INTELLECTUAL & DEVELOPMENTAL DISABILITIES
PALLIATIVE CARE NETWORK

MODULE D: EARLIER IDENTIFICATION GUIDANCE

A Proactive Palliative Approach to Care

April 2026

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ACKNOWLEDGEMENTS

The Intellectual and Developmental Disability Palliative Care Network (IDD PCN) would like to thank the members who worked tirelessly towards the development of this module.

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EARLIER IDENTIFICATION OF PALLIATIVE CARE NEEDS

Earlier identification is an important part of a proactive palliative approach to care. Being proactive in identifying (recognizing) current needs for care and potential future needs to plan for is especially important to close the gaps in health care for people with intellectual and developmental disability (PWIDD)[i].

It is never too early to implement a palliative approach to care, but it can be too late. Too late negatively impacts the ability to deliver responsive and effective care in a timely manner. Unmet needs, late care, and planning leads to avoidable hospitalizations and unnecessary suffering.

Earlier identification includes the interprofessional team recognizing a person:

- Who would benefit from a palliative approach to care.
- When there are changes or a decline from the person's cognitive, adaptive, and/or health baseline.
- Understanding where the person is in their illness journey to support essential conversations and anticipating future needs for care planning.

Accurately assigning meaning to the cause of change(s) or decline, avoiding diagnostic overshadowing and unconscious bias, is important for timely and responsive care. Changes may be due to:

- A new health concern.
- Pain or other symptom(s).
- A pattern of decline is emerging (health, functional, cognitive) due to illness progression.
- The person may be entering the last year of life or less.

Ethical Reminders:

Equitable access to palliative care for PWIDD requires early identification of palliative care needs, for which IDD-specific training, tools, and approaches are necessary.

Early identification allows for proactive and ongoing planning, inclusion of the person's *Circle of Support*, and more dignified engagement with them.

Earlier identification requires understanding the expected illness journey. An illness journey is a combination of the stages of illness (new diagnosis, chronic, advanced, end-stage, and end-of-life) and the expected illness trajectory (pattern of decline). For PWIDD it is important to be aware of the:

- Medical complexity of PWIDD (the combination of living with IDD and health conditions (comorbidities).
- Frailty specific to PWIDD.
- Person's specific baseline to be able to identify changes.
- Comparing the person's cognitive, adaptive, and health baseline to identify changes to inform signs of illness progression.
- Adapting communication to plain language.
- Including communication partner(s) for people who are atypical communicators to assist reporting health concerns.
- Accommodating for sensory needs.
- Pain or other symptom burden can be a cause of behaviour(s), changes, or decline.

BENEFITS OF EARLIER IDENTIFICATION[ii]

- Proactive person-centred care, rather than reactive.
    - Helps us to look for people who are at risk for health concerns or may be showing signs of being less well now
    - These people need more help and care now, and a plan for care in the future (Advance Care Planning)
- Enabling timely conversations and understanding of person's wishes, values, traditions, culture, beliefs, hopes, and fears.
    - Through *Advance Care Planning*, *Goals of Care* discussions, and *Healthcare Consent*.
    - Using *Supported Decision-Making* frameworks (not to be confused with *Substitute Decision Maker*). (See Module A)
- Empowering the person to identify and communicate who is their *Circle of Support*.
    - These are those people the PWIDD has chosen, trusts, and knows them well that support them in their decision making.
    - Their *Substitute Decision Maker (SDM)*.
- Responsive care planning that reflects the person's choices and preferences.
    - Identify present and anticipate future potential holistic needs of the person and their *Circle of Support*.
    - Build the interprofessional team (Core, Extended, Specialist) to support the person and their *Circle of Support*.
    - Better person-directed outcomes including improved illness understanding, improved symptom management, decreased psychosocial distress, and living and dying in the location of their choice.
- Allows for more care in place (at home) through primary care, fewer crisis hospital admissions, and avoiding unnecessary ER transfers.
    - **Note:** Although not all ER transfers are avoidable, each ER visit carries risk of stressors that can contribute to further destabilizing fragile PWIDD, cause delirium, and trigger any past history of institutional and medical trauma.
- **Ultimately, earlier identification helps ensure the *right care* is provided at the *right time*, in the *right place*, by the *right team*, using the *right communication*, to be proactive ensuring the person's needs are met as they emerge for responsive and timely care delivery.**

Ethics Pearl: Societal Benefit of Earlier Identification

In a society impacted by social inequities and inequalities, ensuring that all PWIDD have early and equitable access to palliative care reduces the burden of caregiving on those who need support. Early identification of palliative care needs will also ensure equitable stewardship of limited resources and is fiscally and ethically responsible.

KNOWLEDGE POINTS:

NORMS OF PRACTICE

3-STEP PROCESS

1. Identify & Screen

2. Observe & Assess

3. Plan & Manage

- When thinking about earlier identification, it is important to understand that PWIDD experience premature aging and premature death.[iii, iv, v]
  - Premature Biological Aging
    - Estimated 20-30 years older than chronological age
  - Neuro-Atypical Aging
    - Dementia presents earlier (at approx. 30-40 years old)
    - High incidence of rapidly progressing Alzheimer's (especially in Down syndrome)
  - Premature Death
    - 4 times more likely to die prematurely
    - Median age at death = 55-64 years old (30-40 years old if severe/profound level of IDD)
  - Leading Causes of Death are comorbidities (other health conditions/diseases at the same time as the IDD condition)
    - Cardio/pulmonary: 36%
    - Cancer: 29%
    - Sudden Unexpected Death in Epilepsy: 30%
    - Nervous System Disorder (congenital/chromosomal): 7%
    - Distinct Frailty: 4%
- Premature aging means that PWIDD will need care approaches earlier, including geriatric screenings, assessments, care considerations and care planning.
- Geriatric screening and assessment require IDD specific tools. **The MMSE and MOCA are not used.** The expected tool to use for dementia screening in IDD is the NTG - Early Detection and Screen for Dementia (NTG-EDSD).
- Understand the IDD condition and baseline.
- Understand what stage of illness the person is in (acute/new diagnosis, chronic, advanced, end-stage, end-of-life).
- Understand the expected illness journey and illness trajectory (pattern of decline) of the comorbidity the person is living with (cancer, organ failure, neurodegenerative, frailty).
- **Important questions for the interprofessional care team to ask and have answered:**
  - ***What stage of illness is the person currently experiencing?***
  - ***Is there a pattern of change(s) or decline being seen and what does it mean?***
  - ***What can be expected and how might the illness progress?***
  - ***What might the changes look like and what should we be watching for (e.g. illness, needs, symptoms)?***

  Answers to these questions equips the interprofessional care team's proactive approach and timely response of the Core Team, Extended Team, Specialists Team (Chronic disease, Palliative Care).

ACTION POINTS: "GOOD" PRACTICE STANDARD

A palliative care approach is practiced using a 3-step process:

1. **Identify and Screen (using appropriate tools)**
2. **Observe and Assess (based on role and scope of practice)**
3. **Plan and Manage (based on identified needs and future care planning)**
   (See Norms of Practice in Module B: Domains of Holistic Care)

- Identify the person(s) who would benefit from a palliative approach to care. A person:
  - at risk of pre-mature death.
  - with an IDD condition that may shorten life.
  - with one or more health conditions that may shorten life (comorbidity).
  - considered medically complex.
- Screen to establish the baseline of the person and ***then*** screen on-going as changes or decline are noticed.
- Apply approaches to plan and manage current needs and ***proactive planning*** for future needs.

PALLIATIVE CARE THROUGH THE STAGES OF ILLNESS

A palliative approach to care is appropriate at every stage of illnesses that shorten life. For PWIDD, an illness journey is their life's story, not just a stage of illness consideration alone associated with a comorbidity.

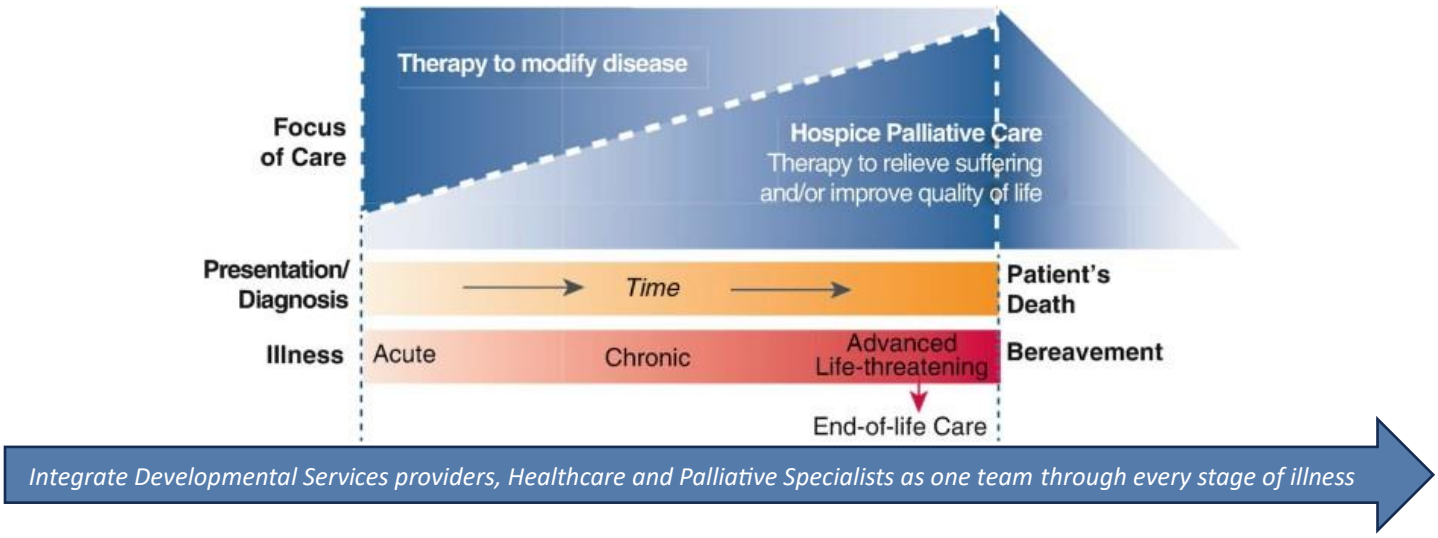
STAGES OF ILLNESS (Illness Journey)

- New Diagnosis (Acute)
- Chronic Stage
- Advanced Stage
- End-Stage (Last year of life)
- End-of-Life (last 3 months of life)

The following figure illustrates the typical shift in focus of care over time, and how palliative care plays an increasingly significant role in providing care as a person moves through the stages of illness. At the beginning of an illness that will shorten life, for which there is no cure, the focus is mainly on therapy to slow progression of the chronic progressive illness and to manage any associated pain and symptoms. In the case of cancer, earlier identification of changes that may be warning of cancer increases the possibility of cure in many types of cancer that PWIDD are at high risk for.

Figure 1.

Illness Journey (Stages of Illness)[vi]



Earlier identification of needs and changes are included in the acute and chronic stage of illness, using earlier identification principles and tools are specifically important in the later stages of illness to be proactive in applying a palliative care approach. The chart below begins at advanced stage illness for this reason.

Advanced Stage	End Stage	End-of-Life Stage	Imminent Death Stage
• Can have greater than 1 year to live • General health is poor and getting worse • Troublesome symptoms • With recurring health events or fluctuations does not return to previous baseline • Frailty is getting worse • May experience weight loss despite dietary efforts • Unplanned (emergency) admission(s) to hospital and often start happening closer together and more frequently • Increasing care needs due to increasing physical and/ or mental health problems. • May have cognitive changes • *Circle of Support* needs more help and support	• Death would not be a surprise if happened in the next 12 months • Irreversible decline in health • Cognitive changes • High frailty • Troublesome symptoms most of the time despite good treatment of their health condition • Often seizures begin. If previously had seizures will often see them happening more often, getting worse and harder to control • May be fluctuating but nonetheless ongoing decline • Response to treatments are losing effectiveness despite adjustments • High intensity care needs • Disease specific signs	• Death expected in 3 - 6 months • May happen gradually or suddenly following serious or devastating health event • In clinical medicine, the 'end of life' is the period preceding an individual's natural death from a process that is unlikely to be arrested by medical care • Palliative Specialist Teams join the Core Team to deliver end of life care at home • May consider transfer to Residential Hospice • May need admission to Palliative Care Unit (PCU) if care needs exceed what can be given at home	• Death expected in hours to days • Body functions are shutting down

ILLNESS TRAJECTORY (Type and pattern of decline)

Chronic illnesses that shorten life expectancy and worsen (progress) over time tend to follow a particular pattern in the health decline observed in the person based on the underlying condition. A person's illness experience may follow one or more illness trajectory(s). Any person has the potential to progress along multiple illness trajectories if they have multiple concurrent chronic illnesses. PWIDD will tend to have an illness experience that follows more than one trajectory. This is as a result of multi-comorbidity. Research indicates that 98.7% of PWIDD have multimorbidity of three or more illnesses, compared to 23% in the general population[vii].

The four trajectories are:

- Neurodegenerative/Cognitive illness conditions
- Frailty in IDD and/or frailty in aging
- Organ Failure illness conditions
- Cancer

RECOGNIZING ILLNESS TRAJECTORIES (Patterns of Decline)

- Recognizing the illness trajectories and patterns of decline is important to earlier identification as understanding these trajectories and expected patterns can provide guidance for discussing expectations of what will happen regarding a person's anticipated health changes over time. It is also essential to conversations as part of *Healthcare Consent*, *Goals of Care*, and *Future Care Planning*. See Figure 2 below.

Figure 2. ***Illness Trajectories (Patterns of Decline)***[viii]

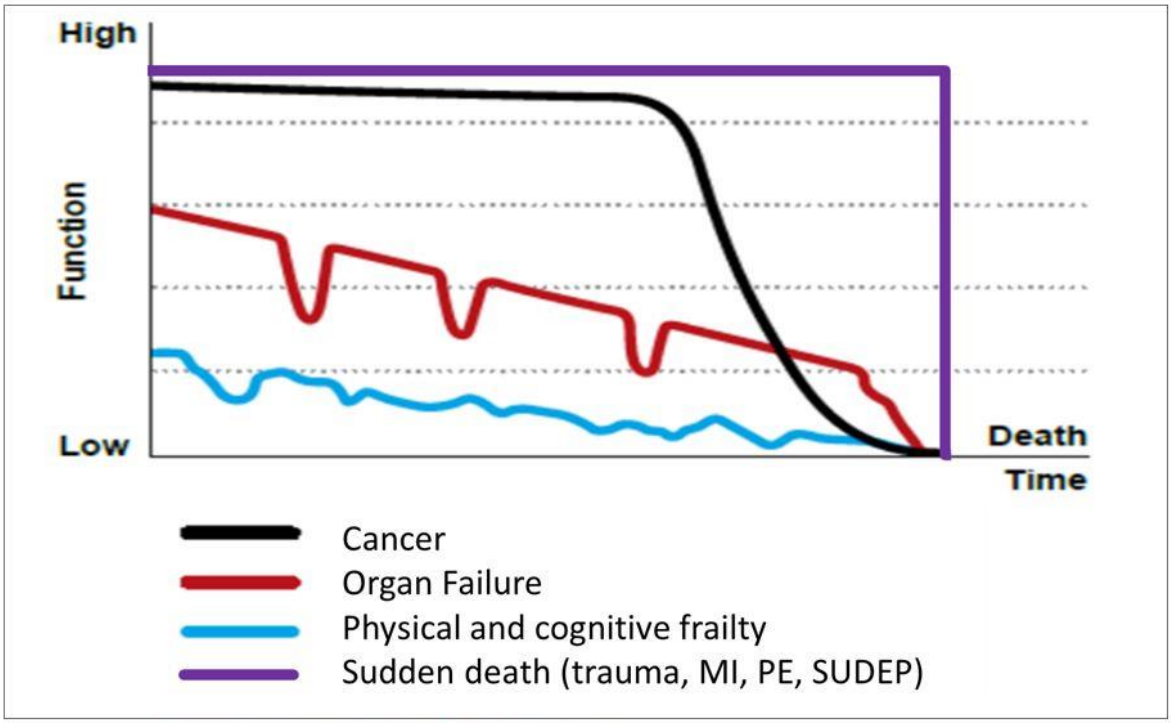
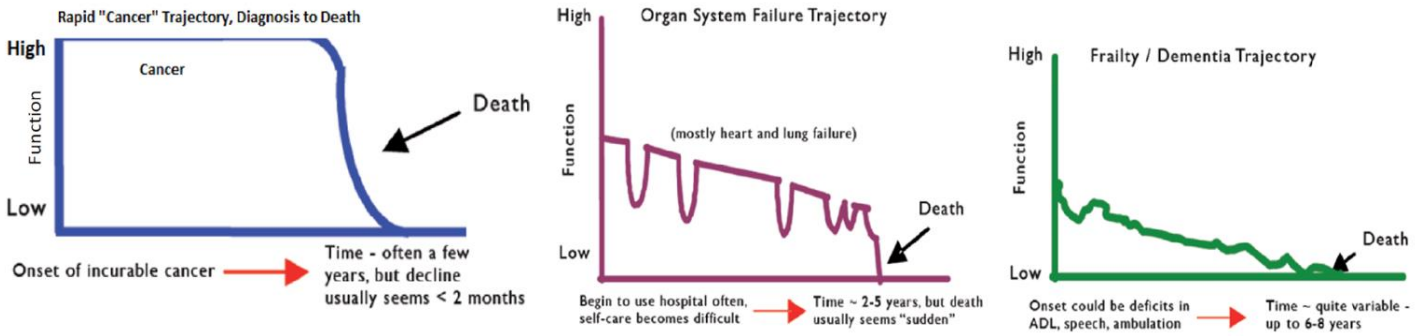


Figure 2. ***Illness Trajectories (Patterns of Decline)***[ix]



Functional Decline from Baseline = Symptom Burden

- **Correlates to increasing frailty (instability)**
- **Correlates to signs of disease progression (illness stage)**
- **Warning signs of health events or brewing complications (2 or more comorbidities)**
- **High risk signs coming closer together (↑ care needs; wt loss; recurring infections; ER transfers/hospital admissions; falls; breakthrough seizures etc.)**
- **Can answer the Surprise Question intuitively (*Would you be surprised if the individual were to die in the next year?*)**

Illness Trajectories with features common to PWIDD				
Neurodegenerative/ Cognitive	**Frailty**	**Organ Failure**	**Cancer**	**Sudden Unexpected Death**

Pattern of dwindling cognitive and/or physical disability
 	
Progresses over years
 	
IDD Specific
• Onset increasing deficits in ADLs, speech, ambulation, cognition
• Dementia onset is earlier, on average 40 yr of age with more rapid progression
• In dementia with trauma history (>70% in PWIDD) there is higher risk of regression to past trauma/flashbacks
• Falls
• New seizure on-set
• In existing seizure disorders, begin to see breakthrough seizures and/or seizures become more challenging to manage
	Pattern of dwindling cognitive and/or physical disability
	
	Progresses over years
	
	IDD Specific
	• Frailty is distinct from disability with some overlap
	• Frailty subtypes:
	  ○ Frailty from birth (lifelong frailty)
	  ○ Frailty associated with aging
	• Nearly most decline signals advancing frailty = high risk for sudden and erratic decline
	• Use Proportion of Accumulated Deficits Approach – more important than specific deficits
		Pattern of erratic fluctuating decline, recurring health events (exacerbations)
		
		IDD Specific
		• Often heart and lung failure
		• Progresses more rapidly
		• Start to see increased need for emergency department visits and hospital admissions requiring longer length of stay
			Pattern of relatively stable period followed by steep continuous decline in the last 3 – 6 months of life
			
			IDD Specific[x]
			• Increased risk of any cancer
			• 4-fold mortality from malignant neoplasms
			• Late diagnosis of cancer[xi]
			• Lack of pre-emptive screening
			• 45% of cancers diagnosed in emergency
			• 45% of cancers at stage IV when diagnosed
			  ○ later recognition of symptoms
			  ○ diagnostic overshadowing
			
			High incidence cancers[xii]:
			• Gastro-intestinal
			  ○ Gastric (stomach), colorectal
			  ○ 43% die before reaching the colorectal screening age
			  ○ H. Pylori 4x higher incidence, 7x recurrence (despite triple therapy increases cancer risk
			• Lymphoid haematopoietic and related tissues
			  ○ leukemia (acute lymphocytic and acute non-lymphocytic)
			  ○ Lymphoma, non-Hodgkin
			• Liver, breast, lung, bladder, testicular
				Death occurred unexpectedly, without corresponding illness
				
				An abrupt change from normal physical function to either death or significant medical disability, often from trauma or an acute cardiopulmonary or neurologic event e.g.
				• Traumatic accident
				• Heart Attack
				• Aneurysm
				• Stroke
				• Sudden unexpected death in epilepsy
				
				Not to be confused with expected death due to life shortening illness conditions (columns to the left)
				
				IDD Specific
				• Sudden unexpected death in epilepsy

FRAILTY IN PWIDD

Frailty is a medical condition of physiological decline, characterized by marked vulnerability to adverse health outcomes. Frailty refers to physical status, not intellectual, mental, or cognitive function. Frailty can be a risk factor for the development of dementia, which is a decline in cognitive function. Frailty is a combination of signs and symptoms that come together in a worsening of functional status compared to the normal process of aging. The functional decline observed warns of an increased state of vulnerability because the body systems are having a difficult time coping with illness burden and stressors making the person's health status unstable.

IDD specific frailty recognition is part of earlier identification. Although there is an intersection between frailty and disability, they are considered different but overlapping concepts[xiii].

Frailty is one factor used to predict people at higher risk of poor health outcomes [xiv, xv] such as an increased risk of health complications, hospitalization, and likelihood of death[xvi].

Age by itself is not what defines frailty, although most people commonly associate frailty with aging. PWIDD can have frailty from birth or experience frailty earlier than the general population. Frail people often present with an increased burden of symptoms including weakness and fatigue, medical complexity, and reduced tolerance to medical and surgical interventions. Awareness of frailty and associated risks for adverse health outcomes can improve care for this most vulnerable subset of people.

KNOWLEDGE POINTS:

- PWIDD may experience:
    - Frailty from birth
    - Frailty associated with aging
- Frailty in PWIDD occurs 30 years younger than the general population.
- Nearly most decline in PWIDD signals advancing frailty and high risk for sudden and erratic decline.
- Advancing frailty in PWIDD significantly reduces survival:[xii]
    - Expected death in under 3 years in greater than 60%
- PWIDD in community settings receiving home care services:[xvii]
    - 21% are pre-frail
    - 27% are frail (does not account for congregate living homes)

ACTION POINTS:

- PWIDD must be screened and assessed for frailty earlier:
    - To slow frailty progression where possible
    - To meet the needs for those who are frail
- Screening for frailty should begin at 30-40 years of age:
    - Frailty is correlated to some biochemical markers and should be part of bloodwork done (inflammation, anemia, metabolic issues, and poor renal functioning)[xviii]
- Use IDD specific frailty identification and screening tools.

- Frailty tools used in the general population fail to account for life-long disabilities[xii] and tend to focus on physical limitations, which are known to be more common in PWIDD regardless of age.
- *Clinical Frailty Scale (CFS)* and *Changes in Health, End-Stage Disease, Signs & Symptoms Tool (CHESS)* have limitations and are not appropriate for PWIDD.

IDD SPECIFIC FRAILTY SCREENING TOOLS:

- **Health Care Access Research and Developmental Disabilities (H-CARDD) Frailty Index with InterRAI - ID[xix], [xx]**
  - is a 42-item frailty index that better characterizes frailty in PWIDD as an early warning sign. Access to this tool requires use of the Inter-RAI electronic healthcare suite of tools. Providers currently do not have access to this tool for use at point of care where earlier identification must be enabled.
- Accumulation of Deficits approach[xii] can be used at point of care for IDD frailty identification and screening.
  - An **IDD-Frailty Screening Tool: Accumulated Health Instability Indicators** was developed specifically for inclusion in this Toolkit by Samuel Neumark, Jenna Mistry, Dasha Choitova, Angie Gonzales, and Tracey Human. (See Resource Links and Tools)

Figure 3.

Earlier Identification, Step 1: Identify & Screen

Step 1 a

IDENTIFY the person(s) who would benefit from a palliative approach to care.

A person:

- at risk of pre-mature death
- with an IDD condition that may shorten life
- with one or more health conditions that may shorten life (comorbidity)
- considered medically complex

If unsure ask physician/Nurse Practitioner/ Medical specialist

Step 1 b

IDENTIFY STAGE OF ILLNESS

If unsure ask physician/specialist

- New Diagnosis (Acute)
- Chronic Stage
- Advanced Stage
- End-Stage (Last year of life)
- End-of-Life (last 3 months of life)

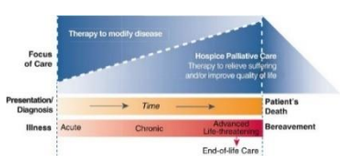


Figure 1

Step 1 c

IDENTIFY ILLNESS TRAJECTORY

- Neurodegenerative/ Cognitive
- IDD Specific Frailty or Frailty in Aging
- Organ Failure
- Cancer

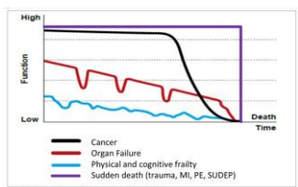


Image from Illness trajectories and palliative care

Figure 2

Step 1 d

IDENTIFY PATTERN OF DECLINE FROM BASELINE

- Gradual steady decline (over years)
- Fluctuating erratic decline (over 1 year)
- Rapid decline (days or weeks)

DECLINE WARNING SIGNS:

- Falls
- Frequent exacerbations (sudden temporary worsening of a chronic disease or its symptoms)
- Repeated emergency department or hospital admissions (2 or more in last year
- Breakthrough seizures +/- increasing difficulty in seizures being controlled

Step 1 e

SCREEN FOR CHANGES FROM BASELINE

SCREEN USING TOOLs

- HELP (behaviours that challenge)
- NTG-EDSD (dementia)
- STOP & WATCH (early warning signs of condition change)

SCREEN FOR PAIN & SYMPTOMS

- ESAS or 4-Point Scale
- CPS-NAID & DISDAT
- ABBEY

See Module F

SCREEN CIRCLE OF SUPPORT for EXHAUSTION and SUPPORT NEEDS

- Burden Scale for Family & Caregivers
- FAMCARE
- NCCN Distress Thermometer

Step 1 f

SCREENING RESULTS

Inform needs that should be explored thoroughly by assessment(s)

- Type of assessment depends on the type of need, or concern identified
- Assessment conducted by the appropriate provider(s). See STEP 2
- Screening is ongoing as changes are identified

OUTCOME

Right care

- for stage of illness

Right Place

- Primary care as appropriate
- Specialist Clinic
- ER/ Hospital as appropriate
- Preferred location EOL

Right Time

- Earlier
- Proactive vs crisis management

Right Team

- Developmental Services Working with Healthcare

Right Communication

- Unimpaired between Developmental Services and Healthcare
- SBAR/SBOR
- Connecting Ontario
- Shared Chart
- Proactive ACP
- GOC with Supported Decision-Making

REPEAT STEPS 3 – 6 All along the illness journey

Figure 4.

Earlier Identification of Changes, Step 2: Observe & Assess

Step 2 a

OBSERVE FOR CHANGE(s):

- Changes in health status have meaning
- Any change observed should prompt a timely assessment to understand the possible cause

A Change may be Indicating:

- New illness/diagnosis
- Illness stage progression
- A specific health care event
- A comorbidity disease exacerbation
- Impending sentinel or serious illness event

Step 2 b

RECOGNIZE PATTERN(s) OF CHANGE:

Gradual Progressive change(s)

- Progressively more unwell (over time, changes in behaviour, etc.)
- Increasing care needs

Change(s) in Behaviors that Challenge

- New behaviour
- Change in known behaviour that is increasing or suddenly stops
- More withdrawn

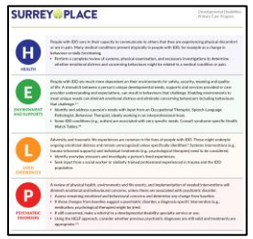
Sudden or Erratic change(s)

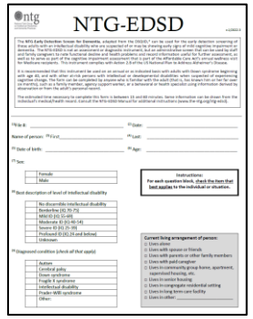
- Rapid signs of decline
- Erratic decline (frequent fluctuation between being stable and unstable)
- Sentinel (unexpected) events e.g., Falls; Breakthrough seizures

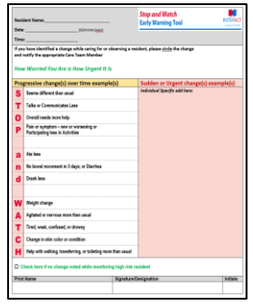
Step 2 c

SCREENING TOOLS FOR CHANGES:

- HELP (behaviours that challenge)
- NTD-EDSD (dementia)
- STOP & WATCH (early warning)







Step 2 d

ASSESS:

Conducted by the appropriate provider

- Developmental Services
- Health Care

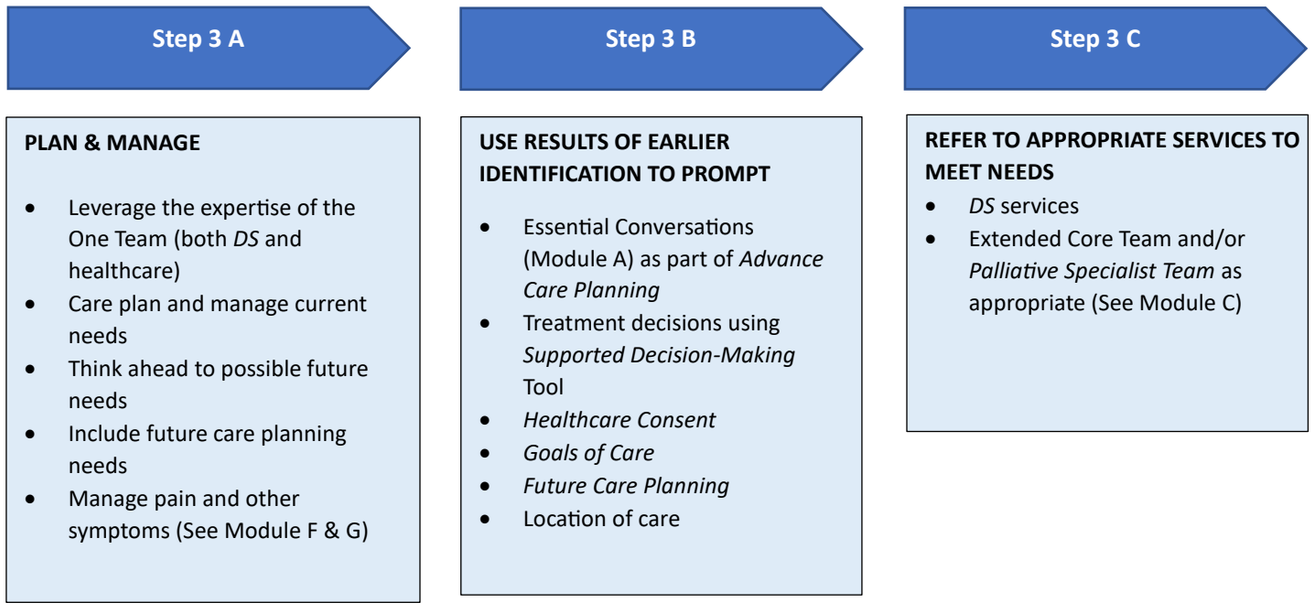
Step 2 e

Further assigning meaning is beneficial:

- Is this a health event the person will stabilize from and return to their original baseline?
- Following the event did the person NOT return to their baseline and what does that mean?
- Are there indications of health status decline present?

Figure 5.

Step 3: Plan & Manage, Developmental Services with Healthcare Providers as One Team



EARLIER IDENTIFICATION OF THE LAST YEAR OF LIFE

Early identification of the last year of life is specific and not to be confused with early identification of illness progressing from advanced to end-stage illness. The goal of early identification of the last year of life is to ensure a proactive approach to whole-person care in preparation for the transition to end-of-life.

People are 'approaching the end-of-life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life threatening acute conditions caused by sudden catastrophic events

KNOWLEDGE POINTS:

- Recognizing the pattern of change/decline over time helps to ensure the best care at the right time with the right team to meet the needs of the person. This includes when *Palliative Care Specialists* should be involved due to the medical complexity and unique pain and symptom management needs of PWIDD.
  - Changes year-to-year suggests life expectancy may be in year(s).
  - Changes month-to-month suggests life expectancy may be in months as in the last year of life.
  - Changes seen week-to-week suggests life expectancy is end-of-life stage and death is approaching (less than 3 months).
  - Changes seen day-to-day suggests death may happen at any time (imminently).

ACTION POINTS: "GOOD" PRACTICE STANDARD

Earlier Identification Steps[xxi]:

1. **The Surprise Question: *'Would you be surprised if this person were to die in the next year, few months, weeks, days?"***
   - Is used when people with progressive life-limiting illnesses are in advanced or end stage of illness.
   - The answer to this question should be an intuitive one, based on the whole picture of health deterioration.
   - If it would NOT surprise you that the person may die in the next 12 months, then it is time to start care measures, referrals, and preparation for the expected months of further decline.
2. **General Indicators of Decline of Health**
   - Signs of poor or worsening health.
   - Unplanned (emergency) admission(s) to hospital.
   - General health is poor or getting worse; the person never quite recovers from being more unwell.
   - Needs help from others for care due to increasing physical and/or mental health problems.
   - The person's carer needs more help and support.
   - Has lost a noticeable amount of weight over the last few months; or stays underweight.
   - Has troublesome symptoms most of the time despite good treatment of their health problems.
   - The person (or family) asks for palliative care; chooses to reduce, stop, or not have treatment; or wishes to focus on quality of life.
3. **Disease Specific Indicators of Decline**
   - See to Earlier Identification Tools:
     - Gold Standard Framework (comorbidity specific indicators)
     - IDD PCN Supplement – Earlier Identification (Appendix D – IDD specific etiologies indicators)

EARLIER IDENTIFICATION STEPS

1. The Surprise Question: ***Would you be surprised if this person were to die within the next year?***

2. Does the person have General Indicators of Decline?

3. Does the person have illness or condition Specific Indicators of Decline?

Ethical Reminder:

Earlier identification of a person's last year of life allows us to form a trusting relationship, ensures that their care plan reflects their preferences and values, and allows for sensitive and timely conversations about end-of-life care.

Equitable and inclusive care also requires incorporating faith, culture, and traditions in their care.

RESOURCE LINKS and TOOLS

- **HELP** (behaviours that challenge)
- **NTG-EDSD** (dementia)
- **STOP & WATCH** (early warning signs of condition change)
- **ESAS** or 4-Point Scale
- **CPS-NAID** (IDD specific non-verbal pain screen)
- **DISDAT** (IDD specific distress and pain screen)
- **ABBEY** (non-verbal pain screen)

EARLIER IDENTIFICATION TOOLS

IDD Specific

- PALLI-Tool (available for Download)
- IDD PCN Supplement – Earlier Identification (available for Download)
- Supports Intensity Scale – Adult Version (SIS-A)
- Frailty Screening
    - H-CARDD Aging Project
    - Inter-RAI - ID Comprehensive Assessment Instruments (see under Adult and Elderly: Intellectual Disability (ID)
    - IDD-Frailty Screening Tool: Accumulated Health Instability Indicators (available for download)

Transferable

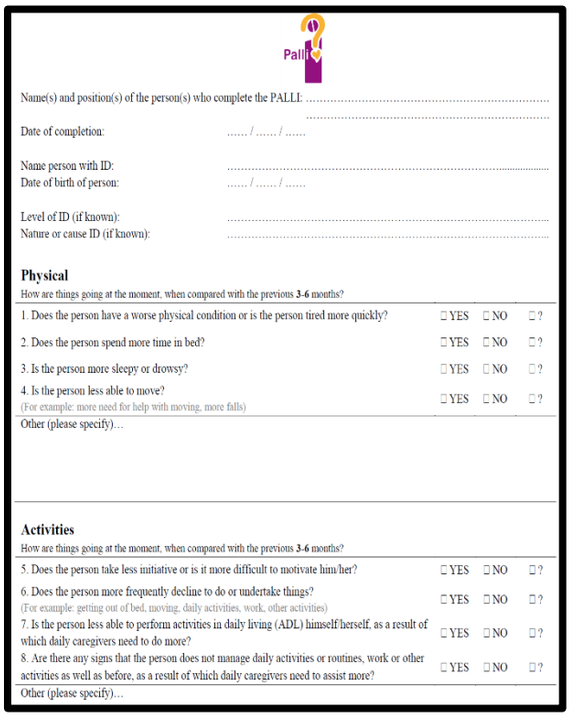
- SPICT-4-ALL
- Gold Standard Framework (used by healthcare providers)

APPENDIX A
PALLI TOOL

(full tool available for download https://iddpcn.org/tools)

PALLI TOOL

- PALLI is the first tool to address early identification of people living with IDD
- The PALLI can be completed for every adult with ID, regardless of the level and nature of disability
- Can be completed by any care provider role and acknowledges a "gut feeling" something is changing or concerning and guides you by questions to focus in on what it is
- is concerned with health, behavior and functioning of the person with ID compared with the previous period – this is comparing the baseline
- Assists the identification of decline and extent of deterioration from baseline
- Triggers further assessment to assign meaning of change e.g. an exacerbation event or transitioning to end-of-life care needs
- Informs Palliative Performance Score (PPS)
- The PALLI, combined with your knowledge of the case history, can help you in timely decision making on whether the care of the person should be refocused in consultation with Core, Extended or Specialists involved



Palli

Name(s) and position(s) of the person(s) who complete the PALLI: .....

Date of completion: ..... / ..... / .....

Name person with ID: .....
Date of birth of person: ..... / ..... / .....

Level of ID (if known): .....
Nature or cause ID (if known): .....

Physical

How are things going at the moment, when compared with the previous **3-6** months?

1. Does the person have a worse physical condition or is the person tired more quickly?	☐ YES	☐ NO	☐ ?
2. Does the person spend more time in bed?	☐ YES	☐ NO	☐ ?
3. Is the person more sleepy or drowsy?	☐ YES	☐ NO	☐ ?
4. Is the person less able to move? (For example: more need for help with moving, more falls)	☐ YES	☐ NO	☐ ?

Other (please specify)…

Activities

How are things going at the moment, when compared with the previous **3-6** months?

5. Does the person take less initiative or is it more difficult to motivate him/her?	☐ YES	☐ NO	☐ ?
6. Does the person more frequently decline to do or undertake things? (For example: getting out of bed, moving, daily activities, work, other activities)	☐ YES	☐ NO	☐ ?
7. Is the person less able to perform activities in daily living (ADL) himself/herself, as a result of which daily caregivers need to do more?	☐ YES	☐ NO	☐ ?
8. Are there any signs that the person does not manage daily activities or routines, work or other activities as well as before, as a result of which daily caregivers need to assist more?	☐ YES	☐ NO	☐ ?

Other (please specify)…

- **PALLI - TOOL description:**
- **The PALLI tool is designed specifically to help identify people with IDD in need of palliative care**
- **Should be completed by care providers who are familiar with the person with ID.**
- **The tool is comprised of 39 questions, each requiring a yes/no response, and does not employ a cut-off point but encourages multidisciplinary discussion of the completed tool to attain a more accurate understanding of the person's current needs in an end-of-life perspective.**
- **Facilitates multidisciplinary discussion about planning and provision of palliative care with those who know the person's history well (e.g., family, long-term workers in the person's congregate care setting, etc.)**

APPENDIX B
SPICT-4-ALL

SPICT-4-ALL

https://www.spict.org.uk/spict-4all/

- Carers and family members can often see that a person is getting less well with one or more health problems.
- SPICT-4ALL aims to make it easier for everyone to recognise and talk about signs that a person's overall health may be declining so that those people and their carers get better coordinated care and support
- SPICT-4ALL uses non-medical words that makes sense to everyone and is similar to the SPICT tool for health professionals
- It can be used to help ask about more help from a doctor, a nurse or another professional

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

- Less able to manage usual activities and getting worse.
- Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

- Unable to dress, walk or eat without help.
- Eating and drinking less; difficulty with swallowing.
- Has lost control of bladder and bowel.
- Not able to communicate by speaking; not responding much to other people.
- Frequent falls; fractured hip.
- Frequent infections; pneumonia.

Nervous system problems (eg Parkinson's, MS, stroke, motor neurone disease)

- Physical and mental health are getting worse.
- More problems with speaking and communicating; swallowing is getting worse.
- Chest infections or pneumonia; breathing problems.
- Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

- Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.
- Very poor circulation in the legs; surgery is not possible.

Lung problems

- Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.
- Needs to use oxygen for most of the day and night.
- Has needed treatment with a breathing machine in the hospital.

Other conditions

- People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

Kidney problems

- Kidneys are failing and general health is getting poorer.
- Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

- Worsening liver problems in the past year with complications like:
  - fluid building up in the belly
  - being confused at times
  - kidneys not working well
  - infections
  - bleeding from the gullet
- A liver transplant is not possible.

What we can do to help this person and their family.

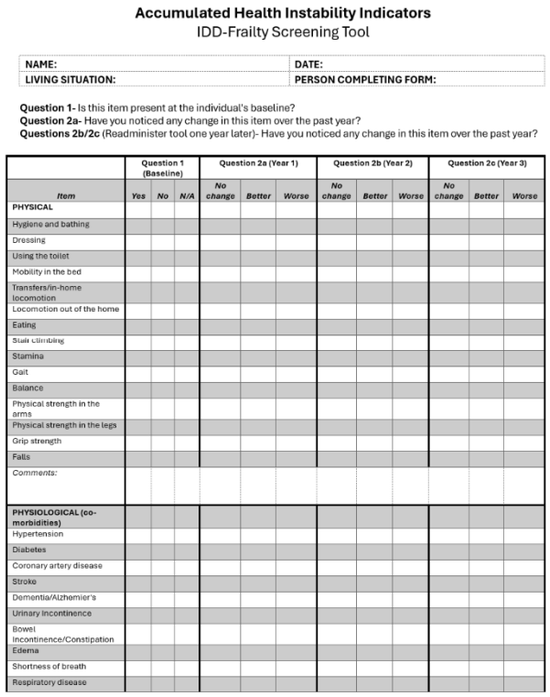
- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

APPENDIX C
IDD Frailty Screening Tool
Accumulated Health Instability Indicators
(full tool available for download https://iddpcn.org/tools)

- Point of care for IDD frailty identification and screening.



Accumulated Health Instability Indicators
IDD-Frailty Screening Tool

NAME:	DATE:
LIVING SITUATION:	PERSON COMPLETING FORM:

Question 1- Is this item present at the individual's baseline?
Question 2a- Have you noticed any change in this item over the past year?
Questions 2b/2c (Readminister tool one year later)- Have you noticed any change in this item over the past year?

	Question 1 (Baseline)			Question 2a (Year 1)			Question 2b (Year 2)			Question 2c (Year 3)		
Item	*Yes*	*No*	*N/A*	*No change*	*Better*	*Worse*	*No change*	*Better*	*Worse*	*No change*	*Better*	*Worse*
PHYSICAL												
Hygiene and bathing												
Dressing												
Using the toilet												
Mobility in the bed												
Transfers/in-home locomotion												
Locomotion out of the home												
Eating												
Stair climbing												
Stamina												
Gait												
Balance												
Physical strength in the arms												
Physical strength in the legs												
Grip strength												
Falls												
Comments:												
PHYSIOLOGICAL (co-morbidities)												
Hypertension												
Diabetes												
Coronary artery disease												
Stroke												
Dementia/Alzheimer's												
Urinary incontinence												
Bowel incontinence/Constipation												
Edema												
Shortness of breath												
Respiratory disease												

Adapted from the publications:

- Brehmer-Rinderer, B., Zeilinger, E. L., Radaljevic, A., & Weber, G. (2013). The Vienna Frailty Questionnaire For Persons with Intellectual Disabilities--Revised. *Research in developmental disabilities*, *34*(6), 1958–1965. https://doi.org/10.1016/j.ridd.2013.03.004

- McKenzie, K., Ouellette-Kuntz, H., & Martin, L. (2015). Using an accumulation of deficits approach to measure frailty in a population of home care users with intellectual and developmental disabilities: an analytical descriptive study. *BMC geriatrics*, *15*, 170. https://doi.org/10.1186/s12877-015-0170-5

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APPENDIX D
IDD PCC SUPPLEMENT – EARLIER IDENTIFICATION

- This resource was developed by the Intellectual and Developmental Disability Palliative Care Committee for Ontario
- It is intended to be used as an IDD specific supplement to Earlier Identification Tools
- It summarizes information for the most common IDD conditions and the associated illness trajectory; and common causes of death to support awareness and recognition of the pattern of changes/decline with the types of serious illness events and comorbidities that may present as signs the person may be entering the last year of life

EARLIER IDENTIFICATION
INTELLECTUAL AND DEVELOPMENTAL DISABILITY (IDD) SUPPLEMENT

This IDD Supplement is intended to be used in conjunction with Earlier Identification Tool(s) to support identification of people with intellectual and developmental disability (PWIDD) who would benefit from a palliative approach to care or may be nearing the end of life

Are there signs of decline from baseline, in general and/or specific to the IDD etiology?
Increasing physical care needs; changes in communication from baseline; changes in behaviors from baseline; changes in personality from baseline; changes or slowing in cognition from baseline

Use the following Tools to assist in identifying changes:
HELP; STOP & WATCH; NTG-EDSD; PALLI-Tool; SPICT-4-ALL

Are the change(s): ☐ **expected** ☐ **predictable** ☐ **Progressing slowly** ☐ **Sudden/Rapid** ☐ **Erratic**

NOTE to Healthcare Sector Providers – MOCA; MMSE are not appropriate for dementia screening and assessment in PWIDD. Use the NTG-EDSD Tool for PWIDD

The Surprise Question

Would you be surprised if the individual were to die in the next year?

General Indicators of Decline

Are there general indicators of decline and increasing needs compared to normal baseline?

- Unstable deterioration changes (Advancing disease, increasing complex symptom burden)
- Treatments no longer effective (decreasing response to treatments, decreasing reversibility)
- Supported Choice of no further disease modifying treatment
- Increased general physical decline from normal baseline
- Declining functional performance status compared to baseline ability (e.g. PALLI TOOL with Palliative Performance Scale (PPS)
- Weight loss >10% in past six months that does not have a reversible cause
- Repeated unplanned or crisis hospital admissions
- Sentinel event e.g. serious fall, bereavement
- Blood test for albumin result <25g/l (Serum Albumin)

IDD Etiology (Conditions & Syndromes) Specific Indictors for Consideration

Flexible criteria with some overlaps, especially with medical complexity, dementia, unique frailty or other co-morbidities associated with IDD Etiology

- 30-50% of IDD etiologies have an unknown cause
- Biological Age est. 20 - 30 yrs older than Chronological age
- 4 times more likely to die before age 75
- Average life expectancy 55-65 yrs

Angelman	**Life Expectancy** – Similar to general population although limited data due to rarity of disease **Trajectory** – Organ Failure **Common Causes of Death:** • High rates of choking/aspiration, related and unrelated to eating • Cardiorespiratory compromise due to scoliosis and contractures; Obstructive sleep apnea • Airway and respiratory compromise due to tongue protrusion • Complications due to seizures (90%)
Autism Spectrum Disorder	**Life Expectancy** – 30-35yrs less than general population in moderate to profound ASD **Trajectory** – Organ Failure • Higher rates of health problems throughout childhood, adolescence, and adulthood, and that may result in elevated risk of early mortality • Significant predictors of mortality were early childhood levels of impairments in social reciprocity and high levels of functional impairments

	Common Causes of Death • Include chronic conditions (such as cancer and heart disease), accidents (such as choking on food and accidental poisoning), and health complications due to medication side effects • Concurrent IDD, epilepsy, mental health conditions, and chronic physical health conditions were associated with a higher risk of death for those on the spectrum. "nervous system and sense disorders" and "injury and poisoning" top-ranked causes for those on the spectrum.
Down Syndrome	**Life Expectancy** – Median age of 55-65 years of age **Trajectory** – Organ failure; Neurodegenerative secondary to dementia/Alzheimer's Disease (AD); Cancer **Common Causes of Death** • 8-fold increased risk of mortality from all causes • 16-fold risk of mortality from Heart Failure (congenital anomalies; ischemic heart disease) • 12-fold greater mortality from Respiratory infections; Pneumonia 2nd most common cause of death (aspiration; influenza) • 4-fold mortality from malignant neoplasms, primarily owing to leukemia (acute lymphocytic and acute non-lymphocytic); testicular cancer, GI cancer (gastric, bowel); liver cancer • Earlier onset, quicker progression of Alzheimer's, advanced stage by 55yo, associated with seizures; prevalence 42% - 55% • Cerebrovascular disease; Stroke; Hemorrhage • Atlanto-axial instability resulting in hyperextension of neck, increased risk of C-spine fractures, spinal cord compression (SCC) • Excess mortality from gastric and duodenal ulcers and cirrhosis of the liver
Deletion Syndrome(s)	**Life Expectancy – median age of 40 years of age in deletions that include the TCF4 gene** • There is a wide range of symptoms and severity among people with 22q11.2 deletion syndrome that may impact life expectancy • Those for shortened lifespan include severity of disease; presence and severity of congenital heart defects (ventricular septal defect, truncus arteriosus, Tetralogy of Fallot); severity of immune system issues due to small or absent thymus gland resulting in immature or absent T cells • Hypoparathyroidism complications related to low levels of calcium in the blood (hypocalcemia) and high levels of phosphorus • Issues with cleft palate and development of the larynx, trachea, and esophagus (laryngo-tracheo-esophageal anomalies) resulting in feeding difficulty, failure to gain weight and gastrointestinal issues • Almost everyone with this syndrome needs treatment from specialists in a variety of fields • Heart defects (74% of individuals) • Immune system problems (77% of individuals) **Trajectory** – Organ Failure **Common Causes of Death** • Sudden unexpected death (suspected due to cardiac arrhythmia) • Infection • Cardio-respiratory • Renal failure due to renal agenesis (absence of one or both kidneys at birth) • Complications due to thrombocytopenia
Cerebral Palsy (CP)* (CP is not considered IDD unless the person meets DSO criteria	**Life Expectancy** – mortality increases with severity of impairment, profound CP median age of 30 years of age • Profound intellectual disability was the strongest single predictor of death followed by severe motor impairment • Factors suggest *chronic* lung disease predisposes to the recurrent pneumonias and respiratory failure seen in people with CP with oropharyngeal dysfunction • Choking or aspiration pneumonias are not prevented with use of G-tubes, as the pneumonias are resulting from chronic lung disease • At the end of life, the chronic lung disease presents as an extremely marked recurrent respiratory infections requiring repeated and prolonged hospitalisations for respiratory support with oxygen or non-invasive ventilation **Trajectory** – Organ Failure **Common Causes of Death** • Respiratory failure • Respiratory infections – recurrent pneumonia (58.6%); aspiration pneumonia (49%) • Seizures
Fetal Alcohol Syndrome	**Life Expectancy** – 34 years (95% confidence interval: 31 to 37 years), about 42% of that of the general population **Trajectory –** Sudden accidental death

	Common Causes of Death • Leading causes of death suicide (15%), accidents (14%), poisoning by illegal drugs or alcohol (7%), other external causes (7%) due to high-risk behaviours as a consequence of frontal lobe impairment, impulse control disorder, personality disorders/dynamics in neurologic damage Other common causes of death are: • Diseases of nervous system (8%), disease of respiratory system (8%), diseases of digestive system (7%), congenital malformations (7%), mental and behavioural disorders (4%), disease of circulatory system (4%)
Fragile X	**Life Expectancy** – normal life expectancy **Trajectory** – Organ failure, Neurodegenerative **Common Causes of Death** – same as for elderly of general population
Prader-Willi	**Life Expectancy** – median age of 50-60 years • Presumed obesity-related cardiopulmonary factors contribute to more than half of all deaths • Males display a significantly higher risk of early mortality compared with females • Males show a significantly higher risk of death due to presumed hyperphagia-related causes relative to females • Lack of vomiting reflex results in high rates of choking • GI perforation, presumably related to uncontrolled hyperphagia and food-seeking behaviors • Seek emergency medical attention for complaints of abdominal pain or distention may be life threatening bowel obstruction or necrosis **Trajectory** – Organ failure **Common Causes of Death** • Respiratory failure (31%) • Heart disease/failure (16%) • Gastrointestinal perforation or obstruction (10%) • CorPulmonale commonly reported in those with obstructive sleep apnea (OSA) • Unexpected death caused by respiratory obstruction/choking
Smith Magenis	**Life Expectancy** – normal in absence of congenital cardiovascular (50%) or congenital renal abnormalities • Very sensitive to medication changes, higher risk of rapid toxicity **Trajectory** – Organ failure **Common Causes of Death** • Heart failure • Renal failure
Williams Syndrome	**Life Expectancy –** normal life expectancy **Trajectory** – Organ failure **Common Causes of Death** • Cardiovascular; complications due to supravalvular aortic stenosis (SVAS) • Complications due to Hypercalcemia
Rhett Syndrome	**Life Expectancy** – 60% survive to age 40 • Risk of premature death can increase by up to 3x based on mutation type • Malnutrition also noted to decrease life expectancy • Breathing problems, irregular heartbeat thin, fragile bones prone to factures, malnutrition due to problems with chewing and swallowing, problems with bowel function **Trajectory** – Organ failure **Common Causes of Death** • Respiratory failure • Respiratory infection, aspiration/asphyxiation • Seizure related

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