



The impact of transition on health and wellbeing in young people with intellectual disabilities: A qualitative investigation

Genevieve Young-Southward, Chris Philo,
Sally-Ann Cooper
g.young-southward.1@research.gla.ac.uk



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qualitative investigation

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University
of Glasgow



Transition to adulthood for young people with intellectual disabilities

Current evidence on transition outcomes for people with intellectual disabilities

- Experience of transition may be discontinuous and turbulent
- Limited health surveillance and lack of support when young people leave school
- Those with intellectual disabilities are less likely to be employed or to live independently than those without disabilities
- Those with intellectual disabilities experience low levels of community involvement and limited opportunities to socialise



Risk of isolation, depression and anxiety; health problems may not be identified

Systematic review

- 17 articles included
- Suggests presence of health and wellbeing issues during transition, including social conflict, obesity and sexual health
- Considerable gaps in the literature
- Methodological limitations eg reliance on proxy reports



? Research Questions

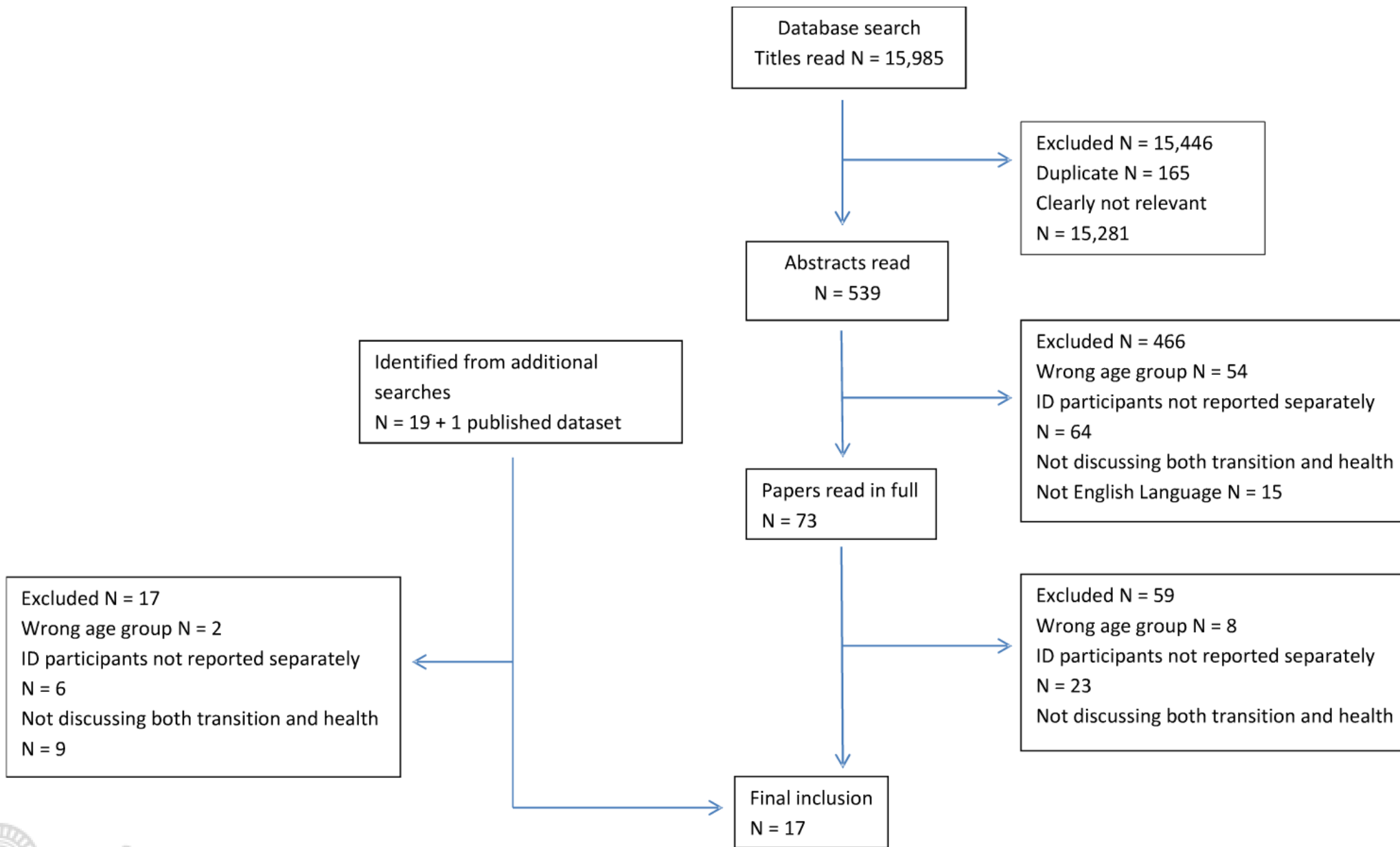
1. Does transition affect health and wellbeing in young people with intellectual disabilities, and in what particular ways?
 - a) From the perspective of young people with intellectual disabilities
 - b) From the perspective of parents/carers of young people with intellectual disabilities
2. What supports (formal and informal) are helpful for young people with intellectual disabilities during transition?

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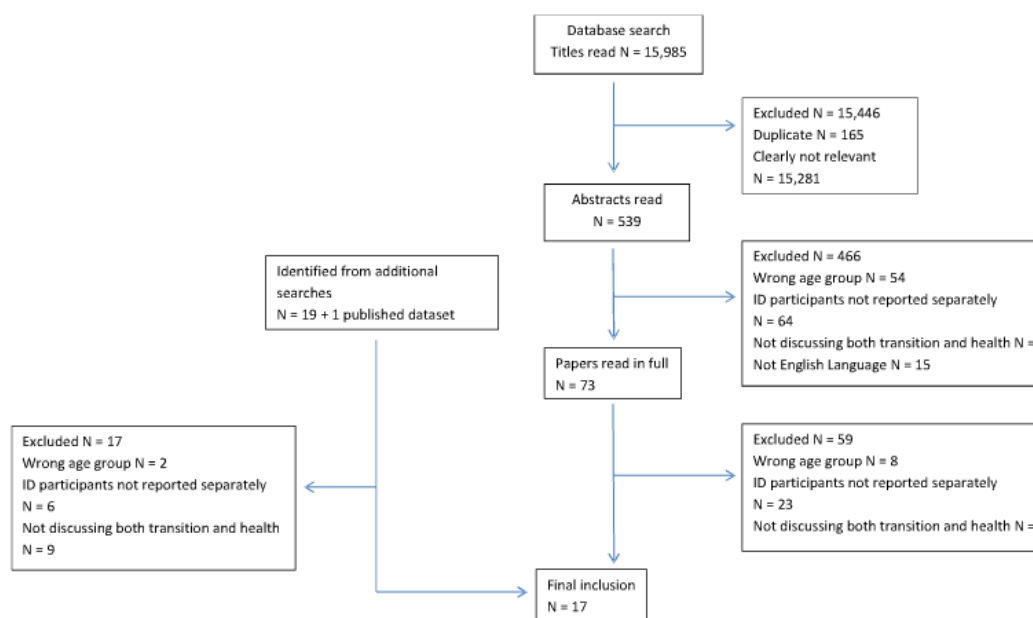


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Methods

Semi-structured interviews with young people with intellectual disabilities (n = 10) age 16 - 24 years (mean = 18.3) and their parents/carers (n = 18)

Participant Demographics

Category	Count
Age	10
Gender	5
Ethnicity	5
Education	5
Employment	5
Relationship	5
Income	5
Disability	5
Location	5
Other	5

Recruited via postal invitation/social media through special education schools and charities eg Share Scotland, Enable

Participant Demographics

Disability	N
Mild	2
Moderate	5
Severe	5
Profound	6

Daytime Activity	N
School	9
College	5
Work placement	1
No organised activity	3

Living Situation	N
Childhood home	16
Independent accommodation	1
Residential care	1

Funding
Future
Transition
Confidence
Anxious
Uncertainty
Routine
Worry
Stress
Independence

"Everything's really up in the air"
Uncertainty and lack of options for the future

"It's not knowing, not knowing what's going to happen in five or when he's going to go" Sarah (Mother)

"That's the danger, when with great needs, there's nothing there for them at all - which is really quite hard, cause you try to fill a gap for somebody with such complex needs, very very difficult" John (Father)

"He will turn on and off his own ... I think what it is his friend, there's no stimulation there for him" John (Mother)

"Now that I'm not in school I find myself absolutely bored out of my mind ... sitting in the house all day's kind of annoying in my opinion" Charlotte (P)

"She hasn't got the capability"
Dependence vs Independence

"I like and I hope he is calm / focused but ... they can do things a lot" Thomas (Mother)

"It's not in some home system, there's no way to the point, it would go with him" John (Father)

"There's my life and my own and my dad and my brother ... are challenging to help me and give me the skills, but I'm not like all my things I find it's hard to keep or just think back to the school" Thomas (P)

"We never have special time sometimes because they are like well you're meant to be an adult, looking after yourself ... but not all of a sudden someone has to help because they're healthy now" John (Mother)

"There's only so much I can do for you"
Lack of parental planning and educational courses with resources

"We all have a plan for the next 10 years but it's not like a plan for a year and a half, because we're not going to school and we're going to go with it" Thomas (Mother)

"We're gonna go to the next stage, we're gonna go to the next school, we're gonna go to the next school, we're gonna go to the next school" Thomas (Mother)

Limitations

- ✘ Parents were present for the majority of young peoples' interviews, which may have affected responses
- ✘ Self-selected sample, which may be biased

Implications

Transition from school should be facilitated gradually and start early in a young person's school career in order to ease anxiety during this period

"Everything's really up in the air"

Uncertainty and lack of options for the future

"The not knowing, not knowing what's going to happen to him or where he's going to go" Sarah (Mother)

"Youth, teenagers, adults with special needs, there's nothing there for them at all ... which is really quite hard, cause you try to fill a day for somebody with such complex needs, very very difficult" Sally (Mother)

"He self harms an awful lot now ... I think what it is is he's bored, there's no stimulation there for him" Sally (Mother)

"Now that I'm not in school I find myself absolutely bored out of my mind ... sitting in the house all day's kind of annoying in my opinion" Charlotte, 17

"She hasn't got the capability"

Dependence vs Independence

"If they could keep him at school forever, but ... they can't do that, I know" Deborah (Mother)

"If he was to come home, eighteen, 'Mum, I'm away to the pub', I'd need to go with him" June (Mother)

"This is my life and my mum and my dad and my brother ... are just trying to help me and give me tips on life ... but it's my life ... it's my choice if I just want to keep on going or just think 'nah it's too much'" Stephen, 16

"He comes home upset now sometimes because they say like well you're meant to be an adult, looking after yourself ... he's not all of a sudden seventeen this day because his birthday was yesterday" June (Mother)

"There's only so much fight in you"

Inadequate transition planning and adversarial contact
with services

"In all these glossy books you get it's supposed to take a year to a year and a half, transition, we've still not got a word yet ... we're left to get on with it" James (Father)

"We're gonna get it from every angle, we're gonna get it from school, we're gonna get it from health, we're gonna get it from money" Lucy (Mother)

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