



Implementing the Principles of Participant-Direction into Everyday Lives



**The Statewide Advisory Council
November 14, 2008 Meeting**

What is Participant-Direction?

Participant-Direction means that a person:

- makes his or her own decisions
- plans his or her own future
- determines how money is spent for his or her supports
- takes responsibility for the decisions he or she makes

From *My Voice, My Choice*, A Manual for Self-Advocates

Principles of Participant-Direction

- ***Freedom***...to plan a real life
- ***Authority***...to control a given amount of resources
- ***Support***...for building a meaningful life in communities your choice
- ***Responsibility***...for wise use of public dollars and contribute to ones community
- ***Confirmation***...of the leadership role of self-advocates

Participant-Direction Differences From Current Way

- **Current Way:** Agency offers a set of services from those it operates
- **Participant-Direction:** Person and circle choose or build supports from any source

Participant – Direction: Differences From Current Way

- **Current Way:** Individualization is the effort to match the person's preferences with agency offerings.
- **Participant-Direction:** Individualization is tailoring supports to achieve the person's dreams.

Why Participant-Direction Can Be Hard?

- Trying to make good choices
- Realizing what funds you have and what things cost
- Being afraid of how others will react to your decisions
- Having the courage to say what you want
- Knowing when to ask for help
- Finding people to help you

From Consumer-Direction at a Glance, Access to Independence, Inc., 1999.



Making It Work!

Why is Self-Advocacy Important?



“What If...”

- ... you never got to make a mistake?
- ... you were never given a chance to do well at something because you were always working on something you couldn't do?
- ...the only risky thing you could do was to act out?
- ...you never got a chance?

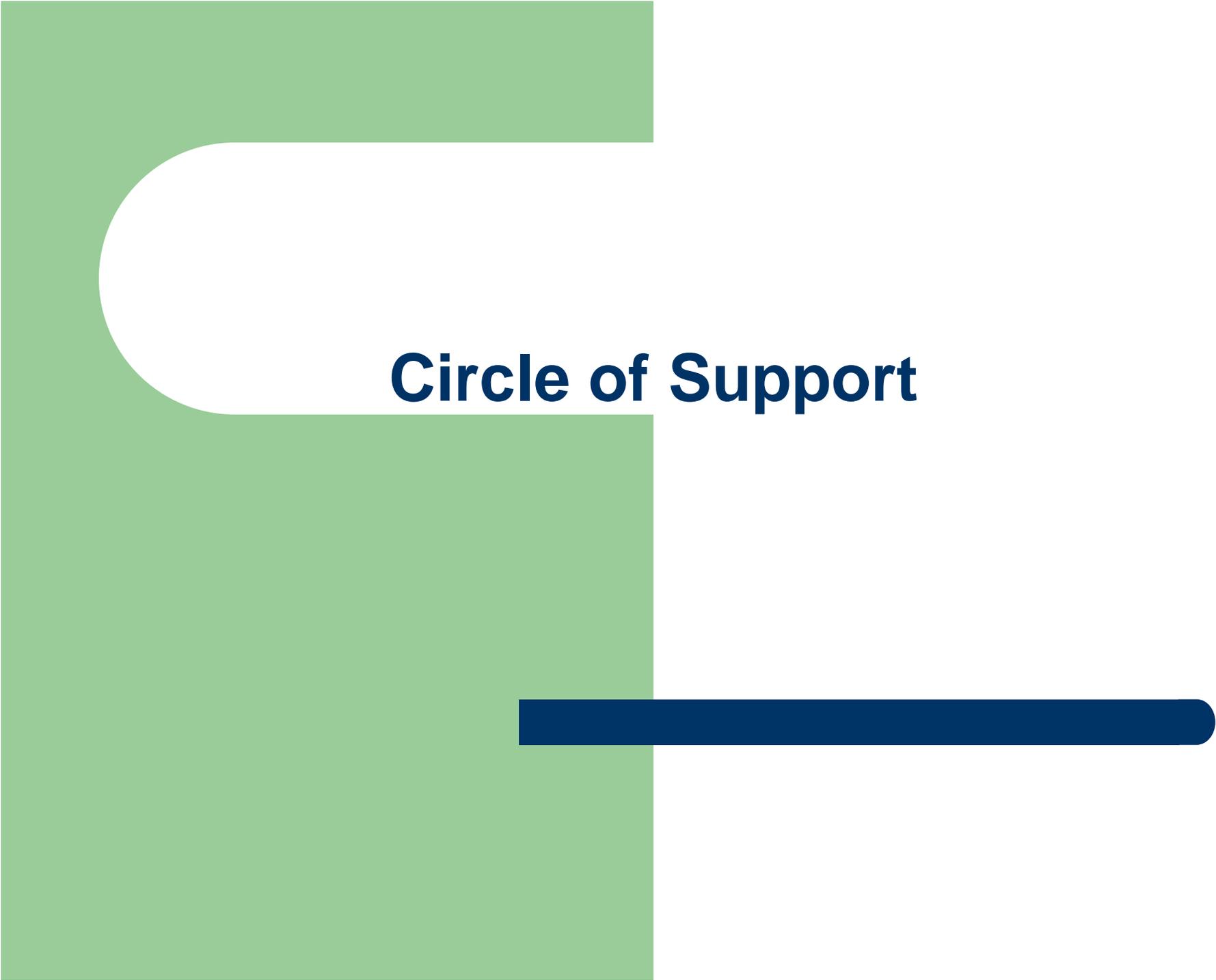
From the ARC of Iroquois County, Watseka, Illinois

What Is A Self-Advocate?

A Self-Advocate is ...

- A person who speaks up for himself or herself.
- Someone who speaks up and lets others know what he or she thinks

From *My Voice, My Choice*, a Manual for Self-Advocates



Circle of Support

What is a Circle of Support?

- Concept does not belong to any one person
- A group of people who agree to meet on a regular basis to help the person attain their hopes and dreams
- Paid people, non-paid people

Circles, Circles and Circles

1. Circle of **INTIMACY**
2. Circle of **FRIENDSHIP**
3. Circle of **PARTICIPATION**
4. Circle of **EXCHANGE**

Person Centered Planning Process

**“Person centered planning is not planning for someone.
Person centered planning is not planning with someone.
Person centered planning is assisting someone to plan for themselves.”**

Marty Gould

Key Elements of the PCP Process

- Is driven by the person and his/her preferences
- Establishes a vision based on strengths, capacities and preferences
- Is based on informal and formal knowledge and supports
- Requires collaborative teamwork
- Requires a commitment to action
- Uses a facilitator
- Is for everyone !!!

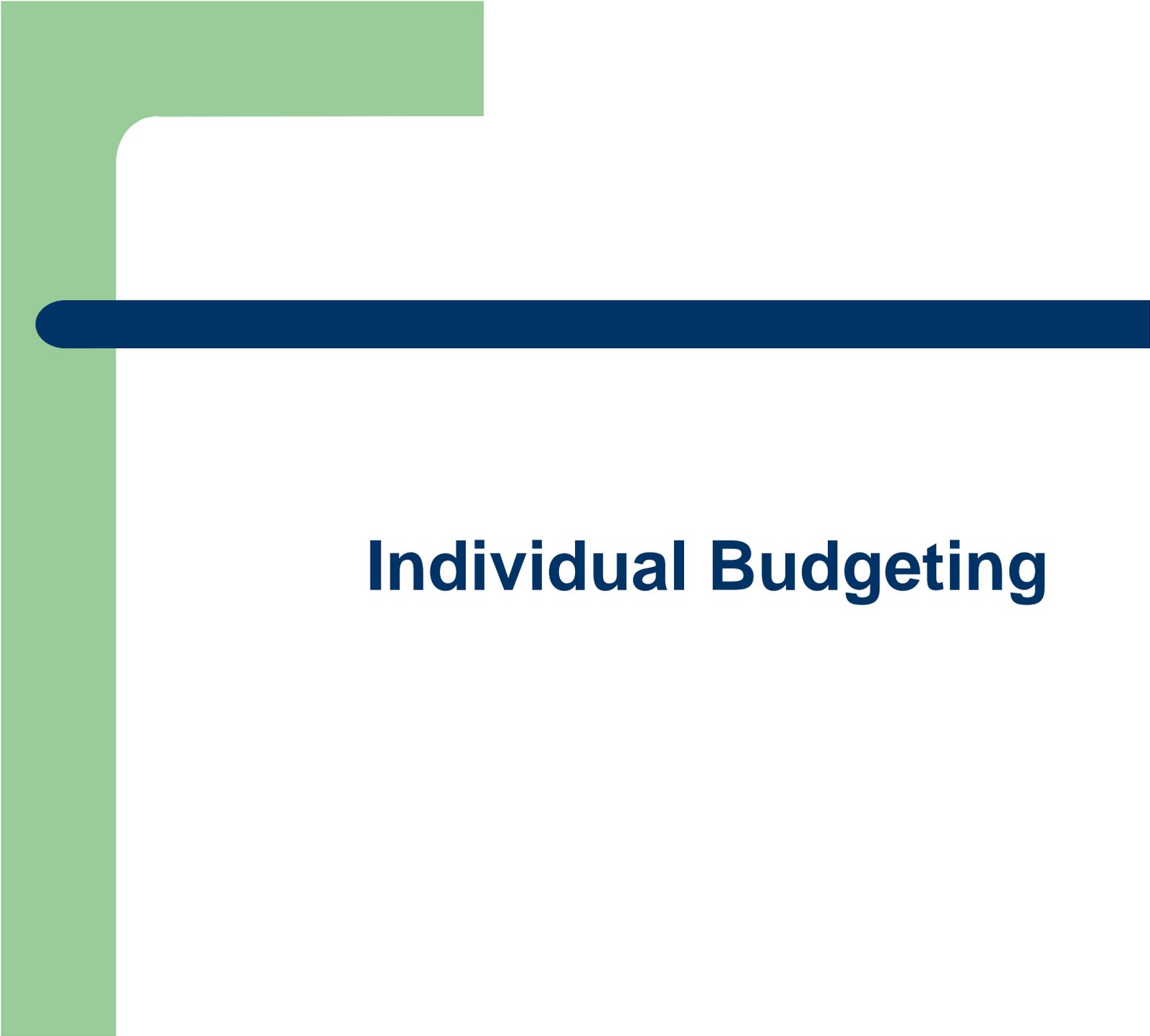
PCP and “Traditional Planning”

PCP:

- Individual directs form and focus of planning
- Emphasis on network building
- Not required, no formal product
- Accountability based on relationship
- Broad resource focus
- No boundaries

Natural/Informal Supports

- Foster interdependence
- Just because it is natural does not mean it is good
- Not cheaper, faster alternatives to traditional support strategies



Individual Budgeting

Individual Budget

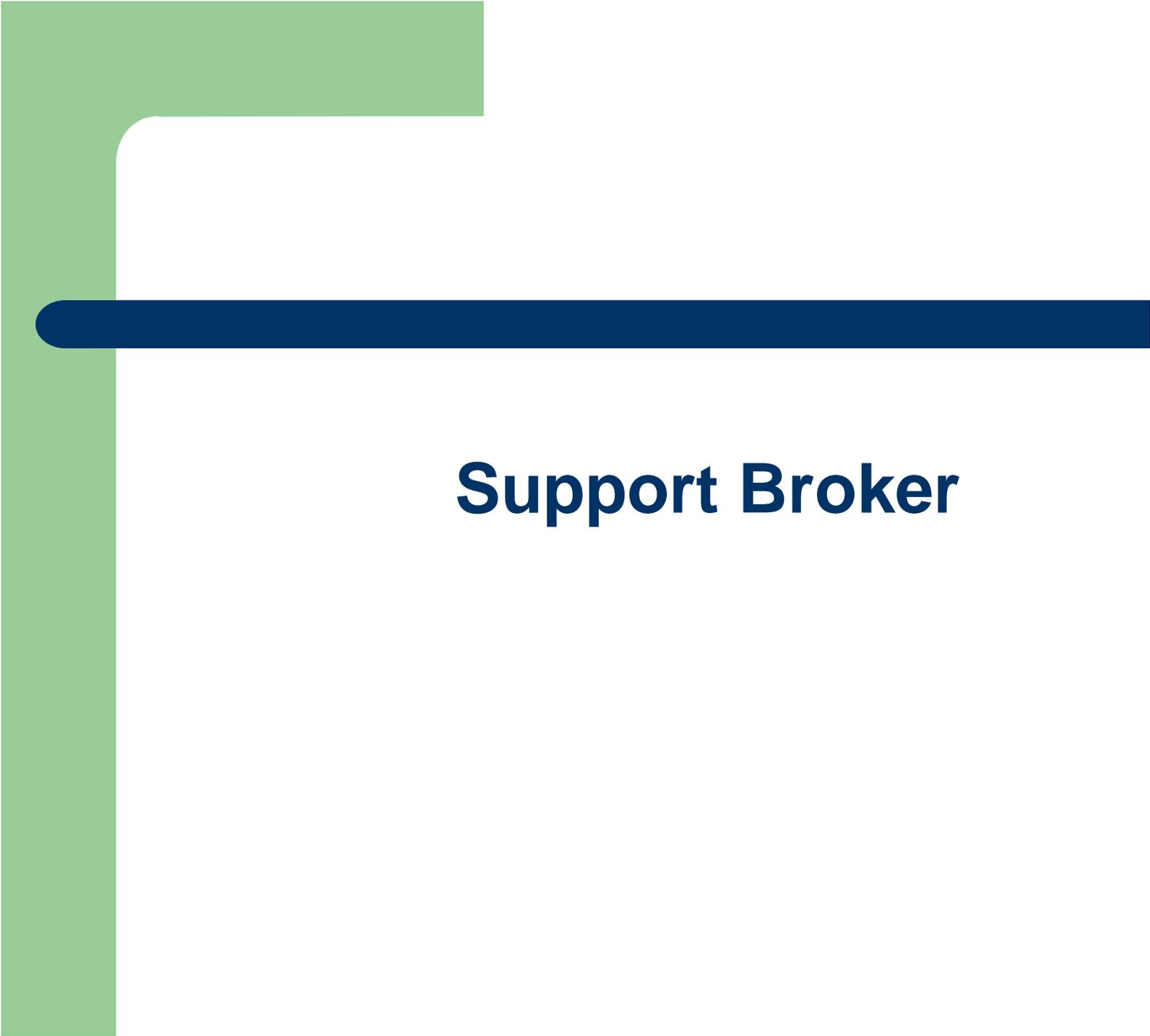
A mechanism that establishes an amount of funding for a participant to direct and manage the delivery of services s/he is authorized to receive. The intent is to have the individual control a specific amount of funds so the individual has the freedom and responsibility to purchase supports from a variety of sources.

Key Considerations

- Individual's personal resources
- Availability of natural/informal supports
- Basic health and safety needs
- Clinical needs of individual
- Support needs for activities of daily living
- Unique needs for the individual

Benefits

- People will purchase only what they need
- Offers the opportunity for people to purchase individually tailored supports, not total programs
- Increase community capacity
- Increase choice
- Better quality of life
- Greater fiscal accountability



Support Broker

What Does a Support Broker Do?

- helps people to plan, create and manage a network of services and supports;
- helps people to manage individual budget
- acts on behalf of the individual as his or her personal agent to arrange for needed services;
- helps define the needs and dreams of the person
- provides information on resources, and evaluates effectiveness of supports;
- A support broker should not provide services.



Skills Training

Skills Training for People who are Self-Directing

- Geared to people of different abilities
- What does individual budgeting mean
- Understanding all aspects in building and managing an individual budget
- Hiring and firing of staff
- Service monitoring



**Fiscal Intermediary/Fiscal Agent
(Financial Management Services)**

Fiscal Intermediary/ Fiscal Agent

An independent person or agency who helps individuals or families to manage the state or federally provided funds that they receive to pay for services and supports. The Fiscal Intermediary/Fiscal Agent manages the bookkeeping, payroll, taxes and cutting checks, as directed by the individual or family.

Fiscal Intermediary/Fiscal Agent

- Pays providers on behalf of participants in accordance with each participant's individual budget
- Serves as the agent for families and individuals who want to employ staff
- Ensures compliance with applicable laws and regulations (DOL, IRS, etc.)
- Ensures compliance with state agency requirements
- Provides financial monitoring and reporting
- Assists participants to implement their own choices, within available resources



Quality

**Satisfaction and,
Oversight**

Quality, Satisfaction and Oversight

- Person-centered planning
- Circle of support/relationships
- Support broker
- Real control over decisions
- Fiscal accountability
- Peer support from self-advocates
- Individual defines satisfaction
- Individually driven outcomes

Quality, Satisfaction and Oversight (continued)

- Persons with disabilities, families and loved ones know quality:
- They need to be empowered to purchase supports that meet their specific needs
- They need the opportunity to change if they are displeased

Implication For The Future

Roles are changing:

- People with disabilities
- Family members
- Support providers
- Government
- Community

Risk and Public Accountability