

## **Request for Bids #2023-SA-9100**

### **Title: Partners in Policymaking Curriculum Project**

This is a request for bids to develop a Partners in Policymaking (PIP) curriculum and associated activity materials for a target audience of people with cognitive disabilities, requiring supports based on moderate-to-severe functional levels, at a Grade 2 to 3 reading level or below. The curriculum and associated activity materials will be developed to run in conjunction with and parallel to the current existing Florida Partners in Policymaking program with the goal of supporting more participants with intellectual and developmental disabilities (I/DD), and specifically cognitive disabilities, to be integrated into this program.

Development of this curriculum (i.e., scope and sequence) and its associated activity materials will be based upon the PIP Core Competencies as well as the Minnesota Governor's Council on Developmental Disabilities' PIP curriculum and follow the sequencing of the existing six-session Florida PIP program. The PIP Core Competencies are included as Appendix A within this bid request; the existing Florida PIP program schedule is included as Appendix B within this bid request; and the Minnesota Governor's Council on Developmental Disabilities' PIP curriculum highlights are included as Appendix C in this bid request. Passive, virtual observation of the 2023-2024 existing Florida PIP six training sessions is required and materials associated with this existing Florida PIP training will be provided to the winning bidder. This requirement would be waived if the winning bidder has already participated in and successfully completed the Florida PIP program.

The curriculum and associated activities will be structured in a six-session format with elements to support integration into the existing Florida PIP training through pre-class preparation, in-class participation, and after-class homework and follow-up. The six-session format is delivered through 2 days of content per month for 6 months. Special consideration must be paid to how the PIP Core Competencies will be taught to an audience requiring supports based on moderate-to-severe functional levels, at a Grade 2 to 3 reading level or below. The curriculum and associated activities must support participants with cognitive developmental disabilities to take what they have learned from the curriculum and apply it through their leadership and advocacy engagement. Curriculum and associated activity design should be structured to also provide for breakout needs from the larger Florida PIP class, based on the audience, to best assure maximum accessibility and full understanding of the material. Appendix B depicts likely breakout curriculum and activity needs based on the existing Florida PIP schedule.

It is currently anticipated that there will be subsequent years of work on this project, with development of this curriculum and associated activity materials being followed by translation of all materials into Easy Read formats and the development of a Leader Training Guide, as well as curriculum piloting and revisions. Included in this request for bids is information relating only to the Scope of Work for the first segment of this project (i.e., 17 months of work focused on development of curriculum and associated activity materials) and bid information to be submitted.

**Date of Release:** February 15, 2023

**Due Date: Electronic bids will be accepted until 4:00 pm ET on Monday, March 27, 2023.**

All submissions must be marked with Request for Bids #2023-SA-9100. Please allow enough time to upload your bid into the FDDC's Dropbox. Depending upon the size of the bid, it may take additional time to upload. Any bids received after the date and time set forth above will be considered unresponsive and will not be considered by FDDC.

Bids shall be electronically submitted via FDDC's Dropbox at <https://www.dropbox.com/request/UR9ruUgnbf5Qfmq8dLMU>

**Contact:** Questions regarding the requirements of the Request for Bids for the Partners in Policymaking Curriculum project may be emailed to [proposal@fddc.org](mailto:proposal@fddc.org) and must be received by 4:00 pm ET on Wednesday, March 1, 2023.

**QUESTIONS ARE TO BE SUBMITTED IN WRITTEN FORMAT ONLY. THIS IS A LEGAL PROCESS AND WE CANNOT ANSWER QUESTIONS VERBALLY.**

**Answers to the questions received will be posted on the Council's website ([www.fddc.org](http://www.fddc.org)) by Monday, March 6, 2023, at 4:00 pm ET.**

**Bid results will be posted on the FDDC website on April 5, 2023.**

**Protest Period:** Any bidder who desires to protest either the content of this bid or the proposed ranking must do so in writing to Christina DeMeo at [proposal@fddc.org](mailto:proposal@fddc.org) within the 72-hour protest period. FDDC Protest Procedures will be made available upon written request. The protest period is within 72 hours of the posting of the Request for Bids or the posting of the selected bidder.

**Cone of Silence:** For purposes of this solicitation, FDDC has established a solicitation silence policy (Cone of Silence) that prohibits oral and written communication regarding all formal solicitations for goods or services (formal proposals, Request for Proposals, Invitation for Proposals, Request for Bids) issued by the FDDC with the exception of the formal written questions that may be submitted as described above. The period commences from the date of advertisement until award of contract.

**Applicable Laws and Regulations:** All applicable Federal and State laws, county and municipal ordinances, orders, rules and regulations of all authorities having jurisdiction over the services to be provided shall apply to the bid/proposal throughout, and they will be deemed to be included in the contract the same as though they were written in full therein.

**Funds Available:** The Florida Developmental Disabilities Council, Inc. (FDDC) has set aside a maximum of **\$225,000** federal funds for a period not to exceed 17 months for fiscal support of this bid request. The award will remain firm for the contract period unless addendums to the scope of work are required by the funder.

**Funding Source:** 100% federal funds, CFDA #93.630 from the U.S. Department of Health & Human Services, Administration on Intellectual and Developmental Disabilities, through FDDC.

**Ineligible Entities:** Federal regulations limit and restrict the ability of individuals or entities debarred or suspended by a Federal Agency from doing business with, or contracting for the use of federal funds with, the Council. See 29 CFR, Part 98; 45 CFR, Part 76.

## **Background**

### **A. Statement of Need**

The Florida Developmental Disabilities Council (FDDC) received public input in 2021, during its last State 5-Year Plan development process, that there was a need for the development of a Partners in Policymaking curriculum strand specifically for individuals with I/DD. Sixty-five percent (92 respondents) of those surveyed rated PIP, including developing a Partners in Policymaking curriculum strand specifically for individuals with I/DD, as “strongly agree” in terms of their agreement that this was a need; 32.6% (46 respondents) of those surveyed rated it as “agree” regarding it being a need. Overall, 138 respondents detailed strongly agreeing or agreeing that this was a need, comprising 97.6% of all respondents surveyed. Survey respondent comments included input related to this type of curriculum strand best assuring inclusivity; increasing the ability to listen to self-advocates more directly; as well as updating, refining, and improving the PIP program model. Due to this identified need within the Comprehensive Review and Analysis section of the FDDC 5-Year State Plan, FDDC’s Self-Advocacy and Leadership Goal included an activity focused on enhancing the capacity of the Partners in Policymaking (PIP) to include more self-advocates with significant disabilities in the PIP program through development of an additional curriculum strand.

### **Background on the Issue:**

Since 1987, Partners in Policymaking (Partners or PIP) programs have been implemented throughout the United States and internationally. Florida’s Partners in Policymaking program was modeled after the Minnesota Governor’s Council on Developmental Disabilities’ PIP program. More than 27,000 Partners graduates in the United States and internationally are part of a growing worldwide network of community leaders serving on policymaking committees; commissions; and boards at local, state, and national levels. Partners is an innovative, competency-based leadership training program for adults with disabilities and parents of children and young adults with developmental disabilities. The purpose of the program is two-fold: 1) to teach best practices, and 2) to teach the competencies needed to influence public policy.

Over the course of Florida’s implementation of this PIP program within the state, there have been far less self-advocate participants than family member participants. Typically, no more than five self-advocates are trained per year through PIP, often less (i.e., 2-3 annually). This is compared with traditionally 20-30 family member PIP participants annually. Self-advocates with more significant cognitive disabilities have not been highly

represented within past PIP program alumni, as PIP self-advocate graduates have typically had fewer support needs and higher reading levels.

Resources to obtain more information on this program include:

- Appendix A which provides the Partners in Policymaking Core Competencies,
- Appendix B which provides the Florida PIP program schedule, and
- Appendix C which provides the Minnesota Developmental Disabilities Council’s PIP curriculum highlights. These highlights can also be viewed at: <https://mn.gov/mnddc/pipm/curriculum.html>.
- The Partners in Policymaking Coordinators Guide can be viewed at: [https://mn.gov/mnddc/pipm/pdf/Partners\\_Coord\\_Handbook2016.pdf](https://mn.gov/mnddc/pipm/pdf/Partners_Coord_Handbook2016.pdf).
- The Minnesota Governor’s Council on Developmental Disabilities’ Partners in Policymaking main website can be viewed at: <https://mn.gov/mnddc/pipm/>.
- The Minnesota Governor’s Council on Developmental Disabilities’ Partners in Policymaking Online Curriculum can be viewed at: <https://partnersonlinecourses.com/>.

## **B. Project Description**

This project’s focus is to develop a Partners in Policymaking (PIP) curriculum and associated activity materials for a target audience of people with cognitive developmental disabilities, requiring supports based on moderate-to-severe functional levels, at a Grade 2-3 reading level or below. The curriculum and associated activity materials will be developed to run in conjunction with and parallel to the current existing Florida Partners in Policymaking program with the goal of supporting more participants with I/DD, specifically people with cognitive disabilities, to be integrated into this program. Development of this curriculum and its associated activity materials will be based upon the PIP Core Competencies as well as the Minnesota Governor’s Council on Developmental Disabilities’ PIP curriculum and follow the six-session sequencing of the existing Florida PIP program.

## **Scope of Work to Be Provided**

1. Appoint an advisory committee that will minimally include two people with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, two family members of people with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, two special educators who serve students with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, and one speech-language pathologist and/or professional with an expert literacy background relating to people with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below.
  - a. Select advisory committee members with input from FDDC staff. (May 1, 2023-June 2, 2023)
  - b. Hold virtual advisory committee meetings at least once each deliverable period. (May 1, 2023-September 30, 2024)
  - c. Develop meeting minutes and document input from advisory committee members. (May 1, 2023-September 30, 2024)

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- d. Submit minutes of advisory committee meetings with each deliverable. (July 3, 2023; September 29, 2023; January 2, 2024; April 1, 2024, July 1, 2024; September 30, 2024)
2. Develop a draft curriculum strand and associated activity materials which would serve a target audience of people with cognitive disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below.
  - a. Review the PIP Core Competencies (Appendix A) and associated materials (to be provided to the winning bidder by FDDC), the Florida Partners in Policymaking six-session schedule (Appendix B), as well as the Minnesota Governor’s Council on Developmental Disabilities’ Partners in Policymaking curriculum (Appendix C). (May 1, 2023-July 3, 2023)
  - b. Provide a detailed outline of the curriculum for sessions 1-6. (May 1, 2023-July 3, 2023)
  - c. Participate virtually as a passive observer in the 2023-2024 Florida PIP Program via Zoom or provide documentation of past successful completion of the Florida PIP program. Appendix B includes a general schedule for these 6-sessions. (September 2023-February 2024)
  - d. Prepare initial draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP sessions 1-2, engaging in PIP sessions 1-2, and completing follow-up homework after PIP sessions 1-2. (July 3, 2023-September 29, 2023)
  - e. Prepare initial draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP sessions 3-4, engaging in PIP sessions 3-4, and completing follow-up homework after PIP sessions 3-4. (September 29, 2023-January 2, 2024)
  - f. Prepare initial draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP sessions 5-6, engaging in PIP sessions 5-6, and completing follow-up homework after PIP sessions 5-6. (January 2, 2024-April 1, 2024)
3. Revise the draft curriculum and associated activity materials consistent with FDDC staff input received.
  - a. Submit the revised draft curriculum and associated activity materials incorporating FDDC staff input for PIP Sessions 1-2. (November 15, 2023)
  - b. Submit the revised draft curriculum and associated activity materials incorporating FDDC staff input for PIP Sessions 3-4. (February 15, 2024)
  - c. Submit the revised draft curriculum and associated activity materials incorporating FDDC staff input for PIP Sessions 5-6. (May 15, 2024)
4. Conduct structured interviews with minimally two people with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, two family members of people with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, two special educators who serve students with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, and one speech-language pathologist and/or professional with an expert literacy background

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relating to people with moderate-to-severe cognitive developmental disabilities who are at a Grade 2-3 reading level or below, to obtain input on the curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP sessions 1-6, engaging in PIP sessions 1-6, and completing follow-up homework after PIP sessions 1-6. Structured interviews would begin following integration of all FDDC staff revisions and with FDDC staff approval and after sufficient time has been allowed for curriculum review by these seven identified individuals. Structured interview participants may include the same individuals identified as advisory committee members, but the seven structured interview participants are not required to be the same individuals. For those completing structured interviews, their time reviewing the curriculum itself in preparation for the structured interviews could be paid on a consultant basis. Structured interviews should be conducted individually for all seven required participants. (January 2, 2024-September 30, 2024)

- a. Conduct structured interviews with each of the seven individuals identified based on the criteria identified above to obtain input on draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP Sessions 1-2, engaging in PIP sessions 1-2, and completing follow-up homework after PIP Sessions 1-2. (January 2, 2024)
  - b. Conduct structured interviews with each of the seven individuals identified based on the criteria identified above to obtain input on draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP Sessions 3-4, engaging in PIP Sessions 3-4, and completing follow-up homework after PIP sessions 3-4 which incorporate all FDDC staff directed revisions. (April 1, 2024)
  - c. Conduct structured interviews with each of the seven individuals identified based on the criteria identified above to obtain input on draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for PIP sessions 5-6, engaging in PIP Sessions 5-6, and completing follow-up homework after PIP Sessions 5-6 which incorporate all FDDC staff directed revisions. (July 1, 2024)
  - d. Incorporate structured interview input, in close collaboration with FDDC staff, into draft curriculum and associated activity materials which would support someone with cognitive disabilities in preparing for each of the 6 PIP sessions, engaging in each of the 6 PIP sessions, and completing follow-up homework after each of the 6 PIP sessions. (January 2, 2024-September 30, 2024)
5. Participate in curriculum evaluation activities designed by the Council's evaluation consultant and any related curriculum evaluation activities conducted by Council staff. (January 2, 2024-September 30, 2024)
    - a. Provide an analysis report relating to the curriculum evaluation activities. (September 30, 2024)
  6. Submit final curriculum and all associated activity materials in an editable format, inclusive of all FDDC staff revisions and agreed upon revisions arising from structured interviews. (September 30, 2024)

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7. Fulfill Council programmatic requirements.
  - a. Complete and submit an updated work plan. (July 3, 2023; September 29, 2023; January 2, 2024; April 1, 2024, July 1, 2024; September 30, 2024)
  - b. Participate in a mid-term review of the project. (No later than January 15, 2024)
  - c. Complete and submit an Executive Summary with the final deliverable that provides all components set forth in the contract (e.g., overview of major activities, outputs, outcomes, summary and analysis of data, recommendations for future action). (September 30, 2024)

### Timeline

The timeline for the work for the Partners in Policymaking Curriculum project is May 1, 2023, through September 30, 2024.

### Bid Submission Instructions

Interested individuals must submit the following Bid Information by 4:00 pm ET on Monday, March 27, 2023:

- **The bid must include the following:**
  - A signed Letter of Transmittal confirming that you understand the Scope of Work required; confirming that you will be able to perform all the work specified in the Scope of Work within the specified timeframe; and providing your name, the name of your organization (if applicable), your address, phone number, email address, SAM Unique Entity ID (if available), and SAM.GOV registration status including expiration date or date registration was submitted.
  - A completed Budget Request Form, which must include the requested FDDC budget funds, including FTE and/or hourly rate information for all personnel and/or consultants.
  - A narrative description of your experience in the development of educational resources (e.g., curriculum, training toolkits) for people with cognitive disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below. Experience must include direct experience working with this population. Include information about the personnel and/or consultants who will be engaged in implementing all facets of the Partners in Policymaking Curriculum project.
  - A completed Partners in Policymaking Curriculum Bid Work Plan Template to include Person(s) Responsible and Bidder's Qualifications to Deliver Planned Scope of Work and Services.
  - A sample of a product (e.g., curriculum, training toolkit) you have developed for people with cognitive disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below.

### Bid Selection

The lowest and most responsive bid will be selected contingent upon a Letter of Transmittal confirming that the bidder can (1) perform all the work outlined in the Scope of Work within the specified time frame, and (2) demonstrate responsiveness in meeting the minimum requirements described within this bid request as indicated through the narrative description; Partners in Policymaking Curriculum Bid Work Plan Template; and sample of a product (e.g., curriculum,

training toolkit) you have developed for people with cognitive disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below. The Council reserves the right to select the next lowest bid if the lowest bid is not found responsive in meeting the minimum requirements. The FDDC reserves the right to reject any or all bids. Verification of mandatory terms and conditions must be met prior to contract execution. No work shall begin until a contract is executed by the FDDC.

**Minimum Requirements to Determine Responsiveness**

- **Budget narrative:** Sufficiently supports FDDC funds.
- **Collaboration with a diverse population of community members:** Identifies experience in collaborating with and facilitating diverse community member groups to minimally include people with cognitive developmental disabilities, family members, and professionals who support them.
- **Curriculum development experience for project’s target population:** Identifies experience in developing educational resources (e.g., curriculum, training toolkits) for people with cognitive developmental disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below.
- **Organizational capacity:** Identifies sufficient and qualified staff and resources to fulfill the Scope of Work as prescribed in the work plan and/or narrative. Experience must include direct experience working with people with cognitive developmental disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below.
- **Product review:** Product submitted is professionally written; provides lessons, activities, and/or training materials that would be understandable and meaningful for the targeted population (i.e., people with cognitive disabilities, requiring support at moderate-to-severe functional levels, at a Grade 2-3 reading level or below); and contains a clearly defined outline, objectives, and/or competencies.



## Appendix A

### Minnesota Governor’s Council on Developmental Disabilities’ Partners in Policymaking Core Competencies:

- Describe the history of services for, and perceptions of, people with developmental disabilities.
- Describe significant contributions of the parents' movement.
- Describe the history of the self-advocacy and independent living movements.
- Describe the benefits and values of a quality, inclusive education for students with and without disabilities.
- Outline specific strategies to achieve a quality, inclusive education.
- Demonstrate knowledge of the service coordination system and what services may be available.
- Describe the importance of futures-planning and self-direction for people with developmental disabilities.
- Understand the principles of choice and control of resources in futures-planning.
- Understand the reasons for and the importance of proper positioning techniques for people with physical disabilities.
- Describe examples of state-of-the-art technologies for people with significant disabilities.
- Describe the importance of supported, competitive employment opportunities.
- Understand that a flexible, responsive system of supports for the families of children with disabilities is the cornerstone for a true system of community supports for people with developmental disabilities.
- Understand the need for all individuals to experience changes in lifestyle across the lifespan.
- Know/understand the importance of home ownership/control as one of the defining characteristics of adult life in our culture.
- Understand the basic principles and strategies being used to support people with developmental disabilities in their own homes across the lifespan.
- Create a vision for the year 2024 (and beyond) for people with disabilities.
- Understand how a bill becomes a law at the state and federal levels.
- Identify critical federal issues and the process by which participants can personally address their concerns.
- Demonstrate successful techniques for advocating for services to meet the needs of unserved and underserved individuals.

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- Draft and deliver testimony for legislative hearings.
- Learn how to meet a public official and discuss issues.
- Identify strategies for beginning and sustaining grassroots-level organizing.
- Understand the role of when and how to use the media to effectively promote issues.
- Demonstrate proper procedures for conducting a meeting.
- Gain a basic understanding of parliamentary procedure and serving on boards.

## Appendix B

### Florida PIP Annual Six-Session Schedule:

- Session 1: September instruction focuses on Program Orientation, History of PIP, Disability Movements, Perceptions, People First Language, Philosophy of Inclusion, and a Walk Down Memory Lane.
  - Day 1: Friday from 12:30 p.m. to 8:00 p.m.
    - Introduction to PIP – Getting to Know One Another & Getting the Most Out of Partners
    - Florida Developmental Disabilities Council presentation
    - Vision Board Creation and Sharing
    - Voice from a Partners Graduate
    - Overview of Major Project & Travel Policies\*
  - Day 2: Saturday from 9:00 a.m. to 4:00 p.m.
    - History of the Disability Rights Movement
    - Background on Partners in Policymaking
    - Valued Roles in Society
    - Making Your Case
    - Travel and Expense Reimbursement Review, Wrap Up, and Homework\*
- Session 2: October instruction focuses on Inclusive Education and Beyond.
  - Day 1: Friday from 12:30 p.m. to 8:00 p.m.
    - Florida Inclusion Network presentation
    - Special Education: Inclusion and Legal Rights
    - Mock Testimony Group Discussion\*
  - Day 2: Saturday from 9:00 a.m. to 4:00 p.m.
    - Florida Alliance for Assistive Services and Technology presentation
    - Inclusion, Making It Meaningful
    - Leading with Inclusion
    - Self-Advocacy Leadership
    - Homework review\*
- Session 3: November instruction focuses on Employment Preparation, Employment for All.
  - Day 1: Friday from 12:30 p.m. to 8:00 p.m.
    - Welcome and Debrief
    - Introduction to Vocational Rehabilitation
    - Marketing and Job Development: The Business Side of the Process
    - Workgroup Collaboration Opportunity\*
  - Day 2: Saturday from 9:00 a.m. to 4:00 p.m.
    - Project 10 Overview
    - Financial Stability, Discovery, and Employment
    - PIP Graduate Story
    - Homework Review\*

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- Session 4: December instruction focuses on Self-Determination, Self-Advocacy, and Community Living.
  - Day 1: Friday from 12:30 p.m. to 8:00 p.m.
    - Welcome and Debrief from Previous Session
    - The Dream, Reality, Next Steps, Self-Determination, and Community Living
    - Policy Process
    - Wrap Up for the Day and Work Groups/Break Out Rooms \*
  - Day 2: Saturday from 9:00 a.m. to 4:00 p.m.
    - Debrief and Introduction Day
    - Person-Centered Planning
    - Decision-Making and Community Living
    - Homework Review and Work Groups/Break Out Rooms\*
  
- Session 5: January instruction focuses on the Legislative Process, Creating Systems Change and Communicating with Policymakers.
  - Day 1: Thursday from 12:30 p.m. to 8:00 p.m.
    - Advocacy To Change Policy
    - Update on Current Legislation
    - Family Care Council Overview Presentation
    - Wrap Up and Go into Groups for Final Review\*
  - Day 2: Friday from 9:00 a.m. to 4:00 p.m.
    - Mock Testimony
    - Wrap Up – Homework Review\*
  
- Session 6: February instruction focuses on Community Organizing and Graduation.
  - Day 1: Friday from 12:30 p.m. to 8:00 p.m.
    - Social Capital & Community Building
    - Advocacy and Leadership Opportunities Guide
    - Dare to Dream Exercise
  - Day 2: Saturday from 9:00 a.m. to 4:00 p.m.
    - Group Action Planning: Advocacy Across the Life Span
    - Graduation
    - Homework Review\*

\*Note: These agenda items would be conducted through break-out sessions for this target population to best assure maximum accessibility.

## Appendix C

### Minnesota Governor’s Council on Developmental Disabilities’ Partners in Policymaking Curriculum Highlights:

(Extracted from <https://mn.gov/mnddc/pipm/curriculum.html> on 01/30/2023)

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#### 1. History of Services

##### Competencies

- Participants will be able to describe the history of services for, and perceptions of, people with developmental disabilities.
- Participants will be able to describe significant contributions of the Parent Movement.
- Participants will be able to describe the history of the Self-Advocacy and Independent Living Movements.

##### Why This Topic Is Important

The past is always with us. It shapes the present—how we think about issues and how we see people. We can't make the past go away. We can, however, shape the future, and we need to take

the past into account as we do so. Every day, what we do and don't do makes a difference in shaping the future.

According to the United States' Congress (in PL.101-136: The Americans with Disabilities Act of 1990):

*Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.*

This history of discrimination, combined with the segregation of people with disabilities in “special” environments, caused people with disabilities to be separated from people without disabilities. Thus, many in the general public don't know any people with disabilities. They don't know what it's like to be segregated and devalued, to be treated as “different,” to be denied access to ordinary opportunities that most people take for granted, and more.

Unfortunately, discrimination, isolation, and segregation—relics of the past—still exist in the 21st century! In order to make changes today, and for the long-term future, we need to understand history and how the past continues to influence the present.

We also need to develop visions of inclusion for all, what services for people with disabilities should look like, and what kind of communities we want. Learning from the past will help us move forward without repeating yesterday's mistakes or ignoring the lessons of the past.

#### Concept Highlights

- In the past, and today, people with disabilities have been discriminated against.
- In the past, and today, people with disabilities have been segregated from the rest of society.
- The way people with disabilities are treated influences how other people see them. If a person is treated as “not one of us” and “less than,” others see the person that way.
- We need to take a close look at today's services and service delivery systems: what they do that helps, what they do that hurts, and what they do that continues isolation and segregation. We need to figure out how services can be better.

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- The Parent Movement has made a big difference in improving services and opportunities. Self-advocacy groups are gaining power and making a difference as well.
- Some professional and advocacy organizations have helped to improve services.
- To make a big difference in services, we need to dream big. Small dreams get small changes. Big dreams get big changes.
- Our work must be focused on supporting inclusion, participation, choice, responsibility, and full citizenship.
- Since 1973 in North America, the Self-Advocacy Movement has led to the creation of self-advocacy groups, and people with disabilities are self-advocates who are assertive and speak for themselves.
- The Independent Living Movement also began in the late 1960s and early 1970s, and has helped people with disabilities live better lives.
- Parents, professionals, and/or others need to be supportive of self-advocates and their desire to be in control of their lives.

We need to work together to create visions of the way the world should be, and ensure children and adults with disabilities and their families are part of the process.

### Concepts

There have been dramatic changes in services and attitudes. Wolf Wolfensberger helped us understand that persons labeled with a developmental disability have been seen as sick, subhuman organisms, a menace, objects of pity, burdens of charity, and as holy innocents. In many ways, these perceptions are still with us.

Many people, as well as the service system, are beginning to recognize that each person is an individual with his or her own personality, likes and dislikes, strengths and needs, talents and weaknesses.

Wolfensberger notes three consequences of people being devalued:

- Devalued people are more apt to be rejected and treated in ways that diminish their dignity and their opportunities to develop a positive social role.
- Devaluation sanctions acceptance of poor treatment, social isolation, and discrimination against people who are viewed as being "different" in a way considered negative.
- How a person is perceived and treated by others will strongly influence the person's self-assessment and self-esteem and, subsequently, how the person thinks about himself/herself and how the person behaves.

At the same time, some progress is being made. Many people now see individuals with disabilities as people with potential and abilities, and as full citizens. Less and less, people with disabilities are seen as “all alike.” We don't hear, "They like to be with their own kind," as much as we once did. More often, people with disabilities are seen as “people, first,” instead of the label first.

Many ordinary people, as well as those in the service system, are beginning to recognize that each person who happens to have a disability is an individual with his or her own personality, likes and dislikes, and strengths and needs, just like people without disabilities.

The history of services and perceptions is one of change:

1850s to 1890s

- Centralized services in institutions begin. The idea was first to train people to return to the community and then to protect people with disabilities from society. Training gave way to custodial care.

1900s

- People with disabilities are segregated in institutions or “hidden” in their own homes. Laws are passed that forbid them from marrying, so they won't create any of “their own kind.” Warehousing in institutions continues.

1910s

- People with disabilities are sterilized so they will not have children; state laws permit this practice. Institutions do nothing about rehabilitation; warehousing, dehumanization, and stigmatization continue.



1940s

- People with disabilities are the first to be put to death in Germany followed by six million Jewish people, criminals, "politicals," gypsies, and people said to be antisocial.

1950s

- The Arc is founded. There are 128,000 people in public institutions. Parents begin to create "community" services in church basements or vacant buildings. Parents are on their own; public funds are not available.

1960s

- Parent organizations are now in 60+ countries. Most states offer special education in some form. There are 190,000 people in public institutions. A few institutional reforms begin. The U.S. President's Committee on Mental Retardation is formed. The civil rights of people with disabilities come into focus. The concept of "normalization" is introduced in Sweden.

1970s

- Normalization is introduced to the United States. Decentralization and deinstitutionalization begin. Lawsuits against institutions are filed. Federal funds are available for residential care (ICF—Intermediate Care Facilities). The law and services recognize concepts such as: least restrictive environment, the developmental model, and behavior modification. The Self-Advocacy and Independent Living Movements are born.

1980s

- The Home and Community Based Waiver is included in the Omnibus Budget Reconciliation Act. Family support and other cash subsidies emerge. Early intervention programs are mandated. The U.S. Supreme Court rules in favor of group homes in neighborhoods, and institutional closures and downsizing are on the increase. By 1986, there are fewer than 100,000 people with developmental disabilities in public institutions. Major strides are made in employment programs. Apartment living becomes more common. The goals of inclusion, choice, and self-advocacy are pursued with vigor.

1990s

- By 1993, there are fewer than 80,000 people with developmental disabilities in public institutions, and fewer than 60,000 people by 1996. Some states are institution-free. Between 1996 and 1998 alone, 31 large state-run facilities for people with developmental

disabilities are closed. An additional eight large state-run facilities are projected to close between 1999 and 2000.

- The move from public care to private care continues. Families receive credit cards to purchase “units of service.” New community- and family-living amendments pass. States adopt supported living. The 14th Amendment is used to mandate deinstitutionalization in states that have been slow to move toward community- and family-based programs. Self-advocacy is commonplace and People First groups are consulted, along with The Arc, on developing advocacy and self-assertiveness programs for young adults in regular education classrooms. The Americans with Disabilities Act (ADA) ensures the “most integrated setting.” Family members and people with disabilities are community leaders, become public officials, and set new policy directions.

## 2000s

- The number of people with developmental disabilities living in public residential facilities or nursing homes continues to decline; more people are living in their own homes or smaller group homes (six or fewer people). However, the ideas of deinstitutionalization and inclusion remain controversial in some states; approximately 30,000 people with developmental disabilities remain in institutions; some facilities change their names (“supported living centers”). The work to close institutions is still unfinished.
- The federal “New Freedom Initiative” focused on “removing barriers to community living for people of all ages with disabilities and long-term illnesses.”
- “Money Follows the Person” demonstration projects in several states allowed long-term support funding to follow the individual rather than be assigned to a place.
- The “Independence Plus Initiative” made it easier for states to direct their own health care services. “Transitions from Institutions” allowed people with disabilities to use waivers to cover one-time expenses related to the transition to life in the community. Community First becomes a common expression in 2012.
- A “menu” of support services offered greater independence to people with developmental disabilities. Waiting lists grow.
- While more students with disabilities are being educated in general education classrooms, the National Council on Disability determined that every state was out of compliance with special education law, and accused the government of not enforcing compliance.
- Employment of people with disabilities continues to lag well behind their peers without disabilities.
- Self-employment is a successful employment alternative for people with disabilities.

- Person-centered planning is becoming more common. For some people with disabilities, it's an addition to traditional “individual service plans” (ISP) or “individual habilitation plans” (IHP). Some state legislatures have mandated that person-centered plans *replace* the traditional ISPs, IHPs, etc. This seems like a move in the right direction. However, caution is in order, for some people have reported that these mandated person-centered planning processes are actually no different than what they were supposed to replace; in some instances, the person with a disability isn't present at the meeting, and *that* is not a true person-centered plan!
- Smart phones and iPads coupled with easy-to-use, inexpensive communication “apps” are enabling many children and adults with disabilities to be more included at home, school, work, and in the community.

### The Importance of Self-Advocacy by People with Disabilities

For too long, the voices of people with disabilities were not heard. There are many forces that have worked against people with disabilities speaking up for themselves:

- Many have lived in institutions. Their lives were controlled. They were punished or their behavior was “modified” if they “got out of line.” They had no say in what happened to them. Control and punishment were also part of some community-based services.
- Society generally viewed them as children. We spoke of their mental or developmental age. We did not see them as people of value. We did not value their opinions.
- Because other people did not value them, many people with disabilities did not value themselves.
- Laws and policies prevented people with developmental disabilities from speaking up in important ways like voting.
- Parents, educators, service providers, and/or others “with authority” often made decisions for people with disabilities.

The emergence of the Self-Advocacy Movement (also known as the People First Movement) has helped change all of this. In the early 1970s, People First started growing as a movement in Canada and the United States. Similarly, the Independent Living Movement (originally focused primarily on people with physical disabilities living in the community instead of nursing homes

and/or other congregate care facilities) focused on people with disabilities taking control of their lives and the supports they needed.

In some communities, self-advocacy groups are formed mainly for social reasons. In other communities, the focus is on issues and advocacy. Always, there is mutual support. In some instances, unfortunately, self-advocacy groups have been weakened when strong leaders leave their posts after being recruited for positions on human service agency “consumer advisory panels” and/or similar positions. While these positions may seem to offer “better perks,” they can also result in true self-advocacy being co-opted when self-advocates are expected to “get on the bandwagon” in support of an organization's activities.

The strength of self-advocacy is growing, but so are threats to its practice. We have important choices to make about self-advocacy: support it, be part of it, or get out of its way. *Its time has come.*

- Whether a person is his/her own guardian or not, practice in self-advocacy develops capacity.
- Self-advocacy requires that people speak up for themselves. Supporting people in this effort requires us to recognize people with disabilities as our equals—just as we do with our co-workers, friends, neighbors, etc. People with disabilities must be seen as first-class—not second-class—citizens.
- As citizens, it is important for self-advocates to exercise their rights and their responsibilities; they have the right *and* the responsibility to speak up.
- The voices of self-advocates must be heard: in their homes; in their schools, churches, and other community organizations; in organizations that provide services; and in our local, state, and federal governments.
- People with disabilities, regardless of the degree or type of disability, should always be part of the decision-making process about their own lives.

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## **2. Inclusive Education and Life Long Learning**

Competencies

- Participants will be able to describe the benefits and values supporting a quality, inclusive education for all students.
- Participants will be able to outline specific strategies to achieve inclusion a quality, inclusive education for all students.

### Why This Topic is Important

A quality education can pave the way for a life of opportunity and contribution. An education that does not prepare children for a successful future guarantees they won't have a successful future. Schools are for learning and much, much more. In addition to helping children learn academics, schools can help children develop values, responsibilities, and social skills. They can enable children to learn important lessons about life. If students miss out on these opportunities as children, they will be ill-equipped as adults and will miss out on even more as adults. All of these things are equally true for children with and without disabilities.

In 1954, the U.S. Supreme Court ruled in *Brown v. The Board of Education* that “separate is not equal.” In 1970, twenty-five years later, exclusion was still the rule. According to the National Council on Disability:<sup>1</sup>

In 1970, before enactment of the federal protections in IDEA (Individuals with Disabilities Education Act), schools in America educated only one in five students with disabilities. More than 1 million students were excluded from public schools, and another 3.5 million did not receive appropriate services. Many states had laws excluding certain students, including those who were blind, deaf, or labeled persons with "emotionally disturbance" or "mental retardation." Almost 200,000 school-age children with developmental or emotional disabilities were institutionalized. The likelihood of exclusion was greater for children with disabilities living in low-income, ethnic and racial minority, or rural communities.

In 1993, almost forty years after *Brown*, segregation and an unequal education were still the rule for children with developmental disabilities. Despite IDEA, in 1993, fewer than 7 percent of school-aged children with developmental disabilities were educated in general education classrooms. Forty-four states (including the District of Columbia and Puerto Rico) educated less than 9 percent of their students with developmental disabilities in general education classrooms.

In 1997, the Individuals with Disabilities Education Act (IDEA) was reauthorized by the 105th Congress with a number of changes. P. L. 105-17 ensured that the education of children with

disabilities moves from merely *access* to public education to ensuring quality outcomes. Congress specifically mentioned implementation problems resulting from “low expectations, and an insufficient focus on applying replicable research on proven methods of teaching and learning for children with disabilities (20 U.S.C. 1400 (c)(1)) During the 1997 reauthorization, there were several new requirements including the addition of individualized transition plans, and functional behavioral assessment and intervention plans.

The National Council on Disabilities documented the positive consequences that can result:

In the more than two decades since its enactment, IDEA implementation has produced important improvements in the quality and effectiveness of the public education received by millions of American children with disabilities. Today almost 6 million children and young people with disabilities ages 3 through 21 qualify for educational interventions under Part B of IDEA. Some of these students with disabilities are being educated in their neighborhood schools in regular classrooms. These children have a right to have support services and devices such as assistive listening systems, Braille text books, paraprofessional supports, curricular modifications, talking computers, and speech synthesizers made available to them as needed to facilitate their learning side-by-side with their nondisabled peers. Post-secondary and employment opportunities are opening up for increasing numbers of young adults with disabilities as they leave high school. Post-school employment rates for youth served under Part B are twice that of older adults with disabilities who did not benefit from IDEA in school, and self-reports indicate that the percentage of college freshmen with a disability has almost tripled since 1978.<sup>2</sup>

But, the gap between law and practice continues:

In the past 25 years, states have not met their general supervisory obligations to ensure compliance with the core civil rights requirements of IDEA at the local level. Children with disabilities and their families are required far too often to file complaints to ensure that the law is followed. The Federal Government has frequently failed to take effective action to enforce the civil rights protections of IDEA when federal officials determine that states have failed to ensure compliance with the law. Although Department of Education Secretary Richard W. Riley has been more aggressive in his efforts to monitor compliance and take formal enforcement action involving sanctions than all his predecessors combined, formal enforcement of IDEA has been very limited.<sup>3</sup>

The Office of Special Education and Rehabilitative Services (OSERS) reported the following in 1999:

In 1996-97, over 95 percent of students with disabilities received special education and related services in regular school buildings, and 46 percent were removed from regular classes for less than 21 percent of the day.<sup>4</sup>

The Americans with Disabilities Act (ADA) was passed in 1990, prohibiting segregation and discrimination based on disability. And still, a quality, inclusive education remains a distant vision—not a reality—for too many students with disabilities in our public schools.

The emergence of special, segregated educational programs mirrors the paradigm that created institutions. Children with developmental disabilities were virtually denied a public education from the beginning of this century until the 1970s. The first step was to develop special schools and/or special classrooms. Integration was first seen as being included in the public education system (special schools), then into public education schools (special classrooms). Now in the era of community and family living, inclusion, participation, and full citizenship, integration means inclusion in general education classrooms and activities.

During the decade of 2000-2010, schools were focused on the implementation of No Child Left Behind, the Elementary and Secondary Education Act of 2001 (P.L. 107-110). During these years, advocacy focused on including students with disabilities in the general education curriculum, including students in the testing requirements, and ensuring students were graduating from high school and transitioning to adult life.

The reauthorization of IDEA in 2004 (P.L. 108-446) required high qualification standards for teachers and stipulated that all students with disabilities participate in annual state or district testing or documented alternate assessments.

<sup>1</sup>*Back to School on Civil Rights: Advancing the Federal Commitment to Leave No Child Behind. National Council on Disability, January 25, 2000.*

<sup>2</sup>*Graduation rates have increased significantly for students with disabilities.*

<sup>3</sup>*Back to School on Civil Rights: Advancing the Federal Commitment to Leave No Child Behind. National Council on Disability, January 25, 2000.*

*<sup>4</sup>Twenty-first Annual Report to congress on the Implementation of the Individuals with Disabilities Education Act. U.S. Dept. of Education, 1999.*

### Concept Highlights

- For many years, children with disabilities were not allowed to attend public schools.
- “Special” schools were created, providing a separate, segregated education.
- Today, more children with disabilities are welcomed and included in general education classrooms, fulfilling the concepts in IDEA.
- Most states are not doing enough to develop more inclusive schools; even some disability groups oppose inclusive education practices.
- Inclusive education costs less than segregated programs.
- Brothers, sisters, and other children from the neighborhood should be educated together in the neighborhood school.
- Our schools are microcosms of our communities. Our communities are stronger and better when all children learn and grow together in inclusive classrooms and inclusive community activities.
- “Dumping” students in general education classrooms without the necessary supports for the student and the teacher and/or isolating a student with a disability in the back of the room with a one-to-one aide are not inclusion.
- Inclusive schools are better for students with and without disabilities, academically, socially, and in every way. Teachers in inclusive classrooms become better teachers.
- Schools need to do a better job in following the mandates in IDEA, regarding “least restrictive environment.” They also need to do a better job with the “I” in the Individual Education Program (IEP) mandated by IDEA. Students are not supposed to “fit” into a school's “program;” schools are supposed to create an individualized program for each student who qualifies for special education services.



Special education is not a separate entity; it is part of general education. A “special ed issue” needs to be viewed as an “education” issue.

## Concepts

### The Learning Community in the 21st Century

1. An inclusive school represents a community where children and adults engage in a reciprocal learning process that is fun, engaging, relevant, and affirmative, and meets the life-long learning needs of everyone.
  - The learning environment supports a sense of community and respect for individual differences and abilities.
  - Community-building and respect for individual differences best occurs when students of different backgrounds and abilities learn and socialize together in classrooms designed to develop and enhance the abilities of all children.
2. Inclusion means that students:<sup>5</sup>
  - Are included in general education classrooms and activities for both academic and social opportunities;
  - Receive an individualized education program which supports learning in the general education classroom and community settings;
  - Have the opportunity to participate in school social and extracurricular activities with peers without disabilities; and,
  - Attend schools in their own neighborhoods.

<sup>5</sup>*Separateness (separate-hood). The Arc U.S., Oct. 1992, p7. The Arc Report Card on including children with mental retardation in regular education. The Arc. U.S., 1992, p4.3.*

Questions to ask about a school's policies, practices, and educational opportunities:

- Is there a school district policy in support of inclusive education?

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- Does the school administration emphasize the preparation of all students to live and work in the community?
- Does the school leadership encourage the inclusion of all students via its written materials; flexible scheduling; building accessibility; providing assistive technology, supports, accommodations, and modifications to students and teachers; and by other means?
- Do all school personnel receive annual in-service training on the values of and strategies to achieve inclusive education?
- Do students with disabilities attend the school they would attend if they didn't have disabilities?
- Do students with disabilities ride the same buses as students without disabilities?
- For students with disabilities, are their school days (length of day, time of arrival and departure) the same as for students without disabilities?
- Do students with disabilities participate in extracurricular activities with students without disabilities?
- Do all special education school personnel support students in the general education classroom and/or community settings?
- Is the curriculum modified, as necessary, to ensure students with disabilities can be involved in and make progress in age-appropriate general education classrooms?
- Do supports match the student's strengths, needs, preferences, and interests?
- Are educational objectives based on a comprehensive assessment of the student's strengths and needs?
- Do curricular and extracurricular activities involve mutual interaction with students without disabilities?
- Is learning viewed as lifelong? Are people encouraged to take online courses, enroll in community education courses, and in postsecondary education?

Topics for further review:

- The benefits of inclusion for students with disabilities: opportunities to learn academics and real-world social skills (learning these things are usually not possible in a self-contained classroom), to make real friends, to enjoy grade-to-grade upward progression like other students (this can't happen when, for example, an elementary-aged student is in the same special ed classroom from K-5), and more.
- The benefits of inclusion for students without disabilities: opportunities to develop friendships with a peer who may be different in some ways, to better understand the range of human differences, to benefit from valuable lessons that can only be learned from a person with a disability, and more.
- The difference between learning from your teacher and learning from your peers: positive role model carry-over, incidental learning, deductive learning, peer support, consensual validation of behaviors and positive skills, having something in common that can lead to friendship and bonding. A teacher may be wonderful, but there are many more opportunities for peer-to-peer learning.
- Read the [OSERS Report to Congress](#), particularly as it relates to your state.
- Strategies for opening the doors for brothers, sisters and neighbors to all go to the same school and classrooms.
- Using natural supports (such as peers and cross-age tutors) to facilitate inclusion.
- The role technology can play in supporting a student in the general education classroom.
- The relationship of *Brown v. The Board of Education* to the ADA.
- Participation in the lifelong competencies of digital literacy and media literacy deemed essential for employment in the 21st Century.
- Participation in postsecondary education that is inclusive and lifelong learning opportunities.

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### 3. Service Coordination

## Competencies

Participants will be able to demonstrate their knowledge of the service coordination system and what services may be available.

## Why This Topic is Important

Service coordination has evolved into a very important part of the service system. At one time, people with disabilities and/or their families had to “manage” the system on their own. It was up to them to figure out what they needed, who might provide it, if they qualified, and so on. Once they became a client of a particular agency, they might receive some help with coordinating the different services. In too many cases, however, they were simply added to the “caseload” of the “case manager”—an individual and/or a family became a “case to be managed.”

The intent of service coordination has always been relatively straightforward: help people identify and get what they need, coordinate the activities of the services and resources they get, and make sure service providers and others do what they're supposed to do. The intent is not to “manage” people as “cases.” Case management should have evolved into service coordination by now. But some states and/or agencies have been slow to make the change, both philosophically and in practice.

Partners participants should compare the *concept* of service coordination to what *really* happens. Think about what is being provided. Think about how well it's being done. Decide what to do to make it BETTER!

High quality service coordination is the hub of service provision. Service coordinators should be very knowledgeable about their roles, and about the needs of the people they serve. Training for service coordinators should be on-going. Service coordinators must have the authority to secure needed services. The number of people that a service coordinator is assigned to support should be small enough that he/she has the time to know each person/family well and be a rock-solid advocate for each.

## Concept Highlights

Service coordinators need to:

- Coordinate services, instead of managing cases.

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- Recognize the individuality and potential of the individuals/families they serve.
- Support the power of the individual/family to get what they need, and not be a bureaucratic barrier.
- Provide assistance for individuals/families to gain access to social, medical, educational, and other needed services.
- Be knowledgeable, and continue to enhance their knowledge-base.
- Be strong advocates on behalf of the people they serve.
- Ask for, value, and respect the wants, needs, and opinions of the individuals/families they serve.
- Ensure the implementation of program plans, and evaluate how well they do what they're supposed to do.
- Be assigned only the number of individuals/families they can serve well; service coordination fails when service coordinators are stretched too thin.

It's possible for people with disabilities and/or their families to be their own service coordinators, with or without support to do so. The service coordination system and the individual/family should be working together to ensure inclusion, choice, participation, integration, and quality of life.

### Concepts

Service coordination is the formal link between the individual with a disability/family and the service system. When a plan is written for an individual/family, the service coordinator may play an active role in getting the service system to respond. In more regulated and formal systems, the plan may be seen as a piece of information that the system takes into account, but it may not take the place of the forms and processes required by law. Thus, the service coordinator's role may need to ensure the plan makes it through the bureaucratic red tape.

The goal of service coordination should be to improve the quality of life of an individual/family, ensure that the individual's/family's needs are met, and foster the individual's/family's

autonomy. To accomplish this goal, service coordinators are generally responsible for four types of activities: assessment, planning, implementation, and evaluation. Each activity informs the next, so the cycle is ongoing, and includes:

- Assure the ASSESSMENT accurately determines the individual's/family's current needs and what the individual/family wants to happen in their lives.
- Coordinate PLANNING of services to meet the needs, wants, preferences, and learning objectives of the individual/family.
- Assure the IMPLEMENTATION of the service plan.
- EVALUATE the adequacy of supports and services in meeting the goals and objectives of the individual/family.

Service Coordination should:<sup>6</sup>

- Identify the full range of services needed.
- Identify the range of resources available, including each individual's natural supports and public resources available to the individual/family.
- Coordinate the activities of all services and resources.
- Refer individuals/families to all needed resources.
- Monitor and follow-up to see if services are received.
- Monitor and follow-along to prevent problems or to identify problems in service provision through on-going contacts with all services utilized, and with the natural support resources (i.e., family and friends).
- Assess and evaluate the effectiveness of all services or resources used.
- Continually advocate with and on behalf of each individual/family to maximize quality of life.

<sup>6</sup>Section adapted from Shaping Case Management in Minnesota ..., 1991.

Service coordinators should base their services on these values:<sup>7</sup>

- Every individual/family has worth.
- Long-term relationships enhance self-worth.
- This is an interdependent world where we all share the responsibility to assure the health, education, and welfare of all citizens.
- Learning is an essential and important part of human existence.

<sup>7</sup>*From Caragonne, 1994.*

Service coordinators should ensure that the support provided to the individual/family is consistent with the following principles:

- Non-intrusive.
- Easily accessible.
- Efficient.
- Growth-enhancing.
- Promotes inclusion into the community.
- Involves the opinions, wants, needs and preferences of the individual/family.
- Age-appropriate.
- Enhances dignity.
- Encourages connectedness and friendships.
- Promotes a positive social role.
- Protects the rights of the individual/family.
- Cost-effective.

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- Produces positive changes in the life of the individual/family.
- Fosters full citizenship of the individual/family.

The life and learning experiences encouraged by service coordinations should:

- Support and maximize growth.
- Emphasize the whole person/whole family.
- Maintain or increase the individual's/family's sense of community.
- Ensure that decision-making by the individual/family is fundamental.
- Enhance the relationship-building capacity of the individual/family.
- Occur in a variety of settings.
- Include the provision of supports and adaptations.
- Include real experiences and their consequences.

If you are an individual/family who receives services, you should expect your service coordinator to:

- Treat you with respect.
- Ask for your opinions.
- Talk with you and listen carefully when discussing your concerns, your likes and dislikes, what you want to learn or do, etc.
- Help you with the things you want/need to learn.
- Help you get the services you may need.
- Talk with your family or friends, with your permission, if that would be helpful.



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- Give you the opportunity to make your own decisions and/or be involved in making decisions that affect your life.
- Encourage you to be involved with community activities (recreational, social, religious, work- or school-related, etc.)
- Ensure you have opportunities to experience new things.
- Coordinate the annual team meeting and arrange for support and services based on your needs and preferences.
- Help you become more successful, interdependent, and self-reliant in the life you want to live.
- Be concerned with your whole life.
- Protect your rights.
- Do what he/she promises to do.
- Be reasonably available when needed.

If you are a person with a disability, your service coordinator should work with you and for you. Your service coordinator should talk with you about your needs, wants, concerns, aspirations, feelings, likes and dislikes regarding:

- Dental services
- Medical services
- Housing
- School
- Work
- Family involvement

- Friends
- Community, recreational, and/or social activities
- Transportation
- Religious activities
- Future plans
- Protecting rights
- Promoting growth and opportunities
- Roles and images that support your choices

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#### **4. Whole Life Planning (Person Centered Planning)**

##### Competencies

- Participants will be able to describe the importance of whole life planning (person centered planning) and self-determination for people with developmental disabilities.
- Participants will understand the principles of choice and control of resources in whole life planning.

##### Why This Topic is Important

The idea of planning for people with disabilities has been around for a long time. What's changed is *who* is in charge and *why* it's done.

In the beginning, delivery systems and service providers were in charge of planning. Professionals developed individual program or teaching plans. Sometimes they consulted with the individual or family to identify what was to be taught; sometimes they didn't. These plans prescribed the steps that staff, and sometimes families, had to follow in order to teach the individual new skills. Effective teaching required consistency on everybody's part, so there had to be a plan.

Then came service or habilitation plans that detailed the services and supports an individual needed. Some agencies invited the individual and the family to help the agency develop the plan. These plans identified which of the agency's services would meet the person's needs. Again, professionals developed the plans. Later, agencies were often required to *ensure* the individual and/or family was present at the planning meetings. Soon, individuals and/or their families figured out they should simply ask about “what the agency had to offer.” They learned that if you asked for what you really needed, you might have to get on a waiting list for those services and/or you put yourself at risk for being seen as a “troublemaker” by asking for “too much.”

If more than one agency or program was involved in a person's life, representatives from those agencies/programs would be involved in the planning. The plan was supposed to be an effective method of coordinating the services and the actions of the relevant personnel.

In traditional program or service planning, agencies were in control. The focus was on teaching or services. These plans were an orderly method to identify service needs, then match what agencies had to offer with those needs. Plans could be used to anticipate future service needs, but they had little impact on shaping what services were currently available.

Over the last 30 years or so, significant changes have taken place. Far more attention is focused on ensuring the individual/family is in control, and the plans are moving away from program/service planning to a focus on the individual's whole life. Such plans may be referred to as: futures planning, personal futures planning, lifestyle planning, person-centered planning, etc.

By whatever name, everyone involved in the process—the individual, the family, friends, advocates, service coordinators, and others—must understand what whole-life planning really means. In addition, they need to recognize how easy it is to slide backwards toward the older models of planning, where agencies and/or professionals were in charge.

Some states have mandated that any plan written for an adult with a disability who receives services must be a person-centered plan. This seems like a step in the right direction. However, people who are involved in some of these states report that what they're calling “person-centered plans” are no different than what they've always done. In some cases, the individual who is the focus of the plan isn't even present when the plan is written! This is not a person-centered plan.

Because of waiting lists for services and/or anticipated cuts in services that always seem to be on the horizon, no one can ever be sure that the services one has today will be there tomorrow. Thus, it's important that we all recognize the value of the natural supports (family, friends,

neighbors, church members, etc.) and the generic services (the same things used by people without disabilities like businesses, park and rec, YMCAs, libraries, child care facilities, and/or any other entities) in our communities that could meet the needs of a person with a disability and/or family. When people with disabilities and/or families use natural supports and generic services, they're automatically included. Connecting with others, based on shared interests, opens the doors to opportunities, experiences, and relationships that can change a person's life. When thinking of whole-life planning, include the “ordinary people” in the community who know, care about, and can make a difference in a person's life.

### Concept Highlights

- People with disabilities are whole people; they are not their labels; whole-life planning focuses on the whole person.
- Regardless of what it's called—futures planning, personal futures planning, person-centered planning, etc—everyone involved in the process needs to share a mutual understanding of what whole-life planning means.
- Every person with a disability has strengths and needs; when we meet people's needs and build on their strengths, they can experience unlimited potential, just like people without disabilities.
- What are the person's best hopes? Worst fears? What needs to happen so the best hopes happen and the worse fears do not? Who is in the person's life that can assist in these efforts?

### Concepts

Whole-life planning has a number of features that distinguish it from service planning:

- The focus is on the individual's whole life, not just services.
- The plan is the person's plan, not an agency's.
- The people involved in the planning are there at the individual's invitation; no agency and/or professional decides who participates.

- The individual, family, and friends are the most active participants; professionals participate to advise and support, not to control.
- The focus is on a vision for the present and the future, finding do-able ways to get there, and building commitment, instead of accepting “what is” and/or what’s “realistic.”
- The emphasis is on (1) identifying a person's strengths, gifts, and talents, and building on those, and (2) meeting the person's needs, instead of focusing on assessments of "what's wrong” with the individual.
- The challenge is how the individual, family, friends, and services (not only services) can work together to achieve the vision.
- The person's whole-life plan can serve as the foundation for exploring what services may be needed; at that point, a service plan to formalize those services may be written.

Whole-life or futures-planning represents a radical shift. It amplifies the voice of people with disabilities, their families, and friends. It looks at capacity in people and communities. According to John O’Brien and Beth Mount,

*Futures planning did not ignore disability, it simply shifted the emphasis to a search for capacity in the person, among the person's friends and family, in the person's community, and among service workers. A person's difficulties were not relevant to the process until how the person wants to live was clear. Then it was necessary to imagine and take steps to implement creative answers to this key question, "What particular assistance do you need because of your specific limitations (not labels) in order to pursue the life that we have envisioned together?"*<sup>8</sup>

<sup>8</sup>Connie Lyle O'Brien, John O'Brien and Beth Mount, *Person-Centered Planning Has Arrived ... Or Has It?. Mental Retardation, December 1997.*

Whole-life planning represents a vision created by a group of caring, involved, and committed people, and it’s very practical. There are many different approaches to whole-life planning, but they involve similar steps:

- People who know and care about the individual, *and who are chosen by the individual*, come together to plan and make things happen. The person's life and the planning process are richer if these people share a commitment to the person, and it's

okay if they have different perspectives. Family, friends, staff, and professionals can contribute to the richness.

- The group shares its insights in “who” the person is, and listens very carefully to what the person has to say. Who is important to the person? What are the person's gifts and talents? How does he or she make the lives of other people and the community richer? What are the person's desires and dreams for the future?
- Develop a shared vision of what the future can look like for the person. The vision is wide open. The group can focus on key questions regarding the person's participation in the community, choices/rights, respect, competence, and more.
- Identify barriers, obstacles, opportunities, and capacities in the environment that can stand in the way or help achieve the vision. This becomes the practical action plan to move toward the vision. Create two timeframes for action: short-term (what can be done now/soon to move things along), and long-term (what might take more time).
- Identify who does what, when, and how, so everyone's on board. If agency representatives are involved in the planning, this is when they make commitments to develop or offer supports. If not, other members of the group may plan to meet with agencies to get such commitments.
- Go for it! Members of the group do what they said they would do.
- Stay in touch and stay focused. The group meets regularly to see how things are going, keep their focus, change direction if needed, and celebrate their accomplishments.
- This process of planning and taking action can and should be fun and enjoyable!

Whole-life planning is based on the fundamental human right to live a self-determined life. Self-determination is not a program or a service, but a set of principles. A commitment to these principles ensures that people with disabilities have the FREEDOM to decide how they want to live their lives and receive the support they need. They have control over their resources and take RESPONSIBILITY for their decisions and actions.

The principles of self-determination include:

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- Freedom to choose how to live, where to live, and with whom to live and, if necessary, to receive assistance from friends and close family members.
- Relationships that are freely created, nurtured, and protected.
- Contribution and community that are meaningful—to be employed, have a home of one's own, to participate in and contribute to building a stronger community for everyone.
- Responsibility for personal decisions and actions; as necessary, families, friends, and professionals help people with disabilities create more meaningful relationships, connect them with needed supports, remove barriers, and develop safety networks to help make personal dreams come true.
- Authority to make decisions about financial resources, determine needed supports, and control the hiring and evaluating of those who provide support.
- Dreaming is encouraged and respected; supports are provided to help make dreams come true.
- Dignity and respect of and for people with disabilities, with a safety network in place to provide support and encourage continued growth when mistakes are made.
- Support for spending money efficiently, and finding the best quality for a reasonable price within and outside of the system.
- Doing whatever it takes to ensure success for the person.

Imagine...

Imagine that any person with a disability and/or the family can call on talented facilitators in their communities to help them develop whole-life plans. These facilitators might be other people with disabilities or family members, community members, or professionals trained to facilitate high quality planning processes. The facilitators are not tied to service providers, so they don't have any vested interest in the outcome, other than being true to a set of values. They help form support circles, facilitate planning, give advocacy advice, and so forth. They are not managers or coordinators, just facilitators and helpers.

Imagine that every individual with a disability is surrounded by people who truly care about him/her, and this group works together in decision-making, planning, plotting and scheming, and occasionally, just having fun. Imagine that human service agencies believe part of their mission to connect people with disabilities to others in the community, based on shared interests. New friendships emerge. Families trust the new friends and the person's circle of support grows. The individual is now free to go off with friends and have fun—perhaps for the first time in his/her life. The person's life gets better and better; new friendships mean many new opportunities and experiences... maybe even a real job for real pay.

Imagine that a person's whole-life plan, as a clear statement of what the person needs, is the basis for funding allocated directly to the person or a family member. Maybe the person's plan was developed independent of any agency, so the person can buy the services he/she needs from any agency or from the open market. Or perhaps the plan was created with a particular agency in mind, because the person/family likes the services it has to offer. Regardless, the funding goes directly to the person/family; they're in charge.

Imagine that whole-life plans are the basis for accountability in the system. The government measures its performance in terms of how well it's doing in supporting people to get what they say they need. There is sufficient respect and trust in the system that everyone assumes people will only ask for what they reasonably need.

Imagine that the system is so responsive you don't have to follow a format when developing a plan. All you have to do is communicate clearly what you need and how you expect to be treated.

Imagine—then get organized!

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## **5. Assistive Technology**

### Competencies

- Participants will understand the reasons for and the importance of proper positioning techniques for people with disabilities.
- Participants will be able to describe examples of state-of-the-art technologies for people with disabilities.

Why This Topic is Important



Disability can be defined as "any condition that challenges the development or functioning of an individual, such as sensory, physical, or mental impairments..." Assistive technology can help people with disabilities meet these challenges and become more self-reliant, productive, and included in schools, workplaces, communities—anywhere.

An "assistive technology device" is any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. (29 U.S.C. Sec 2202(2))

An "assistive technology service" is any service that directly assists an individual with a disability in the selection, acquisition, or use of an "assistive technology device." (Assistive Technology Act of 2004)

Assistive technology can help people communicate, move around, meet their own needs, learn, control their environment, work, and be more self-reliant, anywhere, all the time. Technology allows us to identify and build on a person's abilities, rather than focusing on what the person cannot do. Assistive technology can make inclusion, productivity, and participation a reality.

The quality of life for many people with significant disabilities can radically improve when we're creative in identifying, developing, applying, and/or funding the appropriate adaptive or assistive technology devices.

### Concept Highlights

- Technology can assist a person who may have a functional limitation; it can help people see, hear, move around, communicate, work, learn, and be more self-reliant.
- Technology is not always affordable or accessible for many people who could benefit from it.
- Technology helps us see the abilities of people who are labeled with disabilities, and these success stories need to be shared.
- Policymakers need to understand how assistive technology can save money by enabling self-reliance, helping people learn in school, and get real jobs.

- People with disabilities, families, and professionals need to understand what's possible with technology. People need to be strong and clear in their advocacy for the increased availability of assistive technology.

### Concepts<sup>9</sup>

There are many ways we can improve the lives of people with disabilities through environmental changes and assistive technology:

- We can eliminate attitudinal barriers that, in turn, lead to environmental barriers that prevent people from disabilities being able to enjoy the ordinary relationships, experiences, and opportunities that people without disabilities take for granted.
- We can ensure places and activities are physically and programmatically accessible so that all are welcome and all can participate.
- We can ensure people with disabilities have the supports, modifications, and/or accommodations they need to fully participate at home, in schools, at workplaces, and in community activities.
- We can identify and provide the technology that extends and enhances the abilities of people with disabilities.

Assistive technology—new or old, simple or complicated, low cost or expensive—can enable people with disabilities to:

- Be more successful in school and participate in online learning opportunities.
- Fully use the power of social media to stay connected.
- Pursue productive employment.
- Develop more autonomy and self-reliance in determining how and where they live.
- Discover their talents and gifts.
- Enjoy greater social and recreational opportunities in ways that are not possible without technology.

- Shift the focus from their functional limitations to their abilities.
- Be prepared for emergencies.
- Become, and be seen as, contributing members of society.

We've never had greater opportunities for developing and applying assistive technology. There is much more support for the idea of helping people to be more and more independent. A number of pieces of important legislation are in place, including the [Rehabilitation Act Amendments](#), the [Technology-Related Assistance for Individuals with Disabilities Act](#), and the [Fair Housing Act](#).

To take advantage of these opportunities, we must take action to:

- Assure technology is applied creatively.
- Make sure people have access to appropriate technology.
- Share information.
- Fund training.
- Carry out the research and development that expands on the promise of technology for people with disabilities.

The cost of these actions will be small in comparison to the resulting savings in productivity, economic growth, human dignity and well-being.

*<sup>9</sup>Adapted from *Abilities and Technology* (1986). MN Governor's Council on Developmental Disabilities.*

Possible Actions to Improve Accessibility and Use of Technology:

- Lobby for full implementation of the Americans with Disabilities Act.
- Allow people to try out assistive technology until they find what works best.

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- Make sure people with disabilities, families and friends, professionals, policymakers and the general public are aware of advances in technology and what these can mean.
- Train professionals from a wide range of disciplines on the uses of technology for people with disabilities.
- Provide people who need assistive technology with access to adequate services for assessment, prescription, training, and follow-up.
- Establish advisory boards on the use of technology for people with disabilities. Such boards could recommend public policy changes, ways to use technology, and how to get information out to people. Advisory board members should include people with disabilities and families, and could also include service agency representatives; family, friends and advocates; third party payers; and educational and government representatives.
- Develop technical assistance and resource centers to promote the understanding and application of technology.

### Examples of Assistive Technologies:

- Augmentative communication to help a person communicate more effectively.
- Environmental controls can include making a switch larger or a device easier to use. This can increase the ability of people with physical disabilities to independently control their environment. Examples include turning on the television, lights, and appliances; answering the phone; opening doors; and driving a power wheelchair.
- Custom seating systems include a wheelchair insert that's fitted to the shape of an individual (without compromising the ability to maximize trunk strength where applicable). This can enhance body-system functioning, prevent skin breakdown, and improve learning/participation in all life areas.
- Postural supports inserted into a power wheelchair can help a person sit in a comfortable position and reduce the loss of muscle tone. The person can then work at a desk or table along with friends and classmates, and participate in more activities.

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- Independent mobility is a first step toward independent living. Many kinds of power wheelchairs are available. The controls can be modified and/or placed to match a person's particular abilities.
- Vocational and employment adaptations can include modifications to a worksite, such as raising the height of a desk, or fabricating work areas, or adapting machinery to make it accessible to employees with disabilities.
- Home modifications can include lever door hardware and grab bars in the bathroom, lowered light switches and shelves, toe-space at counters and the sink, and lowered counters and paddle faucet controls to promote greater self-reliance at home.
- Self-transfer lift systems include a track installed in the ceiling. Many lift systems require an assistant to "place" the person in a sling. But a self-transfer system can enable a person to get in/out of the lift without assistance. In one person's home, the lift can help the person get out of bed, then transport the person through the bedroom, across the hall, and into the bathroom (directly to the toilet or the shower/tub).
- Environmental modifications can include ramps at state and local parks; improved accessibility at restaurants, theaters, retail stores, businesses, and other places of public accommodation to ensure access to public recreational, commercial, and business opportunities.
- Lifts for public transportation.
- Environmental control systems, including high and low technology, can provide the confidence and support to enable a person to be safer and more self-reliant in his/her own home. One man had an amplifier installed on his phone to accommodate hearing limitations and a personal alarm system to notify health personnel if he has a medical emergency.
- Ultra Voice Unit is a loudspeaker with a rechargeable battery that fits on an upper denture or orthodontic retainer; volume and pitch are set by a handheld control.
- Mind Control Tool Operating Switch (MCTOS) is a switch controlled by bioelectrical activity measured at a person's forehead. The switch operates using eye movement, muscle activity, or the mind; the switch is "off" when the mind is quiet and "on" when the

mind is excited. Communication devices, environmental control devices, and computers can be operated by MCTOS.

- A variety of adaptive driving aids can enable people with disabilities to drive their own vehicles.

### Digital Literacy and Media Literacy

In the 21st Century, information and computer technology, social media, and electronic communication (computers, smart phones, iPads, and more) can be critically important in helping students with disabilities learn and succeed in school and helping adults with disabilities acquire and maintain real jobs. (See <https://mn.gov/mnddc/asd-employment/6a-ict-competencies.html>.)

Partners participants, and others with disabilities, can improve their lives, and the lives of others, by taking the various online courses at [www.partnersinpolicymaking.com](http://www.partnersinpolicymaking.com). As described in the Partners in Policymaking® Coordinator's Handbook Supplement: *Integrating Online Learning*, the online courses can supplement in-person Partners sessions, or be useful stand-alone learning opportunities.

A four-year-old child with cerebral palsy could not write with a pencil. His parents helped him learn how to use a computer at this young age. When he began kindergarten, and throughout his school career, he was included in general education classrooms, doing most of his schoolwork (including language arts, math, social studies, and more) on the computer. Worksheets could be scanned into the computer. His parents and teachers found computer software programs that mirrored the content being taught in the classroom. During the high school years, he began using voice-recognition software; instead of one-finger typing, he was able to wear a headset microphone and dictate his words to the computer. Today, he's a successful college graduate, and he uses a very simple device—a name stamp—as his legal signature.

An inclusive education provides great benefits for everyone, but if homeschooling is the preferred option, or if parents want to provide something in addition to the public school, students with and without disabilities, as well as adults, can experience great success via online learning, at sites like <http://www.k12.com>, <http://www.khanacademy.org>, and other sources.

Online courses are also available through public and private colleges and universities. A person can earn a college degree (and then move on to a great job) without ever setting foot on a college campus.

Encourage Partners to share the latest technology with one another and keep up-to-date with the latest technology advancements.

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## **6. Supported, Competitive and Customized Employment**

### Competencies

Participants will be able to describe the importance of supported, competitive and customized employment opportunities.

### Why This Topic Is Important

The Rehabilitation Act recognizes that “disability is a natural part of the human experience” and “in no way diminishes the right” of individuals to:

- Live independently,
- Enjoy self-determination,
- Make choices,
- Contribute to society,
- Pursue meaningful careers, and
- Enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.

Real work for real pay is an important part of all of these dimensions of life. It means making choices and decisions. It means getting paid, and being more financially-independent. It means being a part of things, and *being seen* as being a part of things.

Work is an important part of defining who we are. "Hi—what's your name? What do you do?" That's an ordinary greeting when meeting a new person. Imagine what it would be like to have to answer, "Nothing..."

Through work, we contribute to our community and our society. Work gives us a reason to get up in the morning. It creates relationships with other people. When we do a job well, we're proud.

Without work, it's hard to be connected to other people. It's hard to feel that you're part of anything—where do you belong? People with disabilities have been denied opportunities to work; we need to figure out why. Once we know why, we can work to make changes.

Some people with disabilities may not choose to work competitively. Others may find themselves without a job from time to time. We need to figure out how everyone can still contribute to their communities. If other people do not recognize the contributions that people with disabilities make to the life of the community and the lives of all individuals, people with disabilities will continue to be vulnerable and at risk.

We need to focus on what work is and what it means for each of us. We need to look again at what the absence of work would mean for us or for another person. This is a remarkable era of inclusion and of breaking down some of the last great walls that segregate people with disabilities. Employment, choice, esteem, and empowerment are among the great victories we're just beginning to be able to celebrate together.

### Concept Highlights

- Employment gives workers self-esteem.
- Employment can help workers feel happy and productive.
- Most adults with developmental disabilities are either unemployed or underemployed.
- Most adults with developmental disabilities are ready, willing, and able to work. Some need individual supports to do so.
- Only one in every four Americans with disabilities has a full-time job.



- Many adults with developmental disabilities have been in sheltered settings for most of their adult lives.
- Employment issues such as wages, benefits, advancement, and retirement that are a natural part of the career development process are often not addressed for people with disabilities.
- Employers generally feel that people with disabilities are good employees.
- Workers with disabilities may be more reliable on the job than many workers without disabilities.
- Supported employment is a way to help people with more significant disabilities be successful in jobs/careers.
- Productive work helps people achieve greater self-reliance.
- Employment enhances empowerment and choice.
- People with disabilities who have paying jobs also pay taxes.

## Concepts

### 1. Willing Workers, Satisfied Employers, and a Supportive Public

A series of Lou Harris and Associates polls and surveys<sup>11</sup> from 1991 discovered some important facts about employment, people with disabilities, employers and public attitudes.

- More than 8 million Americans with disabilities, ages 16-64, want to work but cannot find employment.
- Only one of every four people with disabilities who work have a full-time job.
- Forty percent of people with disabilities over 16 did not finish high school.
- Americans with disabilities are much more likely to be poor and much less likely to be able to find work than most Americans.

- Harris concluded that lack of employment was a major indication of what it means to have a disability in America.

Unfortunately, not much has changed since those 1991 findings.

The [Kessler Foundation](#) and the [National Organization on Disability](#) commissioned [Harris Interactive](#) to conduct the 2010 Survey of Americans with Disabilities. Among the findings:

Employment represents the largest gap between the two groups. Of all working-age people with disabilities, only 21% say that they are employed, compared to 59% of people without disabilities – a gap of 38 percentage points. People with disabilities are still much more likely to be living in poverty. People with disabilities are less likely than those without disabilities to socialize with friends, relatives or neighbors, once again suggesting that there are significant barriers to participation in leisure activities for this population. The second-largest gap between people with and without disabilities is regarding Internet access. 85% of adults without disabilities access the Internet, whereas only 54% of adults with disabilities report the same – a gap of 31 percentage points.

Recent polls asked business managers about the employment and lack of employment among people with disabilities. The poll found that employers think:

- People with disabilities are good employees,
- The cost of job accommodation is not burdensome, and
- There are not enough “qualified” people with disabilities to hire.

<sup>11</sup>*Hopkins. K.R. (1991). Willing to act. A summary of Louis Harris and Associates survey findings on public attitudes toward people with disabilities.*

## 2. Supported Employment

According to Michael Shafer, supported employment is based upon the philosophy ... that all individuals are capable of engaging in meaningful and remunerative vocation activity ... that individuals with severe disabilities should be provided only with rehabilitative services that support the opportunity to engage in meaningful and socially valued vocational activity ... and that employment opportunities should be made available only in integrated settings.

SUPPORTED EMPLOYMENT means providing on-the-job support so that someone can find and keep a job. It is an approach that has helped people who used to be thought of as too severely disabled to work. Supported employment makes it possible for persons with severe disabilities to work at typical jobs in the community. It provides the specialized training and support services they need to be successfully employed.

In 1985,<sup>12</sup> Paul Wehman and his colleagues in Virginia placed 145 people with disabilities into competitive employment. They worked in integrated work places for at least minimum wage. There were no wage subsidies. They were on the job for an average of 15 – 112 months. Many were considered too disabled to be employed. Individual support extended the abilities of those workers so they could do the job. Forget the labels – focus on the job and what it takes for the person to do the job.

The challenge is to use our creativity to help people find and hold competitive jobs of their choice.

Factors that make supported employment successful include:

- A process to figure out what each individual has as skills and passion. (the discovery process)
- A match between the person and the job. (job match)
- Training for the individual.
- Changes to the work site that help the individual do the job. (work site accommodations)
- Support that makes sense for the individual. (individualized supports)
- As much support as it takes, for as long as it takes. (follow-along and ongoing supports)

<sup>12</sup>*Psychology Today, March 1985.*

### 3. Job Coaches and Natural Supports

Supported employment often involves an individual placement. In this approach, one individual is placed in a job in a community business or industry. A job coach (or employment training specialist) provides training to the individual on the job site in job skills and work related

behaviors, including social skills. When the individual's performance reaches the employer's standards, training and on site support is gradually faded. Intervention is increased when needed, for instance, when job duties are increased or the person is promoted to a new job. There is ongoing communication from time to time with the employee and employer.

#### 4. Direct Employment and Career Planning

In the regular employment world, employees directly hire their workers, place them on their payroll, and provide them with benefits (health insurance, sick and vacation time, training and development opportunities, continuing education reimbursements). Businesses that are successful recognize and value their employees, and encourage them to improve/strengthen their work skills. These employees in turn contribute to a more stable work force, and experience personal growth and development. They are on a career path.

These same opportunities should be available for people with disabilities. Career planning is an essential component of employment.

A planning tool that organizes necessary resources to support a person in employment, emphasizes a lifelong approach, and recognizes that personal priorities can and do change throughout life. Career planning is characterized by:

- Personal preferences, interest and needs.
- Focus on the quality of an individual's employment, recognizing that each of us defines the quality of our life using different priorities.
- Concern with a variety of personal life outcomes that employment creates within and outside the work place.
- A lifelong process. It recognizes that the relative importance of specific outcomes will change as a person changes.
- A support circle of those people who know a person well.
- Interrelationships with all parts of a person's life.

#### 5. The Importance of Public Policy

In 1989, Michael Shafer noted the following:

Philosophically, the importance of productive work as a means of achieving social equality and financial independence has now been recognized to apply to individuals with severe (disabilities) ...

The U.S. Senate spoke powerfully about the rights of people with disabilities to work:

The committee intends that references to the terms "inclusion and integration" reinforce the principle that individuals with disabilities, regardless of the nature, type, or severity of disability, should have the same opportunity as their nondisabled peers to experience and enjoy working, leisure time activities, and other like experiences in our society. (Senate Report 102-357, The Rehabilitation Act Amendments of 1992 P.L.102-569).

It is well-documented by the Institute on Community Inclusion that people with disabilities have a significantly lower rate of employment than people without disabilities (36 percent versus 74 percent according to the 2006 American Community Survey (ACS) ... People with disabilities constitute 6.5 percent of all working-age individuals who are employed in the United States.

The majority of adults with developmental disabilities still work in segregated, sheltered employment settings, as opposed to integrated settings in the competitive labor force. Despite the continued reliance on these programs, critics have consistently questioned the effectiveness of segregated employment settings. These issues continue into the 21st Century and Partners must continue to strive for best practices and work with each other to open employment doors.

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## **7. Supported Living/Home of Your Own**

### Competencies

- Participants will understand that a flexible, responsive system of supports for the families of children with disabilities is the cornerstone for a true system of community supports for people with developmental disabilities.
- Participants will understand the need for all individuals to experience changes in lifestyle across the lifespan.

- Participants will know/understand the importance of home ownership/control as one of the defining characteristics of adult life in our culture.
- Participants will understand the basic principles and strategies being used to support people with developmental disabilities in their own homes across the lifespan.

### Why This Topic Is Important

For most of the last two centuries, there were only two choices for families and people with developmental disabilities:

- Stay at home, with no support outside of the family; or
- Live in an institution.

Then we, as a society, learned two important lessons:

- It makes far more sense—morally, socially and economically—to support families to stay together.
- It makes no sense—morally, socially, economically, medically, or legally—to deny people their rights by institutionalizing them. It is better for everyone if people with developmental disabilities are supported to live in the community, as part of the community.

Together, we have made a lot of progress in the fight to make sure families have the resources they need to stay together. As a society, there is a great deal of agreement that children with [developmental disabilities] should:

- Live in a family;
- Grow up enjoying nurturing adult relationships both inside and outside a family;
- Learn in their neighborhood school in a regular classroom [with] children without disabilities;
- Play and participate with children, with and without disabilities, in community recreation and other leisure activities.

While some people contend there will always be a need for traditional institutions, the trend is clear: in the 21st Century, it is COMMUNITY FIRST.

We must remain vigilant in our efforts to ensure families are supported and institutions are closed. We must also turn our attention to other challenges confronting people with developmental disabilities, their families, friends, and allies. The full inclusion of people with disabilities as valued members of our communities can be achieved by ensuring presence, participation, competence, choice, and contribution.

How we live, where we live, with whom we live—each of these have an important impact on inclusion and belonging. The nature of our homes has a lot to do with how other people see us. People who are seen as deserving only a “home-like” environment are not as valued as those who are seen as worthy of owning their own homes. People who live in residential facilities or other segregated places are not as valued as people who have a home to go to. People who are not allowed to choose with whom they live, or where they live, or when they eat, or what they eat, and so on, do not have control over very important parts of their lives.

The challenge is to impress upon policymakers, administrators, university researchers and educators, direct service providers, and our neighbors that community support of people with developmental disabilities and families requires fundamental changes in how we think and act. Family support cannot be seen as simply 14 days of respite per year, parent counseling, or sibling support groups. It must be seen as "whatever it takes, for as long as it takes." Family support means responding to the needs of each family as a unique family. At the same time, families and/or individuals with disabilities don't always have to be dependent on the service system for their needs. They can also investigate the natural supports (friends, neighbors, church members, and/or many others) and generic services (the same things used by people without disabilities, like local businesses, park and rec, volunteer organizations, etc.) that are already available in their communities. When individuals/families use natural supports and/or generic services, they're also assured of being included, just like people without disabilities.

Having a home of your own should not be a game of “let's pretend”—trying to convince ourselves and others that a group home is really just like a college dormitory or an army barracks, where people with a shared interest live together.

Not long ago, it was unimaginable to think about people with developmental disabilities owning their own homes. It was unimaginable to think of families having control over the resources they

receive and having a real say in what those resources should be. Today, the unimaginable is not only imaginable, but is actually possible and real.

Together, we can create opportunities that are *better* than we can imagine. We can continue to make the unimaginable happen.

### Concept Highlights

- The majority of people with developmental disabilities have always lived at home with their families or on their own. But the majority of funds are used for out-of-home placements.
- Children with disabilities have the same rights as all children to grow up in the security of a nurturing family home.
- Family support means a commitment to do whatever it takes to assist families of children with disabilities to live as a family.
- People with disabilities need to be able to move out of the family home and establish their own identity as adults.
- Control over your own life—particularly where and how you choose to live—is essential to the definition of adulthood in modern America.
- Despite great progress, reform efforts of the last 30 years continue to place control in the hands of human service organizations.
- Supports for families and for individuals with disabilities require a new role for human services, built on a problem-solving partnership and recognition of the primacy of “consumer control.”
- Providing an array of supports for daily living is far different than providing a continuum of residential options.
- “Supported living” provides a useful framework for exploring how housing can be separated from supports.
- Individuals with the most significant disabilities can be supported in their own homes.



## Concepts

### Being in Control

Most of our service models, funding structures, quality assurance mechanisms, and public policies related to people with developmental disabilities have their roots in the institutional model. Community membership of people with disabilities requires totally new ways of planning, funding, and supporting people. Choice and control are central to developing these new ways.

The system should be there to support families and people with developmental disabilities to make choices and be in control of their lives. The system should not be there to take control over what people need, how they should live, and/or a narrow range of choices that are offered. The fact that families and individuals need assistance and support should not overshadow or define their entire lives. There is nothing inherent in raising a child with a disability that should require families to complete myriad forms and await endless approvals to confirm what families already know about the needs of their children. The need for support in certain aspects of life should not require adults to give up their rights to make decisions about how they wish to live. We need policies, practices, and funding systems that support, respect, and affirm the home, the family, and the choice of each individual.

### Supporting Families

Many people with developmental disabilities have grown up at home with their families and lived as adults in our communities. Yet only in the last 25 years or so has there been a sustained movement to assist families to meet some of the additional demands that may come with raising a child with a developmental disability.

In the past, public policy (or the absence of it) was based on the belief that raising a child is a private, not a public or shared, responsibility. The advice of medical professionals and friends alike was, "Put the child away and get on with your life." Children with disabilities were seen as burdens. In this climate, many families had limited options: it was go it alone or place their children in institutions. When families did not have the resources to meet their child's needs and continue to function as a cohesive family, the choices narrowed.

Parents who chose to ignore professional opinion and raise their children at home frequently had to continually justify this decision to others. Our society did not see children with developmental

disabilities as children. “They” were not like other children. “They” did not need the nurture, warmth, care, concern, and commitment of their parents to develop into well-rounded people, since “they” would never fully develop.

The efforts of advocacy organizations and decisions in court cases began to dismantle the institutional model, and community-based services replaced institutional-based services for adults with disabilities. It became clear that it *is* possible to support people with significant disabilities to successfully live in the community.

Policymakers were then called on to provide community services and supports to help parents, and “alleviate the stress of raising a child with a disability.” Respite programs emerged, as well as parent counseling aimed at “assisting parents to come to terms with their child’s disability.” There were calls for investing public money in supporting the family rather than replacing it with institutional care.

Advocates pointed out that most states operated two distinct systems of child welfare. One system was for children without disabilities. It emphasized the importance of strengthening and maintaining the family home, and supported the right of children to grow, develop, and be nurtured in the natural family environment. The other system—the Developmental Disability system—generally denied the importance of a natural home-life and failed to recognize any rights of the child. When the fight for a free and appropriate public education was won, the door was opened to eliminate the separate and unequal approach to child welfare.

Since about 1980, grassroots parent organizations have pressured policymakers to change their thinking, priorities, and funding methods. Advocates have insisted that all children have a right to grow up in a real home with a family. They have fought for family-focused services as the first priority in the state’s developmental disabilities budget. This family support movement has developed a core of policies and practices that begins to define a true community system of services and supports.

The cornerstone of a family-centered approach is the idea that families need to exercise choice and control over decisions that impact their daily lives. Parents need to be affirmed in the depth of knowledge they have about their children and family. Professionals are most effective when they abandon a judgmental diagnostic model of service and join in partnership with families to address the unique needs of the family. When the community (including public, private, formal,

and informal resources) joins with families of children with disabilities to mobilize resources and build connections, great progress can be made.

The trends in family support are quite positive. Nevertheless, constant vigilance is still required to protect the progress made and push for increased responsiveness to families. The threats are real:

- In some areas, children with disabilities are still admitted to institutions and/or nursing homes.
- There is not universal agreement that group care settings (nursing homes, group care homes, etc.) are totally inappropriate for children.
- Family support programs still receive a small percentage of total funds in developmental disabilities budgets.
- In many areas, family support still leads a precarious existence because it is not firmly embedded in the core of legislation or budgets.

A number of barriers continue to make it difficult for people with developmental disabilities to have their own homes:

- They are poor.
- Their parents might be so desperate for security in the future, they take the first placement that comes along.
- There is a huge human services industry based on housing adults with developmental disabilities in congregate facilities.

There are also many more opportunities for people with developmental disabilities to purchase or lease single-family homes, duplexes, condos, and units in housing cooperatives. Service and funding options are expanding to make home ownership and housing rental a reality.

The advantages of home ownership or consumer-controlled housing support the principles of self-determination:

- Permanency: Homes are not lost when service providers change.

- Community inclusion: Living near people and places of one's choice increases community participation.
- Freedom: Privacy is more easily assured; the rules are made by those who live in the home.
- Respect: Home ownership is part of the American Dream!
- Responsibility: Managing a home and household activities are equated with being an adult and having a meaningful role in the community.
- Economic Gain: Choice of housing and housing arrangements can free up funds for other expenses. Homeowners and renters contribute to the local economy.
- Location: Living close to work, transportation, shopping areas, friends, and family reduces dependence upon others.
- Choice: Control of housing includes controlling with whom one lives.
- Independence: Selecting services and service providers that best meet one's individual needs, regardless of where the person lives.

#### Support for Adults in Their Own Homes

Just like people without disabilities, people with developmental disabilities want a piece of the American dream. They want a home of their own. Home—your space, where you're in charge, where you can be yourself and not who someone else wants you to be. Home—the place where you pick your housemates. Home—the place that the United States Constitution protects from government intrusion. Moving out of your parents' home, getting your own place, and setting up housekeeping are the signs that you're an adult.

In addition to government sources, individuals with developmental disabilities, often with the help of family and friends, are developing other strategies:

- Using the Fannie Mae Foundation and its approved lenders to finance the purchase of a home.
- Becoming part of Habitat for Humanity.

- Parents bequeathing the family home directly to the family member or putting it in trust, for use by the family member.
- Family and friends financing a house, and renting out part of it to earn money toward paying off the mortgage.
- Several people with disabilities pooling their own resources to buy/rent a home together.

In every community across the nation, parents look forward to the day when their sons and daughters settle into a stable and secure adult lifestyle. Parents of young adults with developmental disabilities may look forward to the help of the adult services industry. Unfortunately, however, the way many service providers operate can cause parents to feel nervous and fearful, instead of feeling secure.

When a person with a disability needs daily assistance, the best that many systems can offer is a place on a waiting list for “placement” in a group home. Often, the waiting lists are far too long. A person may move up higher on the list only if he/she is in crisis. There's little hope that families will be able to arrange a smooth transition into adult life for their children. Often, adult children with disabilities live with their parents until the parents die or become incapacitated.

Fear, anxiety, panic prevail. Time is running out; parents wonder, “What happens when we're gone?” Many become so desperate for some sense of security that they'll grab at anything that looks like a solution. Decisions are often made based on “what's available,” rather than the desires or preferences of the person with a disability, or even the parents. The priority is some measure of security for the future. It's easy to appreciate how any available placement right now might be seen as better than the uncertainty of a future driven by crisis. Sadly, the result may be same. Whether parents act out of desperation, or systems respond in crisis, the person with a disability is placed in a facility where the rhythm of daily living is managed and controlled by others.

Unfortunately, much of the professional literature and popular media perpetuate the myth that people with developmental disabilities require housing in "home-like environments." The institutional mindset is alive and well. On top of that, a huge industry has developed to provide residential services. This industry manages and controls the lives of adults with developmental disabilities.

This community residential services system has great diversity. At one extreme, there are community organizations that support people to live in their own homes. The organization provides support, but does not control the housing. There are also small group homes managed by efficient, responsive organizations. They try to make it possible for the people they serve to have some degree of control over the places they call home. At the other extreme are large, corporate, adult foster care homes where people with developmental disabilities are commodities.

Several factors are creating a climate that is ripe for reform:

- **Strain:** An unresponsive system that places high stress on families and plays on their worst fears.
- **Awareness:** An awareness of advocates and committed service providers that a "community system" designed and operated within an institutional framework doesn't work. Carefully managed, normalized environments hurt rather than help.
- **The Voice of Self-Advocates:** A persistent demand from adults with developmental disabilities that they want choices and control over their own lives.

As the segregation of the past is being rejected, new ideas emerge:

- A continuum of services and the idea of least restrictive environment create the illusion that people need tightly managed settings. The real need is not restriction or limited options, but services and supports in the most integrated setting that are geared to each person's needs and preferred living situation.
- Group living and home-like environments must be replaced with services and supports to individuals in their own homes.
- We must engage in more respectful relationships with people with disabilities. We need to really listen, so we can hear what they say: "I want an education, a home, a job, friends, a family." These are achievable goals that were once written off as unrealistic.
- Professional roles must be redefined as assisting people to achieve a wide range of natural and diverse human goals, and figuring out what it means to work "with" or "for" people with disabilities.

We must redefine our priorities:

- Concentrate on identifying individual and collective strengths rather than deficits.
- Explore personal hopes, dreams, and goals.
- Abandon "unrealistic expectations" based on diagnostic categories. Expectations related to the attainment of personal life goals supersede minimal expectations related to the achievement of programmatic goals.
- Replace a crisis-intervention mentality with a proactive crisis-prevention perspective that identifies formal and informal resources, and develops multiple back-up strategies.
- Understand that support is not a program that ends; it's a long-term commitment.

Most service systems have not begun to figure out how to get out of the real estate business and convert resources to providing supports. However, a growing number of responsive organizations are beginning to provide truly individualized supports to adults with developmental disabilities, including individuals with very complex and significant needs, in their own homes. The poverty that's so often associated with people with developmental disabilities raises new challenges as housing is separated from supports. If people are not living in a program, they need to go out into the marketplace to obtain housing. While these difficulties are not insurmountable, they underscore the many barriers that still hamper adults with developmental disabilities from choosing where and with whom they live.

#### The *Olmstead* Decision

The right of people with developmental disabilities to live in the community was reinforced by the July 13, 1999 decision of the United States Supreme Court in *Olmstead v. L.C. and E.W.* Lois Curtis and Elaine Wilson wanted to receive services from the state of Georgia in the community instead of in a psychiatric institution. They argued that Georgia violated their right to services in the most integrated setting under the Americans with Disabilities Act (ADA). Their case went all the way to the Supreme Court, and the Court ruled that the ADA requires States "to place people with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individuals, and

the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

Unfortunately, the decision still leaves room for states to maintain "a range of facilities." The court recognized that the ADA does not necessarily require a state to serve everyone in the community, but those decisions regarding services and where they are to be provided must be made based on whether community placement is appropriate for a particular individual in addition to whether such placement would fundamentally alter the state's programs and services.

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#### **8. Strategies for System Change**

- Creating a Vision
- Community Organizing
- State Legislation
- Federal Legislation
- Serving on Boards
- Parliamentary Procedure

#### Competencies

- Participants will create a vision for the year 2020 (and beyond) for people with disabilities.
- Participants will understand how a bill becomes a law at the state and federal levels.
- Participants will be able to identify critical federal issues and the process by which they can personally address their concerns.
- Participants will be able to demonstrate successful techniques for advocating for services to meet the needs of unserved and underserved individuals.
- Participants will draft and deliver testimony for legislative hearings.



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- Participants will learn how to meet a public official and express concerns.
- Participants will be able to identify strategies for beginning and sustaining grassroots level organizing.
- Participants will understand the role of when and how to use the media to effectively promote their issues.
- Participants will be able to demonstrate proper procedures for conducting a meeting.

### Why This Topic Is Important

Most of the Partners in Policymaking curriculum focuses on the “what” of change—changes in policies and actions, and values and attitudes that are necessary if people with developmental disabilities are to enjoy a good life as participating, contributing, and valued members of the community.

This topic focuses on the “how” of change: basic skills, actions and strategies that can be used to influence professionals, policymakers, and politicians.

The problem, of course, is that there is no magic formula for successful change-making. Sometimes you don't know what worked until you've succeeded. And it's not enough to complain or even to be right. Successful change-making requires creativity, tenacity, focus, vision, determination, and the ability to negotiate and persuade. The issues, concerns, and strategies discussed here have been identified as important considerations among effective policymakers.

### Concepts

It's critically important that you:

- Have an idea of what you don't like and/or what's not good enough based on your own personal experience.
- Know what you like, what's working, and why.
- Clarify for yourself (so you can communicate it to others) why, “This is right...”
- Have a clear vision of the type of world you'd like to have.

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- Figure out who might agree with you, turning “you” into “we.”
- Figure out why others might be reluctant to agree with you or support your ideas.
- Determine if your vision, or your shared vision, can be divided into smaller parts or steps that could be achieved more easily one step at a time.
- Explore with others, when possible, various ways to pursue your vision in part or in whole. Dream Big!

This process of planning for change is similar to developing an individual plan:

- Have specific measurable goals and objectives.
- Decide which strategies to try first.
- Decide who is going to be responsible for working on which objective and how they'll proceed.
- Determine how and when you'll monitor/measure your progress toward each objective.
- Understand when it's time to regroup and/or re-examine your strategies, your successes, and the appeal of your current objectives.

### Concept Highlights

People with disabilities, families, and allies need to be a part of the change process. We need to:

- Know what's possible.
- Define the issues.
- Develop a vision.
- Work together.
- Involve elected officials.

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- Clearly communicate with policymakers about what needs to be done, what's possible, and what's right and what's wrong.
- Involve the media.
- Know what advocacy organizations exist and if they would be helpful allies.
- Know how to run meetings.
- Learn how to organize.
- Be creative.
- Be persistent.
- Generate win/win outcomes!

### Review of Issue/Action Planning/Organizing

Here are some considerations for developing a strategic plan:

- **Pick an Issue.** Beyond knowing what you like or don't like, you need to select issues that you care about. The Partners training sessions have covered a number of issues that may have motivated you, and there are many other issues that desperately need attention, too.
- **Build Your Energy.** Visit the best and the worst disability-related programs. This will give you something to support, something to be outraged about, and a great deal to share with others about how great a difference there is between the best and the worst.
- **Join With Others.** If you're part of an organized group, discuss the issues and select those that generate the most passion. If you're not part of an organized group (or if your group isn't willing to take action), look for other committed people to recruit to the cause.
- **Hold Public Officials Accountable.** Know your elected officials. Keep their names, addresses, phone numbers, and email addresses handy. Visit your elected officials as a constituent. Provide them with written information about your concerns. Write letters to them. Vote in every election. Support good candidates. Volunteer in their campaigns. Make sure they know about—and maybe visit—good and bad programs, and that they

understand (with help from you), *why* the good ones are good and the bad ones are bad. Share your vision of the way things could be and should be. Otherwise, how can they make the right choices?

- Take the Making Your Case online course to help guide you through the process of partnering with policymakers (<http://www.partneronlinecourses.com/partners-in-making-your-case/>).
- Court the Media. Get to know local reporters and editors. Develop a positive relationship, and let them know about positive human-interest story ideas, as well as disability programs that are models of the way things should be. Reporters and editors need to know you as a valuable “source,” so they'll call you when they have questions or need more information. React to stories that don't reflect best practices or your vision, or stories that encourage/promote pity, segregation, devaluation, etc. You want a close relationship with people in the media so that when conditions are so bad that something needs to be exposed, they'll respond to your request. This won't happen unless you nurture the relationship and develop mutual respect before the sky is falling!
- Reward Positive Behavior. If you're part of an organization, make sure you publicly give awards for positive articles and positive behavior (in support of "the cause") by legislators, media representatives, employers, school personnel, or anyone else who deserves to be reinforced. Say "Thank You" frequently.
- Don't Forget Politics. Be active in the electoral process, especially if there are positive candidates from any party who share your values and who need your support. Run for public office—many Partners graduates are now elected officials; they *are* the policymakers!
- Get Connected. Join social justice organizations, parent groups, advocacy and/or self-advocacy organizations. Join groups online. Learn what organizations exist, what their missions are, and whether you need to work with them for change.
- Speak Up and Out. Speak out against labels, abuse, neglect, suffering, segregated programs, and the lack of involvement of people with disabilities and families in issues that impact their lives.

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- Support Allies. Actively support colleagues and friends. Show your support with calls, emails, and thank you notes. Stand up with and for people who are allies.
- Write. Write letters and emails; letters to the editor; letters of support; letters to complain; letters to suggest; letters to officials. Letter-writing campaigns can have a major impact. (Keep copies of letters for your files, for officials, for attorneys, and for follow-up).
- Testify. Share your personal stories. Any constituent can give testimony. Learn about it. Ask about it. Just do it!
- Educate. Sponsor workshops, meetings, speakers' bureaus, speeches, information brochures, posters, newspaper articles, conferences, and more.
- Communicate. Post videos, use all the social media available to you to convey your personal story. Consider phone campaigns, advertisements, press releases, press conferences, booklets, pamphlets, seminars, PowerPoint presentations, movies, resource guides, cable TV programs, radio or TV talk shows, exposés, public service announcements, websites, Facebook, online petitions, Twitter, and listservs.
- Legal advocacy. Law is a strategy. Review all it has done. Review what changes would not have been made without litigation. Think about it.
- Fact-finding forums. Think about citizen investigation panels, team meetings, community polls (of consumers, of parents, of neighbors, of the electorate-at-large), seminars by expert panels, radio and TV question and answer programs.
- Demonstrations and Flash Mobs. These are an established part of the American landscape of social change. From women's suffrage to civil rights to the rights of people with disabilities, this is an acceptable and a powerful way of sending a message by showing up. The powers-that-be don't expect traditionally powerless groups to make demands. Be creative! Be effective!
- Learn How to Run a Meeting. Every activist needs to know how to organize and run a meeting to be effective.

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**Relevant Website Links:**

- Minnesota DD Council Partners in Policymaking Curriculum:  
<https://mn.gov/mnddc/pipm/curriculum.html>
- Partners in Policymaking Coordinators Guide:  
[https://mn.gov/mnddc/pipm/pdf/Partners\\_Coord\\_Handbook2016.pdf](https://mn.gov/mnddc/pipm/pdf/Partners_Coord_Handbook2016.pdf)
- Minnesota DD Council Partners in Policymaking Main Website:  
<https://mn.gov/mnddc/pipm/>
- Minnesota DD Council Partners in Policymaking Online Curriculum:  
<https://partnersonlinecourses.com/>
  - To view this curriculum, note that you will need to register and confirm your registration via email. Registering for the online curriculum is free.