

Working with Children

Best Practices for Serving Kids

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ChildServe

Pre-Test Link:

<https://www.surveymonkey.com/r/WWC-Pre>



Objectives

1. Describe common developmental, behavioral, and medical characteristics associated with children who have intellectual, developmental, and complex health care needs.
2. Identify evidence-informed approaches that promote positive outcomes for children through trauma-informed, family-centered, and coordinated care practices.
3. Recognize the roles of families, providers, and systems of care in supporting assessment, service planning, and ongoing child development.



ChildServe's Mission



ChildServe partners with families to help children with special healthcare needs live a *great* life.

About ChildServe

INDIVIDUALS FROM



OF IOWA'S 99
COUNTIES SERVED



OF PAYMENTS COME
FROM MEDICAID



FAMILY
ENGAGEMENT

30+

PROGRAMS & SERVICES

Complex Medical

Pediatric Rehabilitation

Autism & Behavioral Health

Community Services



5,978
CHILDREN SERVED



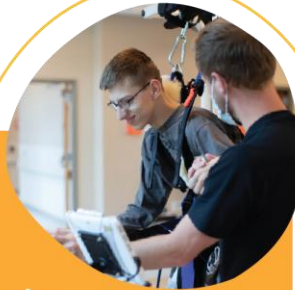
1,677
TEAM MEMBERS
EMPLOYED

OUR SERVICES



Complex Medical

- Inpatient Complex Medical Care ^D
- Homecare ^D
- Medical Group Home ^D
- Medical Childcare ^{A, D}



Pediatric Rehabilitation

- Outpatient Therapy ^{A, C, D, I}
 - Physical
 - Occupational
 - Speech
- Inpatient Pediatric Rehabilitation ^D
- Physical Medicine & Rehabilitation ^{D, I}
- Adaptive Equipment/Orthotics/Prosthetics ^{A, D}

Autism & Behavioral Health

- Autism Day Program ^{A, C, D, I}
- Applied Behavior Analysis (ABA) ^{A, C, D, I}
- Psychology ^{D, I}
- Mental Health Therapy ^{A, D, I}



Community Services

- Case Management ^{A, D}
- Childcare ^{A, D}
- Day Habilitation ^{A, D, I}
- Homes ^D
- Respite ^{A, C, D, I}
- Supported Community Living (SCL) ^{A, C, D, I}

Social Services & Supports:

Care Coordination, Medical Social Work, Family Education & Support ^{A, D, I}

ChildServe excels at coordination and collaboration between services. Along with comprehensive care across the continuum, we partner with families to recommend the right programming, resources, and funding options that children need to thrive.

^A Service offered in Ames

| ^C Service offered in Cedar Rapids

| ^D Service offered in Des Moines

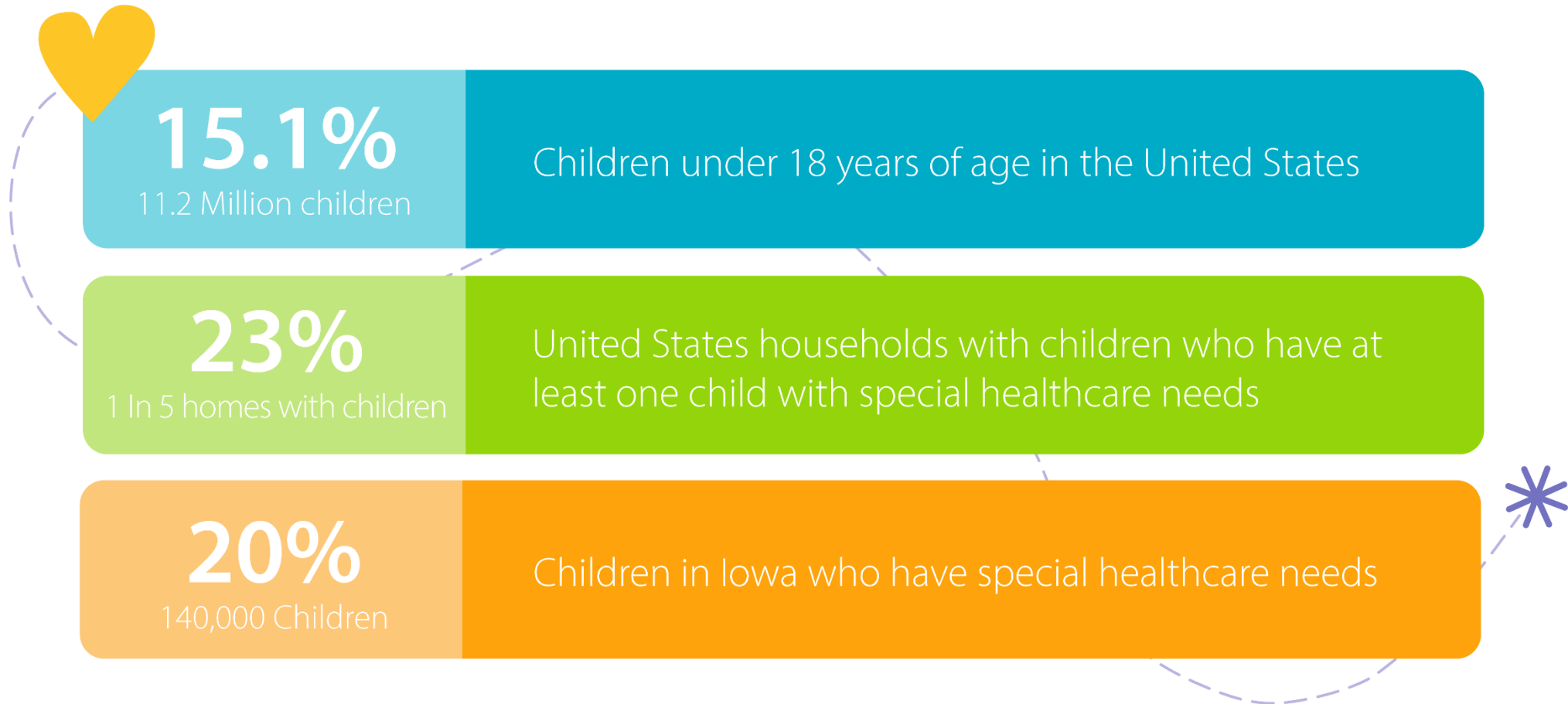
| ^I Service offered in Iowa City

Medically Complex Children

- Multiple and/or severe organ dysfunction
- Necessitates a high intensity of medical resources and technology
- Often require high ED use
- Dependence on multiple medications
- Requires attention, adaptation and accommodative measures beyond what is considered routine



Medically Complex Children



Medically Complex Children

- May include one or more of the following:
 - Physical limitations
 - Mental limitations
 - Heightened or decreased sensory attributes
 - Behavioral, cognitive, or emotional impairment
- Origination
 - Congenital
 - Developmental
 - Disease-related
 - Post-trauma
 - Environmental



Medically Complex Children

- Congenital and Acquired
- Tracheostomies
- Mechanical Ventilation
- GTs
- Adaptive equipment
- Communication devices
- Multiple subspecialists, medications, and therapies



Complex Children

- 13-20% have a mental or behavioral condition in the US
 - Anxiety
 - Behavior disorders
 - Depression
- 1 in 5-6 are neurodivergent
 - ADHD, Autism, Dyslexia



2022 National Healthcare Quality and Disparities Report [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2022 Oct. CHILD AND ADOLESCENT MENTAL HEALTH.

What are the CDC statistics for mental health in children (2024). <https://hicsiowa.org/blog/what-are-the-cdc-statistics-for-mental-health-in-children/>

Common Diagnoses



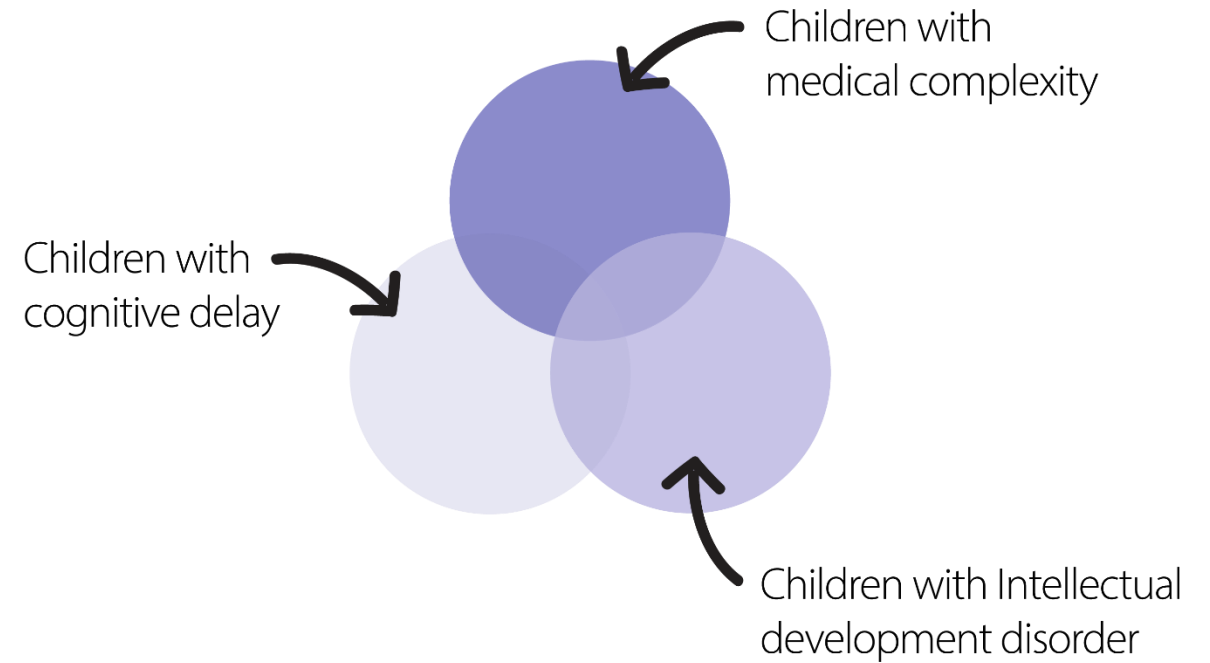
Cognitive Impairments

- Difficulty processing thoughts or instructions
- May still be aware of your actions and words
- May choose to communicate via behavior
- Young adults may still need a caregiver
- May have difficulty obtaining history



Intellectual Developmental Disorder

- Generalized disorder appearing before adulthood
- Characterized by significantly impaired cognitive functioning and deficits in two or more adaptive behaviors
- Syndromic intellectual deficits are associated with other medical and behavioral signs and symptoms
- Non-syndromic intellectual deficits appear without other abnormalities



Cerebral Palsy (CP)

- Chronic & non-progressive
- Caused by damage to the motor centers of the brain
- May occur any time during the first two years of life while the brain is developing
- Characterized by:
 - Abnormal muscle tone and posture
 - Muscular spasms
 - Hearing and vision problems
 - Seizures
 - Some communication difficulty
- Do not assume cognitive disability



Brain Injuries

- Traumatic brain injuries
 - Falls
 - Struck
 - Motor Vehicle Accident
 - Assault
- Concussions
- May impact:
 - Physical, cognitive, emotional, behavioral



Autism Spectrum Disorder (ASD)

- Developmental disability
 - Genetic condition
 - Unknown etiology
- Assessing children with ASD:
 - They are aware of what is happening
 - Explain your actions
 - Include caregivers
 - No sudden movements – distal to proximal
 - Show the child what you will do



Trisomy 21



- Chromosomal abnormality
- Common physical signs
 - Intellectual developmental disorder
 - Decreased muscle tone
 - Upward slanting eyes
 - Small, abnormally placed/shaped ears
 - Hyperflexibility
 - C-spine instability
 - Large tongue
- Common mental and social complications
 - Wandering off or eloping
 - Obsessive/compulsive behaviors
 - Stubborn/oppositional behaviors
 - Impulsive behaviors
 - Poor judgment
 - Short attention span
 - Slow learning

Respiratory Complexities

- May begin subtly
- Often progressive in this population
 - Lung injury
 - Respiratory insufficiency
 - Chronic respiratory failure
- Bronchopulmonary dysplasia
- Impaired airway clearance
- Sleep disordered breathing
- Pulmonary aspiration



Congenital Heart Disease

- Present at birth
- Cyanotic vs Acyanotic
- Verify baseline saturation and perfusion with caregiver
- Apply oxygen and use only to reach child's baseline saturations
- Assess circulation: color, capillary refill time, central and peripheral pulses, and blood pressure



Hydrocephalus

- CSF build-up
- Often a symptom of another problem
- Check for neurological symptoms
 - Breathing pattern
 - Pupils
 - Fussiness or lethargy
- History
 - When did last shunt revision occur?
 - What s/s were present during prior shunt malfunction events?



Seizure Disorders

- Sudden events that cause acute changes
- Caused by abnormal electrical or chemical changes
 - Generalized
 - Focal
- Keep safe, consider oxygen, PRNs



Trisomy 13 & 18

- Chromosomal abnormalities
- Includes a combination of birth defects
 - Severe intellectual disability
 - May affect nearly every system
- Most die before age 1
 - BUT...



Medical Devices



Tracheostomy Tubes

- Surgical opening in the trachea
 - Craniofacial syndromes
 - Neurological impairments
 - Lung conditions
 - Blockages
 - Prolonged intubation
- Care:
 - Keep clean and dry
 - Suction as needed
 - Do not hyperextend neck when transferring child
 - Replace if any concerns about patency
- Common complications



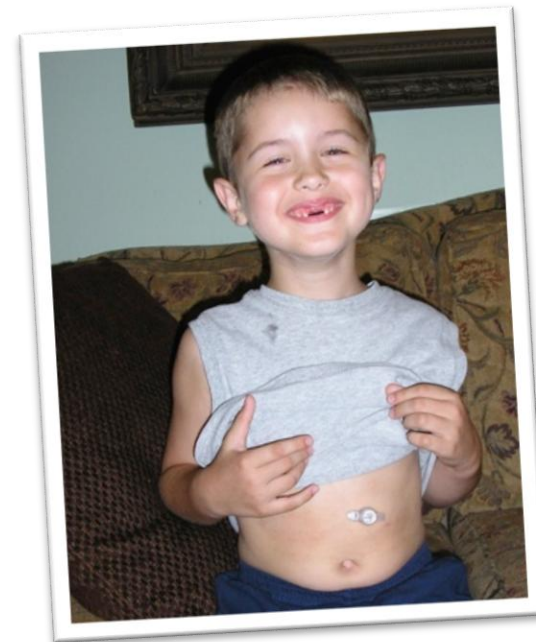
Home Ventilators

- All day or only during sleep
- Care:
 - Family involvement
 - Home: Educate two adults
- Common complications:
 - Know who can make changes
 - Know alarms
 - Know troubleshooting



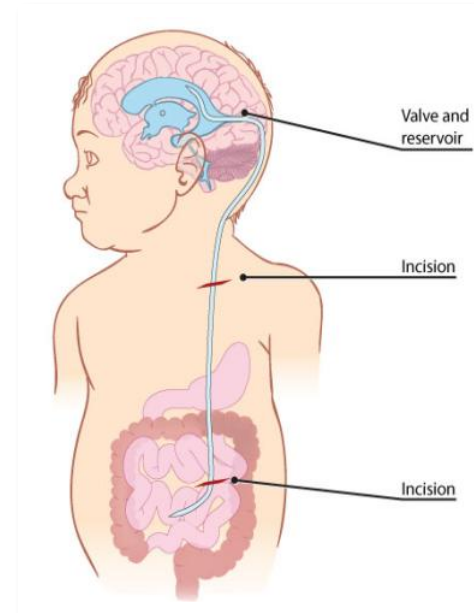
Feeding Tubes

- Unable to eat by mouth or reach full volumes/calories, d/t:
 - Weak suck, gastrointestinal issues, respiratory distress, neurological problems, other
- Types:
 - NGTs, GTs, Mic-Key, GJTs
- Common complications:
 - Infection
 - Occlusion
 - Malpositioned/dislodged/removed tube
 - May need transport to ED for tube replacement
 - Tube deterioration



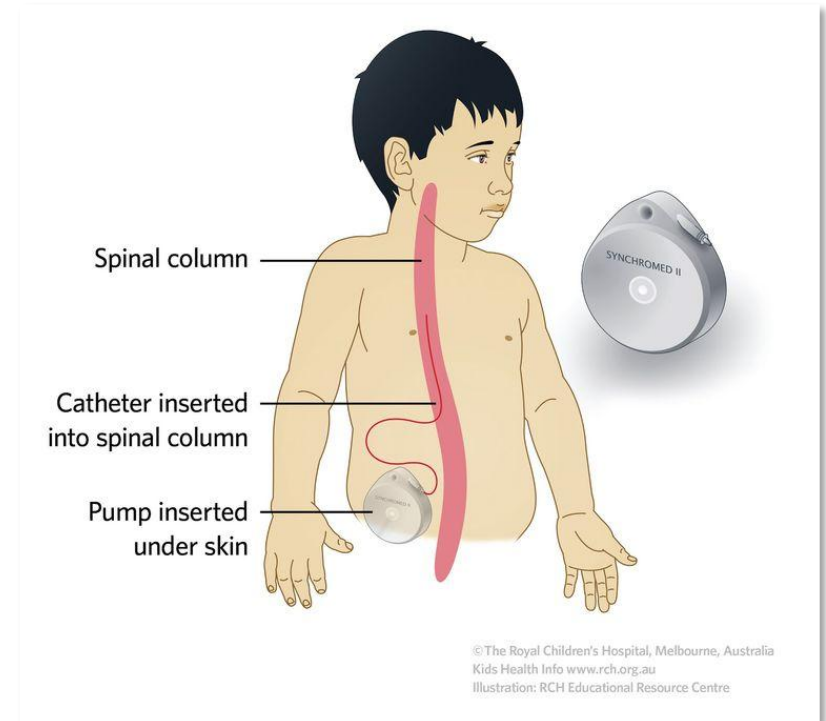
CSF Shunts

- Treat Hydrocephalus
 - Shunt runs from a ventricle in the brain, under the skin, and down the neck into either the peritoneum or the abdomen or the right atrium
- Common complications:
 - Obstruction
 - Infection
 - Growth!



Baclofen Pumps

- Delivers baclofen directly into the intrathecal space
- Used to control spasticity & dystonia
 - Brain injury
 - Cerebral palsy
 - Spinal cord injury
- Common complications
 - Withdrawal
 - Catheter malfunction
 - Infection
 - Toxicity



Vagus Nerve Stimulators

- Sends electrical signals to vagus nerve
 - Intractable seizures
- Care:
 - Keep the magnet with the child
- Complications:
 - Battery life
 - Infection
 - Voice alterations



Assessment and Care



Clinical Baseline

CLINICAL BASELINE	Diagnosis/problem list (list all) starting with most important
	Baseline physical findings
	Baseline vital signs
	Baseline neurologic status
	Immunologic competency status
	Synopsis of clinical status
	Medications (doses, purpose)
	Antibiotic prophylaxis (drug, dose, indication)
	Significant baseline lab/imaging/diagnostic studies
	Prostheses, appliances, advanced technology devices, life support
	Allergies: medications, foods, substances to be avoided and why
	Advanced directives (include date of last review)
	Procedures to be avoided and why

American College of Emergency Physicians:

<https://www.acep.org/Clinical---Practice-Management/Emergency-Information-Form-for-Children-With-Special-Health-Care-Needs/#sm.000i57o5p1bf2cubtey2meelli585>

Pain Assessment

FLACC Pain Rating Scale for children one - three years of age

The FLACC (face, legs, activity, cry and consolability) is a behavioral pain assessment scale used for non-verbal and pre-verbal patients unable to self-report their level of pain. The children should be rated in each of the five measurement categories, then add together and document the total pain score (0-10).

	0	1	2
Face	No expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, clenched jaw, quivering chin
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arches, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or “talking to”, can be distracted	Difficult to console or comfort

Pain Assessment

r-FLAAC (revised FLAAC) Pain Rating Scale for individuals with developmental disabilities unable to self-report their level of pain

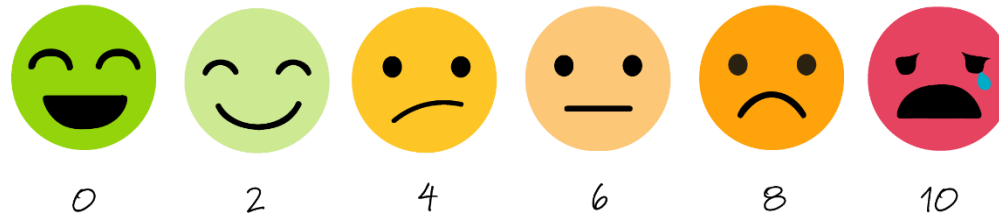
The FLACC (face, legs, activity, cry and consolability) is a behavioral pain assessment scale used for individuals unable to report their level of pain due to developmental disabilities. This pain scale can be personalized with behaviors described by the family/guardians. The individual should be rated in each of the five measurement categories, added together and document the total pain score (0-10).

	0	1	2
Face	No expression or smile	Occasional grimace or frown, withdrawn, disinterested; appears sad or worried	Frequent to constant frown, clenched jaw, quivering chin; distressed looking face; expression of fright or panic Individualized behavior described by family: _____
Legs	Normal position or relaxed; usual muscle tone and motion to arms and legs	Uneasy, restless, tense; occasional tremors	Kicking, or legs drawn up; marked increase in spasticity; constant tremors or jerking Individualized behavior described by family: _____
Activity	Lying quietly, normal position, moves easily; regular rhythmic breaths (respiration)	Squirming, shifting back and forth, tense or guarded movements; mildly agitated (head back and forth, aggression); shallow, splinting breaths (respirations); occasional sighs	Arches, rigid, or jerking; severe agitation; head banging; shivering (not rigors); breath holding, gasping, or sharp intake of breaths; severe splinting Individualized behavior described by family: _____
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint; occasional verbal outburst or grunt	Crying steadily, screams or sobs, frequent complaints; repeated outbursts; constant grunting Individualized behavior described by family: _____
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or "talking to"; can be distracted	Difficult to console or comfort; pushing away caregiver; resisting care or comfort measures Individualized behavior described by family: _____

Pain Assessment

Face Pain Scale - Revised (FPS-R) for children over three years of age

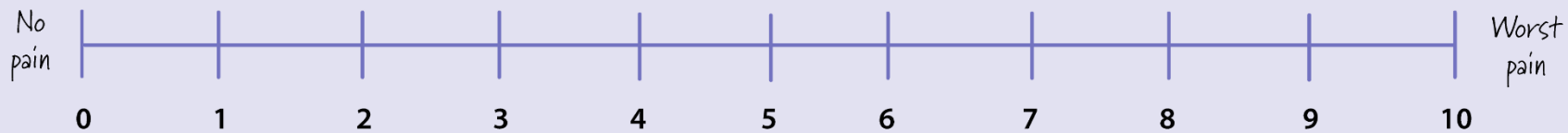
Point to the face that shows how much you hurt



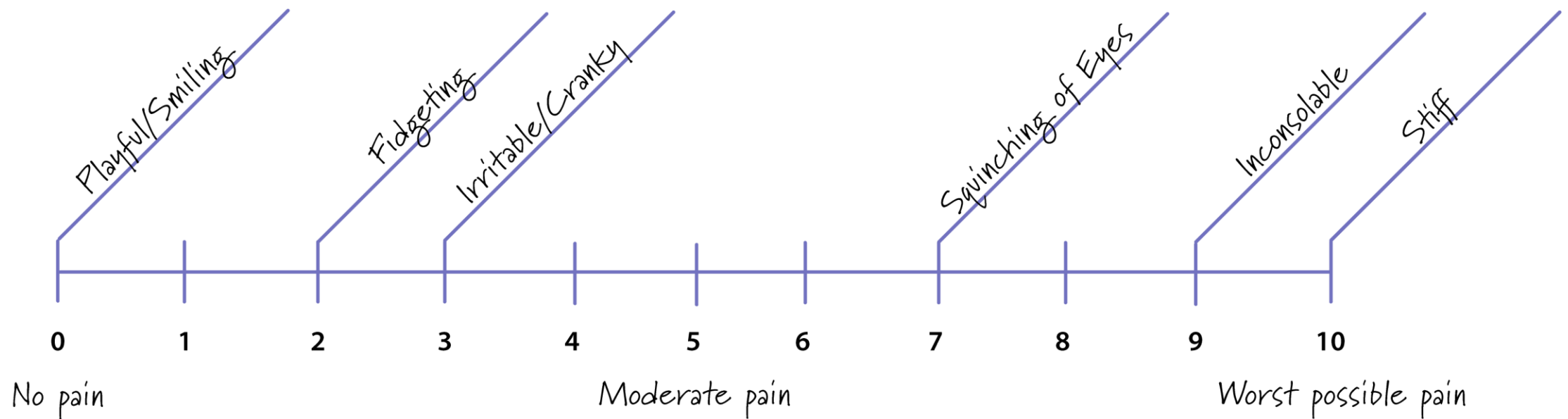
These faces show how much something can hurt. The left side indicating low-to-no pain and the right side showing a lot of pain.

0-10 Scale for children over seven years of age

On a scale of 0-10, with "0" being no pain and "10" being the worst pain you can imagine, what number are you feeling right now?

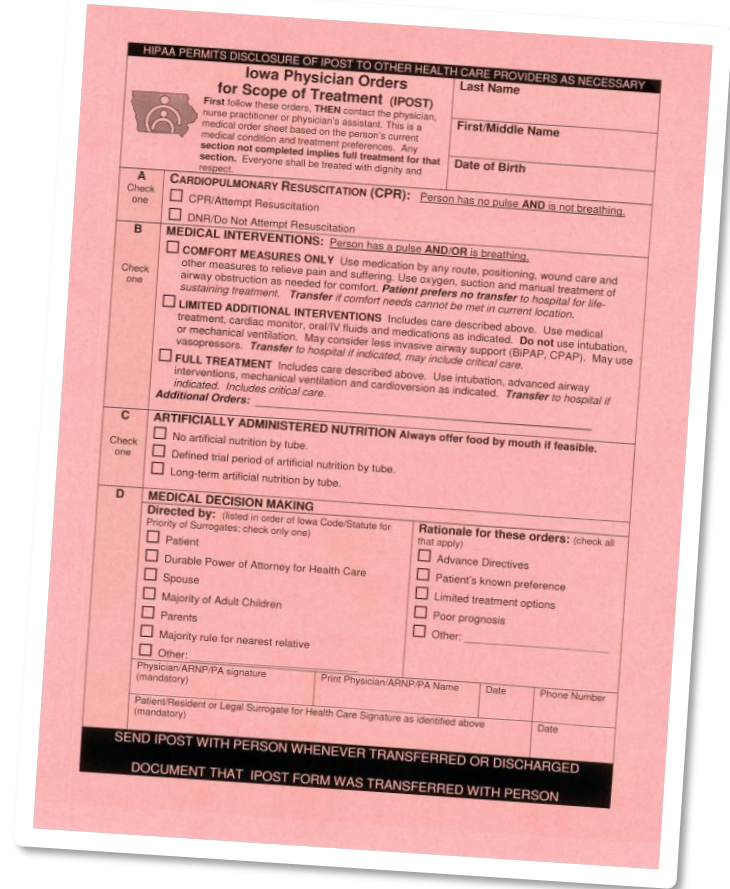


Pain Assessment



Preparing for an Emergency

- Communication
- Collaboration with EMS
- IPOST
 - Iowa Physician's Order For Scope of Treatment



The image shows a pink form titled "Iowa Physician Orders for Scope of Treatment (IPOST)". The form is designed for medical professionals to document patient preferences for life-sustaining treatments. It includes sections for patient information, medical interventions, artificial nutrition, and medical decision-making. The form is titled "Iowa Physician Orders for Scope of Treatment (IPOST)" and includes a HIPAA disclaimer. It is divided into several sections: A. CARDIOPULMONARY RESUSCITATION (CPR), B. MEDICAL INTERVENTIONS, C. ARTIFICIALLY ADMINISTERED NUTRITION, and D. MEDICAL DECISION MAKING. Each section contains checkboxes for different options and instructions for how to use the form. The form also includes a section for the physician's signature and a section for the patient's or legal surrogate's signature. At the bottom, there is a bold instruction: "SEND IPOST WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED. DOCUMENT THAT IPOST FORM WAS TRANSFERRED WITH PERSON".

HIPAA PERMITS DISCLOSURE OF IPOST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Iowa Physician Orders for Scope of Treatment (IPOST)
First follow these orders. THEN contact the physician, nurse practitioner or physician's assistant. This is a medical order sheet based on the person's current medical condition and treatment preferences. Any section not completed implies full treatment for that respect. Everyone shall be treated with dignity and respect.

Last Name
First/Middle Name
Date of Birth

A Check one
CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse AND is not breathing.
☐ CPR/Attempt Resuscitation
☐ DNR/Do Not Attempt Resuscitation

B Check one
MEDICAL INTERVENTIONS: Person has a pulse AND/OR is breathing.
☐ **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. *Patient prefers no transfer to hospital for life-sustaining treatment. Transfer if comfort needs cannot be met in current location.*
☐ **LIMITED ADDITIONAL INTERVENTIONS** Includes care described above. Use medical treatment, cardiac monitor, oral/IV fluids and medications as indicated. *Do not use intubation or mechanical ventilation. May consider less invasive airway support (BiPAP, CPAP). May use vasopressors. Transfer to hospital if indicated, may include critical care.*
☐ **FULL TREATMENT** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated. *Transfer to hospital if indicated. Includes critical care.*
Additional Orders: _____

C Check one
ARTIFICIALLY ADMINISTERED NUTRITION Always offer food by mouth if feasible.
☐ No artificial nutrition by tube.
☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube.

D **MEDICAL DECISION MAKING**
Directed by: (listed in order of Iowa Code/Statute for Priority of Surrogates; check only one)
☐ Patient
☐ Durable Power of Attorney for Health Care
☐ Spouse
☐ Majority of Adult Children
☐ Parents
☐ Majority rule for nearest relative
☐ Other: _____
Rationale for these orders: (check all that apply)
☐ Advance Directives
☐ Patient's known preference
☐ Limited treatment options
☐ Poor prognosis
☐ Other: _____

Physician/ARNP/PA signature (mandatory) Print Physician/ARNP/PA Name Date Phone Number
Patient/Resident or Legal Surrogate for Health Care Signature as identified above Date

**SEND IPOST WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED
DOCUMENT THAT IPOST FORM WAS TRANSFERRED WITH PERSON**

Emergency Information Form

Emergency Information Form for Children With Special Needs

American College of
Emergency Physicians*

American Academy
of Pediatrics

Date form
completed at:
by whom:

Revised: H&A
Revised: H&A

Name: _____	Birth date: _____	Nickname: _____
Home Address: _____	Home/Work Phone: _____	
Parent/Guardian: _____	Emergency Contact Names & Relationship: _____	
Signature/Consent*: _____		
Primary Language: _____	Phone Number(s): _____	
Physicians:		
Primary care physician: _____	Emergency Phone: _____	
Fax: _____	Fax: _____	
Current Specialty physician: _____	Emergency Phone: _____	
Specialty: _____	Fax: _____	
Current Specialty physician: _____	Emergency Phone: _____	
Specialty: _____	Fax: _____	
Anticipated Primary ED: _____	Pharmacy: _____	
Anticipated Tertiary Care Center: _____		

Diagnoses/Past Procedures/Physical Exam:

1. _____	Baseline physical findings: _____
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs: _____
_____	_____
4. _____	_____
_____	_____
Synopsis: _____	Baseline neurological status: _____
_____	_____

*Consent for release of this form to health care providers.

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prostheses/Appliances/Advanced Technology Devices:
5. _____	_____
6. _____	_____

Management Data:

Allergies/Medications/Foods to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____
Procedures to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____

Immunizations (mm/y)

Date	Type	Status	Notes
MM/DD/YYYY	DTaP	☐	
MM/DD/YYYY	Polio	☐	
MM/DD/YYYY	Hib	☐	
MM/DD/YYYY	Pneumonia	☐	
MM/DD/YYYY	Meningitis	☐	
MM/DD/YYYY	Other	☐	

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____

Comments on child, family, or other specific medical issues:

_____ _____ _____
Physician/Provider Signature: _____
Print Name: _____

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Special Considerations

- Speak quietly and calmly
- Employ slower movements and firm, secure contact
- Take time to explain your actions
- May show unusual pain responses like laughing, humming, singing, removing clothes
- Request that the caregiver accompany EMS when transporting the child



Special Considerations

- Latex allergy
 - Greater incidence, especially in children with neural tube defect (e.g. spina bifida)
- Developmental level
- Sensory, vision or hearing problems
- Do not assume that a patient with a physical disability is cognitively impaired
- Determine preferred hospital
- Involve parents/caregivers in the assessment and management of care! They are the experts on their child!

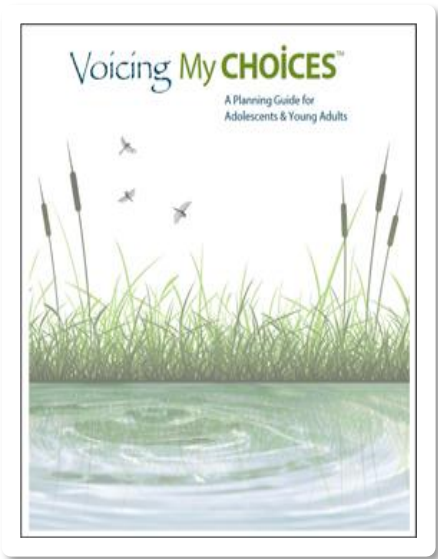


Goals of Care

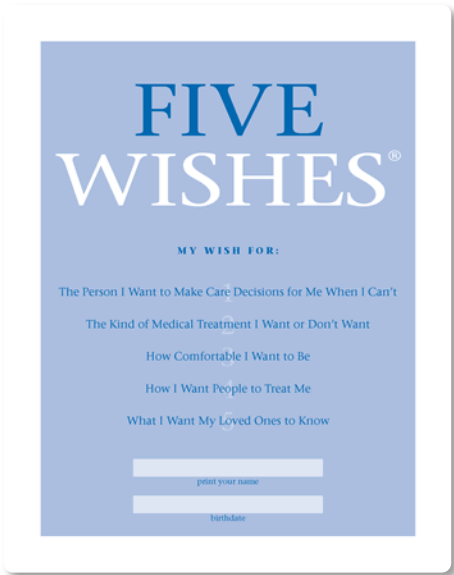
What are the child/family's goals if they become very sick?



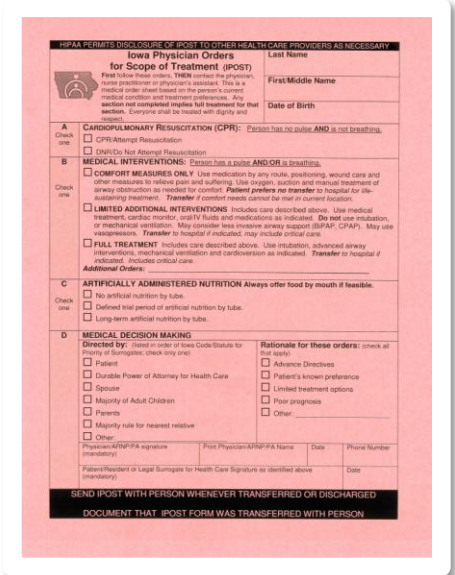
Children



Adolescents
& Young
Adults



Adults



Legal Wishes
0-18yrs

What Do Families Need?

- Collaborative Partnership
 - Informational
 - Emotional
 - Network
- Trust
- Communication
- Expert Clinical Care
- Whole Person Approach



Bethlyn Vergo Houlihan, Cara Coleman, Dennis Z. Kuo, Benjamin Plant, Meg Comeau; What Families of Children With Medical Complexity Say They Need: Humanism in Care Delivery Change. *Pediatrics* January 2024; 153 (Supplement 1): e2023063424F. 10.1542/peds.2023-063424F
Rafferty KA, Nemmers-Bello S, Tietz S, Mothers' Support Preferences With Their Chronically Ill Child's Health Care Team. *West J Nurs Res.* 2022 Oct;44(10):912-919. doi: 10.1177/01939459211030338. Epub 2021 Jul 8. PMID: 34238081.



Communication

- Family-Centered
- Family Involvement
- Emotional Support
- Health Literacy
- Adherence
- Error Reduction
- Builds Trust



Family Considerations

- What is quality care?
 - Physicians say: **Clinical Skill**
 - Patients/Families say: **Communication**
- What do parents say about communication?
 - Information is often withheld
 - Do not get updated as frequently as they wish
 - Often confusing or contradictory info
- Prognosis



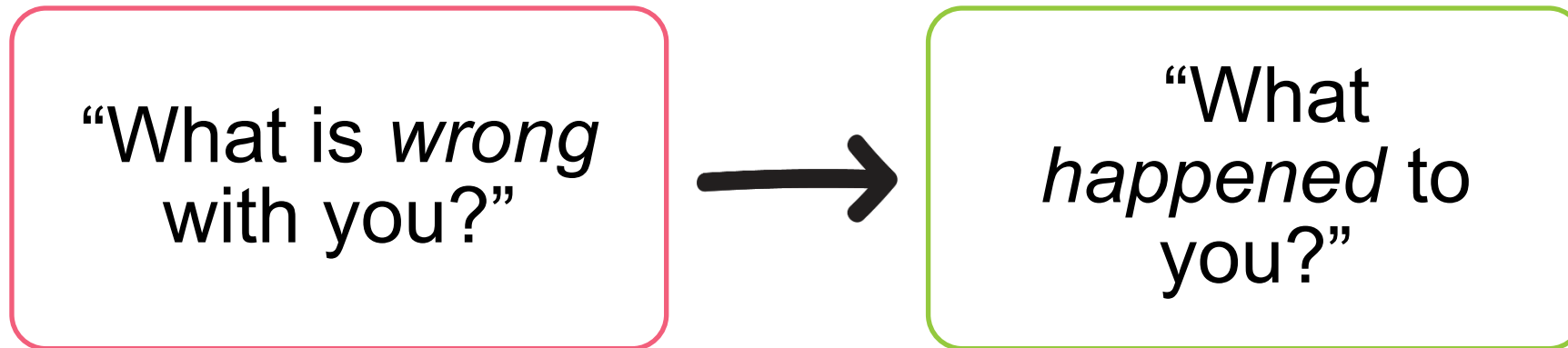
Family Considerations

- How does the child communicate?
- How do you recognize when the child is in pain?
- What are the child's normal functions? (stooling, urination, temp, breathing)
- What assistive devices are used?
- What are the family's specific concerns?
- What comforts the child?
- What have you and your child gone through?



Family Considerations

Trauma Informed Care is a **culture** that promotes safety, empowerment, and healing



Family Considerations



Palliative Care



- Active total care of the child's body, mind & spirit
- Begins at diagnosis
- Different than Hospice
- Goal: to alleviate a child's physical, psychological & social distress & enhance quality of life
 - Symptom management
 - Communication
 - Family Centered
 - Respect
 - Love



SECTION ON HOSPICE AND PALLIATIVE MEDICINE AND COMMITTEE ON HOSPITAL CARE, Chris Feudtner, Sarah Friebert, Jennifer Jewell, Sarah Friebert, Brian Carter, Chris Feudtner, Margaret Hood, Sonia Imaizumi, Kelly Komatz; Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations. *Pediatrics* November 2013; 132 (5): 966-972. 10.1542/peds.2013-2731

Family Centered Care

- Family centered care philosophy
 - Respect & Dignity
 - Information Sharing
 - Participation
 - Collaboration
- Family Input at All Levels
- Environment



COUNCIL ON CHILDREN WITH DISABILITIES and MEDICAL HOME IMPLEMENTATION PROJECT ADVISORY COMMITTEE, Renee M. Turchi, Richard C. Antonelli, Kenneth W. Norwood, Richard C. Adams, Timothy J. Brei, Robert T. Burke, Beth Ellen Davis, Sandra L. Friedman, Amy J. Houtrow, Dennis Z. Kuo, Susan E. Levy, Susan E. Wiley, Miriam A. Kalichman, Nancy A. Murphy, W. Carl Cooley, Joan Jeung, Beverly Johnson, Thomas S. Klitzner, Jennifer L. Lail, Linda L. Lindeke, Amy Mullins, Lee Partridge, William Schwab, Christopher Stille, Debra Waldron, Nora Wells, Calvin Sia; Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. *Pediatrics* May 2014; 133 (5): e1451-e1460. 10.1542/peds.2014-0318

Family Considerations

- Quality of Life Conversations
 - Can you tell me about *[name]* before his accident?
 - How have things changed for *[name]*?
 - How have things changed for your family?
 - Based on your understanding of *[name]*'s current condition, what's most important to you right now?
 - What are you hoping for *[name]*'s future?
 - Do you have any worries?
 - What does quality of life mean to you?



Remember...

Always find opportunities for kids to be kids!



Resources



References

- “A State Multi-Sector Framework for Supporting Children and Youth with Special Health Care Needs.” *Lucile Packard Foundation for Children’s Health*, <https://www.lpfch.org/>.
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- “Identifying and Serving Children with Health Complexity: Spotlights of Efforts to Develop and Pilot the Kaiser Permanente Northwest Pediatric Care Together Program.” (2019). *Lucile Packard Foundation for Children’s Health*, www.lpfch.org/publication/identifying-and-serving-children-health-complexity-spotlight-efforts-develop-and-pilot.
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Thank You

Questions?

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