and companionship.

LifeSPAN believes Personal Networks are the foundation of a future plan.

All of us have informal Personal Networks--people we count on and confide in, people who help us out. They are our friends, our colleagues, our acquaintances, and our relatives.

Unfortunately, many individuals with a disability don't experience the support provided by relationships. The historical care of individuals with developmental disabilities has severed their connections with citizens who would otherwise be in relationships with them. Our social attitudes and fears pertaining to developmental disabilities hinder our relatives even further.

In many cases, people with developmental disabilities require assistance to recruit and maintain a network of friends and supporters. Through the use of network facilitators LifeSPAN develops networks of support around an individual with developmental disabilities.

Where did the idea of Networks come from?

Judith Snow and Marsha Forest in Toronto, Ontario, developed the concept of personal support networks in 1980. A small group of people committed themselves to breaking down the barriers which prevented Judith from leading a full and active life in her community. At the time, Judith was living in an institution and on the brink of death. Judith requires a wheelchair and needs an attendant to assist her with all her physical needs.

This group of caring people became known as the **Joshua Committee**. They have supported Judith in dealing with bureaucrats, politicians, professionals and service providers. Meeting regularly, they have responded to obstacles in Judith's path from housing, employment, recreation, and medical care to marriage. Although Judith now travels the world as a philosopher, lecturer and author, the relationships formed in the Joshua Committee continue to exist.

Since then, networks have surfaced all over the United States and Canada. They are called by various names but they are all dedicated to the same aim--supporting people with a disability and assisting them to live an active, enriched, included life in the community.

Network Members

Who are Network members?

Personal Networks developed by LifeSPAN include anyone who cares for and expresses an interest in the person with developmental disabilities. This may include brothers and sisters, parents, extended family members, friends, neighbors, church members, co-workers, employers, and former caregivers.

LifeSPAN believes that friendships are based upon shared interests. In developing networks of support, LifeSPAN identifies the interests and passions of the focus person. LifeSPAN then invites people who share similar interests and passions to meet with the person for whom the network is being established. Out of this meeting, many individuals express a desire to make a commitment to the person who is the focus of the network.

Where do you find people to be in a Network?

First, we find out who is currently in a relationship with the family member for whom a network is to be established. Then, we look to the immediate and extended family as well as people who have been involved in the past. We invite family, friends, neighbors and people from every walk of life. We look for people who may have similar interests to the focus person--people who want to help them overcome challenges, realize goals and follow dreams. **The key is to ASK.**

What commitment do Network members make?

Network members make a commitment to assist the person for whom a network has been established to lead an enriched and meaningful life. The members of the network agree to work together to help the focus person realize his or her dreams and goals.

The commitment made by network members varies from person to person. It may be something as regular as “*I will call you every day*” to “*I’d like to invite you to dinner once a month.*” The nature and extent of commitment is as individual and varied as the people involved. For some, this will mean giving practical assistance with housing, employment and recreation. For others, it will mean developing closer ties to neighbors and the community.

Do Network members get paid?

The people who participate in Personal Networks are not paid monetarily. Rather their involvement in the network is based on caring, friendship and love for the focus person. People participate in a network because they get something out of it. The payment network members receive includes pleasure, joy, friendship and the opportunity to share their interests with another.

The only person who receives financial compensation is the network facilitator. The facilitator is hired on a contractual basis to develop and maintain the health of the network.

About Networks

How long do Networks continue?

Personal Networks continue for the lifetime of the individual for whom the network is developed. Its existence is especially crucial after the parents die. A network ensures that our LifeSPAN members with developmental disabilities continue to experience a life which is joyful, meaningful, safe, and secure even after their parents are gone.

What can Networks accomplish?

Personal Networks are able to accomplish many things--much more than was ever imagined when they were first established. Networks are rich, vital, and continually evolving. They pulse with their own life and have tremendous creative power. The following is a brief list of accomplishments from Networks that have been formed:

- Clarify eligibility for government programs by meeting with officials.
- Advise on expenditure of trust monies.
- Prevent abuse and neglect.
- Help the focus individual take on volunteer positions within the community.
- Permit family members to take holidays worry free.
- Help the focus individual find suitable housing.
- Enroll the focus individual in cultural, recreation and sports programs.
- Facilitate families who have drifted apart to reconnect with their relative.
- Celebrate birthdays and other festive occasions.
- Apply their ideas and connections in the community to the dreams and aspirations of the person with a disability.
- Find employment for the focus individual and arrange job supports.
- Share information, meals together and rides to important events.
- Monitor health and services.

- Act as legal representatives of focus person in making decisions pertaining to legal, medical, financial and personal matters.
- Share hobbies and other interests.
- Provide families with peace of mind.

What are the limitations of Networks?

Personal Networks cannot replace a family.

LifeSPAN believes families are the foundation of healthy Personal Networks. Without the active support and participation of family members, Personal Networks are more difficult to develop and maintain. Personal Networks are designed to augment family involvement, not replace family involvement in the life of the relative with developmental disabilities.

Personal Networks cannot replace the social service systems.

Personal Networks provide a bridge to the formal service systems by working cooperatively with professionals. They cannot be expected to replace the services provided by governments and professionals.

Personal Networks take time to see results.

Change does not happen overnight. It takes hard work and patience to experience the benefits of a Personal Support Network.

Who benefits from a Network?

Personal Support Networks benefit everyone involved:

- They assist the **individual** at the focus of the network to have a safer, more secure, and richer quality of life.
- They allow the **parents and family members** of the relative with a disability to have peace of mind.
- They provide opportunities for **community citizens** to participate in loving, reciprocal relationships where they come to know the individual in the focus of the network as more than “disabled”. They come to know the gifts and capacities of an individual who has been labeled “disabled”.

This experience changes the individual who is the focus of the network, and it changes every person in the network.

Our experiences at LifeSPAN have taught us that **no disability precludes meaningful relationship**. Everybody can be in a relationship, regardless of how “disabled” the individual might be. Everyone benefits through the personal relationships that are established.

Personal Networks have proven to be effective:

- For elderly parents who are wondering who will replace their continuous dedication to quality of life of their son or daughter with a disability.
- For parents seeking more active involvement by other children, aunts, uncles, or cousins in their child's life.
- For parents struggling with how to let go of their child with developmental disabilities.
- For a family whose relative is moving from an institution or from the family home to living within the community.

What happens if the Network fails?

LifeSPAN's goal is to maintain the network for the lifetime of the individual at the center of the network. When members leave the network it is the responsibility of the facilitator to invite new members into the network.

If for some reason a network collapses, LifeSPAN dedicates staff resources to renew the network. LifeSPAN provides the necessary support and resources until the network is once again healthy.

What does it cost to develop a Personal Network?

LifeSPAN charges an hourly fee to the Lifetime Member for the services of the facilitator. An average of 40 hours of facilitation is required over eight months to develop a network. Established networks average two hours of facilitation per month to maintain the network.

The time required to develop a network varies. Factors that influence the amount of time required to develop a network include the following:

- How easy it is to get to know the LifeSPAN member and their family.
- Connections that are already established.
- What the focus person currently does and wants to do.
- Changes in the focus person's circumstances.
- Amount of change among network members.
- How much involvement the focus person and family want the facilitator to have.

The fee LifeSPAN charges to families for network development represents only part of the actual cost of developing a network. The remaining costs are realized through fundraising, charitable donations and corporate partnerships.

It is LifeSPAN's future funding goal to have limited funding available to support the development of networks for individuals who have no family or whose family has modest income.

LifeSPAN utilizes a flexible payment schedule. Families can be invoiced monthly, pay by installment or arrange future payment through a clause in the will.

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