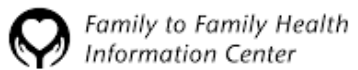


IT'S ABOUT LIVING!

**PALLIATIVE CARE SERVICES
FOR PEOPLE WITH
DISABILITIES**



The Arc of Illinois
Family-to-Family Health
Information Center
Susan Agrawal, Director



ABOUT ME – LIVED EXPERIENCE

Parent of a child who was disabled and medically complex

Diagnoses

- Cerebral Palsy
- Autoimmune Disease

Technology

- Vent
- Central Line
- IV Nutrition
- Feeding Tube
- Oxygen
- Foley Catheter

Needed Services

- Home Nursing
- **Palliative Care**
- Education
- Care Coordination



Karuna, 2003-2014

TODAY'S GOALS

Understand what
Palliative Care is

Learn about
Pediatric Palliative
Care laws and
programs in Illinois

Discuss how adults
with disabilities
struggle to get
palliative care

Palliative Care is NOT Hospice



Palliative Care is NOT (just) End-of-Life Care

SO, WHAT IS PALLIATIVE CARE?

“Palliative care is **patient and family-centered care** that optimizes **quality of life** by anticipating, preventing, and treating suffering. Palliative care throughout the **continuum of illness** involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.”



National Hospice and Palliative Care Organization
National Consensus Project Definition



Palliative Care is All About Living...
and Living Well!



WHAT IS THE PURPOSE OF PALLIATIVE CARE?



Improve Quality of Life



Relieve Suffering from Physical Symptoms



Relieve Suffering from Psychological Symptoms

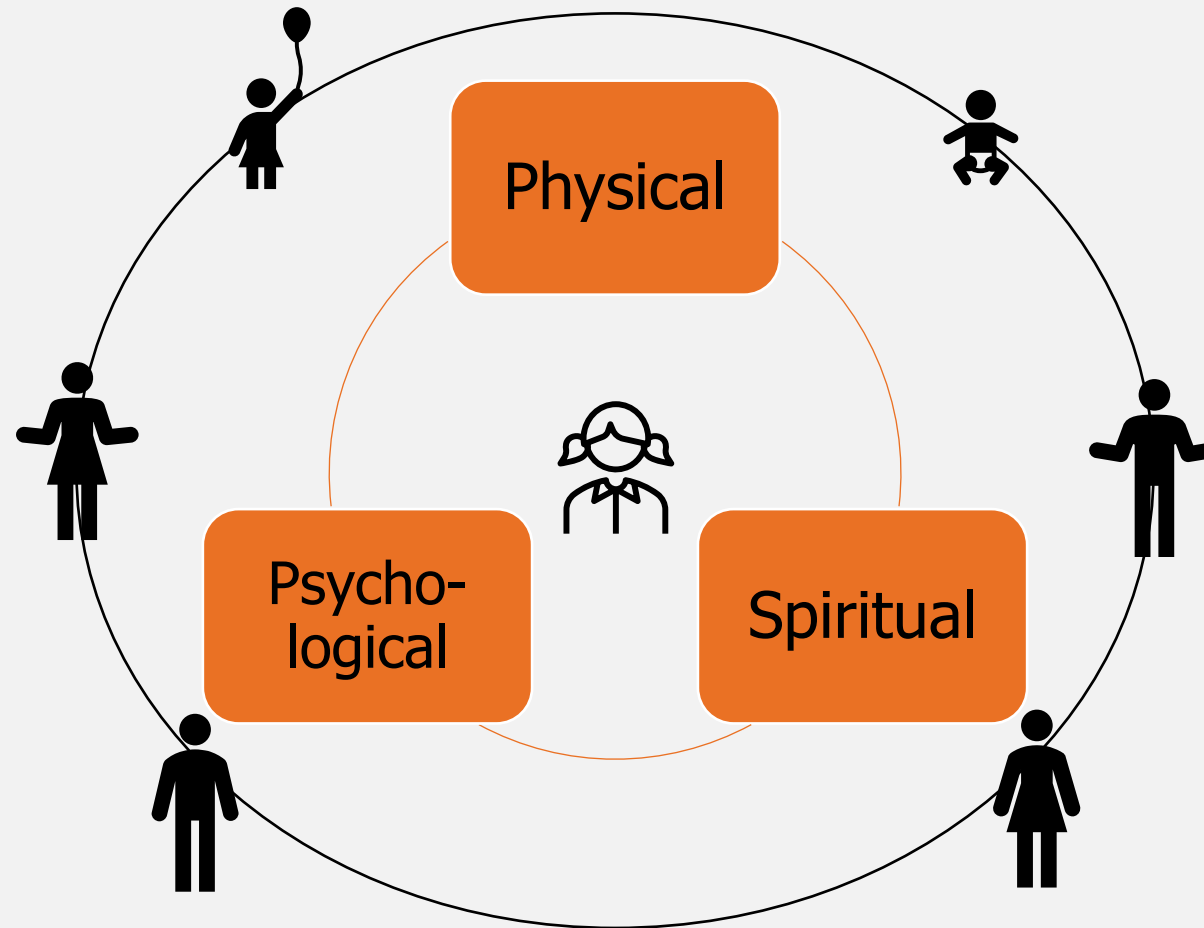


Determine Treatment Options

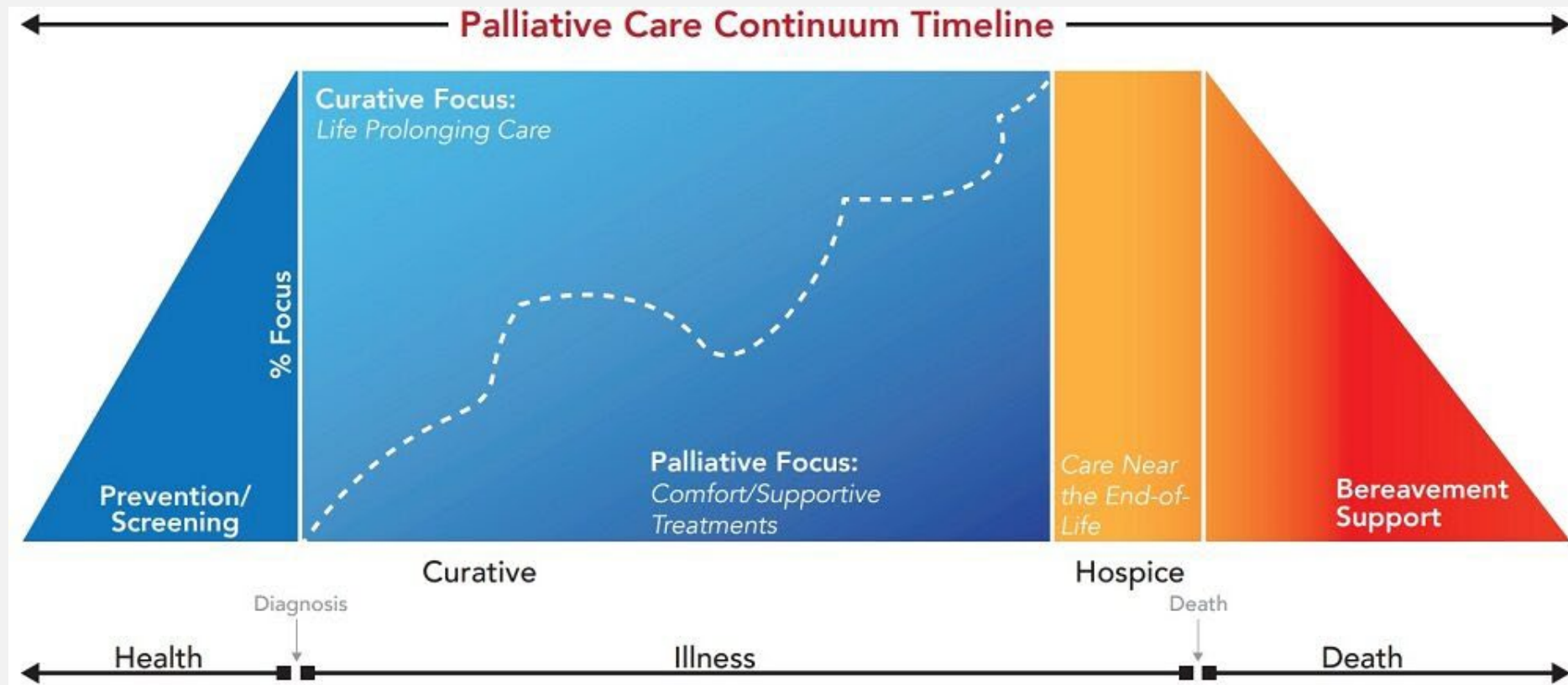


Coordinate Care with Various Doctors

PALLIATIVE CARE IS HOLISTIC



PALLIATIVE COURSE OF CARE



PALLIATIVE CARE VS. HOSPICE

	Palliative Care	Hospice
When does it start?	Diagnosis or any time after	At the terminal phase
How long?	Not time limited – months, years, or decades!	Limited to 6 months
What kind of care?	Can pursue concurrent curative treatment OR comfort care	Comfort care only
Who qualifies?	An individual with a severe or life-limiting illness or condition	An individual with a terminal prognosis measured in months

WHO IS ON A PALLIATIVE CARE TEAM?



Physician



Nurse



Social
worker or
care
coordinator



Psychologist,
counselor,
therapist



Chaplain or
spiritual
leader



Expressive
therapists



Bereave-
ment
specialists

WHAT SERVICES ARE OFFERED THROUGH PALLIATIVE CARE?

Medical care

- Pain management
- Treatment for nausea, shortness of breath, fatigue

Psychological and spiritual care for the entire family

Expressive therapies

- Music or art therapy
- Massage
- Play therapy or child life services

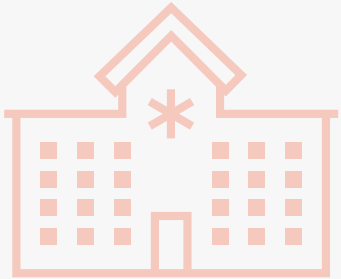
Advance planning

- MOLST or POLST
- Legal directives

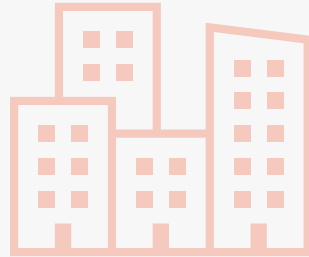
Respite care

Bereavement preparation, support, and counseling for the entire family

WHERE CAN YOU RECEIVE PALLIATIVE CARE?



Hospital



Clinic or Doctor Office



Home or Community Setting



Hospice or Respite House

HOSPITAL VERSUS COMMUNITY PALLIATIVE CARE

	Hospital/Office	Community
Where based?	Inpatient or in an outpatient clinic	In the home or community by an agency
How funded?	Paid by insurance, Medicaid, or Medicare	Medical care may be paid; other care may be unreimbursed in many cases
What services?	<ul style="list-style-type: none"> • Focus on symptom management, care coordination, and more medical factors • Some programs are more comprehensive 	<ul style="list-style-type: none"> • More comprehensive focus • More expressive therapies • More pediatric programs than adult programs

PERSONAL EXPERIENCE WITH PALLIATIVE CARE



Birth

- Umbilical cord rupture
- Rough start, but otherwise mostly healthy with a physical disability



Age 3

- Started developing pain and health problems
- **Began hospital-based palliative care**



Age 5-6

- Health worsening
- **Added community based palliative care**



Age 8

- Severe health crisis
- **Began transition to end-of-life or hospice care**



Age 11

- Death at home



PERSONAL EXAMPLES OF CARE: HOSPITAL-BASED



Pain
management
plan



Plan to relieve
nausea and
vomiting



Creation of a
POLST form to
plan in the last
few years of life



Medical
appointments
arranged all at
one time at the
hospital



Full medical care
coordination
between
specialties

PERSONAL EXAMPLES OF CARE: COMMUNITY-BASED



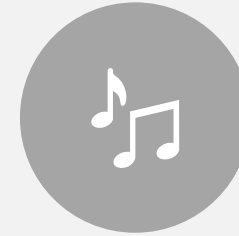
Play therapy
(with siblings) to
prepare them



Nurse visits to
provide IV fluids
or labs to stay
out of the
hospital



Massage therapy
sessions for pain
relief



Music therapy
sessions for fun



Visits with Santa
and other fun
family events

WHAT PEOPLE WITH DISABILITIES NEED PALLIATIVE CARE?

LIFELONG CONDITIONS

Children and adults with lifelong disabilities or conditions that limit the lifespan, such as:

- People with severe neurological disorders, including cerebral palsy or epilepsy
- People with certain genetic, chromosomal, or congenital disorders
- Some people with Down syndrome and significant heart defects
- People with muscular dystrophy or spinal muscular atrophy
- Other degenerative conditions



Most people with intellectual or developmental disabilities end up having shorter lifespans

WHAT PEOPLE WITH DISABILITIES NEED PALLIATIVE CARE?

DISABILITIES OR CONDITIONS THAT DEVELOP LATER IN LIFE



- ALS
- Multiple Sclerosis
- People with Down syndrome who develop leukemia

WHAT PEOPLE WITH DISABILITIES NEED PALLIATIVE CARE?



People with disabilities with a poor quality of life due to chronic pain or other symptoms

People with disabilities who experience serious illnesses such as cancer, kidney failure, or heart disease

FUNDING PALLIATIVE CARE

Children

- State laws will require coverage through both Medicaid and private insurance
- Program development in progress

Adults

- “Medical” palliative care in a hospital or clinic is covered by Medicaid, Medicare, and private insurance
- Other services are less likely to be covered
- Hospice care is usually covered, but must have a terminal diagnosis and forego curative treatment
- Few community based palliative care programs exist for adults; most are hospice-only

PEDIATRIC
PALLIATIVE CARE
IN ILLINOIS



PEDIATRIC PALLIATIVE CARE LEGAL LANDSCAPE

Medicaid

Creation of
Medicaid Pediatric
Palliative Care
Program
(Illinois only)

Private Insurance

Palliative Care must
be covered for
children
(Illinois only)

Affordable Care Act

Children must be
allowed to pursue
concurrent
curative treatment
(federal)

STATE LAWS: MEDICAID

305 ILCS 60 Pediatric Palliative Care Act (effective 1/1/2022)

Medicaid will create a Pediatric Palliative Care program and pay for palliative care services for children under 21

The Department shall develop a **pediatric palliative care program**, and the medical assistance...shall cover community-based pediatric palliative care from a trained interdisciplinary team, as an added benefit under which a qualifying child...may also **choose to continue curative or disease-directed treatments** for a serious illness.

MEDICAID PEDIATRIC PALLIATIVE CARE PROGRAM: WHO QUALIFIES?

Cancer

End-stage lung disease

Severe neurological conditions

Degenerative neuromuscular conditions

Genetic syndromes

Congenital or acquired end-stage heart disease

End-stage liver disease

End-stage kidney failure

Metabolic or biochemical disorders

Congenital or acquired diseases of the gastrointestinal system

Congenital skin disorders

Any other serious illness that the Department determines to be appropriate

MEDICAID PEDIATRIC PALLIATIVE CARE PROGRAM SERVICES

Nursing for pain and symptom management

Expressive therapies (such as music or art therapies)

Client and family counseling (including spiritual counseling)

Respite care

Bereavement services

Case management

Any other services that the Department determines to be appropriate

MEDICAID PROGRAM STATUS

Current Status



Waiting for the state to submit State Plan Amendment [1915(i) plan] to get program federally approved

Pediatric Palliative Care program will be administered by the Division of Specialized Care for Children (DSCC)

Providers will need to register with Medicaid to be paid

Children will need to apply or be referred to program

Only children in the program will have services paid for

STATE LAWS: PRIVATE INSURANCE

215 ILCS 5/356z.53

- Requires private insurance companies to cover pediatric palliative care services
- Self-funded insurance plans are not required to follow this type of law

A group or individual policy of accident and health insurance or a managed care plan amended, delivered, issued, or renewed on or after January 1, 2024 **shall provide coverage for community-based pediatric palliative care and hospice care**

PRIVATE INSURANCE STATUS

Current Status

Law is operational and in effect

Major health insurance plans are being notified of their new obligations

Many are not yet aware of the law and do not have procedures in place for coverage yet



FEDERAL LAW: CONCURRENT CARE

Affordable Care Act (2010) Section 2302

- Concurrent Care for Children Requirement
- Medicaid/CHIP must pay for BOTH curative care and hospice care
- Hospice is a required covered service for children in Medicaid
- Children **must** be certified as in the last **6 months of life**

A voluntary election to have payment made for hospice care...shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the treatment of the child's condition for which a diagnosis of terminal illness has been made

ISSUES WITH CONCURRENT CARE PROVISION

Issues

- Children don't die on typical timelines – 6-month terminal requirement does not make sense
- Primarily a hospice benefit
- Providers can still turn down a child for services who does not meet their individual hospice criteria
- Only available through Medicaid

**ADULTS WITH
DISABILITIES AND
PALLIATIVE CARE**



ADULTS RARELY GET PALLIATIVE CARE

Adults usually only get coverage for hospice

- Must be determined terminally ill
- Must forego curative care

Some medical palliative care services available in hospital or outpatient

Other services are less common and only available through hospice

Adults usually only have access to these services at the end of life

Children may lose services between ages 18 and 26

DISABILITIES AND PALLIATIVE CARE

People with disabilities are MORE likely to develop serious health conditions

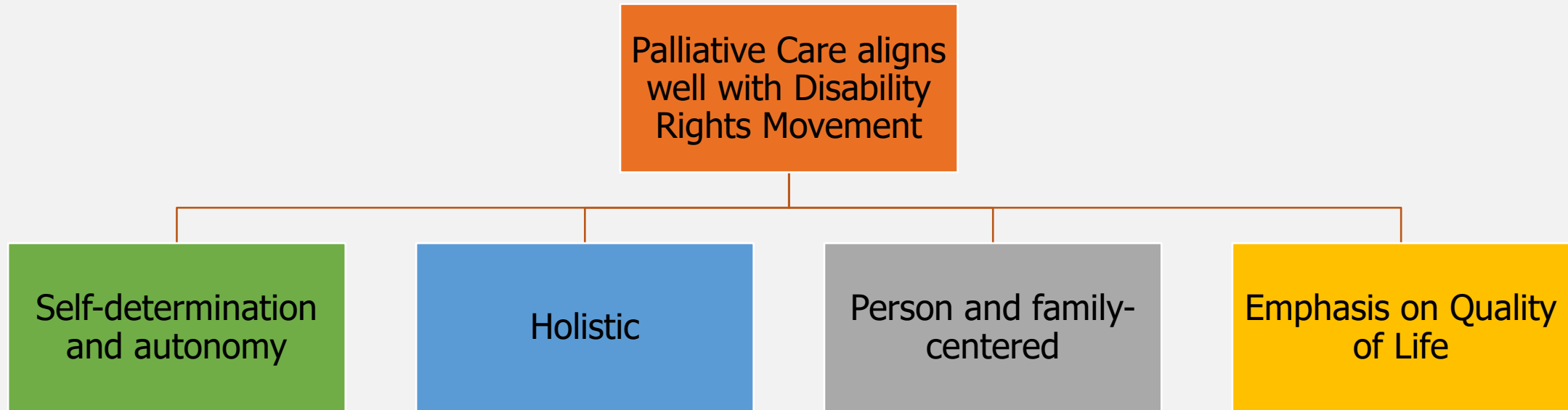
People with ID/DD are less likely to be referred to palliative care, even when it is needed

Clinic Experience

- Some palliative clinics or programs have experience with adults with **physical or health disabilities**
- Very few have experience or training to assist adults with **intellectual disabilities, developmental disabilities, or autism**

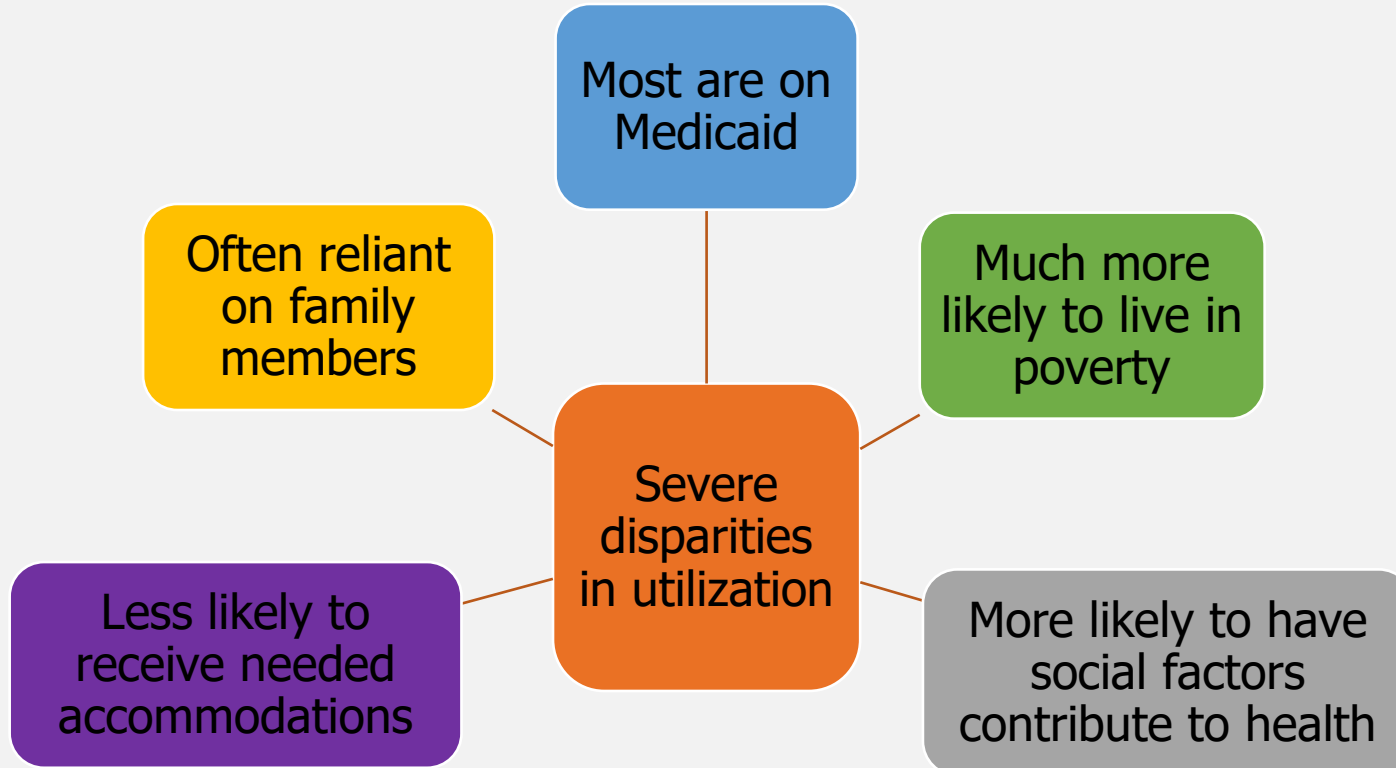
Care of people with disabilities is often siloed

PALLIATIVE CARE AND DISABILITY RIGHTS



But...there may be mistrust of medical professionals

SOCIAL DETERMINANTS RELATED TO PALLIATIVE CARE AND DISABILITY



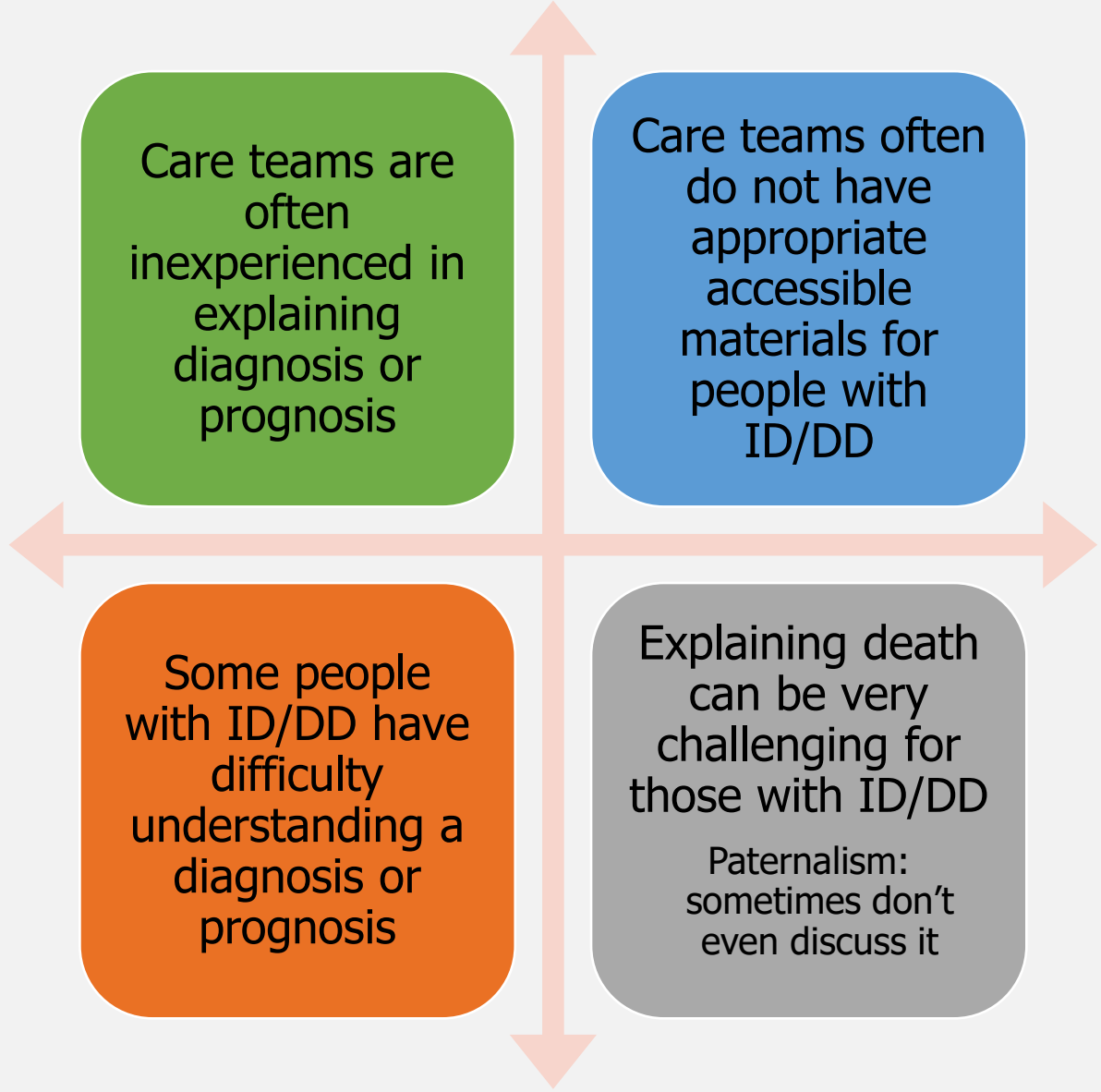
PAIN IN PEOPLE WITH DISABILITIES

Pain is often unrecognized in people with disabilities, especially those who are unable to speak or have difficulty with communication

Those with intellectual disabilities are less likely to be provided comprehensive pain management such as opioids

Other bothersome symptoms are often underrecognized and undertreated

PALLIATIVE CARE IN PEOPLE WITH ID/DD



CALL TO ACTION!

Adults should be entitled to comprehensive community-based Palliative Care funded by Medicaid, private insurance, and Medicare

Palliative Care teams should be trained to know how to work with people with a wide range of disabilities, including ID/DD and autism

Discrimination in people with disabilities who have pain and other negative symptoms must be addressed

MORE INFORMATION

- [HAP Foundation](#)
- [Greater Illinois Pediatric Palliative Care Coalition](#)
- [Illinois Hospice and Palliative Care Organization](#)
- [Courageous Parents Network](#)

CONTACT INFORMATION



779-254-9158
815-464-1832 ext. 1017
866-931-1110
Spanish: 800-588-7002
Language Line for other languages



susan@thearcofil.org



<https://www.familyvoicesillinois.org>



<https://www.facebook.com/ilfamilyvoices>