

Dementia Capable Care Transitions: Better Care and Better Outcomes  
Care Transitions Stakeholder Summit  
Break out session: Public Policy/Systems  
Notes

- Living alone is increasingly how Elderly Americans are living
- Last two census noted an increase in the number of older adults living alone
- An estimated 35 million persons living alone
  - No other countries have seen this # or proportions of older adults living alone
- What happens when dementia patients live alone?
- How do we support them?
- Known cultural barriers surrounding this issue, what can we do?
- In 2010, 70,000 single person household in Clark County – of that 1/3 are over the age of 60.
  - National # 1/9 living alone with dementia
- Medicare beneficiaries – may not always be in the pts best interest
- What is the trajectory, what is the policy that affects the path
- Hospital setting, mandated reporters > EPS opens case, Law of protection

#### Valley Health System Process

- Enter through ED
- Treat the MEDICAL condition and stabilize
- Legal 2000, hold
  - (Judges are not familiar with the psycho aspects)
- What is the criteria for dementia? Diagnosis?
- Transitional environment questionably safe?
- Competing regulations
  - Psychiatrist deem capacity
  - Limited psychiatrist to do the assessment and determine capacity
- Public Policy : Capacity
  - Make roads/tools to regain capacity? Support?
  - When should the capacity evaluation be implemented? Capacity can vacillate from day to day..
  - Hospitals held to rapidly transition pts (too much that can happen to them)
  - Valley Health System > Psychiatrist are the only ones deeming capacity
  - Some may end up in guardianship because no advance directives
  - Can neurologist deem capacity?

#### 2 Situations

1. Illness + Dementia = medical + behavioral/cognitive
  2. No medical concern + delirium, secondary to something else
    - Gerontologist assess capacity, map/explore
- Capacity : who can determine capacity under the law
    - Where does dementia fit under capacity law?

- What are the standards
  - Capacity can vary
  - How frequent assess
- Dementia does not always mean incapacity
- Over medicalization of dementia
- Lock box > advance directives > part of practice
- Larger percentage have no caregivers
- Study of people with dementia whose caregivers are millennials that are removed
- State law designate caregiver for Pts
- Behaviors in hospital may prevent placements

X no care for. X no medical issues. But some behaviors. Still need a safe place

- This level of care does not exist
- Transitional setting for unsafe seniors.
- Need temporary assistance, senior dimensions?

Resources

- Limited finances
- Dementia > Chronic Health conditions
- Capacity is declining

What does the difference look like for someone with financial resources versus someone with no financial resources?

- Public messages : years education, effective dementia Education
- Need Physician education, collaborate with CEUs to include dementia education
- Experienced MD wants biggest bang for his buck for CEUs (not necessarily concerned with content)
- MEC, Care Management utilization, annual competency, national standard of practice
  - 1 Dementia CEU = 2 as an incentive.
    - Program already exists, yet still no noticeable difference in dementia education.
- Newbie MD would be more open to dementia education
- Invest in Residency groups. Get them while they're young and still open. Reshape the culture.
- Don't want to care for the elderly
- Population that no one wants
- Change cultural views with youth and education before and during residency
  - But for now, find pragmatic pathways
  - Engagement and education
- What are the governing policies

Does money and healthcare finances make a difference in the care path?

- Find and weed out the people who do not need to be under the legal 2000
  - L2K logistics from the department of public health

- Navigating pts > Medicaid process
- Dementia and demographics

Is there any world in which care transitions would be an alternative to L2k?

The person with dementia whose caregiver has dementia

- Think about multiple family environments
- Public policy, create environment
- Finances

What are the current environments hospitals can discharge safely to?

Question of physician and hospital care of dementia mass. Adapted mandatory policy > Alice Bonner, Federal Initiative



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## **Stakeholder Planning Summit**

**January 16, 2018**

**Stakeholder Workgroup: Intellectual Disabilities and Dementia facilitated by Kathleen Bishop**

### **Those in attendance:**

1. Kirsten Coulombe with DHCFP
2. Carline DaPrato with DRC
3. Toni Clay with DRC
4. Leigh Kotkou, PhD with DRC
5. Pamela Miller with DRC
6. Jane Gruner with NSS
7. Tim Brown, Caregiver/spouse of Santa Perez
8. Santa Perez, Advocate – Governor’s Council on Developmental Disabilities
9. Peggy Gutting with NSS
10. Celeste Graham with NSS
11. Don Jackson, PhD with UNR – phone participant

### **Identified strengths of NV’s services/resources for adults with IDD & dementia:**

1. ASD programs with Intellectual Disabilities and Related Conditions
2. Guardianship task force
3. Elder Vulnerable Person Committee
4. Positive community engagement
5. Participation in safe d/c
6. DRC’s in-home nursing assessment and quality assurance
7. DRC – once eligible, eligible across the lifespan
8. Collaboration
9. Person Centered approach
10. PASSR
11. Focus on helping & involving family
12. Teachers who are inclusive
13. Representation by IDD
14. Expertise in the field of IDD
15. Support



**Identified weaknesses of NV's services/resources for adults with IDD & dementia:**

1. Lack of knowledge regarding IDD & dementia
2. Lack of facilities
3. Lack of education
4. Lack of resources
5. Lack of participants
6. Lack of consistent assessment tools
7. Ability to provide wrap around services (many who have IDD have elderly parents/CGs with needs as well)
8. Providers lack of knowledge
9. Mirroring & difficulty of cross dx & tx
10. Dx is COMPLICATED!!!!
11. Challenges of personal collaboration
12. High turnover of qualified staff
13. Recruiting
14. Dx process (often dementia is masked by IDD)
15. Behavior – causes & context – labels vs cause
16. Lack of dx
17. Not inclusive – cont. into adulthood
18. Misunderstanding of individuals needs
19. Coordination of services throughout the State

**Terms – for program development and collaboration need to define and understand:**

1. Related condition – in relation to the IDD and dementia dx
2. Evidence based – proven by data &/or feedback to be effective & valid
3. Data – source?
4. Waiver program – what does it cover, will there be conflicts w/ other waivers? Can individuals move from IDD to dementia and vice versa
5. Dx process – baseline definitions and how to proceed (grant states “at risk” for dementia)
6. Baseline functioning for IDD (environmental, sensory, social context) – is it different based on dx?
7. Functional baseline assessment – what does it mean?



## **What do we know?**

1. NV is not serving everyone w/ IDD – currently serving approx. 6,000 individuals while there's an estimated 40,000 with IDD
2. DRC's waiver statistics estimate of the 6000 being served, 5,000 live alone
3. Point of entry into the DRC system is through the hospital (during a d/c), from the CG and from the person with IDD.
4. There's a waitlist for residential service with those d/c from a hospital being a priority.
5. Referrals come from Guardians Office & law enforcement
6. Most common service requested is respite
7. CG burnout & need for socialization are the main reasons for requesting respite.
8. High % of English as 2<sup>nd</sup> language
9. Challenges of respite service availability
10. Rural challenges in serving IDD
11. Accessible transportation is a challenge.
12. Will the criteria for eligibility for services only be for those living I the home?

## **Outcomes:**

1. More collaboration across the board
2. More accessible information – not everyone can read/not everyone can read English – lack of online options
3. Collaborative discharge process with defined roles
4. Understanding of managed care & FFS
5. Enhanced understanding of processes & available placement resources after discharge.
6. Assessing respite and day activity programs
7. Need to have an increased awareness of funding options
8. Need to know if/how the dx will affect funding if/when an the IDD individual is dx with dementia.