Thank you for joining us for “Pain Assessment: An Overview of Practice Considerations for Individuals with Intellectual and Developmental Disabilities” presented by the Quality Monitoring Program at the Texas Department of Aging and Disability Services. This webinar was developed by the Quality Monitoring Program Psychologist and will provide a brief overview of pain and pain assessment methods that may be useful for individuals with a variety of impairments that can impact the pain assessment process. Nursing staff have responsibility for completing pain assessments. This responsibility cannot be delegated. Everyone involved in the care of an individual, however, can contribute information about behavior and function that may be useful to pain assessment and a plan of care. General considerations that are specific to individuals with disabilities in a variety of long-term care settings will be discussed.

**Objectives Slide**
Upon completion of the webinar, participants should be able to:
* define pain
* discuss common sources of pain for individuals with intellectual and developmental disabilities
* list the goals for pain assessment
* identify the general pain assessment methods, and
* identify pain assessment scales that may be useful with individuals who have intellectual and developmental disabilities.

**Slide 1:**
The International Association for the Study of Pain defines pain as an unpleasant sensory or emotional experience that is associated with actual or potential tissue damage.

**Slide 2:**
For individuals who are unable to verbalize their pain due to motor, cognitive, or psychiatric issues, the inability to communicate verbally does not negate the possibility that they experience pain and require appropriate treatment.

**Slide 3:**
Pain can be acute or chronic. Acute pain usually results from disease, inflammation, or tissue injury. It is confined to a given time period and can usually be diagnosed and treated. Acute pain can become chronic. Chronic pain persists over a long period of time and is resistant to most medical treatments. It can be made worse by environmental and psychological factors and often causes severe problems for individuals.
Slide 4:
Pain is subjective; it is a complex perception that can differ among individuals. Even those who appear to have identical injuries or illnesses can have different perceptions.

Slide 5:
There are several syndromes of pain that range in their level of intensity and duration. Among the individuals we serve, there are some common sources of pain which are related to developmental and physical disabilities and include degenerative joint disease, contractures, oral and dental pathology, gastrointestinal conditions, renal conditions, allergy-related symptoms, self-injury, procedures (i.e. positioning and wound care), and infections.

Slide 6:
This slide lists some additional sources of pain that are common in individuals with intellectual and developmental disabilities.

Slide 7:
Untreated and under-treated pain can diminish an individual’s quality of life by limiting functioning and limiting participation in meaningful activity. Providing appropriate pain assessment and pain management can improve a person’s ability to enjoy life. The pain assessment process informs us about the individuals we serve through observation and/or the person’s report of the location, intensity, and impact of pain on functioning. Appropriate assessment paves the way for an individualized approach to treatment.

Slide 8:
There are two general approaches to pain assessment: self-report and observational methods.
Self-report is considered the gold standard for pain assessment and involves asking the individual to identify and describe their pain by indicating the location and intensity. This method is a valid approach to assessment when the individual being assessed is able to communicate verbally. Verbal communication encompasses spoken word, gesture, and written responses.

Slide 9:
There are a variety of pain self report tools that have been standardized for children and adults. Though these tools have not been specifically developed for individuals with IDD, they have been successfully used on individuals with IDD.
Slide 10:
The Faces Pain Scale- Revised can be used by healthcare professionals to assess pain intensity in children and adolescents by self-report. It is easy to administer and only requires the photocopied faces (allowed for clinical and research use). The child is instructed to point to the face that shows how much they hurt right now.

Slide 11:
The Wong-Baker Faces Pain Rating Scale is also a pictorial scale that uses faces and can be used with adults and children as young as 3 years of age in any care setting. Administration involves explaining what each face on the scale represents and then asking the person to choose the face that best describes how he feels.

Slide 12:
The Body Map depicts the body, front and back. The individual can mark any areas on the diagram to show each place they have pain.

Slide 13:
The Visual Analog Scale is meant to express pain as a continuum (no pain to extreme pain). The individual can indicate the point on the horizontal line that represents their perception of their current level of pain. Visual Analog Scales are presented in a variety of ways, including vertical lines and extra descriptors.

Slide 14:
The Pain Thermometer is vertically oriented numerical scale with descriptive words and faces. This scale, too, can be presented in a variety of ways (i.e. horizontally, without faces, etc).

Slide 15:
The Pain Diary is a tool that the individual can use to record pain levels throughout the day. This particular pain diary allows one to note medications, activities, exercise, medication compliance, and use of non-prescription pain coping techniques.

Slide 16:
There is a small body of research that has examined the reliability of self-report tools with children and adults with IDD. In children, the research shows that clinicians tend to overestimate the intellectual abilities of children with mild to moderate intellectual disabilities. Also, few children with IDD could pass tests of their comprehension of the concepts needed to provide a valid self-report of pain ratings on a 0-5 rating scale. When children with IDD were assessed while in pain, about half were able to indicate the location of their pain or rate the intensity of their pain using rating scales which were
modified to provide fewer choices. Most children with IDD were unable to report their pain using a 0-5 numerical scale or faces.

**Slide 17:**
Adults with IDD have demonstrated the ability to use the Faces Pain Scale-Revised. They provided ratings that were consistent over time. They were able to differentiate mild and severe pain, but their ratings were higher than those provided by individuals without IDD. Also, ratings that caregivers gave did not correspond with the individuals’ self-report.

**Slide 18:**
There are no self-report instruments that have been developed specifically for individuals with IDD. Self-reporting instruments that have been simplified by removing the number of available choices that may be used with some individuals who have intellectual and developmental disabilities, but may require “practice” before gathering information that may be useful for assessment purposes. Research has also shown that older individuals who are mildly to moderately cognitively impaired can use a pain rating scale to self-report. More success has been demonstrated with a vertically oriented numerical rating scale and many older adults report this type of scale is easier to use.

**Slide 19:**
When individuals are unable to reliably self-report due to a lack of verbal skills and/or symbolic language, an observational or behavioral assessment is a valid approach to pain assessment. An observational approach is also useful if there are motor difficulties that prevent speech, the individual lacks voluntary motor function, or there are co-morbid psychiatric disabilities and/or an intellectual and developmental disability. When unsure of the reliability of an individual’s self-report, an observational assessment may be used in conjunction with a self-reporting method.

**Slide 20:**
An observational assessment of pain involves monitoring for behavioral indicators of pain. These behavioral indicators may suggest that pain is present if they increase in frequency or intensity or they are not typical for a particular individual.

**Slide 21:**
The list of behaviors that may indicate the presence of pain include frowning, teeth grinding, self-injury, increased restlessness or agitation, aggression/destructive behavior, poor eating or sleeping…
Slide 22:
sighs/groans/cries, decreased activity level, resisting certain movements during care, change in gait, and inability to participate in or avoidance of activities.

Slide 23:
There are observational tools available that have documented validity for children and adults with intellectual and developmental disabilities.
The Pediatric Pain Profile
The Non-communicating Children’s Pain Checklist
The Pain and Discomfort Scale (PADS), and the Pain Assessment in Advanced Dementia Scale (PAINAD).

Slide 24:
The Pediatric Pain Profile is an assessment that can be completed by someone who is familiar with the child and can then share the results with a physician.

Slide 25:
The Non-communicating Children’s Pain Checklist can be used with individuals as young as 3 and up to age 18. The tool is useful in a variety of settings and can be completed by parents or professionals.

Slide 26:
Pain and Discomfort Scale (PADS) was adapted from non-communicating children’s pain checklist for use with adults. It takes 10 minutes to administer and can be used by direct contact personnel. It includes a standardized physical exam.

Slide 27:
Pain Assessment in Advanced Dementia (PAINAD) Scale is a development and psychometric evaluation. It is a 5-item observational tool used in the evaluation of individuals with advanced dementia.

Slide 28:
There are more available choices for observational pain assessment tools for individuals with intellectual disabilities than there are self-report tools. In addition, there are more tools in development and in the process of establishing reliability and validity. The few that have been discussed have demonstrated reliability and validity with individuals with intellectual disabilities and were developed specifically for individuals with these challenges. These instruments can be used in a variety of settings by family and staff, and are easy to use.
Slide 29:
To complete the assessment process when communication skills are present, choose the appropriate self-reporting tool and ask the individual about their pain. Observations for behavioral indicators can also be done. If the individual reports no pain, they should continue to be monitored for changes in status via self-report and observation. Input from others who are familiar with the individual can also be solicited. If the individual does report pain, the intensity and location need to be noted and further assessment conducted.

Slide 30:
After this information is gathered, nursing and medical staff can develop a plan of care and the symptoms or causes of pain can be treated. The individual will need to be re-assessed to monitor for changes in status via self-reporting and behavioral indicators.

Slide 31:
When an individual is not able to communicate verbally (via spoken or written words or gesture), then a behavioral assessment is indicated. This format can also be used when an individual is able to communicate verbally, but there are inconsistencies in verbal reporting. If behavioral indicators of pain are present and represent a change in the individual’s behavior, treatment should be considered when there is a known pathology that could be causing pain. The individual should continue to be monitored for indicators of persistent pain. If the individual has no known pathology, ensure their basic comfort needs are being met and consult with those who are familiar with the individual for insight into the meaning of observed changes in behavior.

Slide 32:
If the pain indicators persist, a pain relieving intervention should be considered. If pain indicators are absent, then the individual should continue to be monitored, reassessed, and the findings documented.

Slide 33:
This slide provides a flow chart for the assessment process; guide through the basic steps in assessing pain.
When working with individuals with intellectual and developmental disabilities, the “gold standard” for assessment – self-report - may not be a reliable option. When evaluating pain in individuals with IDD, we need to consider the person’s ability to comprehend and communicate the concepts needed to provide a valid self-report of pain. Alterations to self-reporting tools and practice with the altered tool may be necessary before you are able to get useful information that can be used for care planning. Although there are no self-reporting instruments that have been developed specifically for those with IDD, there are behavioral observation tools for children and adults with IDD. These can be used in conjunction with a self-report instrument. Utilizing multiple sources of information (individual, staff, family) will result in a comprehensive
assessment which will promote individualized treatment and enhanced quality of life for the individuals we serve.

**Slide 34:**
We will now take questions submitted through the question box.