### PERSON-CENTERED FOCUS ON FUNCTION:

Augmentative and Alternative Communication for Adult with Amyotrophic Lateral Sclerosis (ALS)





## Why target person-centered functional goals?

- To maximize outcomes that lead to functional improvements that are important to the individual
- To optimize the individual's potential to participate in meaningful activities

meaningful activities and roles

- To facilitate a partnership that ensures the individual and family have a voice in the care received and outcomes achieved
- To demonstrate to the payers the value of skilled services

### What is the ICF, and how does it help?

The International Classification of Functioning, Disability and Health (ICF)—developed by the World Health Organization (WHO)—is a framework to address functioning and disability related to a health condition within the context of the individual's activities and participation in everyday life.

# ICF: International Classification of Functioning, Disability and Health

# Health Condition disorder or disease that informs predicted comorbidities and prognosis Body Functions and Structures Activities and Participation

anatomical parts
and their
physiological
functions

execution
of tasks or
involvement in
life situations



### **Case study: Robert**

### **Health Condition: Amyotrophic Lateral Sclerosis (ALS)**

# Assessment Data

# **Body Function and Structure**

### ALS

- Hypernasality, dysarthria and dysphagia
- Progressing weakness to upper and lower extremities
- Uses a walker for short distances, wheelchair for long distances

### Cognition

- Memory adequate for new learning
- Executive functioning adequate for planning and organization

### Speech and Language

- Speech intelligibility poor (FDA-2)<sup>a</sup>
- Average language skills (ASHA FACS)<sup>b</sup>
- Reading/spelling intact

# **Activity and Participation**

- Remains connected to family and friends and continues to attend social, work, and family functions
- Participates in family and household decision making (ASHA QCL)<sup>c</sup>
- Uses speech attempts, facial expression, and some hand gestures for face-to-face communication
- Uses email, texting, and social media to communicate online with assistance from family
- Spends much of the day looking at social media, reading online, and typing emails
- Demonstrates increased frustration and signs of depression as speech declines (ASHA QCL)<sup>c</sup>

### Environmental and Personal Factors

- Robert is 58 years old
- He worked as Chief Financial Officer for a large insurance company and retired 2 months ago due to progression of ALS symptoms
- He is married with 3 grown children and 5 grandchildren
- He enjoys golf, baseball, and spending time with family
- Robert expresses

   a strong desire to
   maintain the ability to
   communicate face to
   face and online
- His wife, children, and friends are very supportive

# **Clinical Reasoning**

What impairments most affect function, based on clinician assessment & the individual's self-report?

What activities are most important to the individual in the current or discharge setting?

What environmental/ personal factors are facilitators or barriers to participation in the current or discharge setting?

### **Goal Setting**

### **Robert's Functional Goals**

### Long-Term Goal:

Robert will use speech attempts as well as multimodal communication (aided and unaided) to participate in activities with family and friends and to communicate about medical care with familiar and unfamiliar listeners.

### Short-Term Goals:

- Robert will use rate enhancement features (word and phrase prediction, pre-stored messages) in 90% of opportunities to communicate during spontaneous conversation.
- Robert will use his speech-generating device (SGD) to access external devices (e.g., phone, computer) for social communication (e.g., texting, emailing) in 4 out of 5 attempts (80% of the time).
- Robert will use his SGD to successfully express personal desires at least 90% of the time during conversations with family and medical staff.

<sup>c</sup> Quality of Communication Life Scale (ASHA QCL) Paul, D. R., Frattali, C. M., Holland, A. L., Caperton, C. J., & Slater, S. C., (2004).

<sup>&</sup>lt;sup>a</sup> Frenchay Dysarthria Assessment: Second Edition (FDA-2); Enderby, P. M., & Palmer, R. (2008).

<sup>&</sup>lt;sup>b</sup> Functional Assessment of Communication Skills for Adults (ASHA FACS); Frattali, C. M., Thompson, C. K., Holland, A. L., Wohl, C.B., & Ferketic, M. M. (1995).