

# **Knowledge-building in the field of ageing with disability: Where are we at? What else do we need to know?**

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# Ageing with disability – as a sub-field

**Social Work**

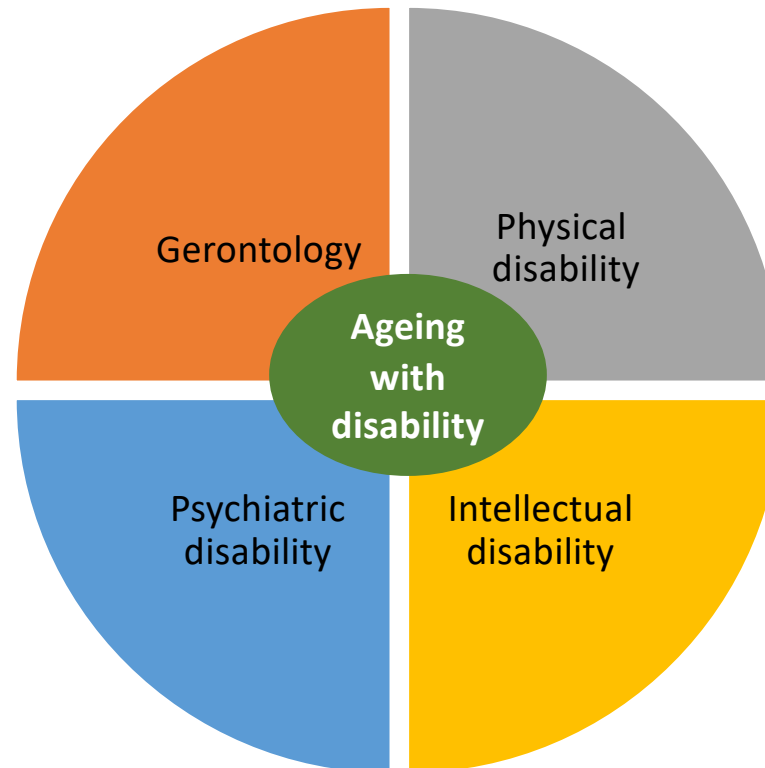
**Public Health**

**Rehabilitation**

**Sociology**

**Psychology**

**Medicine**



**Nursing**

**Environmental design**

**Robotics**

**Economics**

**Occupational therapy**

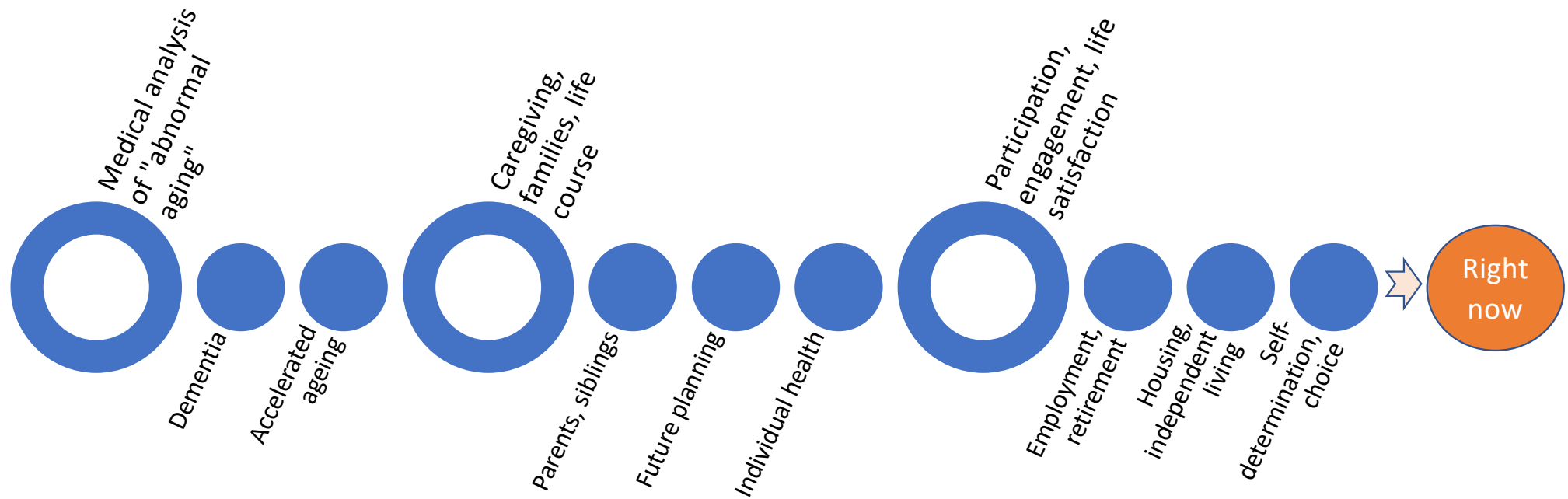
**And more...**

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Knowledge-building - Where are  
we at?

# History of studying ageing with disability – rough timeline



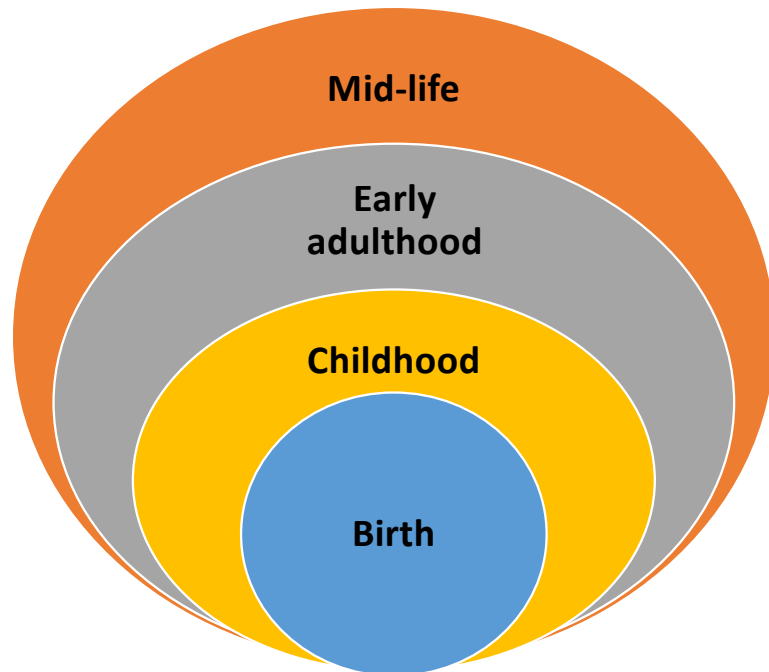
Still working through fundamental questions of parameters – that frame populations & issues

- **How is the ageing with disability population defined?**
- **How big is the ageing with disability population?**
- **Why is ageing with disability a new phenomenon?**
- **How is *ageing with disability* different than *ageing into disability*?**

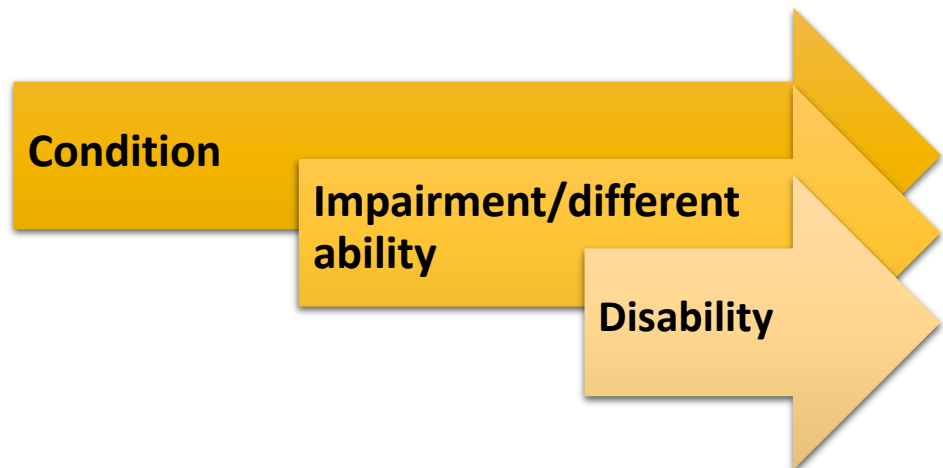
*These remain important, ongoing discussions because the intersection of ageing and disability is not always clear – for example what should be attributed to ageing? To disability? To their unique intersection?*

# How is the ageing with disability population defined?

## Age of onset



## Duration of disability



# How big is the ageing with disability population?

- No clear estimate of population size
  - Hard to measure
  - Definitions of disability vary
  - Diagnosis vs self-report
  - Lack of representation in data sets
    - Questions about timing – that would help identify persons ageing with are not often asked

## Global estimates

2.2 million persons with multiple sclerosis  
55.5 million persons with traumatic brain injury,  
27.4 millions persons with spinal cord injury,  
20.8 million persons with schizophrenia  
114.8 million with intellectual disability



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# Why is ageing with disability a new phenomenon?

- People with early and mid-life disability are living longer than they have in the past

- Social care
- Health care
- Education, employment
- Civil rights
- Economic supports
- And more...

- Although lifespan is still less for many

- Access to, and adequacy of, health, social, & economic resources remain unequal
- Practice, programs – formal & informal – remain under-developed



# How is *ageing with disability* different than *ageing into disability*?

- Differences that accumulate and evolve over the life course.

*Lisa, a woman with intellectual disability lives independently in her community and works at a local supermarket. She never marries or has children.*

*At age 52, Lisa is ready to retire but her family worries that if she does, her social network will shrink and there are few programs for older persons with IDD in Lisa's town to help her make new friends and stay engaged. Her parents are in their early 80's. Her mother cares for her father who has dementia and is unable to engage socially as much as she would like to with her daughter.*

*Lisa's 62-year old neighbor Monique, also never married and is retired, has one parent caring for the other, but has a strong social network through her church and a high-school alumni group and drives a car.*



Source: <https://www.placerarc.org/>

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# How is *ageing with disability* different than *ageing into disability*?

- Differences that accumulate and evolve over the life course.



Source:  
<https://www.pinterest.com/spinalpedia/the-greater-sci-community/>

*An individual who sustains a spinal cord injury at age 40, Mark, and one who sustains a spinal cord injury at age 70, Ben, may share parts of the aging with disability experience – particularly those related to initial medical treatment, rehabilitation and use of assistive equipment to navigate home and community environments. However, what may differ substantially is the impact of the injury on the individual's daily life. Mark, the 40-year-old may no longer be able to work or have difficulty finding work the accommodates his disability. This may impact his ability to save for retirement and he then may be financially less secure in later life than he otherwise might have been if he had not incurred the spinal cord injury.*



Source: <https://www.src.isr.umich.edu/research-themes/aging-and-retirement/>

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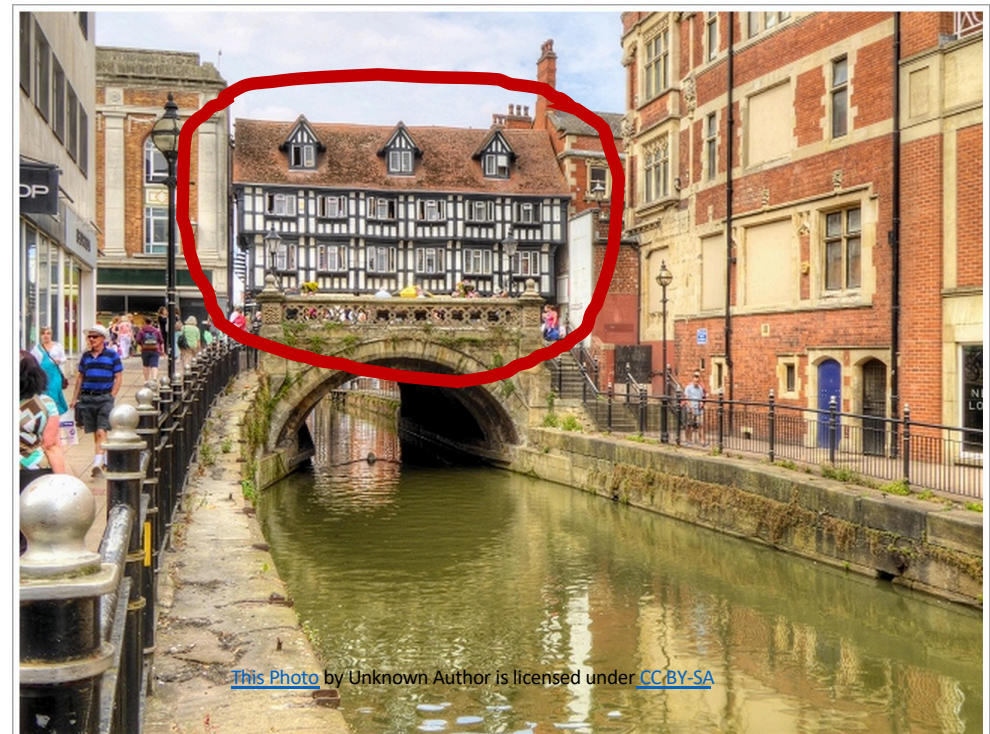
# Still working towards building the knowledge base – in all domains

Advancing theory	Increasing Research	Learning from Stakeholders	Translating to/Learning from Practice
<div><div></div></div>	<div><div></div></div>	<div><div></div></div>	<div><div></div></div>
<div><input type="checkbox"/> Ecological models</div>	<div><input type="checkbox"/> Health, wellness,</div>	<div><input type="checkbox"/> Understand experiences</div>	<div><input type="checkbox"/> Development of practice wisdom</div>
<div><input type="checkbox"/> Social models</div>	<div><input type="checkbox"/> Independent living</div>	<div><input type="checkbox"/> Identification priority knowledge</div>	<div><input type="checkbox"/> Manualization of interventions</div>
<div><input type="checkbox"/> Medical/rehabilitation models</div>	<div><input type="checkbox"/> Symptom management</div>	<div><input type="checkbox"/> Engagement in scholarship</div>	<div><input type="checkbox"/> Community-based care/living</div>
<div><input type="checkbox"/> Social determinants of health models</div>	<div><input type="checkbox"/> Programs and services</div>		
	<div><input type="checkbox"/> Welcoming communities</div>		

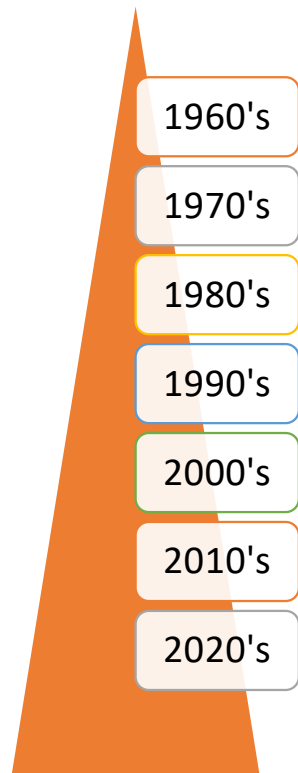


# Only modest progress in bridging fields

- **Why is it important to bridge the fields of ageing and disability?**



# Where is knowledge-building at?



- Some very good research – but a limited amount of it
  - Mainly in health & social care
- Quite modest of number of new scholars in the field
- Limited formal education or training on aging with disability
- *Yet there is a growing number of persons ageing with disability!*



What else do we need to know?

# Areas we need new & more knowledge in

## Supports & service systems

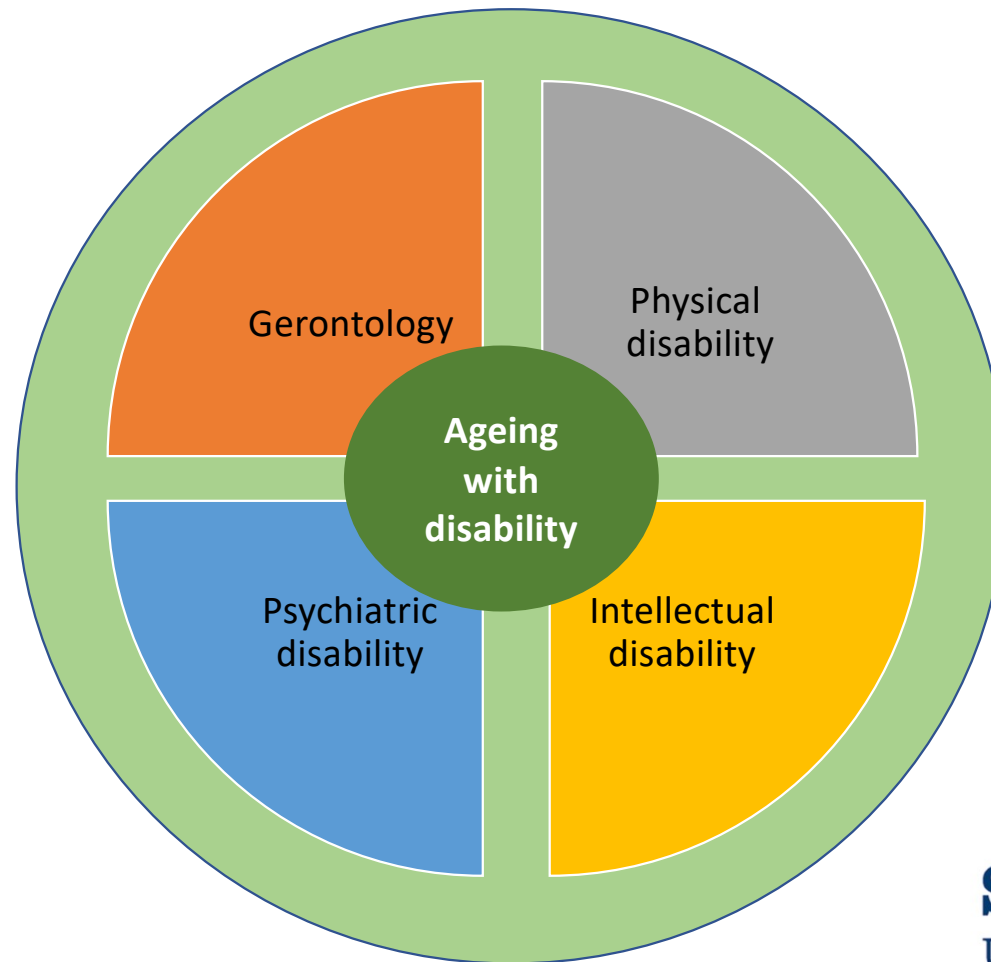
- Innovations to understand outcome of “early” interventions
  - At the time of impairment, recognition of difference, and/or disability onset
- Widened focus on social, cultural, physical & institutional factors
  - Moving outward beyond personal

## Inclusion & exclusion

- Understanding of and interventions to address social, economic, & cultural exclusion
  - Focus on human & civil rights
  - Emphasis on participation & engagement
- Emphasis on the person, family & social unit
  - Self-determination, choice

# Advancing knowledge in aging with disability requires

Ageing with disability needs to be integrated into disciplines and also kept as an interdisciplinary field at the same time.

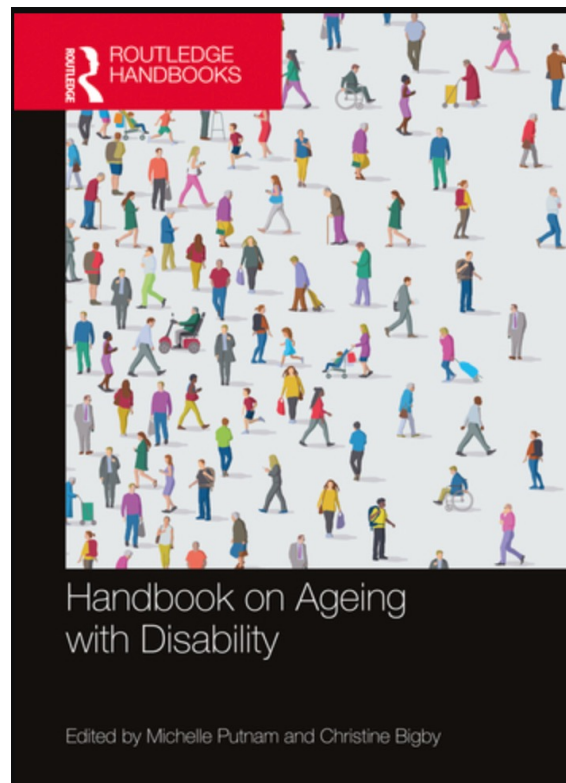


More formal training is needed for researchers & practitioners

Increased efforts to identify & understand what is happening "on-ground" now



# Thank you!



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<https://www.routledge.com/Handbook-on-Ageing-with-Disability/Putnam-Bigby/p/book/9781138611498>

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