



# Dysphagia and Intellectual Disability (ID): A Survey of Practice Patterns in the Intermediate Care Setting

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## Background

### Health Status of Those with ID

- Exponential rise in life expectancy (Patja et al., 2000; Corpus, 2013; Glover 2017, AAIDD, 2020)
  - 1929 ~ 9 years
  - 1979 ~ 18 years
  - 2010 ~ 55 years
  - Today ~ 60 years
- Mortality rates increase sharply at middle age (Scheepers et al., 2012)
  - Doubles every 9.6 years
- Dysphagia associated with pneumonia is commonly reported (Sheppard, 2006)
- After age 40, pneumonia is a frequent cause of death (Day et al., 2005, Glover 2017)

### Effects of ID Comorbidity

**Systems**

- Neurologic
- Gastrointestinal
- Psychiatric

**Swallow Phases**

- Oral
- Pharyngeal
- Esophageal

**Impacts**

- Choking
- Respiratory illness
- Nutritional deficits

(Sheppard, 2006; Pace & McCullough, 2010)

## Rationale

- Dysphagia in those with ID is associated with serious health risks (Robertson et al., 2017)
- There is a need to understand key aspects of dysphagia management in this group to:
  - ✓ Improve health outcomes
  - ✓ Reduce premature death
- No studies have explored practice patterns of clinicians who manage dysphagia in those with ID who live in Intermediate Care Settings (ICF)

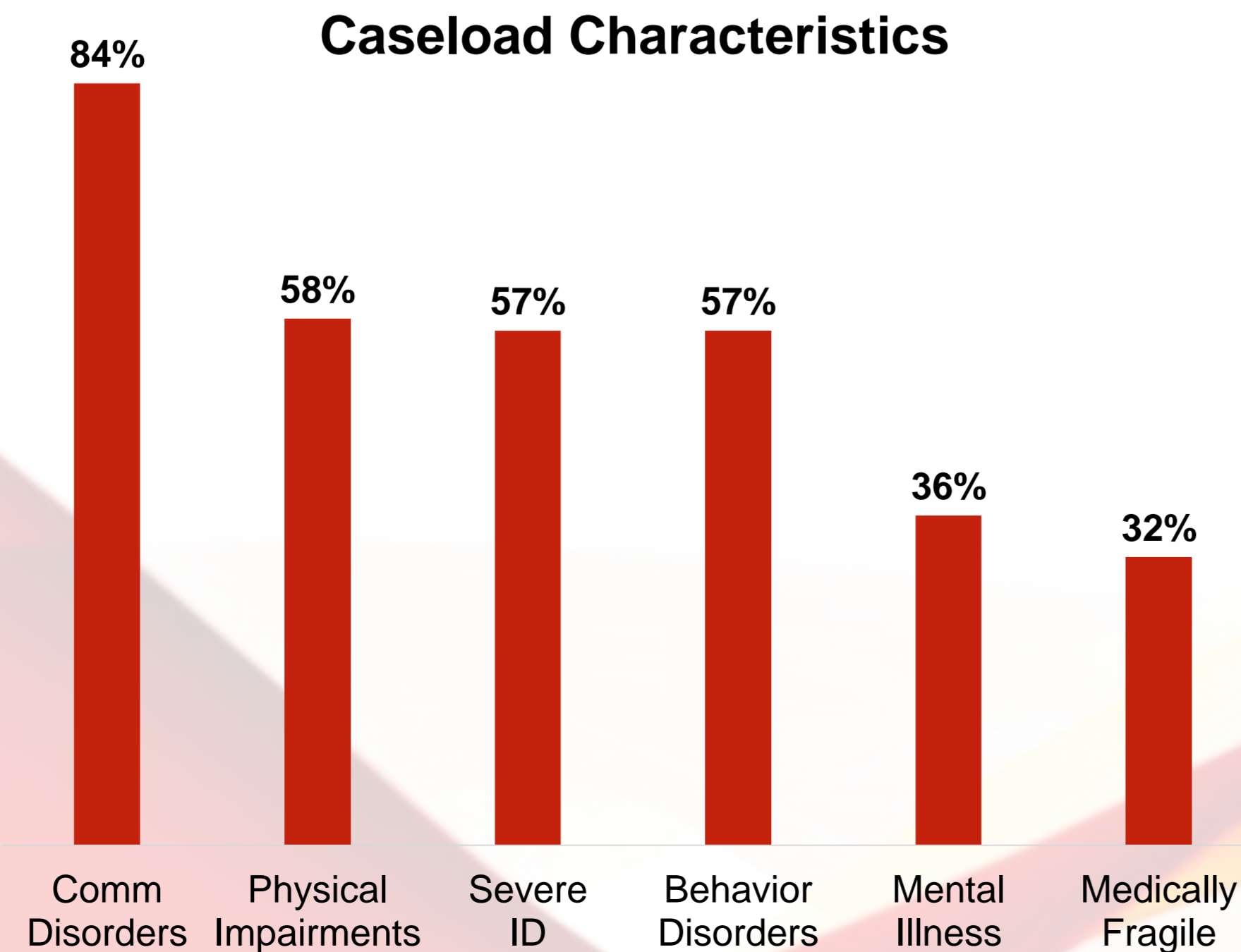
## Methods

- Survey questions reviewed by three independent speech-language pathologists with > 10 years of clinical experience in dysphagia management
- An email request was sent to 118 habilitation therapists from 13 ICFs in Texas
- Survey administration was web-based
- Survey reliability was determined using a test-retest design with a 2-week time period between questionnaire repeats with Pearson's correlation coefficient applied to determine reliability
- Survey analysis was completed using univariate and descriptive statistics

## Demographics

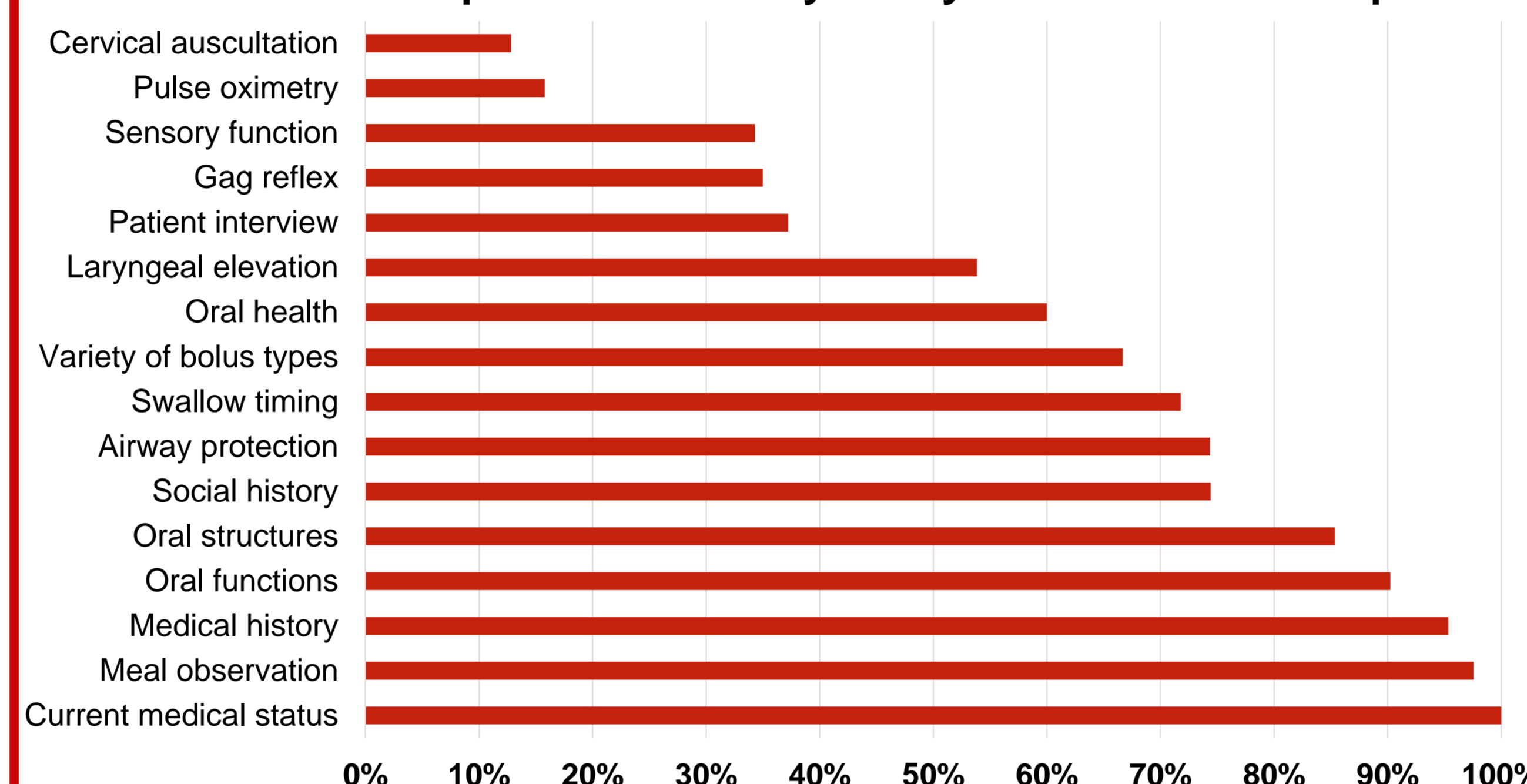
Discipline	Measure	Item	Count	Percentage (%)	
OT (n=17)	Years of experience in dysphagia management	1-5	11	64.7	
		6-10	1	5.9	
		11-15	1	5.9	
		16-20	0	0.0	
		20+	4	23.5	
	Graduate course in dysphagia	Yes	7	43.8	
		No	9	56.3	
		Graduate clinical in dysphagia	Yes	3	17.6
			No	14	82.4
		SLP (n=27)	Years of experience in dysphagia management	1-5	3
6-10	10			38.5	
11-15	5			19.2	
16-20	7			26.9	
20+	1			3.8	
Graduate course in dysphagia	Yes		24	92.3	
	No		2	7.7	
Graduate clinical in dysphagia	Yes		20	76.9	
	No		6	23.1	

### Caseload Characteristics

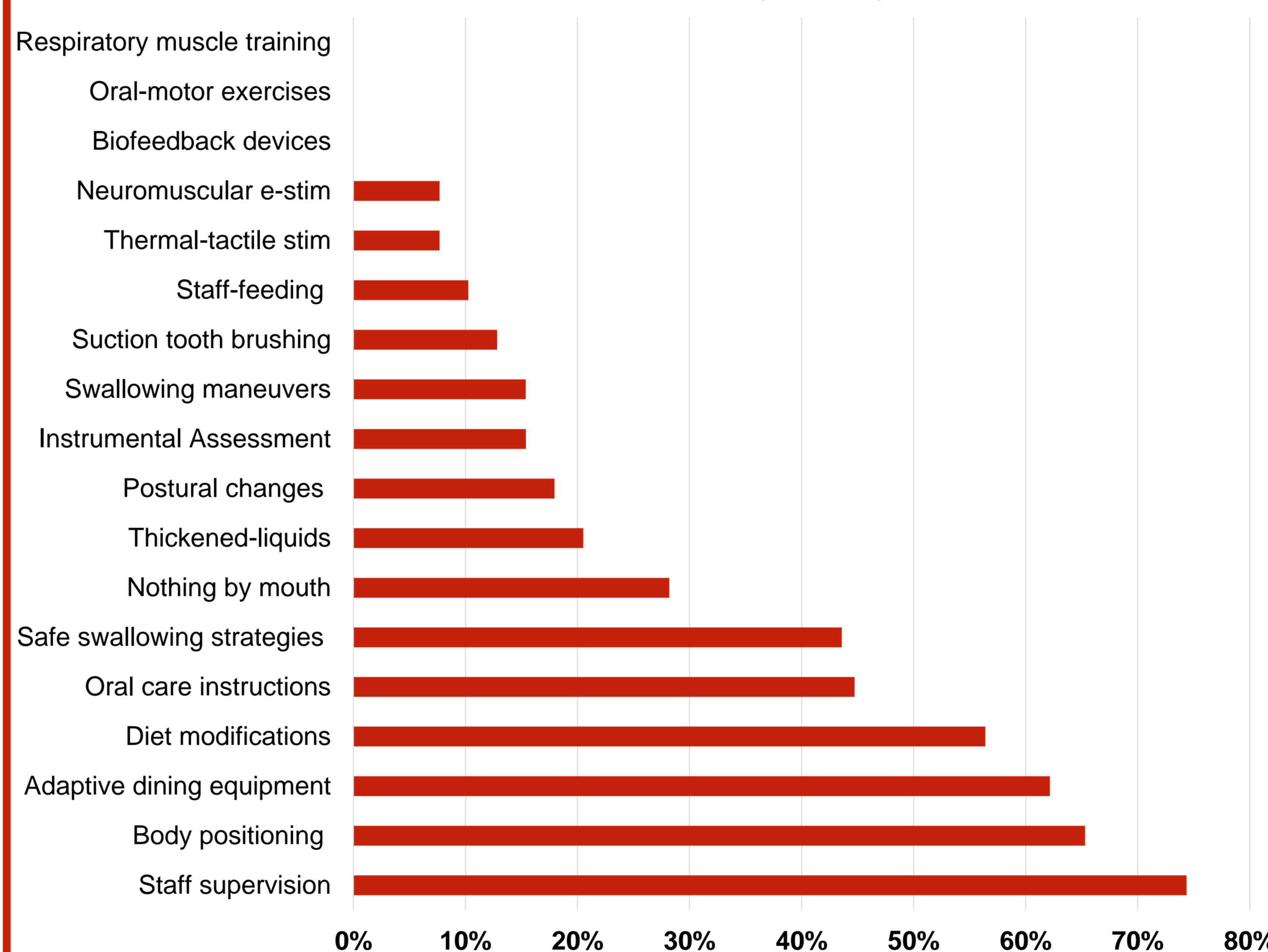


## Results

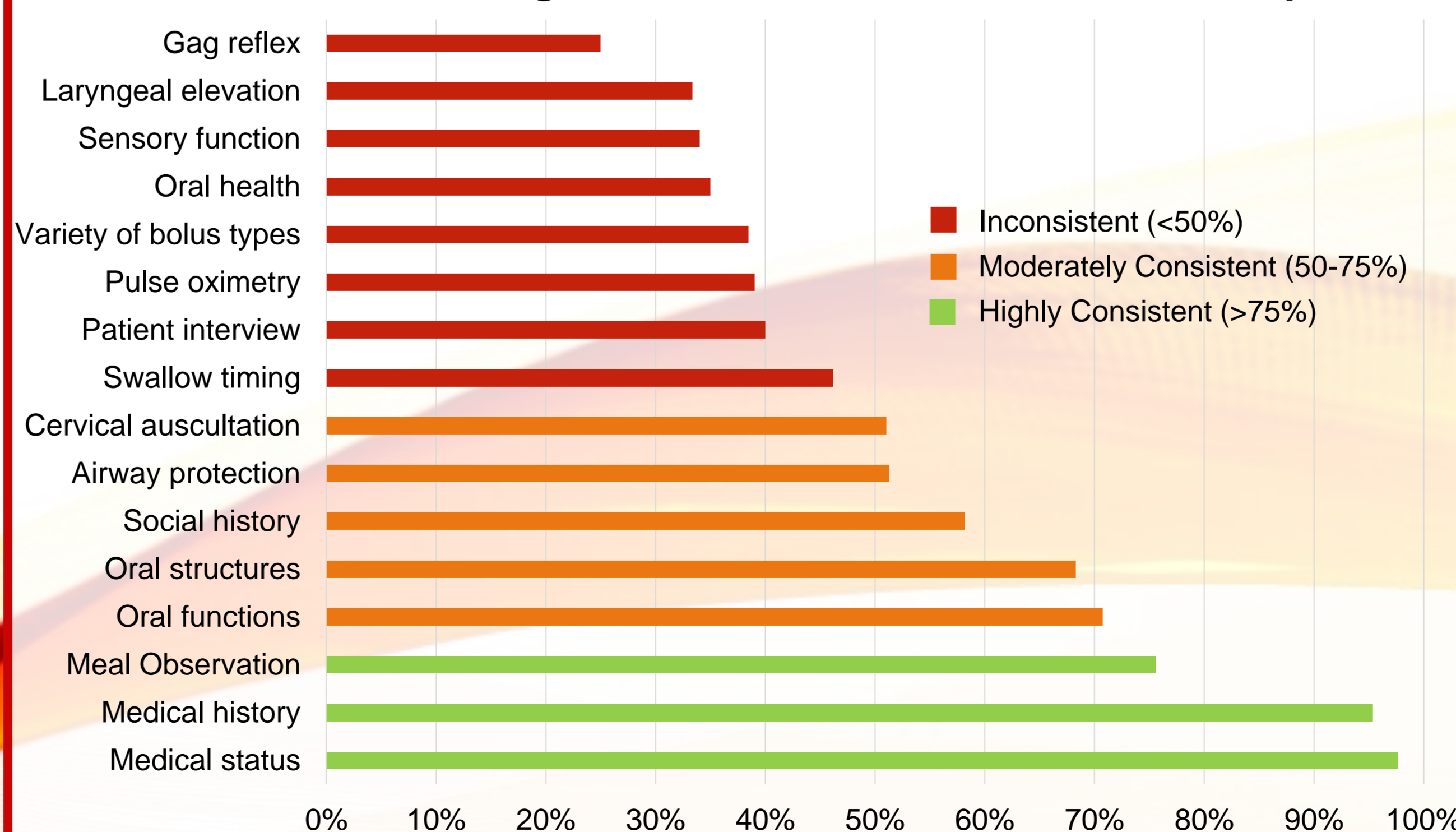
### % Respondents Usually/Always Assessment Component



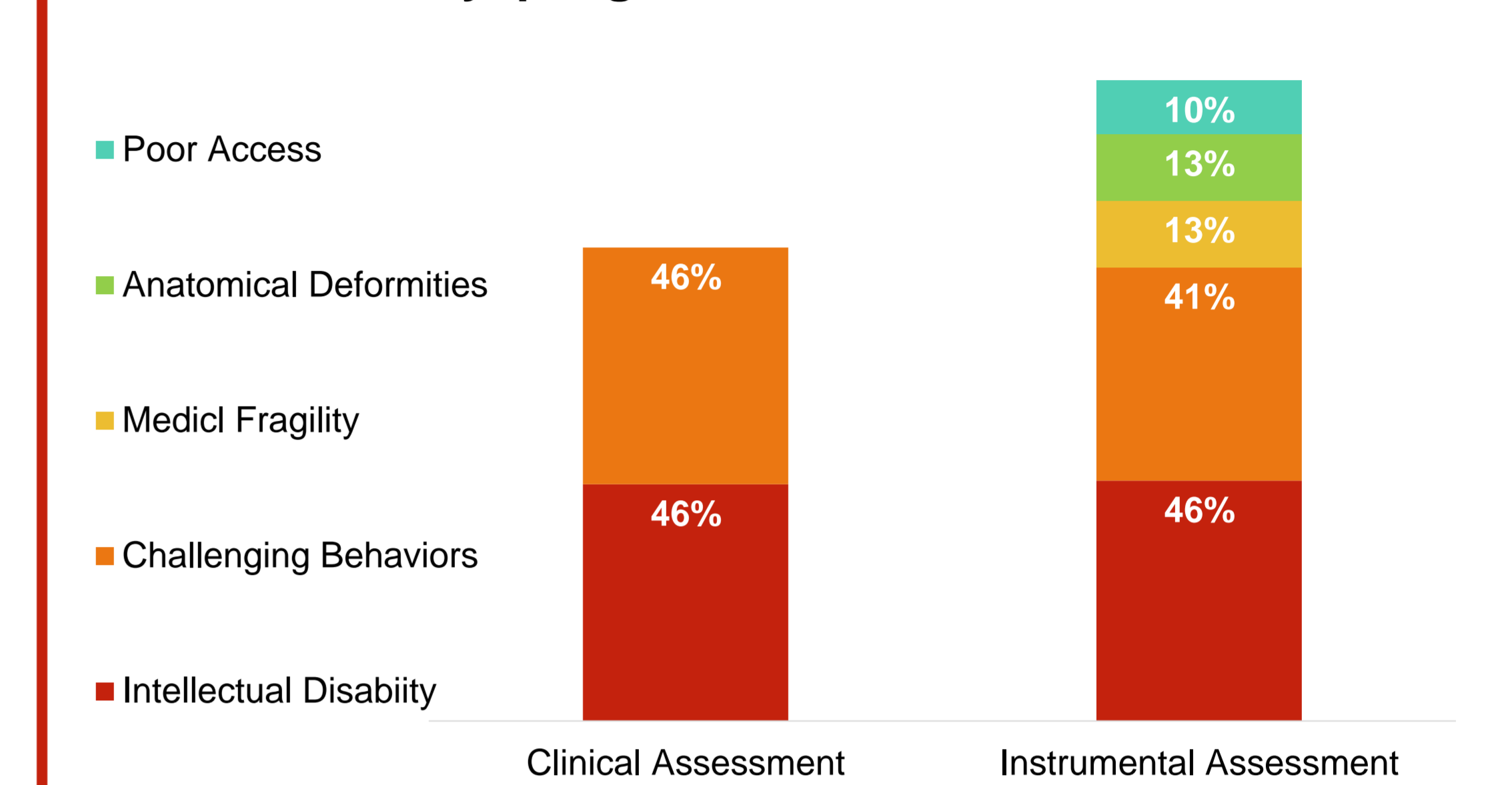
### % Respondents Usually/Always Recommendations



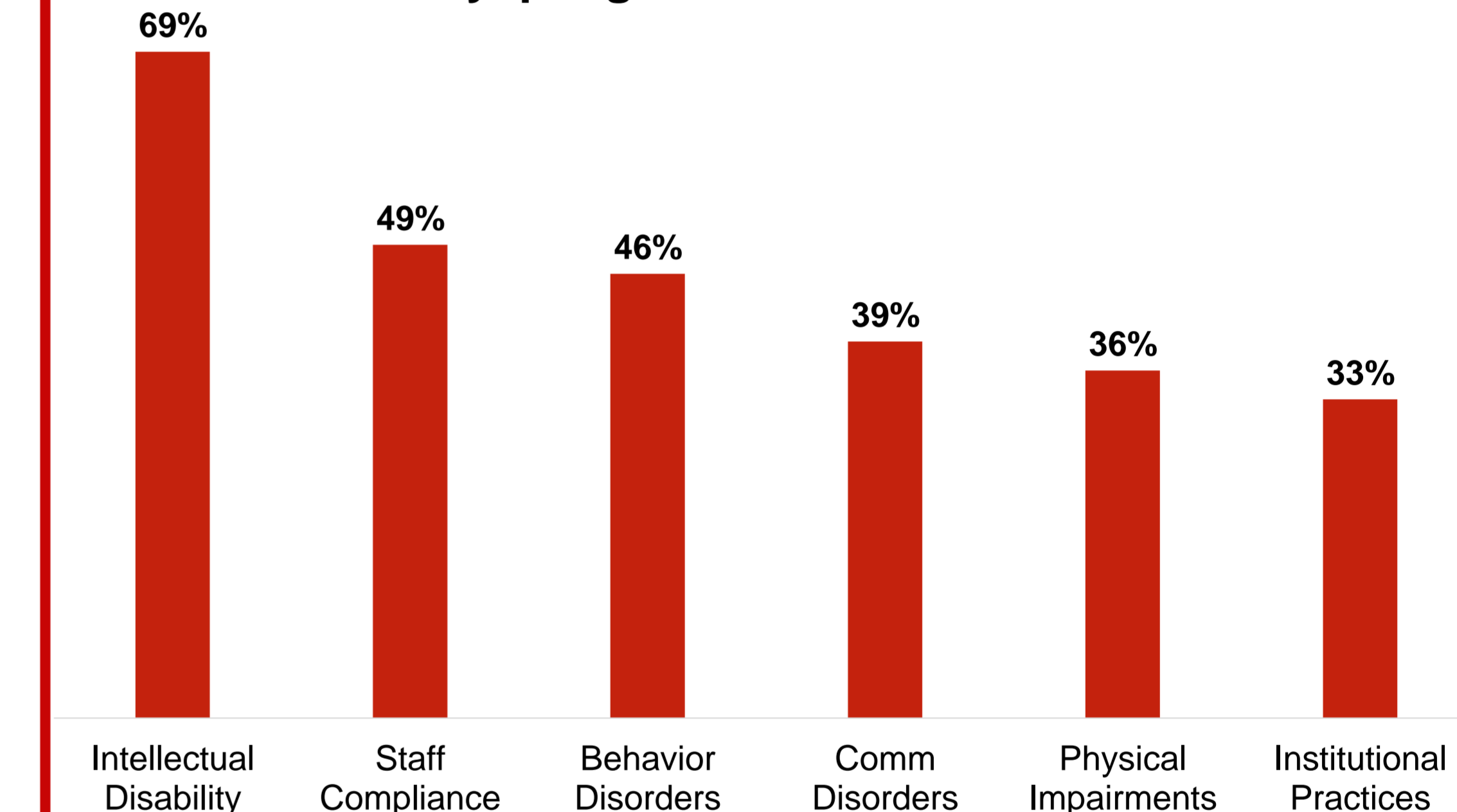
### Clinician Agreement on Use of Assessment Components



### Dysphagia Assessment Barriers



### Dysphagia Treatment Barriers



## Conclusions

- Within the ICF setting, a multidisciplinary approach is used to manage dysphagia in those with ID
- ID and associated co-morbidities impact both dysphagia assessment options and management recommendations
- The strong focus on compensatory strategies over rehabilitative techniques is indicative of a 'risk management' approach and the chronic nature of dysphagia in this population
- The considerable variability in clinical practice patterns in this setting may reflect the heterogenous nature of intellectual disability which often included co-occurring disorders
- In the ICF setting, multiple, often competing factors impede successful treatment of dysphagia in those with ID
- Future research is needed to understand the effectiveness of using compensatory techniques to improve the health and quality of life for those with dysphagia and ID