

Adults with Developmental Disabilities

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History of DD

- 1970's Civil Rights:
Deinstitutionalization
- 1970-2009
Community Health
Services for Children
- 2009-future The kids
grew up! How do we
take care of them?

Developmental Disability (DD) (Administrative Definition-CA)

- Originates before age 18
- Expected to continue indefinitely
- Substantial disability for the individual
- Includes:
 - Intellectual disability
 - Cerebral palsy
 - Epilepsy
 - Autism
 - Conditions like intellectual disability

You know a lot already!

- Medications: start low, go slow
- Minimize poly-pharmacy
- Serious illness presents subtly and at advanced stages
- Functional assessments
- Supported and surrogate decision making
- Pressure sores, osteoporosis, incontinence, urinary retention, constipation, vision/hearing, arthritis, GERD, dysphagia/aspiration
- Nutrition
- Exercise—use it or lose it

What is Different?

- Stable disability—not end of life and not in decline
- After acute illness, tend to return to baseline
- Short term memory intact—learn slowly, but do learn
- Better rehab potential
- Tend to get uncommon illnesses
- Illness presents as change in behavior or function
- Transitions particularly dangerous

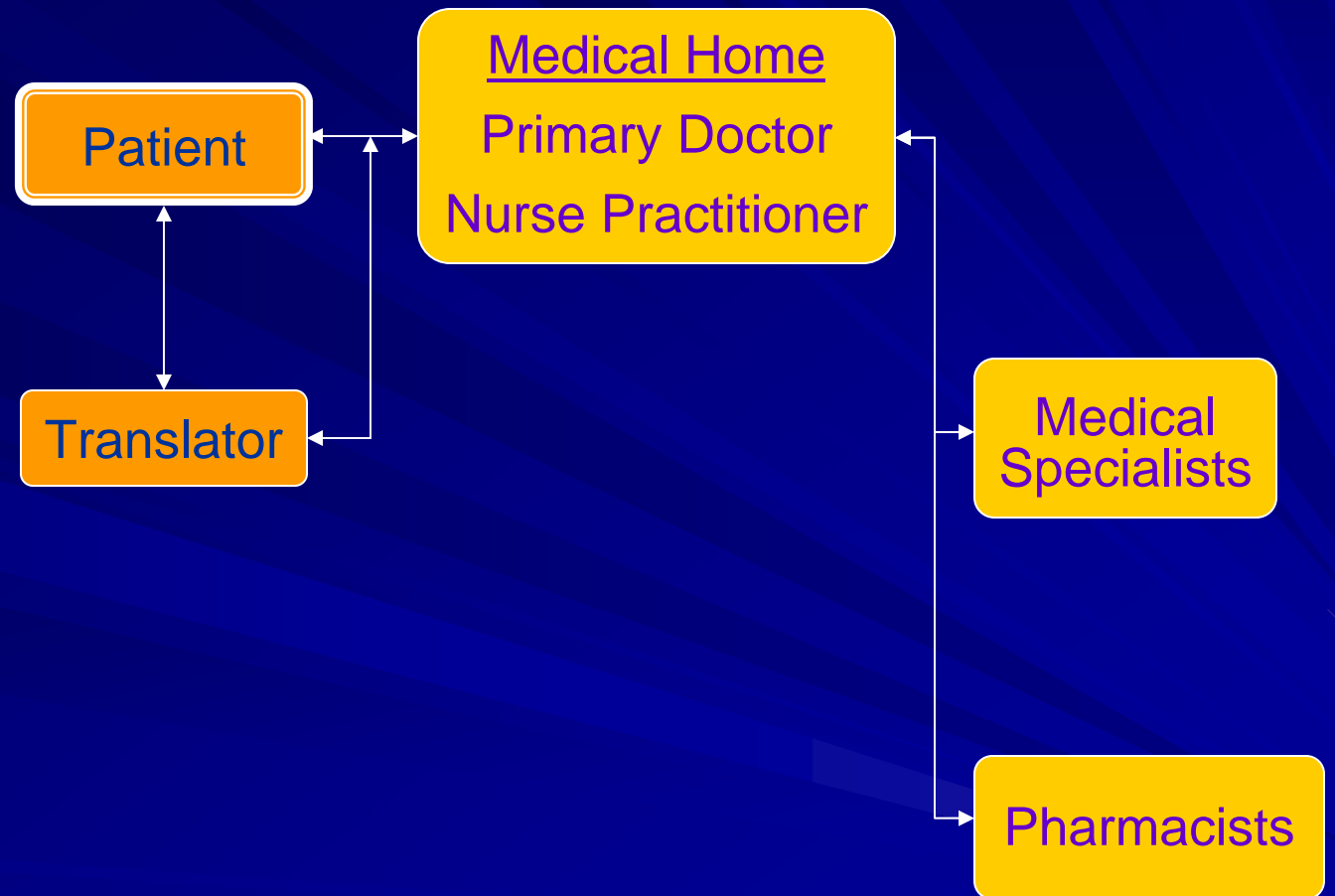
Neurodevelopmental Profile

- Etiology/Genetics
- Cognitive
- Neuromuscular
- Seizure
- Sensory (integration/vision/hearing)
- Behavior/Mental Health

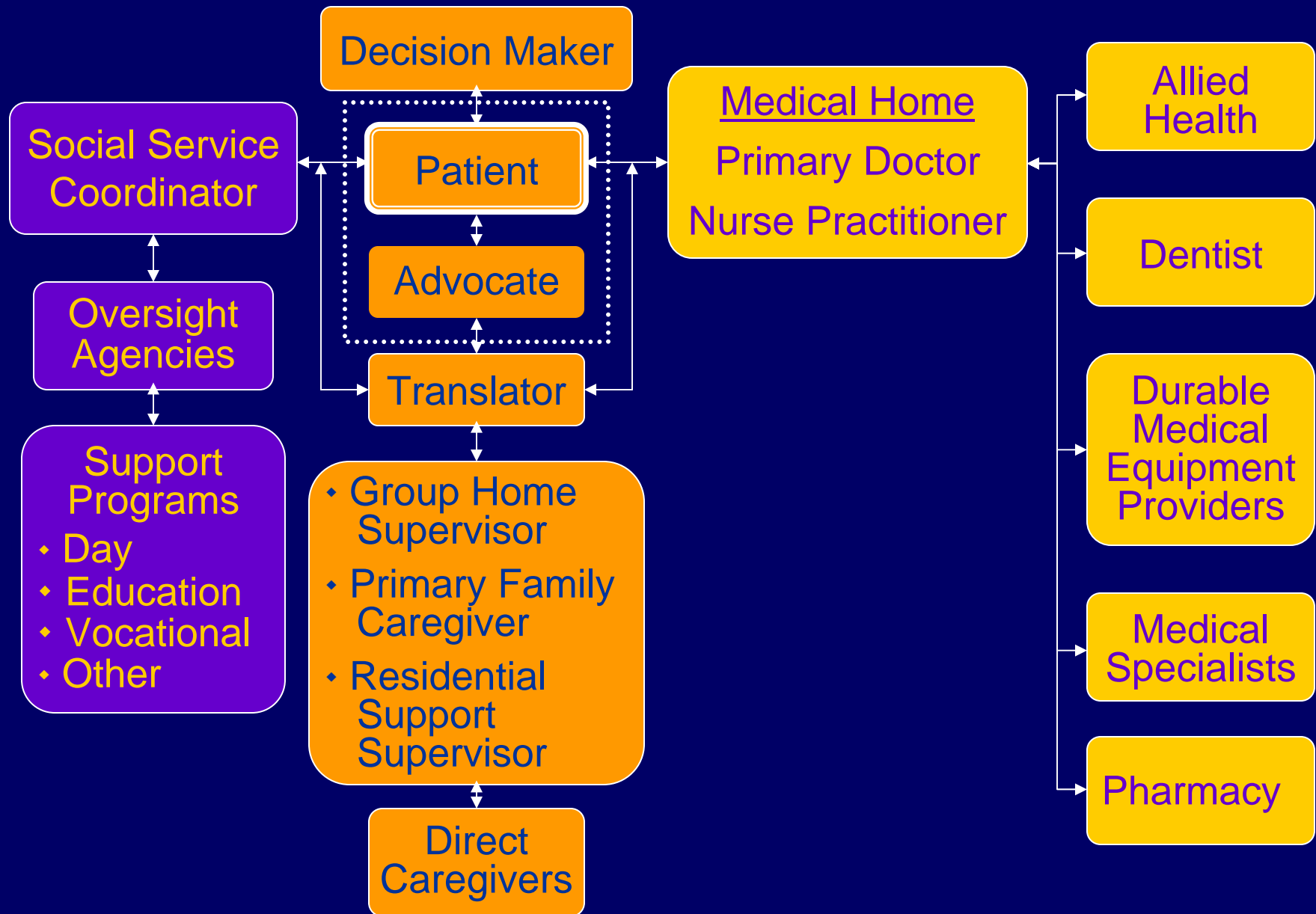
Communicating with People who are Intellectually Disabled or Non-verbal

- Just because a person doesn't talk doesn't mean that they have nothing to say
- All behavior is communication
- Most communication IS non-verbal
 - Body language
 - Tone of voice
 - Visual cues/context
 - Routine/expectations

Typical Health Care Team



Interdisciplinary Health Care Team



Regional Centers

- Entitlement Program in California for DD
- Funds services and supports
- Serve all who meet state definition of DD
- Assign case coordinators
- Individual Program Plan
- Determine services and supports by negotiation based on goal, assessment, personal preference and cost effectiveness
- Acts like a typical bureaucracy—request→ deny→ appeal→ get what you need

Your Role

- Identify needs.
- Make appropriate referrals for service and advocacy.
- Write clear, specific, well-justified recommendations.

Call us for help!

Office of Developmental Primary Care

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Department of Family and Community Medicine

OFFICE OF DEVELOPMENTAL PRIMARY CARE



*Improving outcomes for people
with developmental disabilities*

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