Using the CMS GUIDE Model for:

Young-Onset Dementia + Intellectual & Developmental Disabilities and Dementia

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ADC Alzheimer's and Dementia Care PROGRAM

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YOUNG-ONSET DEMENTIA

What is Young-Onset Dementia (YOD)?

- Young-onset dementia = dementia symptoms before age 65.
- Affects about 3.9 million people worldwide (Hendriks 2021)
- Similar common etiologies – Alzheimer's disease, Frontotemporal, Lewy Body, and Vascular dementia.
- Individuals can often be:
  - Working
  - Parenting children
  - Financially supporting families
  - Physically healthier

Distinctive Challenges in Young-Onset Dementia

- Often overlooked or misdiagnosed, delaying diagnosis by 4-5 years from symptom onset.
- Employment and financial strain
  - Job loss, disability benefits, insurance disruption, retirement.
- Family dynamics
  - Dependent children, spousal caregiving / role disruption.
- Psychosocial issues
  - Stigma, social isolation, loss of identity.
- Care system mismatch
  - Resources are designed for older adults (e.g., Adult day centers).

Why GUIDE Fits YOD Well?

- GUIDE benefits relevant to YOD
  - Longitudinal care coordination and navigation
  - Caregiver support emphasis
  - Social needs screening
  - Behavioral symptom management
- Social aspects of care (e.g., legal, employment issues) and caregiver burden
  - Respite benefit

How do YOD patients qualify for GUIDE?

- Social worker / Benefits counseling
- People with YOD may qualify for Medicare before age 65 through Social Security Disability Insurance (SSDI).
  - Many individuals with YOD stop working because of cognitive symptoms and apply for SSDI.
- After receiving SSDI benefits for 24 months, they become eligible for Medicare and may qualify for the GUIDE Model.
  - The 24-month disability waiting period may delay access to Medicare-based dementia care programs for some people with YOD.

How GUIDE Could Be Adapted for YOD?

1. Tailored Care Navigation
   - Disability/legal counseling
   - Workplace transition support
   - Financial planning referrals
2. Age-Appropriate Programming
   - Younger peer support groups
   - Activity programs aligned with physical ability/interests
   - Technology-enabled engagement
3. Family-Centered Care
   - Support for children and spouses
   - Family counseling
4. Community Partnerships
   - Vocational services
   - Legal services

Potential Challenges within GUIDE for YOD

- Delayed diagnosis may disproportionately affect individuals with lower access to specialty care.
  - Referrals to GUIDE programs will likely come after specialist evaluation.
- Structural Challenges
  - GUIDE is designed primarily around Medicare beneficiaries
  - Limited YOD-specific respite/day programs
- Operational Challenges
  - Lack of standardized YOD screening pathways
  - Limited evidence base for YOD-specific interventions

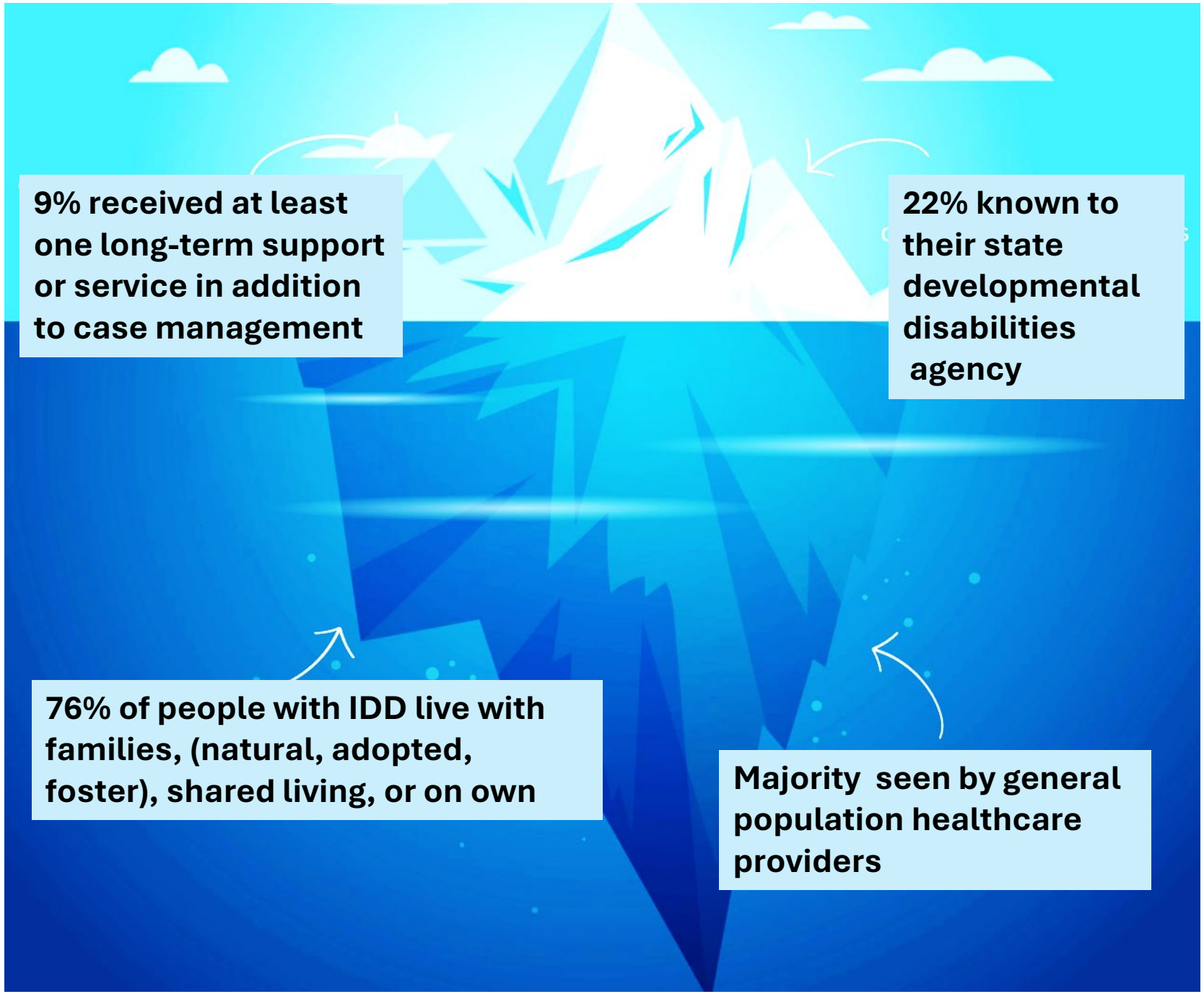
Conclusion

- YOD populations have distinct needs not fully addressed in traditional dementia systems.
- The GUIDE Model provides a strong framework for comprehensive support.
- Adaptations are needed for:
  - Employment
  - Family structure
  - Psychosocial care
  - Age-appropriate services
- Comprehensive dementia care should not be defined by age, but by the needs of patients and families.

INTELLECTUAL & DEVELOPMENTAL DISABILITIES (IDD) + DEMENTIA

To start:

People with Intellectual & Developmental Disabilities



Source: Markes, 2024

Who are the individuals with Intellectual & Developmental Disabilities (IDD)?

- People with IDD are living longer.
- Life expectancy is increasing; however, it still lags behind that of the general population.
- Living with co-occurring physical health co-morbidities- multiple medications and psychological and support factors
- Settings
- Risk of Dementia- Research on most IDD is sparse, and findings vary
- Down Syndrome- high risk

Distinctive Challenges in Dementia People with IDD

- Risk Factors- Age, Genetics, Environment, Lifestyle
- Often overlooked or misdiagnosed
- Philosophical Shift
- Family/Relationship dynamics
- Intersectionality (“to the bazillionth degree”)
- Psychosocial issues (disparities, social determinants, stigma)
- Living with co-occurring physical health co-morbidities- multiple medications and psychological and support factors

More challenges: Systems of Care- Mismatch

- Limited research
- Assessment tools and practices (more than diagnosis)
- Silos of care (legal, “responsibility/ownership”- communication)
- Diagnostic Overshadowing

How do these family caregivers differ?

(Jokinen, et al., 2018, 2024)

Length of time caregiving

- Lifetime vs shorter time frame

Involvement over decades

- With education, health, and social service systems

Long-time exposure

- To stigmatization, discrimination, & exclusion

Changes in philosophy & social support

- Institutional care to community living

(Photos: kind permission of Mary S of brother Pete)

Conclusion

- People w/IDD have distinct needs not fully addressed in traditional dementia systems.
- The GUIDE Model can partner with existing systems of care support.
- IDD systems familiar with certain adjuncts for care:
  - adaptive equipment, valuing communication
  - differences, and assessing behaviors
- Comprehensive dementia care should continue
  - to be person-centered yet relationship guided.
- “Communication-Collaboration-Coordination.”

Srisic –Stoehr, 2013.

REMINDERS

- Upcoming NDCC GUIDE Webinar – June 12th at 12 pm PT
  - Topic: Managing Neuropsychiatric Symptoms in Dementia: Evidence-Based Strategies
  - Presenter: Laura Gitlin, PhD & Brent Forester, MD, MSc
- Next GUIDE Affinity Group – June 24 at 8 am PT
  - Topic: Medication Management and Medication Reconciliation

Srisic –Stoehr, 2013.