Transition from School to Adult Life: perspectives & experiences of people with I.D. & family members

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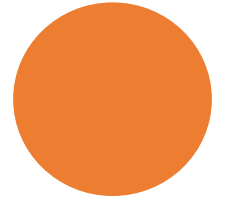
UCD School of Psychology

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Theoretical Context

- Transitions as 'Normative Crises' & 'Extended Adolescence' (Erikson, 1963)

- 'Quarter Life Crisis' (Robinson, 2015)

- 'Emerging Adulthood' (Arnett, 2000)

- School to Adult = Multiple Transitions

- Emerging Adults with Disabilities – Denial of rights & opportunities (Flynn, 2022)

Research Context

- Emerging adults with disabilities experience substantial barriers to education & employment (Scanlon & Kamp, 2016; GOI, 2015)

- Unprepared, not informed on full range of options (NDA-NCSE, 2017)

- More likely to experience poor well-being & life satisfaction (Chalk et al, 2020)

- Persons with I.D., speech or learning disabilities face particular challenges (Watson, Banks & Lyons, 2015)

- Last NIDD Rt: 84 of 57,872 (0.145%) who use day services also attend 3rd Level (Hourigan et al, 2018)

- Disjointed, silo approach between health & education (NCSE, 2021)
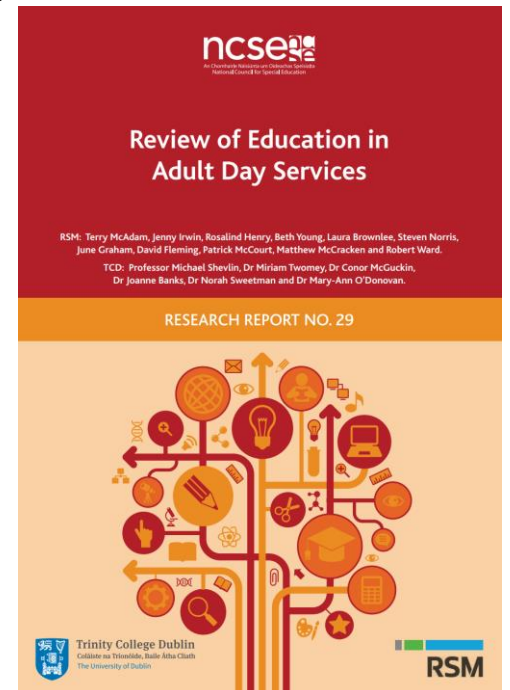
Research Context

Brown et al (2019):

- Fractured transitions
- Reliance on parents' resourcefulness
- Medical hx lost & gaps in follow-up
- Abandonment by services ('ageing out')
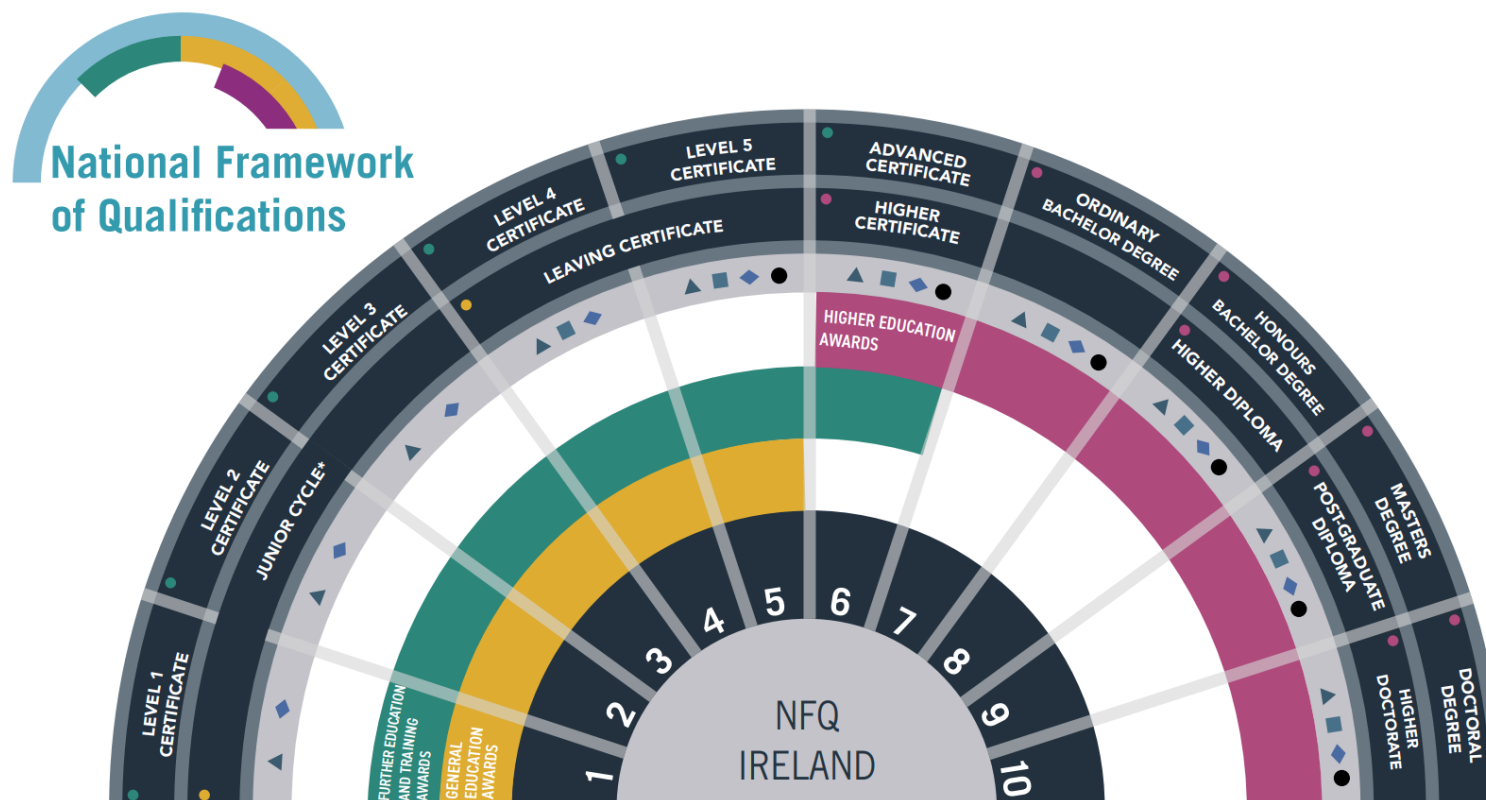- Not ready, lack of information, uncertainty

Gauthier-Boudreault et al (2019):

- Little access to further education
- Limited options: day activity or leisure
- Loss of skills developed at school
- Assumed ongoing dependency

Policy & Legislation Context

International	Ireland
Salamanca Statement (UNESCO, 1994) UNCRPD (UN, 2006) USA: Free Appropriate Public Education (FAPE) (established under RA, 1973 & IDEA, 1975) UK: Education Acts 1944-1996 (especially 1981) UK: Children and Families Act (2014) UK: Special Educ'al Needs & Disability Act (2001)	Seminal court cases (1993-) Education Act (1998) Education for Persons with Special Educational Needs Act (2004) Disability Act (2005)
Canada: New Brunswick Policy 322 (DEECD, 2013)	Report of the Special Education Review Committee (SERC) (DES, 1993) Progressing Disability Services (HSE, 2009) National Plan for Equity of Access to Higher Education 2015-2019 (HEA, 2015) Comprehensive Employment Strategy (2015-25) School Inclusion Model (NCSE, 2020)

Post-Secondary Educational Options in Ireland

https://www.qqi.ie/what-we-do/the-qualifications-system/national-framework-of-qualifications

Post-Secondary Options for Emerging Adults with Intellectual Disability in Ireland

Options (at each QQI Level)	1-2	3	4	5	6+
HSE Day Opportunities: Disability Day Services (Level 1+) Small No. Rehabilitative Training (Level 2-3)	√	√	(√)		
Further Education (FE): Education & Training Boards (ETBs) (Some Level 4, Mainly 5+)			(√)	√	√
Higher Education (HE): Special Programmes (INHEF) (Some Level 3/4, Mainly 5 DARE (Disability Access Route to Education) (Level 6+) Access Programmes (Level 6+) Regular HE Courses + Disability Service Supports (Level 6+)		(√)	(√)	(√)	√
Employment Supports: Solas (apprenticeships & traineeships) (Level 4+) Employability/INTEO (Level 4+) AHEAD WAM (Willing Able Mentoring) (Level 6+)			√	√	√
Other: Disability service-specific initiatives & pilots, AONTAS, NALA, Leisure Opportunities (e.g. S.O., Local Authority Leisure Officers)					

Recent Developments

- Transition Passports recently introduced by DES

- Transition programmes at 3rd level can provide skills for FE/HE or work (Scanlon & Doyle, 2021)

- School Inclusion Model established (NCSE, 2020). Cautious optimism (McCoy, Shevlin & Rose, 2020)

- NCSE and HSE Transition Project Group est. 2019, planning and pilots progressing (NCSE, 2022)

- HSE Day Opportunities Transition Teams (in devt)

- Programme for Access to Higher Education (PATH) Strand 4 Funding 2022-25 https://hea.ie/policy/access-policy/path/

Changing Society = New Opportunities for People with Disabilities?

- General changes in patterns of work and education (Scanlon & Kamp, 2016):
  - Job for life no longer the norm
  - Pathway after school more variable & flexible
  - Not everyone works full-time

- Neurodiversity Model (Singer, 2017)

- Universal Design for Learning (Meyer, Rose & Gordon, 2014)

- Post-pandemic hybrid working patterns

PhD Study: Transition from School to Adult Life: perspectives & experiences of people with I.D. & family members

Study 1

Systematic Scoping Review (SScR)
Transition from School to Adult Life: perspectives, lived experiences & goals of persons with ID and family members

Study 2

Inclusive Delphi Study
Leaving School & Starting Adult Life: What helps and what makes it harder?

Study 3

Survey of Service Leaders
Improving the Transition Pathway from School to Adult life for Young People with I.D.: Opportunities & Barriers
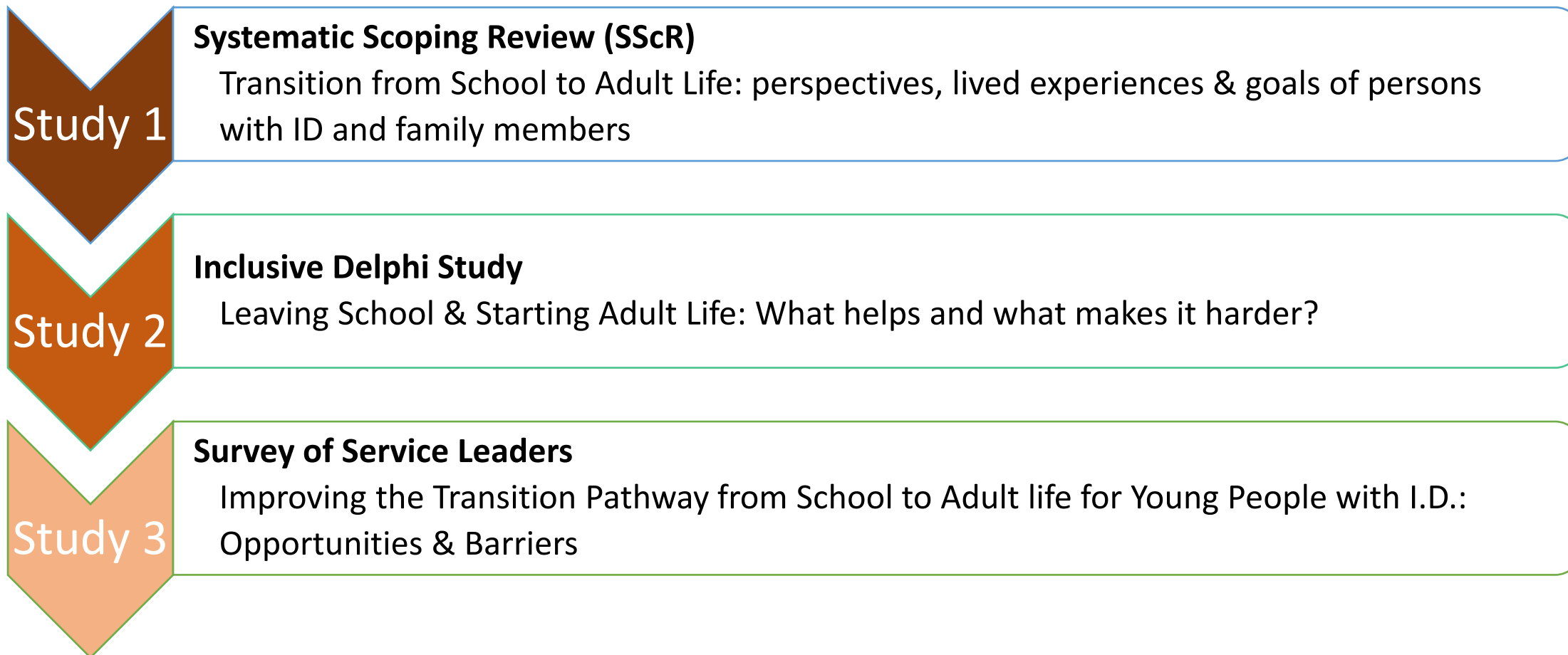
Study 1: Background & Need

5 Scoping & Systematic Reviews on related topics:

Lee & Taylor (2022)
Wilt & Morningstar (2018)
Gauthier-Boudreault et al (2019)

Young-Southward, Philo & Cooper (2017)
Jacobs, Mac Mahon & Quayle (2018)

3 Reviews Close to Study 1 SScR Question & Criteria:

- Alqazlan, Alallawi & Totsika (2019) (PSE focus, various stakeholders, SR)
- Brown et al (2019) (Healthcare focus, various stakeholders, SR)
- Slade et al (In Progress) (Parents, Profound ID, Qualitative Evidence Synthesis)

3 Distinct characteristics of Study 1:

- Systematic Scoping Review
- Persons with I.D. & Family Members (x other stakeholders)
- Broad area of Transition from School to Adult Life

SScR Research Questions

In relation to the perspectives, lived experiences and goals of persons with I.D. & family members regarding the transition from school to adult life:

Q.1.   What is known in the existing body of primary research literature?

Q.2.   What methods have been used to generate these findings?

Q.3.   What gaps exist in the existing literature?

SScR Method

- Systematic Scoping Review, following the PRISMA-Scr (Tricco, 2018a)

- Secondary research

- Systematic search of a defined research area

- Papers are screened against eligibility criteria

- SScRs aim to (Tricco, 2018b):
  - map literature
  - highlight potential research gaps

- Descriptive analysis & thematic synthesis (Thomas & Harden, 2008)

- Qualitisation of quantitative findings so as to include them in synthesis (Heyvaert, Hannes & Onghena, 2017)

SScR Search Strategy

(M)ethodology/Data:

"li* experience*" OR "world view*" OR attitude* OR opinion* OR value* OR preference* OR goal*

AND (I)ssues:

"emerging adult*" OR "life change*" OR "school transition*" OR "life transition*" OR "young adult*"

AND (P)articipants:

"learning disab*" OR "intellectual development disorder" OR "developmental* disab*" OR "mental* retard*" OR "mental* handicap*"
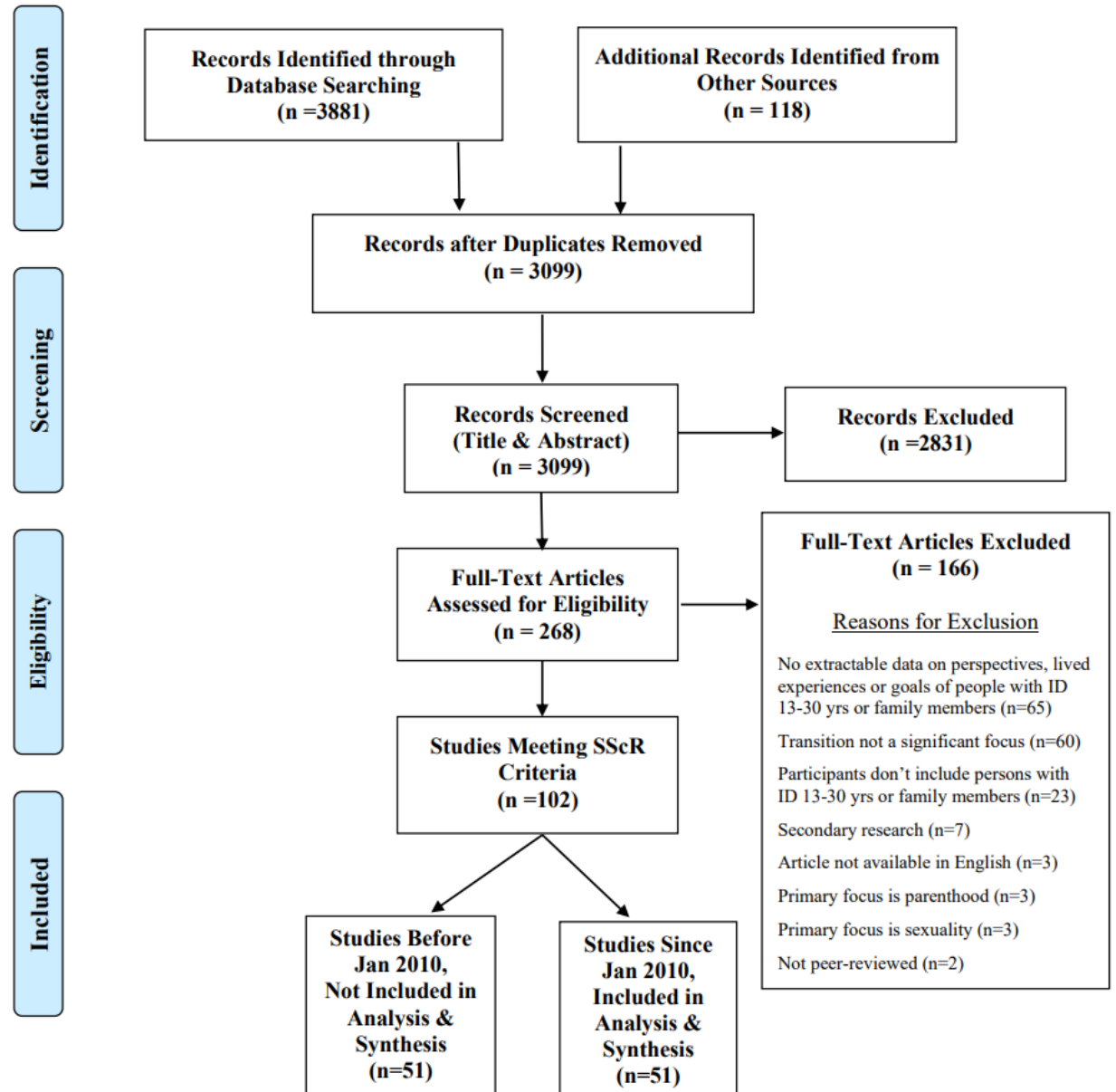
(Strech, Synofzik & Marckmann,2008)

Information Sources:

- Databases: Psycinfo, Cinahl, ERIC, SSCI, Embase (inc. Medline), PubMed
- All Years. Peer-reviewed articles. English language.
- Grey literature: relevant statutory & non-statutory body websites
- Hand search: citation lists of included articles & related-topic reviews

SScR: PRISMA Flow Chart
(Tricco et al, 2018a)

51 Included Papers (Jan 2010-Sept 2021)

Profile of Participants			
Sample Participants	Persons with I.D.	Persons with I.D. & Families	Families	Total
No. Studies	14	7	30	51
Country				
USA	2	1	13	16
UK	4	3	4	11
Canada	3	1	6	10
Australia	1	0	5	6
Other (one study each)	Sweden Mexico South Africa South Korea	Netherlands New Zealand	Ireland Austria	8
Methodology				
Qualitative	11	7	20	38
Mixed Method	2	0	3	5
Quantitative	1	0	7	8

Study 2 Taster: Inclusive Delphi Study

Keep learning

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Leaving School and Starting Adult Life:

What helps and what makes it harder?

Study 2: Background & Need

- Space in the literature for studies including people with I.D. and family members living in Ireland

- 5 Delphi studies have included panelists with I.D.:
  - de Kuijper et al (2022)   Noorlandt et al (2021)
  - Vincente et al (2019)   Salgado et al (2018)
  - Bonell et al (2011)

- 3 Distinct Characteristics of Study 2:
  - Delphi Study on topic of school transition
  - 10 participants with & 10 without disability
  - Inclusive methods - Universal design (CEUD, 2023); continual consent checking (HSE, 2022; NDA, 2009; Lewis & Porter, 2004); Talking Mats (Cameron & Murphy, 2002); reference group with I.D. (NDA, 2009); optional support person; face-to-face interviews

Do these things make leaving school harder?

✓ Yes   🤷 Not Sure   ✗ No

Note: This page is used with participants who prefer to use photo symbols. The participant is given a loose photo symbol card for each statement. The participant is asked to position the card under their choice of response (Yes / Not Sure / No) and the researcher makes a note of the response on the tick-box on the previous page. Examples of loose photo symbol cards to be offered:

Don't Know What You Want	Not Enough Information	Not Possible	Don't Know the Plan
New Teacher	New Clinicians	Service is Late	No Bus Transport

Advice for People Leaving School

This is the Senior Class at Lakeside School.
They are 18 Years Old.
They will be leaving school soon.

There are lots of different things
they might like to do when they leave school.

Some of them know what they want to do.
Some of them have not decided yet.
Some of them do not know what to do.

They need help.
They need advice.

Do these things help when leaving school?

✓ Yes   🤷 Not Sure   ✗ No

Note: This page is used with participants who prefer to use photo symbols. The participant is given a loose photo symbol card for each statement. The participant is asked to position the card under their choice of response (Yes / Not Sure / No) and the researcher makes a note of the response on the tick-box on the previous page. Examples of loose photo symbol cards to be offered:

Know What You Want	Information	Visit Places	Work Experience
Bus Transport	Others Know What You Want	Treated Like an Adult	Transition Plan

Sample Pages: DRAFT Delphi Interview Schedule

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Thank you

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