

Death, dying and older people with LD:ready for what exactly?

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Death and LD services

The limited research in LD has urged servicers to be more 'death ready- to postpone, to talk about, to prepare for and support death and dying.

There are many types of death. Death is not uniform.

Although there exists little research on the types of death LD services will confront.

Older people with learning disability- living AND DYING

FOR THE LAST 30 YEARS, THERE HAS BEEN GROWING ATTENTION PAID TO LIVES AND EXPERIENCES OF OLDER PEOPLE WITH LEARNING DISABILITY

THIS HAS TACKLED THE PROBLEMS OF SOCIAL DISENGAGEMENT AND SOCIAL DEATH ASSOCIATED WITH OLD AGE.

OLD AGE IS A TIME FOR LIVING WELL AND FULL LIVES

HOWEVER, DEATH HAS BEEN PUSHED FURTHER FORWARD IN TIME AND BACK INTO THE SHADOWS

LD SERVICES ARE BUILT UPON LIFE AND LIVING

IT MIGHT NOT BE EASY TO ADDRESS HOW WE TURN TO LOOK AT THE SHADOW



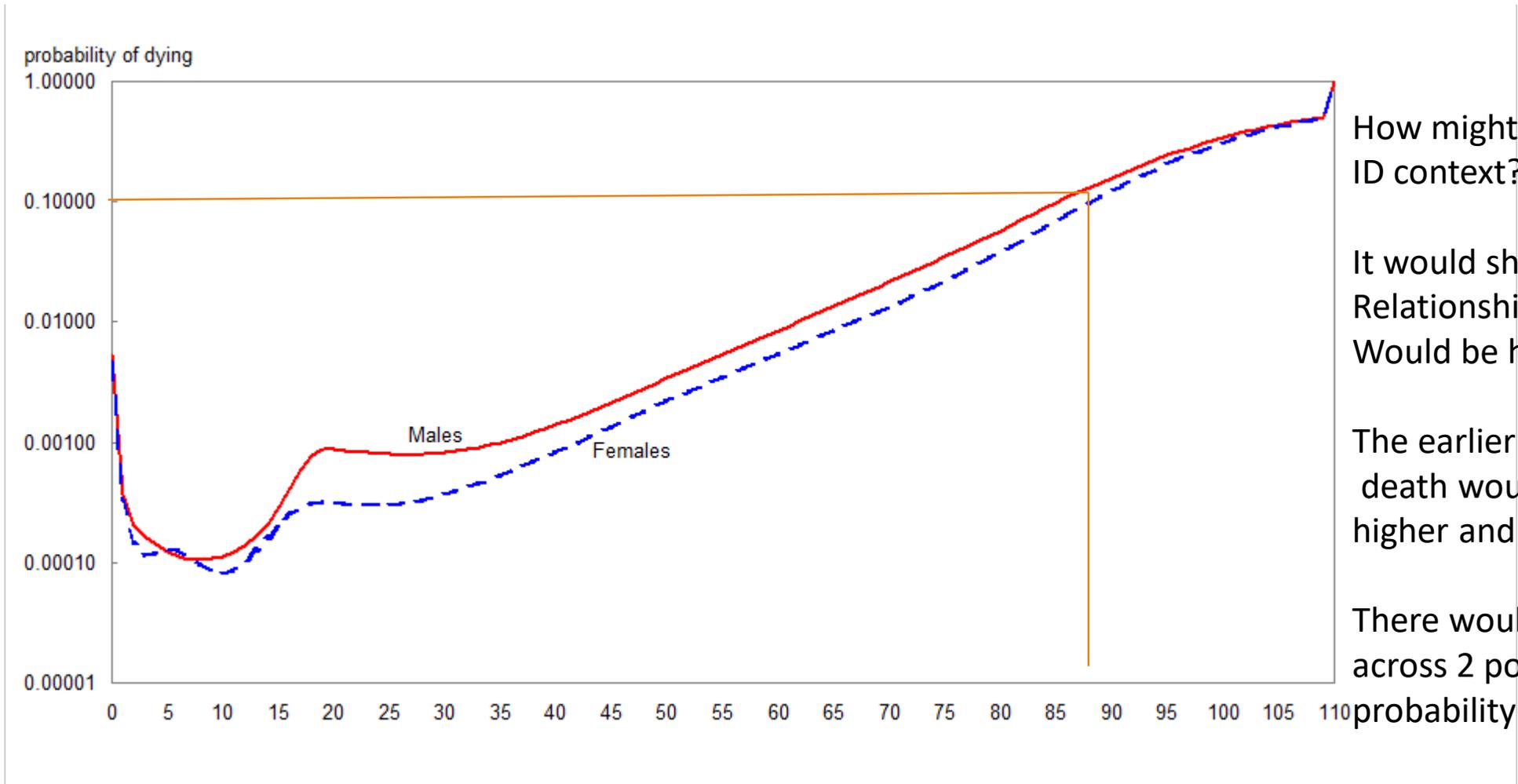
We do not die from but many of us will die in old age.

The most common age at death in England and Wales in 2010 was 85 for men and 89 for women. Age at death peaked at 88 years.

And the longer we live, the longer we die

Younger deaths tend to be more sudden and anticipated

Older deaths are more likely to follow from a life threatening or limiting illness (Cancer or dementia) or a death that will follow gradual and prolonged periods of ill-health



How might like look in an ID context?

It would show a similar Relationship but the lines Would be higher and steeper

The earlier peak in age of death would be both higher and longer

There would be less difference across 2 populations in probability of death in later years

LATER YEARS AND ANTICIPATION OF DEATH

Start to make plans for financial and personal affairs

Advance Care planning is key means of improving care for people nearing the end of life and of enabling better planning and provision of care, to help them live well and die well in the place and the manner of their choosing.

Both enable us to discuss and record our future wishes, thus making the likelihood of these wishes being known and respected at the end of life and after death

Quite simply with increasing age, death becomes factored into our life plans

End of life care

EOLC implies that dying is expected.



Early recognition of End of Life care needs across a population can be shown to bring benefit to the individual by facilitating improved choices about care.

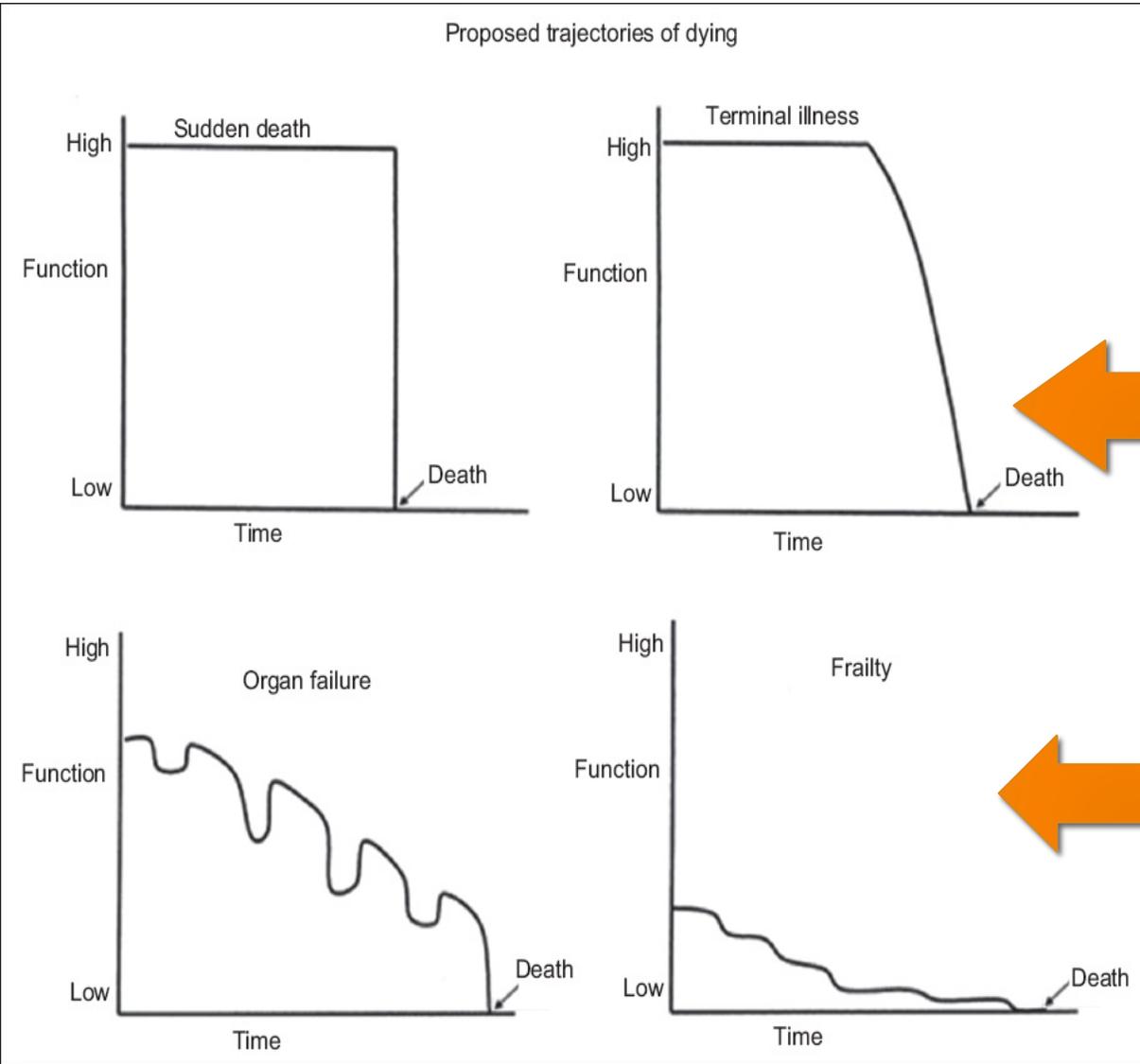
This can be problematic in older people- end of life care services are geared largely towards meeting the needs of people dying with cancer – more recently dementia- access to such services is often based on **diagnostic criteria and not anticipation of dying**

Death and dying old age

Many older people will die in care homes (23% of all deaths occur within care homes- for people aged over 80 it is 37%)

We tend to think about End of life care- as care around particular illnesses- particularly cancer and less so around dementia.

What about those people who die with or from other illnesses? There are concerns that their end of life care needs are poorly recognised and supported?



Dying in old age, in end of life care terms, is seen as a form of disadvantaged dying

End of life care services are more readily developed around individuals with a 'terminal illness'

Research suggests that in later life, the most common dying trajectory is the dwindling trajectory

Do people with learning disabilities die when they are old people with learning disabilities?

CURRENT CONCERNS OVER PREMATURE AND PREVENTABLE DEATHS ARE MORE FOCUSED ON RELATIVELY YOUNGER DEATHS WHERE THE GAP BETWEEN THE RISK OF DEATH IS GREATEST BETWEEN PEOPLE WITH AND WITHOUT LD

AND PERHAPS THE REPEATED RESEARCH FINDING THAT PEOPLE WITH LD LIVE ON AVERAGE UNTIL THEY ARE 60-65 YEARS HAS BEEN MISINTERPRETED

And sometimes researchers are not always looking in the place where older people with learning disabilities are living

WHAT DOES DEATH AND DYING LOOK LIKE IN AN LD CONTEXT

HOW COMMON IS DEATH IN THIS POPULATION

WHAT TYPES OF DEATH DO OLDER PEOPLE WITH LD EXPERIENCE AND WITH WHAT OUTCOMES?

HOW WELL SUPPORTED ARE PEOPLE WITH LD AND SERVICES SUPPORTED AT THIS TIME

IF THE AIM IS TO BECOME READY- WHAT DO WE NEED TO BE READY FOR?

Summaries of 2 Studies

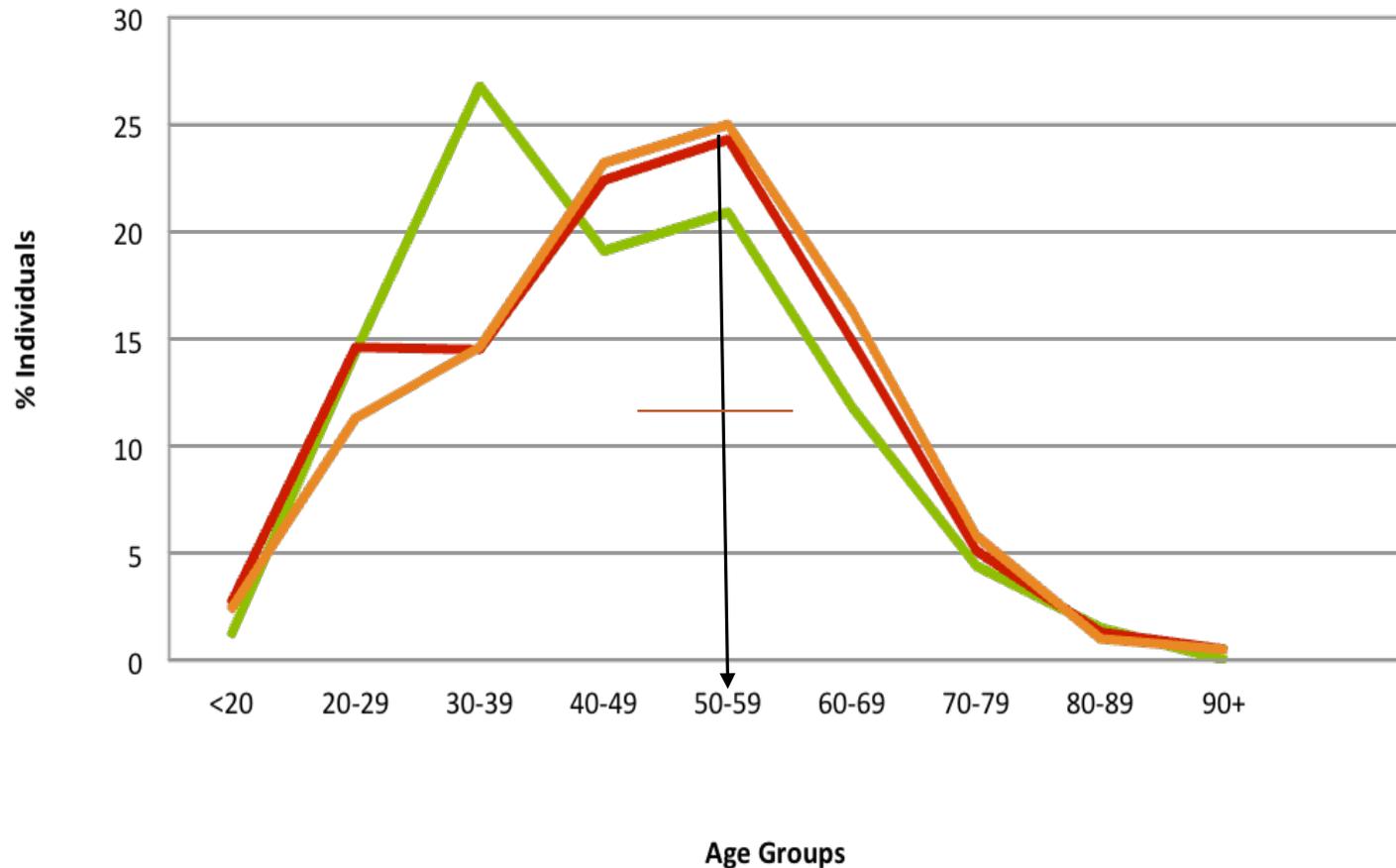
Last months of life study – a study of 222 deaths of people with UK across the UK

Forgotten Lives study: a study of people with LD living and dying in generic care homes

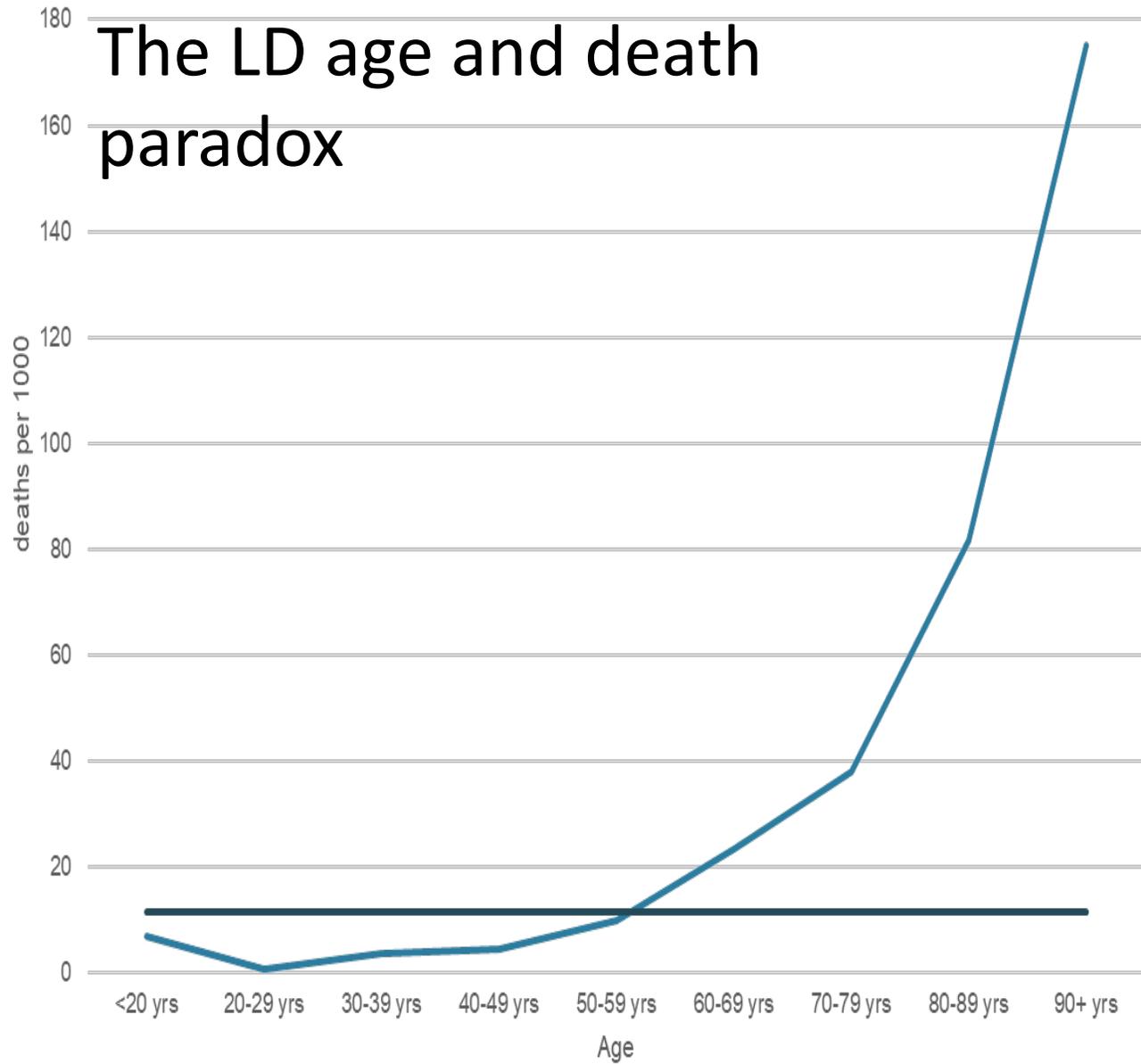
Age of people with LD living in LD services in the UK N=>12000-

52% AGED UNDER 50, 7% AGED OVER 70

222 DEATHS IDENTIFIED-
19% OF DEATHS WERE PEOPLE LESS THAN 50,
24% WERE AGED OVER 70



The LD age and death paradox

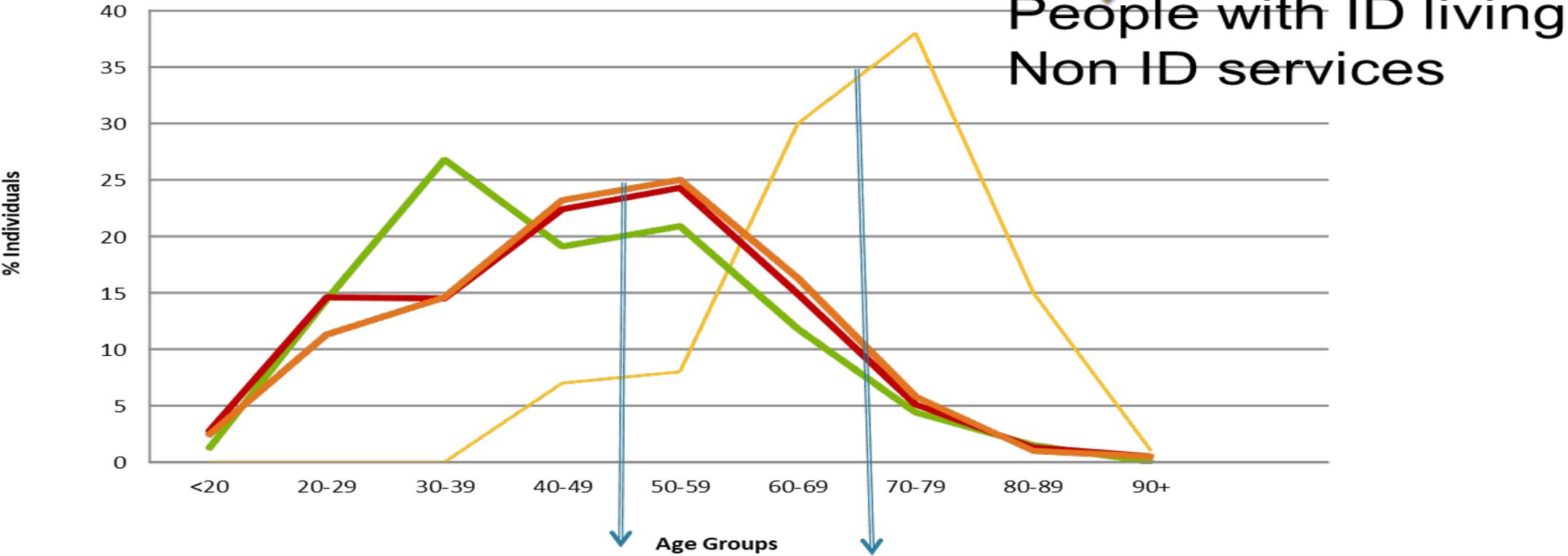


Although older people with LD are a minority group within LD services- their deaths are the most probable- younger deaths are more common but less probable

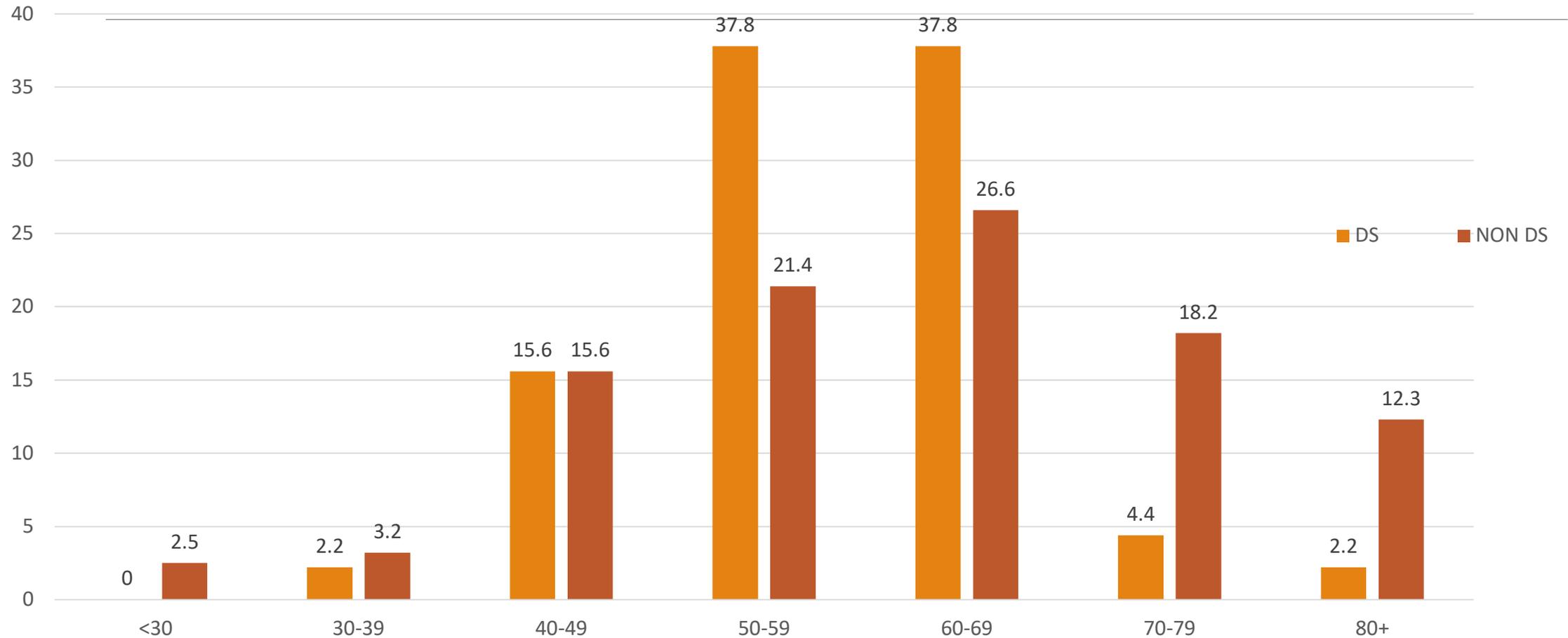
— average death rate

LESS THAN 40 YRS-
3 DEATHS PER 1000
SUPPORTED PER YEAR
40-59- 15.2 DEATHS PER 1000
60-70- 34 DEATHS PER 1000
70+ 67 DEATHS PER 1000

The oldest of the old are not there but here



Age of death in people with DS and people with LD (%): ageing is premature in people with DS by almost a decade



Dementia, Cancer and mortality

65% of the deaths of people with DS were dementia related - 60% OF THOSE DEATHS WERE AGED 60 OR LESS

IN PEOPLE WITH LD AND NO DS- 60% OF DEATHS WERE AGED 67 OR LESS

6.7% of the deaths of people with DS were cancer related

20.1% of the deaths of people with LD were cancer related and the incidence of cancer was greatest for those aged 60-69 - (29.0%) – HOWEVER, CANCER WAS LESS PREVALENT IN DEATHS OF THOSE AGED OVER 70 (9%) COMPARED TO 24% OF DEATHS OF PEOPLE UNDER 70

Dementia, cancer and age IN PEOPLE WITH LD (NO DS)

For those aged under 70 years of age – 73% of deaths did not involve dementia or cancer

For those aged over 70, 64% of death did not involve cancer or dementia and for such deaths cause of death most commonly reported as 'respiratory (52%) or Heart disease (28%) – these deaths were rarely anticipated by staff

THE TYPES OF DEATH WE ASSOCIATE WITH A NEED FOR END OF LIFE CARE ARE NOT COMMON IN PEOPLE WITH LD- NOT EVEN IN LATER LIFE

Anticipation of death

57% of the deaths of people with DS had been anticipated by staff for 3 months or more; 74% had an EoLC plan, 9% had a will

30% of the deaths of other people with LD had been anticipated by staff for three months or more

There was no association between age and anticipation of death 29.6% of those over 60 years and 30.4% in those aged less than 60 had a death that was anticipated for 3 months or more.

50% of deaths of those under 60 were deaths with no EoLC plan; 56% of those aged over 60 had no EoLC – and 6% of those <60 had wills, 12.5% of people aged over 60 had wills

SO

In older people with LD- death is more probable but no more anticipated

The deaths that are the most anticipated are the deaths of people with DS

Disadvantaged dying

There is a particular disadvantage in later life— that is these deaths were more probable but largely unanticipated

21.8% of deaths of those aged over 60 were described as sudden (32% of those aged 70 or older)

27.8% of people aged over 60 had been ill for 6 months or more (18% for those aged 70 or older)

Does it matter?

People whose deaths were more anticipated were more likely to die in the care setting (68%) than those whose deaths were not expected (35%)

90% of respondents of anticipated deaths felt enough choice about place of death compared to 57% of less anticipated deaths

They were more likely to have an EoLC plan – (82%) with good levels of external involvement, compared to 40% of unanticipated deaths and with low levels of external involvement.

34% of people with LD knew they were dying when their deaths had been anticipated, compared to 8% of those whose deaths were not anticipated

For those over 70 not dying from cancer or dementia

41% died in the care setting

52% of staff felt there was not enough support at the time of death

35% of respondents felt that in the last 3 months care was deficient in some significant way

Limitations!

The deaths reported here were only the deaths of people in LD services

Older people with LD may die in non LD services. Heslop et al (2014) estimate that close to 20% of people with LD will die in generic care settings

Current study is looking at this population (living cohort = average age 68.5 years, average age at death = 71.6 years)

Is the high number of unanticipated death within LD settings due to older people with health problems being moved out, (are they moved out for end of life care?)

SO DEATH FOR OLDER PEOPLE WITH LD

IS MORE LIKELY THAN FOR YOUNGER PEOPLE WITH ID

DEATH IS EARLIER AND MORE ANTICIPATED FOR PEOPLE WITH DS

THE RISK OF DEATH INCREASES DRAMATICALLY FOR THOSE AGED 70 OR OLDER

BUT TYPICALLY FROM ILLNESSES NOT ASSOCIATED WITH A NEED FOR END OF LIFE CARE –

FOR MANY OLDER PEOPLE DEATH IS LARGELY UNANTICIPATED AND DYING IS POTENTIALLY IMPROVERSIHED.

IMPLICATIONS

For younger and middle aged adults- death is relatively uncommon- and death prevention should be an imperative

For older adults, there is a need to start thinking less about end of life care and perhaps more about anticipatory care- governed less by diagnosis and more by informed anticipation- where active care need not stop but embraces a possibility of death

Is end of life approaching?

Person's recent, current and projected health status?

Number of Hospital admissions, particularly unscheduled admissions?

Asking the surprise question? And if the answer is 'No I would not be surprised if the person was to die within 6 months?' - what action would you take?

Perhaps applying this to more frequently with older old people with LD?

Future concerns

Prospective studies of older people with LD

What factors precipitate movement out of LD services?

What are the end of life experiences of people with LD in non LD settings? Are these more appropriate places for dying?

How difficult might it be to discuss the risk of dying in LD services?

How do we involve older people in discussions about the anticipation of death?

Dying in old age

EOLC policy and practice in LD needs to respond to the evidence that *dying in old age* is different from dying from cancer or dementia at a younger age.

People with LD, especially people with LD who do not have DS, are less likely than other people to die from cancer or dementia

The deaths of people with LD are very much like the deaths of older people- but the risk of death makes it important that we address the end of life care needs of older people with LD