DQA FOCUS Conference

Legal Protections and Systems Redesign for Persons with Dementia

Tom Hlavacek, Executive Director
Alzheimer's Association of SE Wisconsin

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Goals of Session

- Review Alzheimer's Challenging Behaviors Task Force activities
- Review Helen EF court decisions
- Review Legislative Council Study Committee recommendations and DHS response
- Present redesign principles and activities currently under discussion

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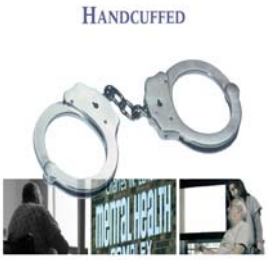
The Alzheimer's Challenging Behaviors Task Force



Task Force Principles

Call together all stakeholders

Goal – solutions, not finger-pointing

Goal – Common understanding

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Challenging Behaviors

Between 60 and 90% of persons with Alzheimer's will exhibit agitated behavior in the course of the disease process

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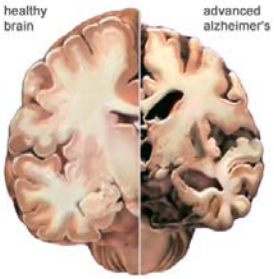
Brain changes



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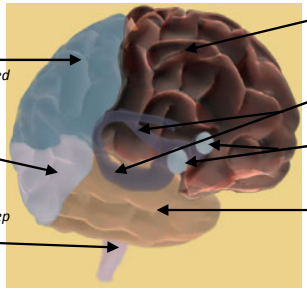
The Brain and Behavior



Understanding Behaviors

An interaction between the person, caregiver/s, and the environment

Underlying physical or emotional pain may be present

All behavior is communication

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Task Force Year One Activities

Five full Task Force meetings

Listening Sessions - groups

Key Informant Interviews

Grew to 140 members

Released report, ***Handcuffed***

More a statement of the problem…

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What was the Helen E.F. case about?

Is it legally appropriate to use Wisconsin's Chapter 51 Civil Commitment process to obtain treatment for an individual whose diagnosis is dementia.

Two legal questions were presented:

Is Alzheimer's / Dementia a "mental illness" within the meaning of the civil commitment statutes?

Is an individual with Alzheimer's / Dementia a "proper subject for treatment" under Chapter 51?

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How Did It Happen??

Helen was an 85 year old, 100-pound woman, with dementia that had progressed to the point of Helen being non-verbal.

She had an activated power of attorney for health care.

Helen was acting out in the nursing home where she resided for 6 years. Police were called by the facility, and she was detained and taken to the locked psychiatric unit of a local hospital. She underwent Chapter 51 proceedings.

While in the hospital a UTI was discovered and treated.

At final hearing, the treating physician testified that while the dementia was not treatable cognitively, the behavioral disturbances were treatable. Helen remained in the hospital throughout the proceedings.

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Lower Court Arguments and Holdings

Trial Court found that Helen's dementia and behavioral disturbances were a treatable mental illness and that Helen was a proper subject for treatment.

Court ordered inpatient commitment and involuntary psychiatric medication. Helen appealed.

The Court of Appeals found that Dementia was not a mental illness within the meaning of Chapter 51, and that Helen was not a proper subject for treatment. Court observed that Chapter 51 is for individuals who are suitable for treatment and "rehabilitation" and that individuals with dementia are not rehabilitatable.

Court of Appeals noted the Handcuffed report prepared by the Alzheimer's Association of SE WI.

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Wisconsin Supreme Court Holding

Fond du Lac County appealed to the Wisconsin Supreme Court

Supreme Court considered arguments from the parties, as well as *amicus curiae*.

Supreme Court found that in this case, Helen E.F. was not a proper subject for treatment, because her Alzheimer's disease was not subject to rehabilitation, and because Chapter 55 protective placement was the more appropriate process by which an individual with dementia should be treated.

Court "left for another day" the question of how to treat individuals with co-occurring mental illness and dementia.

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Ramifications and unanswered questions

Did the decision apply to all dementia patients or just Helen?

Was this case dependent on the doctor's testimony?

Why couldn't Helen obtain necessary treatment when her power of attorney for health care was activated?

What facilities are appropriate for emergency placement of individuals with Alzheimer's and Dementia?

How do law enforcement respond when called by a facility?

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Task Force Year Two

Four Work Groups, Training, Drugs, Law Enforcement,

Two over-arching issues: treat in place, and managing care transitions

Held Summit to share draft findings

Released final report ***We All Hold the Keys***

More a "road map" to a better future…

Final months coincided with Legislative Council Committee

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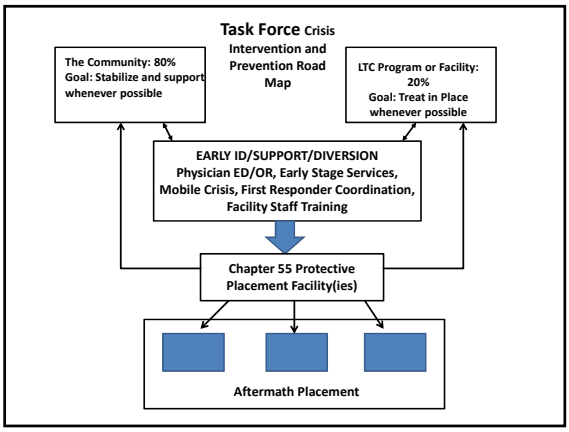
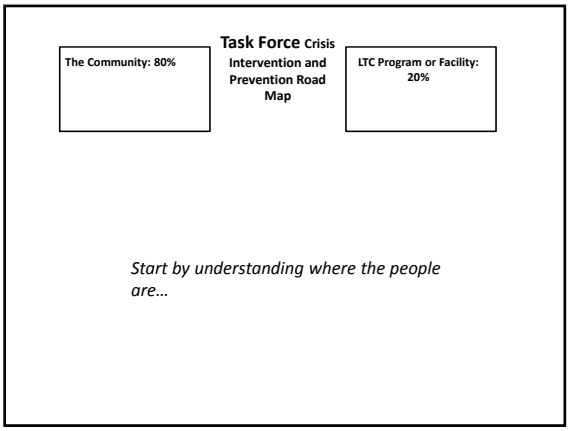

Task Force Crisis Intervention and Prevention Road Map
The Community: 80%
Goal: Stabilize and support whenever possible
LTC Program or Facility: 20%
Goal: Treat in Place whenever possible
EARLY ID/SUPPORT/DIVERSION
Physician ED/OR, Early Stage Services, Mobile Crisis, First Responder Coordination, Facility Staff Training
Chapter 55 Protective Placement Facility(ies)
Aftermath Placement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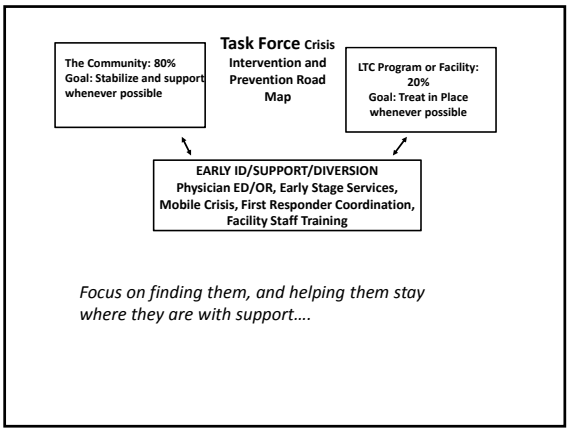
Start by understanding where the people are…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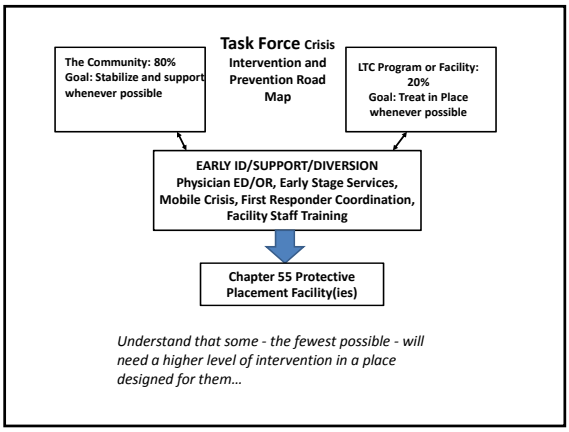
Focus on finding them, and helping them stay where they are with support….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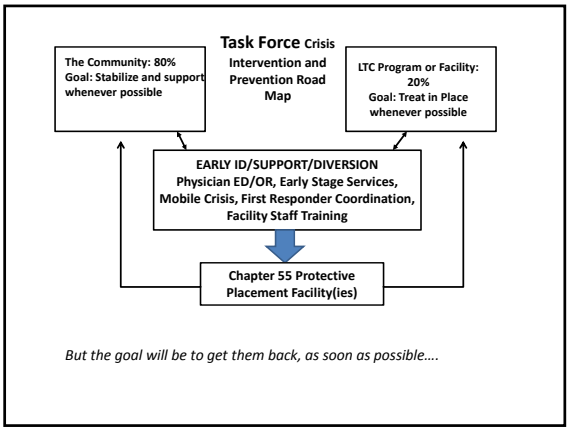
Chapter 55 Protective Placement Facility(ies)
Understand that some - the fewest possible - will need a higher level of intervention in a place designed for them…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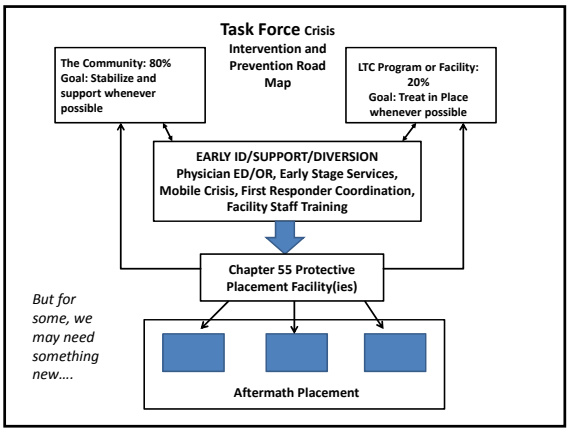
Chapter 55 Protective Placement Facility(ies)
But the goal will be to get them back, as soon as possible….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Chapter 55 Protective Placement Facility(ies)
But for some, we may need something new….
Aftermath Placement

If it's a Puzzle, here's two pieces…..

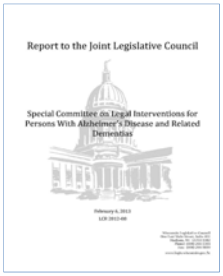
Legislative Council Recommendations: Limited in Scope

Chapter 55 Protective Placement Facility(ies)

State Efforts to Redesign Systems: Broader in Scope

Potentially the whole Road Map and more

Legislative Council Committee



Report to the Joint Legislative Council

Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementias

February 6, 2013
LCR 2012-08

Key Provisions of Proposed Chapter 55 Legislation

The draft does all of the following:

- Specifies individuals with dementia are not subject to emergency detention and involuntary commitment procedures under ch. 51, Stats., the Mental Health Act.
- Creates a new subchapter in ch. 55, "Psychiatric and Behavioral Care and Treatment for Individuals with Dementia", which establishes procedures for evaluation, diagnosis, services and treatment, including involuntary administration of psychotropic medication.

Key Provisions of Proposed Legislation(con't)

- Requires each county department to identify at least one location as a dementia crisis unit for emergency and temporary protective placement.
- Creates procedures with the new subchapter under which individuals may be protectively placed or transferred to dementia crisis units.
- Creates a procedure under which involuntary administration of psychotropic medication may be provided as an emergency protective service.

DHS Response to Legislative Council Study

- In lieu of passing legislation the Department of Health Services advocated taking a comprehensive, multi-system approach to addressing the longstanding and complex issues raised by challenging behaviors in persons with Alzheimer's disease and other forms of dementia.
- The Department proposed that it lead a major system re-design within two years, that would include review of community-based, facility-based, and institutional care delivery systems and capacities.
- This Summit is a first step in the Department's process of review and redesign of the statewide system of dementia care.

DHS Dementia Stakeholder Summit

Held at Wingspread October 1 and 2

Intended to be a first step in the review and redesign of dementia care

Statement of Purpose:

To identify the components of a dementia capable system in Wisconsin and collaboratively develop specific recommendations to narrow the gap between the current system and the identified vision

DHS Summit: top 6 priorities

- Increase community awareness
- Create/expand dementia care specialist/case manager
- Revise state regulation to allow for "safe harbors"
- Create fiscal/systemic incentives for best practice
- Expand mobile crisis teams
- Create placement facilities

Thank you!

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