SUPPORT Patients with Intellectual and Developmental Disabilities in Emergency, Hospital, & Outpatient Care

SEEK INFORMATION
Ask about patient preferences for communication and care.* Many patients with Intellectual and Developmental Disabilities may converse using non-verbal gestures, or augmentative and alternative communication.

USE SUPPORTERS CHOSEN BY THE PATIENT**
Supporters can help obtain informed consent, discuss choices for care, and assist with the patient’s decision-making. Chosen supporters may not always be present with the patient.

RESUME COMPETENCE
Speak directly to the patient using a normal voice and plain language. Do not force eye contact—patients are still listening. Always ask patients or supporters if clarification is needed—do not make assumptions.

PROVIDE ACCOMMODATIONS
Be patient when time is needed to understand or use communication devices. Meet the patient where they are comfortable (e.g. some may sit on the floor or stay in the hallway). Provide a quiet, private environment with minimal distractions, when possible.

OBTAIN PERMISSION
Ask before making physical contact with patients—some do not like being touched. Explain what you are going to do before doing it, and check for understanding.

ROLE-PLAY WITH VISUALS
Use role-play with supporters to provide examples of treatment. Demonstrate on pictures, dolls, or the supporter.

TRAIN OTHERS
Share notes about accommodations, communication needs, and helpful strategies with the care team. Prepare new providers during shift changes. Ensure that patients and supporters understand discharge instructions.

*Patients may provide information in a health passport, one-page profile, or communication dictionary.

**Many states have issued guidance requiring health facilities to allow one support person for a patient with intellectual or developmental disabilities during the Covid-19 crisis.

This tip sheet was written by the self-advocates and family members of Disability Voices United, a California-based disability rights organization: disabilityvoicesunited.org.