# *Self-Advocacy Self-Determination*

## *An Introduction and Overview*

# Self-Advocacy/Self-Determination (SA/SD)

- Introduction
  - required courses for MSCs
  - must stay whole time (3.5 hours or until class is over & released)
  - be sure to sign in

# Self-Advocacy/Self-Determination (SA/SD) – Purpose of Course

To introduce the philosophy of Self-Determination:

- Self-Determination provides people with developmental disabilities the opportunity, with the help of a "Circle of Support," to have:
  - The **freedom** to develop a personal life plan.
  - The **authority** to control a targeted amount of resources.
  - The **support** needed to obtain personal goals.
  - The **responsibility** for contributing to one's community and using public dollars wisely.

# Self-Advocacy/Self-Determination (SA/SD)

- Course Objectives:
  - To understand self-advocacy and self-determination
  - To understand implications of self-determination concepts & changing roles in the service system
  - To provide knowledge about role of service coordinator in SA/SD
  - To inform support staff working with individual interested in SA/SD

# OPWDD Mission Statement

We help people with developmental disabilities live richer lives.

# OPWDD Vision Statement

People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth and live in the home of their choice and fully participate in their communities.

# OPWDD Values

Describe how we as employees of OPWDD interact with the individuals we serve, families, staff, the community and each other:

**Compassion** - The capacity to appreciate what others think and feel.

**Dignity** - The recognition of the worth of each person and the treatment of individual rights and preferences with respect, honor and fairness.

**Diversity** - The celebration, respect and embracing of the differences among us because these differences strengthen and define us.

**Excellence** - The continual emphasis on innovation, increasing knowledge, and delivering the highest quality supports and services.

**Honesty** - The foundation on which trust is built and truth is communicated.

# Guiding Principles that Frame How OPWDD Conducts its Business:

- **Put the person first**

- **Maximize opportunities**

- **Promote and reward excellence**

- **Provide equity of access**

- **Nurture partnerships and collaborations**

- **Require accountability and responsibility**

# Self-Advocacy

## Meeting the Self-Advocate

# Self-Advocacy Association of New York State, Inc. (SANYS)

**SANYS Mission Statement:**

✓ **SANYS is an organization run by and for people with developmental disabilities.**

✓ **We help people with developmental disabilities speak-up for themselves and others.**

people *with*
DEVELOPMENTAL
DISABILITIES
SPEAKING UP
*for ourselves*
*& others*

*Self-Advocacy Association of New York State, Inc.*

# Self-Advocacy Association of New York State, Inc. (SANYS) Projects

**"A community's strength is measured by its ability to include the gifts and contributions of all of its members"**

- Grassroots regional organizing

- Teaching about self-advocacy

- Starting and supporting self-advocacy groups

- Sponsoring state and regional conferences and leadership activities

- Supporting SA Board of Director's system advocacy

# Self-Advocacy Association of New York State, Inc. (SANYS) Projects

- Self-Determination/CSS

- We Have Choices//Beyond Choices

- "Nothing About Us without Us"- member of numerous coalitions of groups working for system change

- Americorps - " Experienced, accomplished speakers sharing personal experiences of living with developmental disabilities" administered this project for 13 years

- For more information, visit http://sanys.org/

# Self-Advocacy in New York State



The grassroots of Self-Advocacy in NYS

Statewide Board

SA Regions

Self-advocacy Groups

Individual Self-advocates

# Definition of Self Advocacy

- "Self Advocacy by people with developmental disability means that individually or in groups (preferably both) they speak or act on behalf of themselves, or on behalf of issues that affect people with developmental disabilities"

# Video:

- "Self-Advocacy: Freedom, Equality, Justice for All"

and/or

- "We Have Choices" – (10 minute version & full length version available on-line at [http://sanys.org/news/?page_id=50](http://sanys.org/news/?page_id=50) )

# Benefits of Self-Advocacy

1. Increases knowledge of self-advocacy
2. Develops self-identity and pride
3. Builds competence, changes images
4. Impacts on quality of human services
5. Increases knowledge of rights and responsibilities
6. Promotes the ability to ask for help when needed

# What is Self-Determination?



- a concept reflecting the belief that all individuals have the right to direct their own lives

- Self-determination "encompasses concepts such as free will, civil and human rights, freedom of choice, independence, personal agency, self-direction, and individual responsibility" (University of Illinois at Chicago National Research & Training Center, 2002)

# Principles of Self-Determination

- Freedom

- Authority

- Support

- Responsibility

- Confirmation

- Self Advocacy

# Personal Outcomes

- Good health or physical well being

- Adequate income, housing and transportation

- Community involvement

- Valued relationships

- Opportunities for education, employment and leisure

- Control of the physical environment

- Opportunities for decision making

# Elements of Self-Determination:

- The Person
- Service Coordinator
- The Circle of Support
- Person Centered Plan
- Broker (Start-up & Support)
- Money
- Choosing Supports and Services (developing the plan)
- Individual Budget
- Financial Management Services (FMS)
- Quality, Satisfaction and Oversight
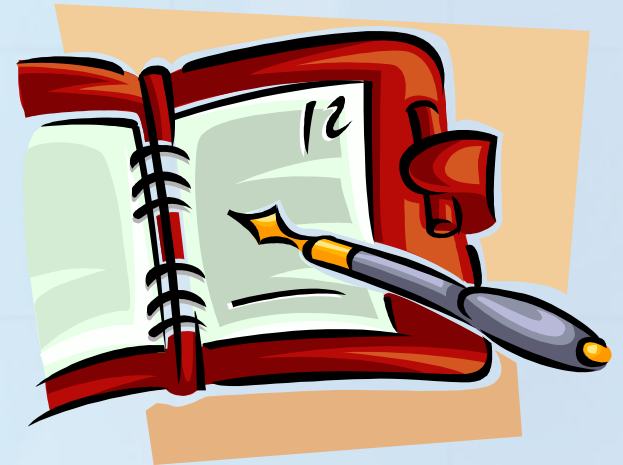
# The Person:

- ***Everything begins and ends        with the person!***
    - *"Nothing about us without us!"*
    - *Person chooses Circle of Support (COS) members*

# Service Coordinator

- Key to success in self-determination

- Medicaid Service Coordination (MSC) –

  – required service for Consolidated Supports and Services (CSS) participants

- Responsibilities of the MSC:

  – Develop, implement and monitor the ISP

  – Advocacy

  – Documentation

# Circle Of Support (COS)

- The PERSON as decision-maker

- Roles and expectations of circle members

- Balancing the circle

- Key to safeguards

- COS is required for CSS participants

- Legal Guardian must be included in the COS

# The Person Centered Plan - Planning with the Person Using Self-Determination

- Process is person-driven

- Start from the person's hopes and dreams and vision for the future

- Build in safeguards

- PRODUCTS:

  1. Individual's Personal Centered Plan

  2. Identification of person's preferred way to access needed supports and services

  3. Development of ISP & service plan (CSS Plan)

# Three Types of CSS Plans

1. Residential Only
   - Focused on development and support of skills associated with living in the community
   - Includes any ISS/FSS type services

2. Other Than Residential
   - Focused on development and support of skills associated with participating in meaningful activities in the community, volunteering, and employment

3. BOTH
   - Includes all services except e-mods/adaptive equipment and Intensive Behavioral Services

# Start-Up Broker (SUB)

may assist person with:

- Circle development and maintenance
- Person Centered Planning
- Defining service and support needs and interests
- Planning for health and safety
- Planning for quality and satisfaction

- Developing individualized services plan and budget
- Brokering individual support agreements
- Working with generic community resources
- Assisting with hiring and firing support staff

# Support Broker (SB)

- Separate and distinct from service coordination

- Primary responsibility - to keep CSS Plan/Budget current

- Person may also hire broker with specific expertise

- Broker role clearly defined & result oriented:
    - Tasks & responsibilities spelled out in broker agreement
    - Salary & number of hours spelled out in broker agreement

# Support Broker (SB)

**Assists person with:**

- Reviewing, revising and updating CSS Plan

**May also assist with:**

- Circle maintenance
- Updating Person Centered Plan
- Updating service and support needs and interests
- Completing and submitting required service documentation

- Monitoring CSS expenditures
- Ongoing planning for health and safety
- Ongoing planning for quality and satisfaction
- Brokering individual staff support agreements
- Assisting with hiring and firing support staff
- Working with generic community resources

# Service Coordinator, Support Broker...What's the difference ?

- Employer

- Qualifications

- Experience

- Training

- Supervision

- Duties

- Cost

- Regulations

# Money

- "Money Follows the Person!" – funding IS individual and portable

- Money is for supports and services, *NOT* for personal spending

- Financing for individual budgets based on PRA

# **Choosing Supports and Services**

- First step in developing the plan is choosing supports and services
  - based on information gathered in Person Centered Planning process
- Funding is limited – person may have to make choices
- Services and supports requested must be reasonable and fiscally prudent - participant and COS are responsible for appropriate expenditure of approved budget

# Individual Budget

- Money is for supports and services, *__NOT__* for personal spending:

    – Participant and COS should be responsible and only ask for services that are NEEDED

    – If needs change, participant is responsible for amending plan to reflect change

    – "Prudent buyer" techniques should apply

- Personal income & entitlements/benefits may be considered

    – If supports other than waiver services are requested

# Budget Breakdown –
## Traditional Services vs. Individualized Services



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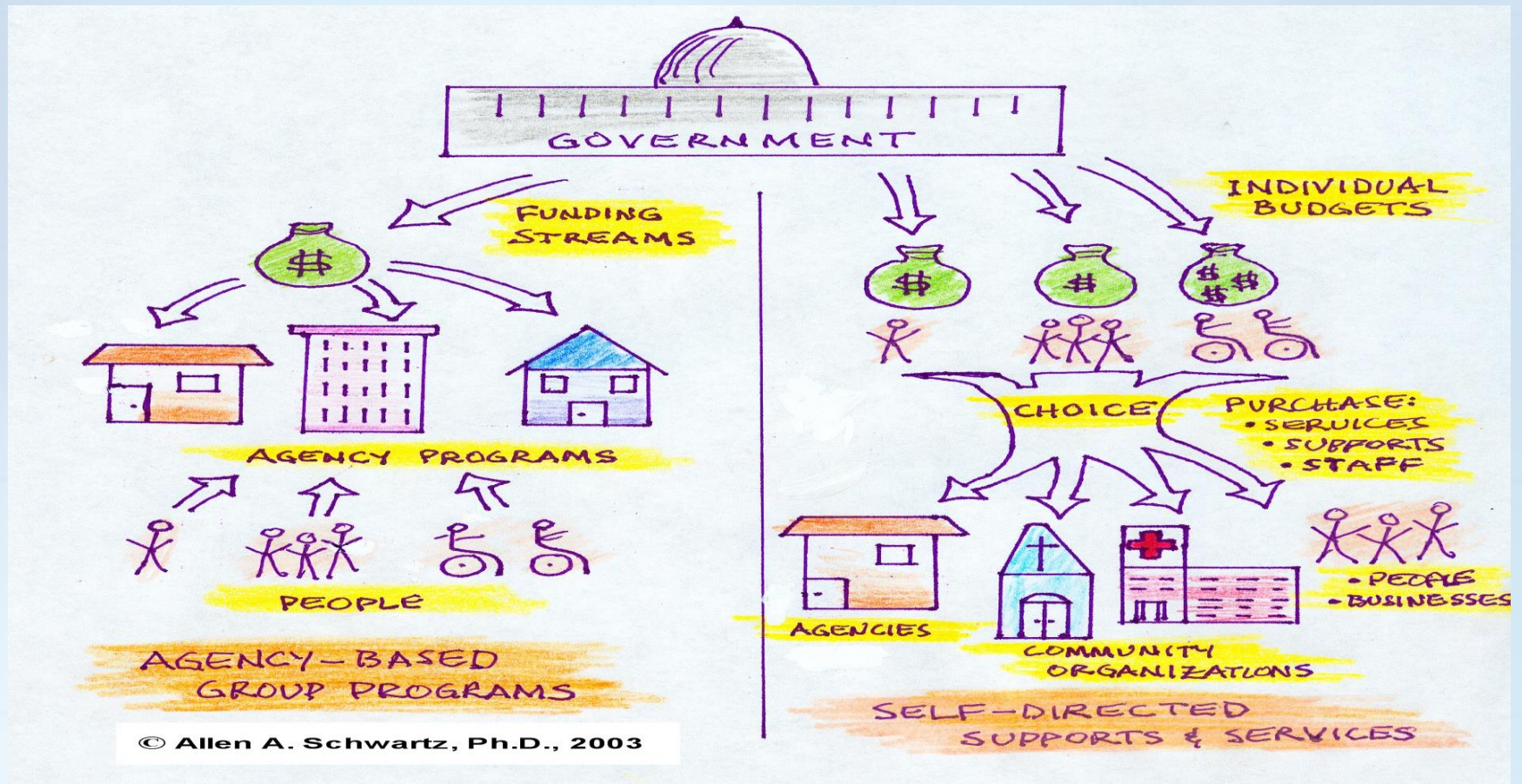
# Financial Management Services Agency (FMS)

- Two main functions:
  - Handles fiscal functions:
    - bills service & pays approved budget expenses,
    - fiscal accounting & reporting,
    - maintains Medicaid documentation& compliance
  - Handles human resources functions for self-directed staff

# Financial Management Services Agency (FMS)

- In NYS, FMS is a <u>not-for-profit agency</u>

  – Must have a Provider Agreement with OPWDD and Department of Labor

  – Must be approved to provide "CSS" (HCBS waiver service)

# Quality, Satisfaction & Oversight

- Quality begins with the person and his/her CIRCLE

- Focus on personal satisfaction

- Emphasis on health and safety

- Existing policies/regulations apply

- *Everyone has a role to play in quality*

# Quality Process for NYS

- Quality and Safeguarding Committee
- "Safeguards" section of CSS Plan/Budget
- ISPs & Monthly MSC Notes
- CSS Monthly Summary Notes
- **MSC Survey Protocol**

# Implications for the Future:

- **Roles are changing for:**
  - ⇨ **Individuals**
  - ⇨ **Circles Of Support**
  - ⇨ **FMS Agencies**
  - ⇨ **Brokers**
  - ⇨ **OPWDD**
  - ⇨ **Other Agencies**