

NINDS/NICHD-NCMRR NeuroRehab CDE Project Activities of Daily Living Subgroup Summary

The following definitions were used by the Activities of Daily Living (ADL) subgroup to determine whether an instrument should be recommended for ADL/IADL studies:

Basic Activity of Daily Life allows one to do things to care for themselves.

Basic ADL Skills: bathing; grooming (nails, hair, teeth); dressing (donning and doffing); eating or drinking; toileting; transferring to chair, toilet, bed, shower/tub; managing and taking medication; rest and sleep; using and maintaining personal care devices (e.g., glucometer, hearing aids, glasses); sexuality.

Instrumental Activities of Daily Life allows one to do things to care for others, maintain a household and identify and use resources to live in the community. Examples of Instrumental ADL skills include: transportation (acquiring or using); finances (managing money, paying bills); mail (retrieving, sending, and managing); food preparation (planning, shopping, cooking and clean up); shopping (clothing and home supplies); maintaining a home (light cleaning, heavy cleaning, organizing for home repair); personal tasks (manage phone, computer); looking for a job, shopping online or outside of the home; visiting healthcare providers; caretaking (inclusive of parenting children, caring for family members and/or pets); work or volunteering; leisure (sedentary and active); fitness and wellness; remembering to go to doctor/health appointments; socialization with friends/family.

Summary of Recommendations

Instrument	Subdomain	Classification
Assessment of Life Habits (Life-H)	Instrumental Activities of Daily Living	NeuroRehab Supplemental – Highly Recommended
Barthel Index	Activities of Daily Living/Performance	NeuroRehab Supplemental – Highly Recommended
Functional Independence Measure (FIM)	Activities of Daily Living/Performance	NeuroRehab Supplemental – Highly Recommended

The three instruments recommended by the Activities of Daily Living (ADL) subgroup are indicated for studies requiring a measure of ADL and are applicable to all neurological disorder populations.

Assessment of Life Habits (Life-H): Anyone, regardless of age, cultural context, impairments, or disabilities, can respond to the LIFE-H. There are three different applications of Life-H: children from birth to 4 years of age; children from 5 to 13 years of age; General (teenagers, adults, and seniors).

Barthel Index: The Barthel Index is for use in adult populations only. The Barthel Index was originally developed as an ADL assessment for long-term patients in hospital with neuromuscular or musculoskeletal disorders. The instrument assesses the ability of an individual with a neuromuscular or musculoskeletal disorder to care for him/herself.



Functional Independence Measure (FIM)*: The FIM is viewed as most useful for assessment of progress for adults during inpatient rehabilitation. The FIM is designed to assess areas of dysfunction in activities that commonly occur in subjects with any progressive, reversible or stable neurologic, musculoskeletal, or other disorder i.e., patients with functional mobility limitations.

* The FIM was mandated as the tool for data collection in inpatient rehab facility (IRF) but has since been replaced.

The Shirley Ryan Abilitylab and Stroke Engine have online databases with extensive neurorehabilitation measures. Many measures in these online databases have not yet been recommended as NINDS CDEs/instruments. Reliable and validated measures that are used in ADL/IADL studies but have not been previously recommended as NINDS CDEs/instruments have been added to the Gaps list below. The ADL subgroup believes that ADL and IADL are not routinely measured in NeuroRehab studies.

ADL/IADL measures are universal and there are no issues unique to Neurorehabilitation.

The gap areas recognized in this initial NeuroRehab CDE project (i.e., potential new instruments) will provide a framework for identifying a continuum of CDE development activities needing to be addressed in upcoming annual reviews.

The following instruments were recommended by the ADL subgroup as gap areas:

- Activities of Daily Living (IADL) Profile Instrumental
- Activities of Daily Living (ADL) Profile
- Activity Card Sort
- Activity Measure for Post-Acute Care (AM-PAC)
- A-ONE
- Assistive Technology Device Predisposition Assessment (ATD-PA)
- Frenchay Activities Index (FAI)
- Functional Assessment of Standardized Items (FASI)
- Katz Index of Independence in Activities of Daily Living (ADL)
- Lawton Instrumental Activities of Daily Living Scale
- Neuro-QOL Adult Bank - Upper Extremity
- Patient-Reported Outcomes Measurement Information System (PROMIS)-Upper Extremity Domain
- Patient-Reported Outcomes Measurement Information System (PROMIS)-Physical Function Assessments
- Performance Assessment of Self-Care Skills (PASS)
- Standardized Patient Assessment Data Elements (SPADEs)

The ADL subgroup did not find any suitable instruments for Sexuality and Work. There is an opportunity to develop appropriate measures for these ADL/IADL domains.