Cross-Network Collaboration:
Leveraging the Aging and the ID/DD Networks

A Supplemental Document to Session 5 in Webinar Series

Manual: How to Build a Coalition

Background

Currently the total developmental disabilities population comprises about 5% of the general population while the 60 and over individuals with developmental disability about 0.5%. Although this is a small number, it will increase over the next 20 years to 1.5% of the general population, a three-fold increase. 61% of individuals with developmental disabilities live with their family while 15% live with a spouse, 14% live on their own and 10% live in some type of supervised setting. Because of the aging needs of the older parent caregiver, who have provided lifelong care, the adult DD population is in crisis.

Prior to 1970, children born with a developmental disability were not expected to grow old. Families were told not to expect to be caregivers all their lives. Beginning in the 1980's, many of these families began to realize that their adult child would grow older and, for the most part, require their care as they themselves age. Today we now recognize that individuals with mild to moderate developmental disabilities will experience the same aging changes and rate of change as the general population. In fact, by the age of 80, the aging differences between older individuals with development disabilities and those from the general population are becoming hard to distinguish.

Only fifty percent of those older adults with developmental disabilities are receiving services from the Developmental Disabilities network. The remaining 50% are not receiving services and, for the most part, are not known to the DD service providers. This is the reason for increasing concern at the federal, state and local government levels. Why is there such a high percentage of individuals not receiving services?

- reluctance on the part of the elderly family caregivers to become associated with the formal developmental disabilities system
- reluctance on the part of families to anticipate the inevitability that a son or daughter with developmental disability will outlive them
- strong interdependency between caregivers and a son or daughter; inability of elderly caregivers to reflect upon their own aging and plan for themselves or an offspring
- lack of coordination between service networks and the immediate and long-term needs of families

This manual is a guide for the aging network to develop inclusion programs.

The social and recreational programs offered by the aging network are core to a successful and sustainable inclusion program to meet the needs of older adults with disabilities. To be successful, the aging network inclusion program must overcome many obstacles that may hinder the integration of older adults with developmental disabilities into senior programs. The success of the aging network inclusion programs is based on the follow four principles:

1. Developing collaborative relationships between the aging and the developmental disabilities networks;
2. Conducting cross-network training to build understanding;
3. Instituting a well thought-out inclusion program;
4. Developing a community-based outreach program to identify adults with developmental disabilities who can benefit from the programs offered by the aging network.

During a time of limited resources and constantly changing demographics, human services organizations are finding it increasingly difficult to meet the needs of their consumers. One approach is combining the limited resources across networks in a non-traditional working relationship. This approach is termed *coalition building* and has worked successfully in meeting diverse needs of many populations.

This manual will describe coalition building and provide practical tips on building coalitions in your local community. Included in the manual will be:

- A theoretical discussion of what are coalitions and why they are an effective approach for human service agencies and their consumers in meeting the needs of a community
- Guide on establishing a coalition
- Facilitation of a coalition

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PART I: COLLABORATION – Building Relationships through Coalitions

A. Frequently Asked Questions

What type of approach should an agency use?

Informal Approach
Networking:
Informally meeting with individuals from different networks can provide information about issues. Informal networking does not necessarily provide common goals between networks.

Shared resources and approaches (e.g. information and referral):
Sharing resources helps to reduce cost and possible duplication of services. This approach does not provide common goals between networks.

Formal Approach
Building coalitions or task groups:
Coalitions have a common goal, which usually reduces cost through sharing of services.

Advocacy for legislation and policy changes:
A coalition is comprised of many agencies working toward a common goal. A coalition can exert more influence than individual agencies.

Why collaborative initiatives work?
- Disability and/or aging providers can cooperatively provide resources when the adult caregiver or an individual with developmental disabilities within the family needs assistance
- Sharing of scarce financial resources can help stretch the available funds
- Many of families may already be in touch with other networks and collaboration will negate duplication of effort or waste of scarce resources

Planning and resource allocations will occur faster if there is cooperation and collaboration.

Who takes the lead?
Although agencies from various networks can take the leadership role, the ADRC are better prepared because they:

- have more of a focus on family issues
- have more information and resources related to issues for older people
- provide more generic aging services, which may result in their outreach being more effective

Is collaboration in favor of aging agencies?
- Aging agencies have a more neutral status in their community
- Older families may perceive less of a stigma attached to getting aid from an aging agency

- Many older and potentially vulnerable families will be less fearful that their child or relative may be taken away by an aging agency
- Aging agencies may be better positioned to help, because many caregivers need aging related services too

B. Getting Started

How to Start
1. Contact the local Arc or APD (Agency for Persons with Disabilities).
2. If you want to start an inclusion program at your site, talk to someone at the state Arc and the ADRC. They may be able to provide some assistance by identifying resources in your community.
3. Call the local Arc or developmental disabilities agency and the ADRC for a meeting to discuss the formation of a coalition.
4. Use the first meeting to:
   a. Establish a goal or purpose for the inclusion program.
   b. Determine who should be members of the coalition
   c. Establish a date, location and agenda for the first meeting of the coalition.
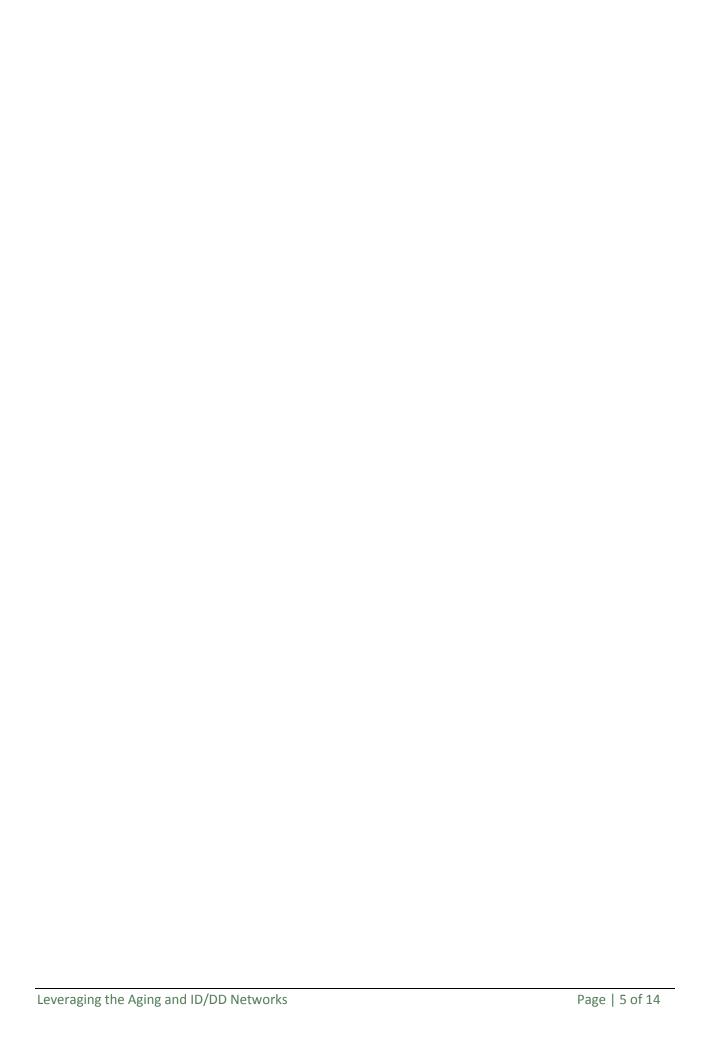5. Send out a joint invitation letter

Goal Setting
1. The purpose of the first coalition meeting should be to establish the goal.
2. Remember the underlying goal is <u>the inclusion of older adults with developmental disabilities into the recreational and social programs of the aging network</u>.

Outcomes
1. Once the goal or purpose has been established the coalition should determine the outcomes. These may include:
   a. Number and age of older adults with DD that have been included in the program
   b. Number and types of programs for inclusion
   c. Number of barriers that were identified and resolved or determined to be un-resolvable
2. Outcome measurements:
   a. The coalition should determine the milestones to determine the success of the outcomes.
   b. Timelines should be established for milestones to be met.

Continuation
1. Inclusion programs should be not developed based on funding, but on need.
2. The development of a coalition is the basis for continuation. The possibility of sharing of resources and staff should be explored by the coalition.
3. The frequency of meetings of the coalition should be determined. There should not be long periods of time between meetings.

PART II: CROSS -NETWORK AWARENESS - Education

1. WHY – Why should there be cross training between the aging and the DD network?
If the inclusion program is to be successful then the lines of communication must be clear. The funding stream, program philosophy, staffing, policy, terminology between the two networks are different and may cause confusion when inclusion programs are being developed.

2. WHO – Who should be trained?
There should be joint training including staff and members of the aging network and staff, family, and consumers from the DD network. The timing of the training should be determined by the coalition.

3. WHAT – What should be included in the cross training?
    a. The videos that accompany the manual include:
        1. "When Older Adults with DD Age"- description of aging changes in the DD population and similarities with aging in the general population
        2. "Dementia and DD"- description of dementia and the older adult with DD
    b. There is an accompanying CD to the manual that can be opened on a computer. Training materials are in PowerPoint and can be printed for information sharing or training. The presentations are:
        1. *Age Related Changes* – describes normal aging changes that occur in the general population with emphasis on similar changes in older DD individuals
        2. *Age Associated Changes* – early aging changes in the Down's syndrome and Cerebral palsy population
        3. *Dementia* – describes the different types of dementia that may or may not occur in the general population and in older adults who are DD
        4. *Medications and ID/DD* – increasing awareness on how medications may mimic, mask, exacerbate, or cause symptoms of diseases
        5. *Aging and DD Networks* - differences between the Aging and the DD networks
        6. *Aging changes for informal caregivers and the older ID/DD adult – w*hat the aging changes experienced by older ID/DD adults are and what the signs of dementia are. What are the environmental barriers for older adults with Down syndrome or Cerebral Palsy?
        7. *Addressing Changing Needs of Aging Parents and their Adult Child with I/DD –* overview of transition and changing needs of aging parents or caregivers of adults with I/DD and the potential role changes between parents and their adult child with I/DD with key interventions and strategies to support the transition of aging parents
    c. The networks should give presentations to each other. Each presentation should include information on the structure, funding, program regulations, authorization statute, staffing regulations, and population served. This will help each network understand the expectations and limitations of the other network.

PART III: INCLUSION PROGRAMS

1. GETTING STARTED

    a. Staff awareness – it is critical to prepare all the staff members for the inclusion of DD adults into the center programs. Many may have misconceptions concerning this population that need to be changed.

        Suggestions:
1. Schedule a trip to the local Arc or other DD provider to learn and understand more about this population. Be sure you attend a program that serves mild to moderate DD.
2. Invite the director or staff from the Arc to explain their system and the individuals they serve.
3. Show the videos on aging and DD and handout the appropriate information from the Power Point material.

    b. Member and caregiver awareness – critical that program members and caregivers are aware of the inclusion programming for the same reason as the staff

        Suggestions:
1. Schedule a trip to the local ADRC, Arc or other DD provider to learn and understand more about this population. Be sure you attend a program that serves mild to moderate DD.
2. Invite the director or staff from the Arc to explain their system and the individuals they serve
3. Show the videos on aging and DD and handout the appropriate information from the Power Point material

    c. Inventory of available programs – this will allow you to share the type of programs that you offer when you meet with the family, individual or the case manager.

    d. Beginning the program – at first it is advisable that you introduce only a few older individuals with DD into the center's programs. You can increase the numbers after a level of comfort for the center and the new members is achieved.

        Suggestions:
1. Establish a "buddy" system between a member of the center and the new member to show them around and introduce them to other center members and help them feel comfortable.
2. Establish a staff and membership committee to address any concerns or issues by other members. Be sure that the membership includes an individual with DD.
3. Start the inclusion with individuals that have a high level of functioning.

2. ASSESSING FOR ACTIVITIES

Ask each new member, or their caregiver, what their interests are or the type of activities preferred. Since this population will have some disabilities, you may have to assess their capacity for involvement. Include the case manager, parent or family caregiver in discussion of participation in programs.

a. Physical disabilities – There are many different types of physical disabilities that the older individual with DD may have; do not assume that these are limitations. Many with Cerebral palsy have coordination problems but have adapted coping skills and have average or above average intelligence.

b. Mental retardation – It is a myth that all individuals with DD also experience some form of retardation. Do not associate communication problems with retardation. May older individuals with Cerebral palsy may have both coordination and communication problems but will have average to above average intelligence. Many older adults who have mild to moderate retardation are employed, living independent, and may be married. Similar to the general population, they can learn new activities and can derive enjoyment in participation.

c. Communication – Many older adults with DD may have various levels of communication difficulties. It takes patience to learn how to listen in order to understand what is being said. Do not equate communication problems with mental retardation.

d. Behavior – Some older adults with DD may have behavioral issues. Once such issues are determined then strategies can be developed to either prevent or intercede in any behavioral situations. Ask the case manager or family caregiver if there are any behavior issues, what they are, and how they are resolved. Staff should be made aware of such issues and how to intercede.

3. QUESTIONS TO ASK

Some individuals may have a history of physical and mental disabilities that may require someone to accompany them to programs. Many may not. You need to determine the needs of these individuals and their families.

a. Caregiver accompanying the individual – You need to be aware if the individual will have an aide accompanying them. What will be the duties of the aide? Must the aide be with the person at all times? Can the aide assist the center staff in any programs in which the DD individual is participating?

b. Medications – Many of these individuals will be taking medications. If an individual has an aide then the aide will dispense the medications. If there is no aide then you need to determine the drug regime and make some arrangements for dispensing the medication.

c. Special needs – What are the most pressing needs of the adults and their families? Some may have special needs due to their disabilities. This, of course, is equally true in an older individual from the general population. You need to inquire what these needs are and determine if you can make necessary accommodations.

d. Number of individuals - How many people with DD (and families) are in the community?

e. Services being used- What existing services and resources are there and what are they doing for these families?

f. Can the Area Agency on Aging interface with existing efforts, or spearhead the initiation of a new effort?

4. PROGRAMS

Programs presently offered by the senior centers are appropriate for older adults from the general population, older adults with developmental disabilities and older adults with aging associated disabilities in the general population. This is inclusion. In addition, new programs or shared programs between the center and the DD agencies can be developed. The coalition can help to develop new or shared programs to serve both populations.

a. These are suggestions of center inclusion programs. You may already be doing some, if not all, of these programs – many overlap in purpose.
   1. Mental exercises:
      a. board games - checkers, chess, Chinese checkers, backgammon, monopoly, scrabble, trivial pursuit
      b. cooking/baking classes
      c. puzzles
   2. Physical strengthening:
      a. walking
      b. weights
      c. yoga, tai chi, etc
      d. weight machines/treadmill/Stairmaster
      e. softball
      f. volleyball
      g. horseshoes
   3. Socialization:
      a. activities centered on meals
      b. volunteering (at center or in the community)
      c. crafts/wood or mineral working
      d. travel
      e. group chorus or band
      f. model plane/cars/train building or collection
   4. Education:
      a. nature programs (birding, plant identification, mineral collection or identification)
      b. reading books followed by oral discussion
      c. discussions on local history
      d. home repair classes
b. You should explore the possibilities of having members of the center participate in programs the Arc may be offering such as bus trips or recreational programs.
c. To increase awareness of the inclusion program an annual lunch could be jointly held. The coalition and other representatives from each network and from the community could be

invited. Awards or certificates of recognition can be presented to individuals or agencies that have contributed to the efforts of the coalition.

PART IV: OUTREACH - Community

It is important to know that only half of the older adults and their family caregivers have been identified by the DD system. There are many who live with their family, especially in the rural areas, that go undetected by the service providers or choose not to receive services. This population is especially vulnerable to a crisis because of the potential for the breakdown in the informal support system. The reason is either due to health concerns or exhaustion of their aging caregiver family member or death of the primary caregiver. It is especially challenging to identify and reach these families. Any outreach program should not be based on identifying the families and doing a visit. Many families have reasons for not wishing to be identified or to receive services. **Rather, the major thrust of the outreach program should be self-identification. The outreach efforts should make families aware of services offered by the aging network that may benefit the adult child with DD and the older family caregiver.**

1. Suggestions:

   a. Develop a laminated information sheet directed to this population with a listing of programs and local contact numbers that can be posted or distributed in English, Spanish, and or Native American languages, reflecting the location.

   b. The information sheet can be posted in:

      - churches and church bulletins
      - drug stores
      - grocery stores
      - dentist and physician offices
      - health clinics
      - gas stations/repair shops
      - community recreational facilities
      - banks
      - post office
      - barbershop/ hairdressers
      - hardware stores
      - local governmental offices (social security, social services for Medicaid or food stamps, driver's license, others)

   c. The information sheet can be used by community service providers who come in contact with families

      - electric, gas or water meter readers
      - trash removal services
      - mailman
      - other

    d. Articles in local newspapers or public service announcements radio shows or on a local talk show can be used to increase community awareness.

    e. Newsletters distributed by area business to employees can be used for communication describing the outreach efforts.

2. Three things to remember when initial contact with families is made:

    a. Some do not have current needs, but are interested in learning about services for a later time

    b. Some will ask for help for a specific concern they have identified

    c. Some are in crisis and are in immediate need

Guide for Establishing a Coalition

Part I: Coalition Planning

1. What is the need?

    a. Describe the need

    b. What is the nature of the need (change a system, introduce a process, expand an existing system, etc)?

    c. Why must there be a change?

    d. What is the geographical area affected by the needs ?

    e. Who is affected by this need?

    f. Describe the population

2. Who has recognized or identified the need?

3. What is the <u>one </u>identified goal?

4. Why a coalition can best address the need?

5. Who can you contact to start a planning group?

6. Who should be part of the coalition?

    a. What networks are affected by this need?

    b. What individuals, agencies, and organizations should be included to participate?

    c. At what level should they be administrators, providers of service, decision makers or others?

    d. Is there a balance, when appropriate, between public and private agencies?

    e. Who will be the core members?

7. Who should be the neutral facilitator? Why?

Part II: Implementation

1. What should be in a concept paper?

2. What outcomes should there be?

3. How can the outcomes be measured?

4. What types of barriers are there?

5. What are the tasks to meet the outcomes?

6. What should be the subcommittee structure?

7. Where will the first coalition meeting be located?

8. What type of funding may be available to support the tasks?

9. What are the possible resources that can be shared?

Part III: Checklist

Yes	No	
__	__	Initial reason for establishing a coalition is driven by need
__	__	Identification of the single obtainable goal to build the coalition
__	__	Identification of a neutral based facilitator
__	__	Formation of a core membership in the coalition
__	__	Establish membership list
__	__	Developed concept paper