

The Merrimack Valley Aging and Disability Resource Center (MVADRC) Cross Training

Session 1

Overview and Philosophical Tenets of the
Elder Services of Merrimack Valley and
Northeast Independent Living Program

September 2004



LTC for Elders – It's Roots and Origin

Session 1

Presented by

Anne Proli Cataldo, Associate Executive Director
Elder Services of the Merrimack Valley, Inc.

and

Merrimack Valley Aging and Disability Resource
Center



The Federal Response to Aging Issues

1935
The Social Security Act



The Advent of the Civil Rights and Women's Movements



Elder Services of the Merrimack Valley, Inc.
Choices for a life-long journey

Mid 1960's

**Medicare
and
Medicaid
begin**





Medicare / Medicaid and Special Needs

For the disabled, mentally retarded, and mentally ill the concept of least restrictive environment was promoted.

Elder Services of the Merrimack Valley, Inc.
Choices for a life-long journey

Remaining at Home





“De-institutionalization” Movement

The "de-institutionalization" movement was initiated, with the most significant changes occurring through class action suits on behalf of the disabled.



1965

**The Older American's
Act**

Signed by President Johnson





The Older American's Act Created:

- The Administration on Aging (Federal)
- State Units of Aging (In Massachusetts, known as the Executive Office of Elder Affairs)
- Sub-state Area Agencies on Aging (ESMV is one of 670 nationwide)



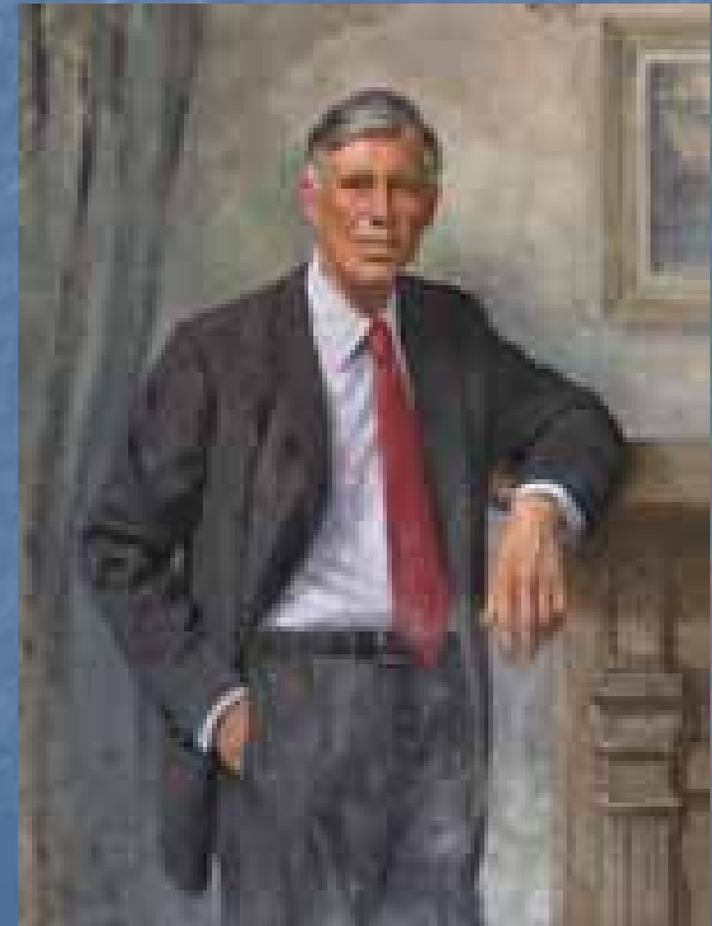
Administration on Aging

As an AAA, ESMV's mandate is:

- To plan and monitor the needs of all people over age 60 living in our service area (23 cities and towns of the Merrimack Valley).
- A needs assessment is required every four years, and a plan developed to address those needs.
- § To administer federal funding to help create the programs needed.

The Massachusetts Response

The Creation of the Executive Office of Elder Affairs





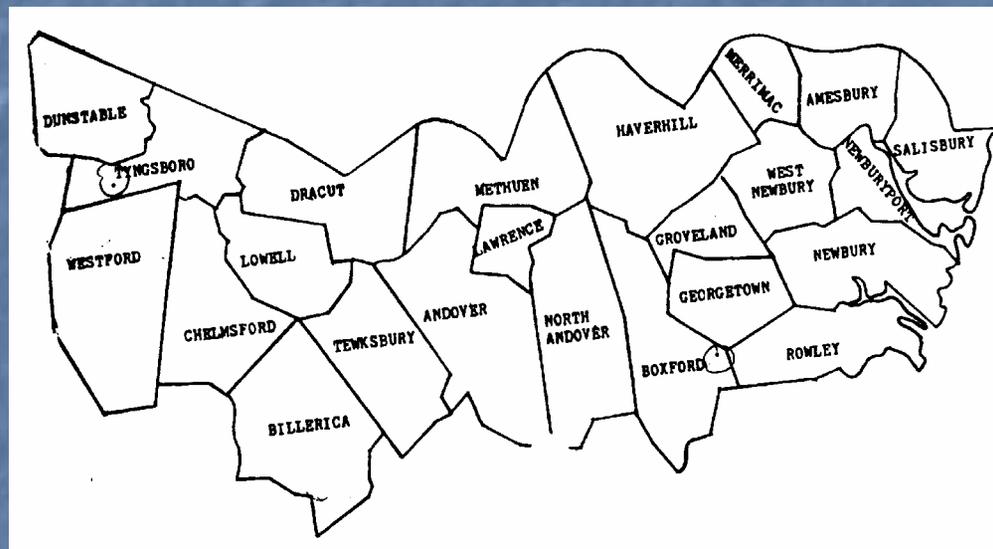
The Massachusetts Response

State-funded Home Care



Frank Manning

The Massachusetts Response



27 Home Care corporations created



1982

Mass Home Care is formed



Mass Home Care

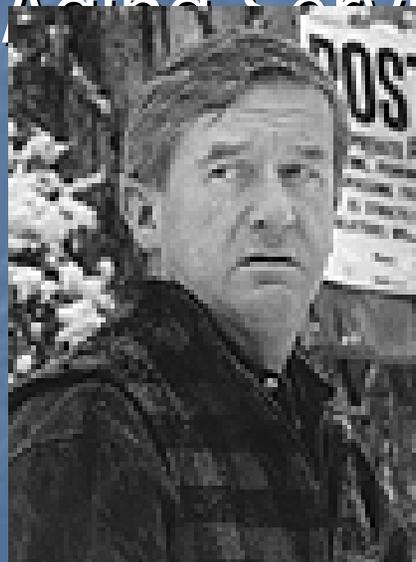


24 Third Avenue, Burlington, MA 01803
“There’s No Care Like Home Care”



1996

The Creation of Aging Service Access Points





1997

The Executive Office of Elder Affairs
is given the authority to designate and
oversee ASAP's

Philosophical Tenets for Service

- Consumer Controlled Non-Profit Organizations
 - ✓ 51% of Board members be over the age of 60
 - ✓ 51% appointed by local Councils on Aging
- Independent Case Management Model
- Interdisciplinary Model



Consumer Controlled Non-Profit Organizations

**51% of Board members must be over the age
of 60**

51% appointed by local Councils on Aging



Independent Case Management Model

ASAP's are only allowed to conduct case management, information and referral, and protective services directly, and must subcontract for all other services.

Interdisciplinary Model Recognizing the Key Role of Social Supports

Case managers coordinate clients' care with nurses, the elders and their families, and outside agencies to provide the best care at home.

The Independent Living Movement: Its Roots and Origin

Session One

“Nothing about us without us”

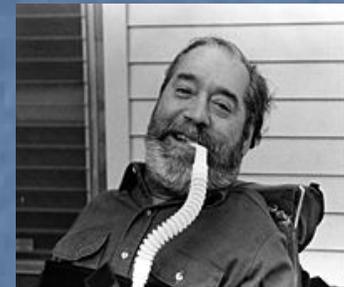
Presented by:

Charles Carr, Executive Director
Northeast Independent Living Program, Inc.

NILP.ORG

The Independent Living Movement

Roots and origin



- Definition:

In its broadest implications the independent living movement is the civil rights movement of millions of Americans with disabilities. It is the wave of protest against segregation and discrimination and an affirmation of the right and ability of disabled persons to share fully in the responsibilities and joys of our society.

Edward V. Roberts,

1977

The Independent Living Movement

Philosophical Tenets

- Consumer Control
- Cross Disability
- Right to Fail (Take risks)
- Choice
- The Exercise of Power

The Independent Living Movement

Philosophical Tenets

- Consumer Control
- Cross Disability
- Right to Fail (Take risks)
- Choice
- The Exercise of Power

The Independent Living Movement

Philosophical Tenets

- Cross Disability

The practice of inclusion of all disability groups in the movement, to ensure independence for all. When we work together, in a unified voice, to advocate for basic survival resources such as housing, benefits and services, and civil rights that cut across all disability types, we're more powerful politically.

The Independent Living Movement

Philosophical Tenets

- Right to Fail

Everyone is entitled to take risks in life. Generally, institutions provide a false sense of security and require compliance and safety. Living in the community for people with disabilities often means trying new and different ways to live that are sometimes very difficult to learn and master. Along the way, like anyone else, some people with disabilities fail to do well enough to make it, and they may return to an institution.

The Independent Living Movement

Philosophical Tenets

- Choice

People with disabilities want to decide for themselves what services they want, how they want them delivered, by whom, and in what context. This means having personal control over life choices, services and activities.

The Independent Living Movement

Philosophical Tenets

- The Exercise of Power

A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people, looking at the same misfortune, see it no longer as a misfortune warranting charitable consideration, but as an injustice which is intolerable to society.

Gerben DeJong, 1979³⁰

The Independent Living Movement

The Struggle and the Journey



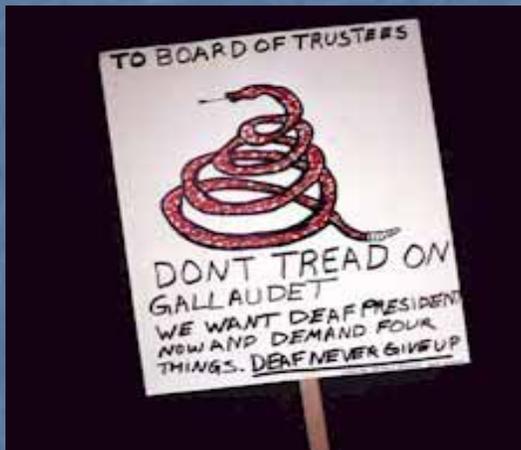
Disabled veterans in wheelchairs protest in late 1940's.

The Independent Living Movement

Section 504 of the 1973 Rehabilitation Act prohibited discrimination against people with disabilities in federally funded programs.



The Independent Living Movement



In 1988, students and alumni of Gallaudet University defied their board of trustees to force the hiring of a deaf person as president.



American Disabled for Attendant Programs Today (ADAPT) demonstration for national Personal Assistance Services , Baltimore, 1990.

The Independent Living Movement

Signed into law in 1990, the Americans with Disabilities Act (ADA) is one of the most significant civil rights documents of the 20th century. Its purpose is to end discrimination, reduce barriers to employment, and ensure access to education for people with disabilities.

Senator Tom Harkin
principal sponsor of the bill, urges
its passage in the US senate using
American Sign Language.

The Independent Living Movement

A Different Model of Services & Advocacy

- Centers for Independent Living
 - *The locus of the problem is not the individual, but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large. To cope with these environmental barriers, the disabled person must shed the patient or client role for the consumer role. Advocacy, peer counseling, self-help, consumer control, and barrier removal are the trademarks of the independent living paradigm.*

*Gerben DeJong,
1979*

The Independent Living Movement

Centers for Independent Living

■ Early Independent Living Centers (ILC's)

■ By the mid-1970s, organizations were being formed that put independent living philosophy and concepts into operation.

■ In Berkeley, California, students from the University of California founded the first center for independent living in 1972 as a means of creating independent living options within the Berkeley community.

■ The Boston Center for Independent living was formed in response to student demands in the Boston area in 1974.

The Independent Living Movement

Centers for Independent Living

■ Early Independent Living Centers

In most of these early centers, it was people with disabilities who were demanding respect through a different form of service delivery. They were putting these organizations together and securing funding for basic human needs based upon the models of service delivery they wanted in order to achieve their own independent living goals. Their services and advocacy activities fit the emerging independent living paradigm and not the rehabilitation or medical model.

The Independent Living Movement

Centers for Independent Living

- The core values of the Independent Living philosophy became the backbone of ILC Advocacy and Services.
 - **Consumer Control** - At least 51% of ILC Board of Directors, and staff at all levels must be *qualified* persons with disabilities.
 - **Cross Disability** - ILC's serve people with all types of disabilities.
 - **Right to Fail** - By promoting and supporting community living, ILC's recognized that there are inherent risks, and prepared consumers for that eventuality.
 - **Choice** - ILC's assist consumers in understanding what choices they have in all aspects of their lives, and support them throughout the decision-making process.
 - **Exercise of Power** - Individuals and systems advocacy are a hallmark of ILC's and unite the disability community to rise up against social injustice and other barriers to independence.

The Independent Living Movement

Centers for Independent Living

- Title VII of the Rehabilitation Act, as amended in 1984 defined core ILC services.
 - **Information and Referral** - To persons with disabilities, service providers, families and community members on disability and independent living topics and issues; and, referral assistance to link individuals with appropriate organizations, services and resources.
 - **Peer Counseling** - A majority of staff have disabilities and serve as role models to consumers, providing information and support, and facilitating decision making.
 - **Skills Training** - Training activities which focus on consumer skill development to achieve or increase independence.
 - **Advocacy** - A service process emphasizing consumer control and self-reliance. An array of approaches aimed at assisting persons with disabilities to take charge of the life choices, act on their own behalf, and overcome situations that reduce the potential for independence.

**The Merrimack Valley Aging
and Disability Resource Center
(MVADRC)
Cross Training**

Session 2

The Nuts and Bolts

September 2004



The Nuts and Bolts of Aging Services Session 2

Presented by

Anne Proli Cataldo

Associate Executive Director

Elder Services of the Merrimack Valley, Inc.

ASAPs Have 5 Key Functions:

1. Provide Information and Referral
2. Conduct a Comprehensive Needs Assessment for Elders
3. Develop a Care Plan to Address Unmet Needs
4. Purchase Services Necessary to Implement the Care Plan
5. Monitor the Effectiveness of the Care Plan Over Time

Home Care Intakes

1. Age Info Department Contacted
2. Age Info Provides Information / Referral or Initiates Home Care Intake
3. ESMV Staff (Nurses, Case Managers) Meet to Assign In-home Assessment
4. Eligibility for Services Determined at In-home Assessment

In order to receive State Home Care Services, an elder must meet the following eligibility requirements:

- ❑ Residency
- ❑ Age Eligibility
- ❑ Income Eligibility
- ❑ Functional Impairment Level Eligibility (FIL)
- ❑ Need Eligibility



Residency and Age Eligibility

Residency – Massachusetts resident

Age Eligibility – at least 60 years old
--or less than 60 with Alzheimer's
Disease

Income Eligibility

Annual Gross Income

- 1-person household
\$20,778 maximum
- 2-person household
\$29,402 maximum

Monthly Gross Income

- 1-person household
\$1,732 maximum
- 2-person household
\$2,450 maximum

Functional Impairment Level (FIL)

The Massachusetts Long Term Care Needs Assessment (MLTCNA) tool determines elders' inability to perform:

- Activities of Daily Living (ADLs)
- Instrumental Activities of Daily Living (IADLs)

Need Eligibility

Unmet Critical and Non-critical Needs

An applicant or client who meets the FIL criteria must also have unmet needs defined by EOEA as being in a "critical" area at the time of the initial assessment.

Case Managers to Address Needs

- Care Plan - Service Providers in _____ Categories
- Service Plan Initiated
- Plan Adjusted as Needed

MassHealth Programs

- Group Adult Foster Care Program (GAFC)
- Family Care for Adults (FCA)
- Personal Care Attendant Program (PCA)

Group Adult Foster Care (GAFC)

- Is in subsidized/housing authority complex
- Requires PCA daily
- May receive 2 days Adult Day Health and Home Health Services up to 8 hours per week without special permission
- Not in 2176 Waiver Program
- Family

Family Care for Adults (FCA)

Families provide a home environment, care, and companionship.



26 elders living with 19 host families.

Personal Care Attendant (PCA)

36 elders enrolled



Program can provide overnight care,
if needed

Supportive Housing Programs

Provide services and supports to elderly and disabled adults in state and federally funded housing developments.



Age Information

In June 2004, staff received 1,725 calls, which resulted in:

- 368 intakes
- 563 Help Desk calls
- 49 Elders at Risk / Protective calls
- 363 requests for information

Coordination of Care



- 400 elders screened on average per month by registered nursing staff for eligibility for MassHealth services (nursing homes, adult day healthcare)

Home Care

- 3,000 elders served on average per month
- 1,174 elders received Personal Care Homemaking
- 4.5 hours of homemaking on average/week
- 105 – oldest homecare client
- 26 years – longest enrolled client

Home Care Programs

Homemaker

Social Day Care

Adult Day Health

Supportive Home Care
Aide

Laundry Service

Emergency
Response/On-call

Adaptive Housing

Medication Dispensing

Habilitation Therapy

Wanderer Locator

Personal Care

Home Care Programs

Companion

Chore

Grocery Shopping

Transportation

Emergency Shelter

Respite

Vision Rehabilitation

Dementia Day Care

Home Health Services

Home Delivered Meals

Respite

- 142 caregivers assisting per month on average
- Adult/Dementia Daycare—most typical service
- \$337 – average cost per month for a family

Protective Services

Investigates Reports of:

Physical Abuse

Emotional Abuse

Sexual Abuse

Caregiver Neglect

Self-Neglect

Protective Services

Provides assistance for 106 elders per month on average

- Allegations investigated
- If confirmed, develop service plan with client
- Alleviate/eliminate the reported abuse

Homeless Elders Program

- Serves an average of 36 elders/ month
- Manages a range of transitional housing sites to support elders while seeking permanent housing

Northeast Independent Living Program

The Nuts and Bolts Session 2

Presented by Charlie Carr
Executive Director

Northeast Independent Living Program, Inc.

NILP Core Services

Throughout all of our Programs and Services are interwoven, at a minimum, the four basic core services required by law to be classified as an ILC. They are:

- ❖ *Information and Referral*
 - ❖ *Peer Counseling*
 - ❖ *Skills Training*
 - ❖ *Advocacy*

Information and Referral

NILP provides Information and Referral to persons with disabilities, service providers, families and community members on disability and independent living topics and issues; and, referral assistance to link individuals with appropriate organizations, services and resources.

Peer Counseling

One of NILP's strongest points is that a majority of our staff have disabilities and serve as role models to consumers, providing information and support, and facilitating decision making.

Skills Training

Training activities, which focus on consumer skill development to achieve or increase independence.

Advocacy

A service process emphasizing consumer control and self-reliance. An array of approaches aimed at assisting persons with disabilities to take charge of their life choices, act on their own behalf, and overcome situations that reduce the potential for independence.

Other NILP Services and Specific Programs

NILP provides advocacy and services to *all* people with disabilities. Individuals with disabilities that do not fit within the parameters of the broad program descriptions are encouraged to ask for general information and referral which will then direct them to the program that is best suited to meet their disability specific needs.

NILP Services and Specific Programs

- Adults with Physical Disabilities Program
- A Smoother Transition
- Deaf and Hard of Hearing IL Services
- Services to Mental Health Consumers/Psychiatric Survivor Communities
- VR-IL
- Aging & Disability Resource Center (ADRC)
- ADA Consulting Services

Adults with Physical Disabilities Program

Program works with adults who have physical disabilities such as spinal cord injury, cerebral palsy and muscular dystrophy. Independent Living services include Personal Care Assistance, peer counseling, accessibility advocacy, and referral for durable medical equipment.

A Smoother Transition

Works with adolescents with disabilities and their families to facilitate the transition from both institutional and public schools into the adult human services system. Specialized services include advocacy and information during the development of Individualized Education Plans and social/recreational activities.

Deaf and Hard of Hearing IL Services

The DHHILS program works with people who are culturally Deaf, late deafened, and hard of hearing in order to provide an environment that is communication accessible where a comprehensive array of IL services are available to assist in living independently. Unique services include ASL classes and peer mentoring.

Services to Mental Health Consumers/Psychiatric Survivor Community

Works with people who have psychiatric disabilities through group empowerment and community organizing campaigns and training to fight against stigma, learned helplessness, and cruel and unusual punishment in mental hospitals. Unique services include coordinating the Lawrence Organizing Voices of Empowerment group, Peer Counseling and Training, and inpatient discharge planning at Tewksbury State Hospital.

Vocational Rehabilitation- Independent Living

The Vocational Rehabilitation/Independent Living Program provides pre-vocational IL assessment, Peer Counseling, Information and Referral, Advocacy and Skills Training to eligible MRC consumers. Additional services, such as Money Management, Transportation, Benefits Counseling and Housing services all optimize a person's readiness for vocational choices, planning, and implementation

Aging and Disability Resource Center

The Merrimack Valley Aging and Disability Resource Center (MVADRC) is a new collaborative project between NILP and Elder Services of the Merrimack Valley that will create a “no-wrong door” entry point of service for people with disabilities and elders, looking to access community-based long-term services. Services such as information and referral, intake, and case management processes will be streamlined between agencies, to make it easier for consumers to acquire long-term services regardless of age or disability in an efficient seamless manner.

ADRC Community Options

Referrals to NILP will come from individuals in the community or from the Elder Services of the Merrimack Valley or eventually other community partners. At NILP there is a centralized Information & Referral (I&R) system whereby the individual/agency calling in, is directed to the appropriate program within NILP or referred behind the scenes to the Elder Services if appropriate. Therefore an individual with a disability, elderly or both will have access to a wide range of services without having to make many phone calls but rather one call to either NILP or Elder Services of the Merrimack Valley to start the process in motion.

ADA Consulting Services

The program works with Department of Public Health providers that are presently not accessible, to educate them on accessibility requirements under the ADA, and assist them in coming into compliance.

The Merrimack Valley Aging and Disability Resource Center (MVADRC) Cross Training

Session 3

So What Does This Mean For Us?

The ADRC Grant

September 2004

Aging and Disability Resource Center Grant Program

- Jointly funded by the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS)
- 3-year grant awarded to the Executive Office of Elder Affairs
- Elder Affairs selected two organizations to pilot the grant
- Collaborative effort between Elder Services of the Merrimack Valley, Inc. (ESMV) and the Northeast Independent Living Program, Inc. (NILP)

ADRC Primary Goal

Create a single, coordinated system of information and access for all persons seeking long term services and supports, regardless of age, disability or income .

ADRC Objectives

- Minimize confusion
- Enhance individual choice
- Support informed decision-making
- Increase the cost-effectiveness of the long term supports system

ADRC Key Functions

- Public Education and Outreach
- Information and Referral
- Options Counseling
- Benefits Counseling
- Employment Options Counseling
- Crisis Intervention
- Clinical and Financial Eligibility Screening
- Intake, Assessment and Service Planning

The Massachusetts Model

- “No Wrong Door” approach versus “Single Entry Point”
- Bring together two organization types serving populations with similar needs
 - Aging Service Access Points (ASAPs) and Independent Living Centers (ILCs)
- Coordination and streamlining of key functions within existing organizations.
- Serve as statewide model for replication.

The Big Picture View

3-year grant award to the MA
Executive Office of Elder
Affairs (EOEA)

Administration on
Aging
(AoA)

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MA Executive Office of Elder Affairs
Contacts: Ellie Shea-Delaney, Sandy Tocman
Project Director: Heather Johnson-Lamarche,
EOEA/CHPR Consultant

EOEA subcontracts to
ESMV and NILP as two
pilot sites for grant.

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Elder Services of Merrimack Valley, Inc. (ESMV)
Contacts: Roseanne DiStefano, Anne Prolie,
Dayna Brown

Program Coordinator: In transition (previously
Nilka Alvarez-Rodriguez)
Intake Worker: AGE-INFO Department Staff

**Merrimack
Valley
ADRC**

**Northeast Independent Living
Program (NILP)**
Contacts: Charlie Carr, Karen Bureau

Intake Worker: Elizabeth Quinn
Outreach & Training Coordinator: Kevin
Farrell

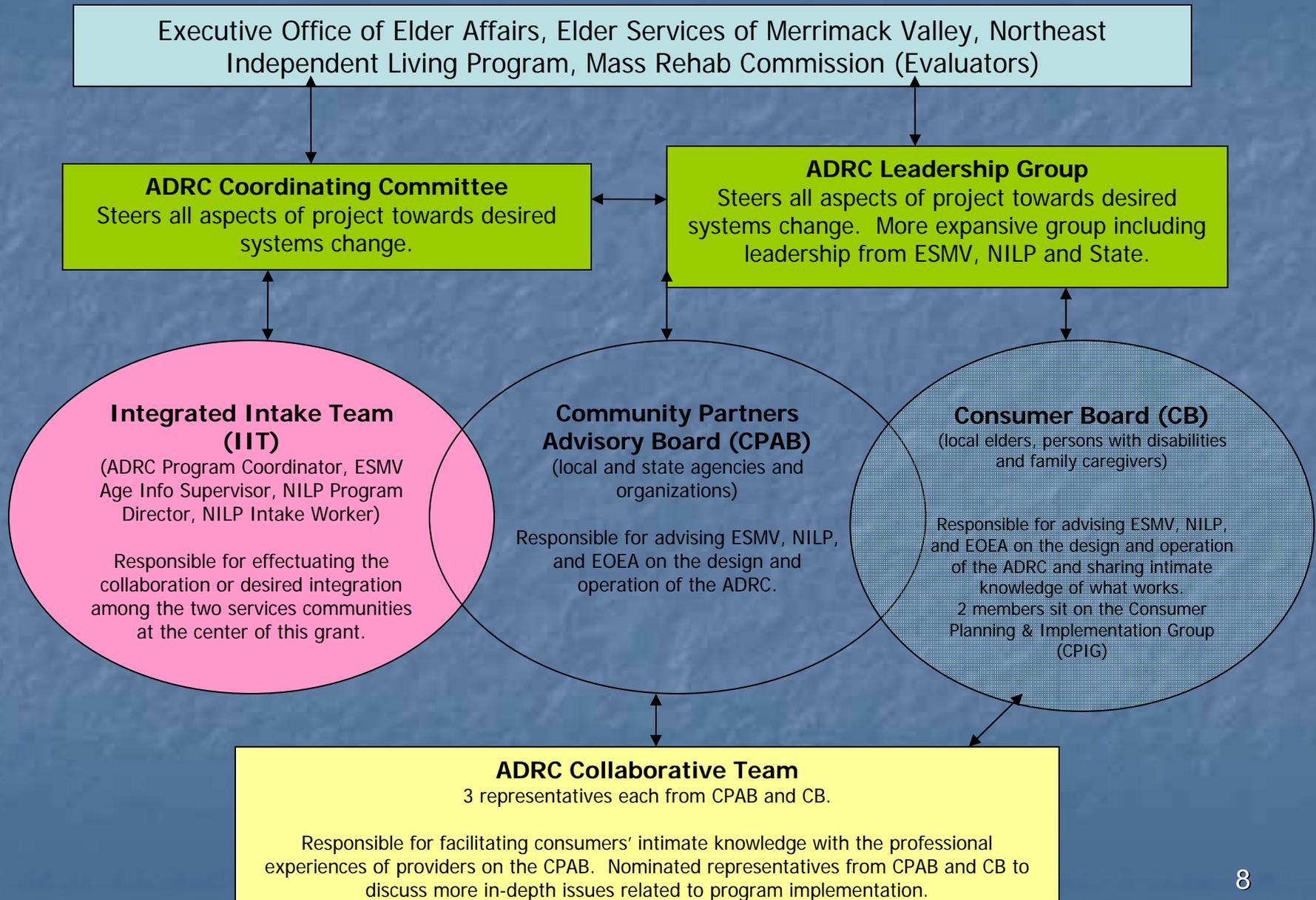
**ADRC Coordinating
Committee**
(EOEA Consultant, ESMV, NILP,
MRC)

**Integrated Intake
Team**

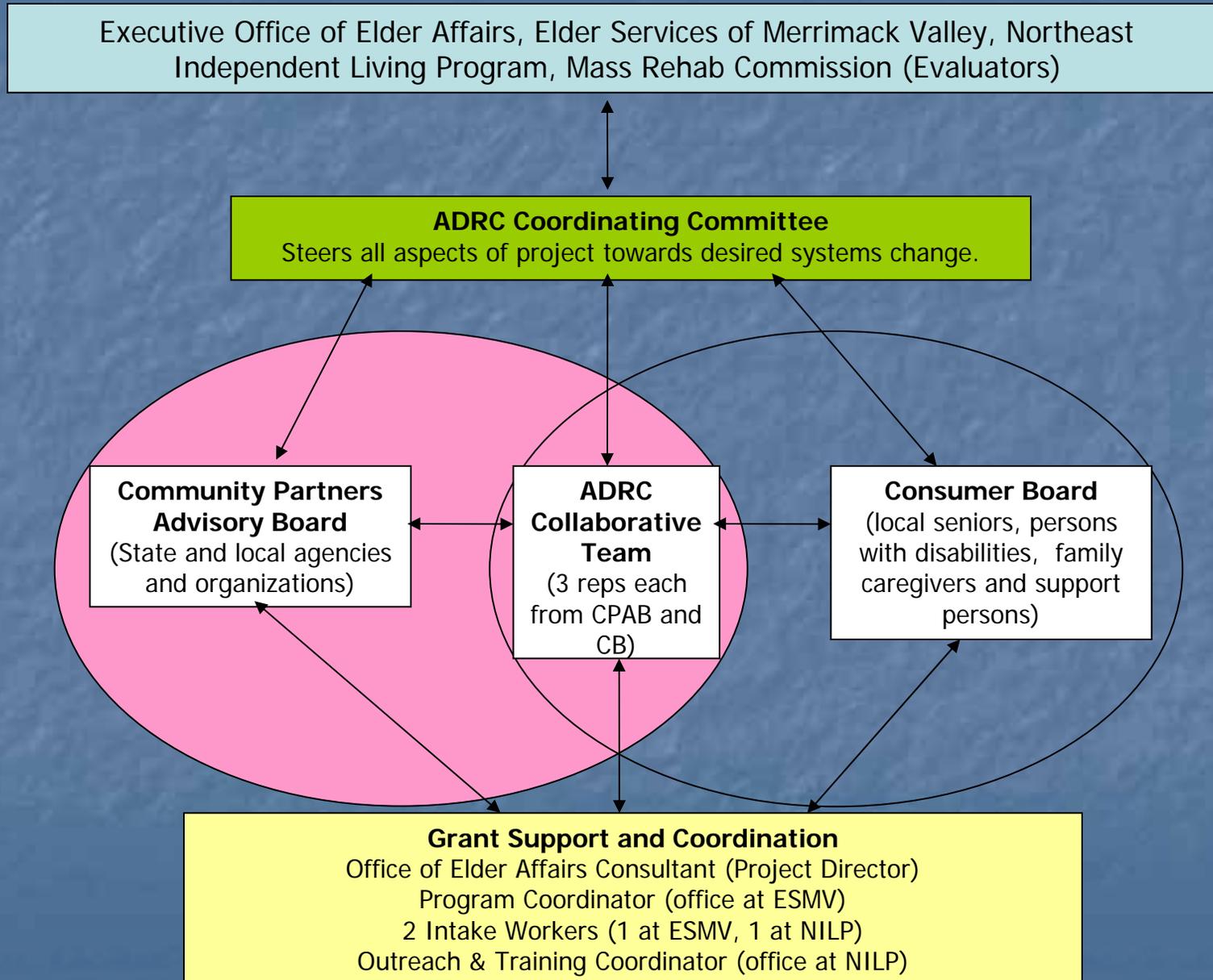
**Community Partners
Advisory Board**

Consumer Board

MA ADRC Grant Implementation and Coordination Model



MA ADRC Advisory Board Structure and Collaborative Decision-Making Model



What Are We Doing?

- Year 1:
 - Coordinate Information & Referral processes across ESMV and NILP
 - Create Consultation Form for common clients
 - Create I&R protocols across organizations
 - Cross train staff within ESMV and NILP
 - Create Community Partners Advisory Board (CPAB) and Consumer Board (CB)
 - Create 3-Year Evaluation Plan

What Are We Doing?

- Year 2:
 - Coordinate eligibility, assessment and service planning services across ESMV and NILP
 - Conduct outreach to un- and underserved populations
 - Train CPAB member staff
 - Target and coordinate efforts with critical access points in community (hospital discharge planners, nursing homes, etc.)

What Are We Doing?

- Year 3:
 - Expand model to entire Northeast Region
 - Conduct outreach & education to identified providers and consumers in new region
 - Evaluate model for replication
 - Ensure sustainability
 - Identify likely expansion areas
 - Develop long-range strategic plan for expansion