Transition from School to Adult Life: Young Adults with Disabilities

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Overview

- Transition: Definitions & Theories
- Transition Process
- Policy & Legislation
- Experiences of Young People with Disabilities & Families
- Outline of Planned Research Study
- Relevance for Social Workers

Transition: Definitions & Theories

Defining Transition

- Transition is a **change in fundamental life patterns** - a passage from one life phase to another and involves process, time span, and perception (Mannino, 2015)

- Transition is **dynamic and variable**, not time-bound or occurring in discrete stages (Mannino, 2015)

- Transition is not just another word for change, but includes the **psychological processes involved in adapting** to the change event (Kralik, 2006)

- Life is full of transitions – '**normative crises**' to be negotiated and resolved for well-being (Erikson, 1963)

Multiple Transitions

- Transition from school-age to adult life involves a **range of transitions**, depending on the person:

  - Management of **healthcare** needs and supports
  - School to **training/FE/HE/employment**
  - Living with family to **more independent living**
  - Development of **new relationships** – friendships, colleagues, intimate relationships, marriage
  - Change or **loss of old relationships** – classmates, friendships, neighbours, healthcare/education staff
  - Loss of connection with **places** – school, clinic, neighbourhood
  - Voting, **advocacy**, activism, public service use
  - **Mobility** – public transport use, taxi use, cycling, driving
  - **Parenthood**
  - Etc

Theories on Transition to Adulthood

- In the 1960s, the concept of the **'Quarter Life Crisis'** emerged from the field of developmental psychology, with Erikson and others describing the period between school and adulthood as 'prolonged adolescence' or 'early adulthood' (Flynn, 2022)

- Arnett (2000) moved beyond the concept of extended adolescence and is credited with the full and detailed description of **'Emerging Adulthood'** as a distinct developmental life stage, spanning approx. 18-29 years of age

- Arnett (2015) sees emerging adulthood as coming about as a result of a number of 20thC **sociological drivers**, which together brought about rapid changes in lifespan development from the 1960s on e.g. technological revolution, sexual revolution, women's movement, youth movement

Theories on Transition to Adulthood

- Arnett describes **5 distinguishing features** of emerging adulthood (Arnett, 2015):

  - Identify Exploration

  - Instability

  - Self-Focus

  - Feeling In-Between

  - Possibilities/Optimism

- Some see this period as **extending to 35 years** (Robinson, 2015), as it can take until then for young people to complete education, become established independent-living adults, separate from their family of origin

Emerging Adults with Disabilities

- Not all emerging adults enjoy freedom to the same extent or pass through this life phase in the same way or with the same outcomes
- **Many factors in a person's life** can affect how they experience and progress during this life stage e.g.

  - Poverty
  - Illness
  - Bereavement
  - Exposure to Abuse/Violence
  - Early parenthood
  - Early marriage
  - Educational disadvantage
  - Unemployment
  - Disability
  - Urban/Rural Living   Etc

Emerging Adults with Disabilities

- Historically, young people with disabilities have often been **denied opportunities to grow up**, through infantilisation, over-protection and discrimination (Flynn, 2022)

- Paternalism in service provision has historically undermined the right for disabled adults to undergo **normative developmental rites of passage** or expressions of adulthood e.g. forming intimate relationships, living independently, travel/moving area, taking risks, pursuing career aspirations (Flynn, 2022)

- Emerging adults with disabilities experience **substantial barriers to education and employment** after school, both of which are key markers of adulthood and can facilitate developing autonomy and economic independence and well-being (Scanlon & Kamp (DCU-NDA), 2016)

Outcomes for Emerging Adults with Disabilities

- Literature suggests many emerging adults with disabilities experience **delays reaching developmental milestones** inc. educational, vocational, and social role achievements (Chalk et al, 2020)

- Emerging adults with disabilities are more likely to experience **poor psychosocial well-being** and lower life satisfaction (Chalk et al, 2020)

- Recent evidence in the Irish context points to the **particular disadvantages** faced by students with intellectual, speech or learning disabilities in post-school life (Watson, Banks & Lyons, 2015)

Outcomes for Emerging Adults with Disabilities

- "People with disabilities are **only half as likely to be in employment** as others of working age. The reasons for this are complex, and include level of education and skills, fears around loss of benefits, employer know-how, low expectations, and limited re-entry to work following onset of a disability, as well as a higher incidence of ill-health." (GOI, 2015, p5)

- "The 2011 census showed **33% of people with disabilities** of working age in work, compared to **66% of non-disabled people**. In total, there were 112,000 people with disabilities in employment. In international terms, Ireland's employment rate for people with disabilities is low." (GOI, 2015, p24)

(Comprehensive Employment Strategy, 2015-2025)

Changing Society = New Opportunities?

- Job certainty and a job for life are no longer the norm – instead **flexibility, lifelong learning**

- **Pathway** from school, through further/higher education to work is more **variable and flexible**

- Not everyone wants to work **full-time**   (Scanlon & Kamp (DCU-NDA), 2016)

- Growing popularity of **Neurodiversity Model** (Singer, 2017) – seeks to de-pathologise differences in the way the brain works, sees individual difference as richness/diversity rather than illness/dysfunction

- Growing popularity of **Universal Design for Learning** (Meyer, Rose & Gordon, 2014), based on the premise that diversity in learning needs, styles and ability levels is the expected norm in education, not the exception

- Post-pandemic, **hybrid home-office** working the norm

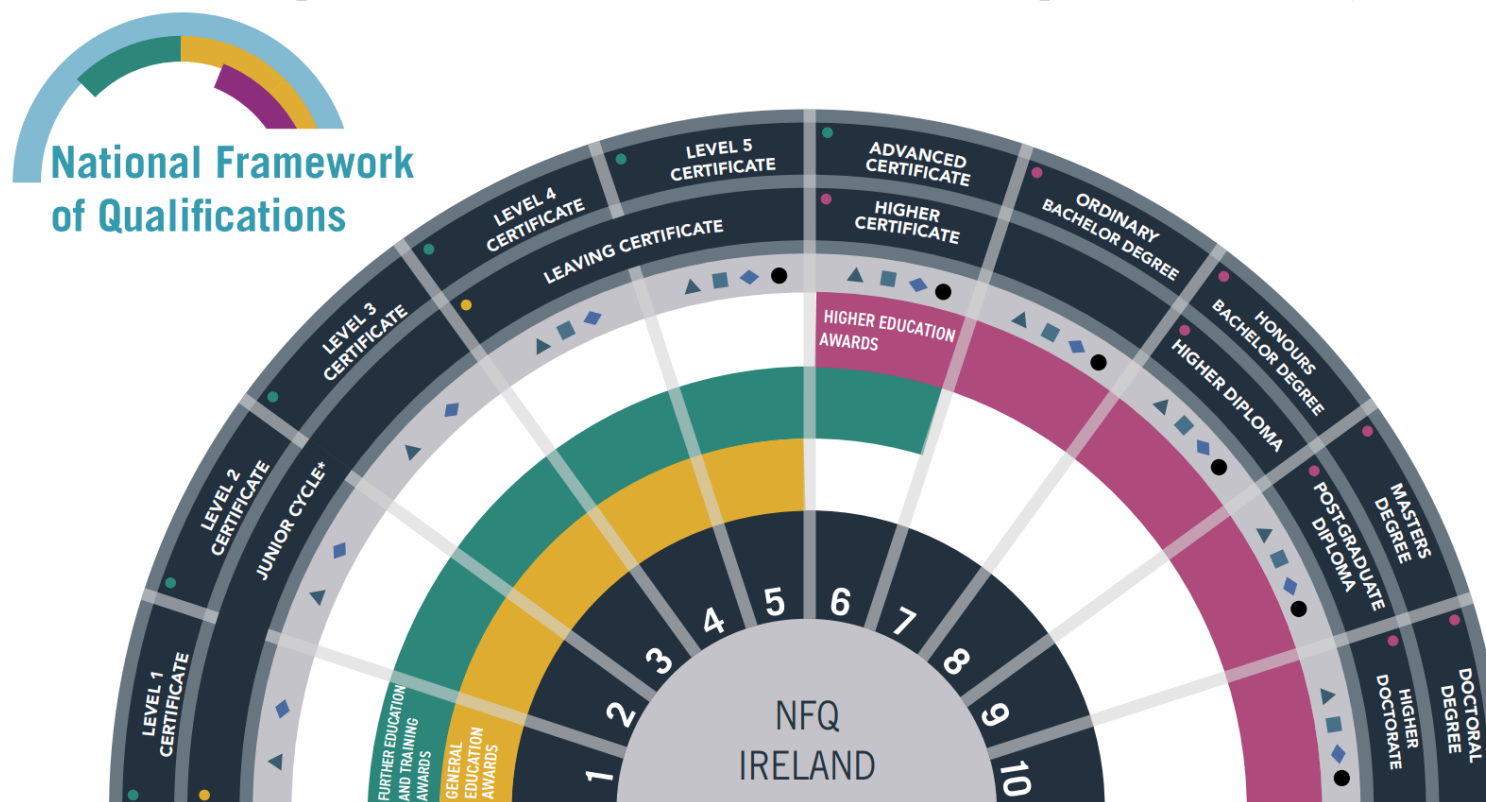⇨ These changes could be seen as **new opportunities** for people with disabilities

Whoever you are! claim your own at any hazard!

from "To You"
by Walt Whitman

Transition Process

Post-Secondary Educational Options (Ireland)

Post-Secondary Options for Emerging Adults with Disabilities (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) (Small No. Level 4, mainly 5+)			(√)	√	√
Higher Education (HE): Special Programmes (INHEF) (Mainly Level 5, some 3/4) DARE (Disability Access Route to Education) (Level 6+) Access Programmes (Level 6+) Regular HE Courses with Disability Services 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)					

Post-Secondary Options for Emerging Adults with Disabilities (Ireland)

- https://www.hse.ie/eng/services/list/4/disability/newdirections/

- https://www.etbi.ie/about-etbi/

- http://inhef.ie/courses/

- https://www.tcd.ie/disability/

- https://accesscollege.ie/dare/

- http://www.solas.ie

- www.ahead.ie

- https://www.gov.ie/en/service/8578c4-access-the-employability-service/

- https://www.aontas.com/membership/cen-members/
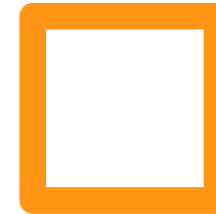
Post-School Transition Programmes

- Specific post-secondary transition programmes for people with disabilities have the potential to **lead to outcomes** such as: college enrolment, self-determination, self-confidence, autonomy, social support, career exploration, and increased living skills (Lindsay et al, 2019)

- Programmes **can vary in format and length** e.g. curriculum-based, online, immersive residential, mentoring, simulation, self-directed, technology-based (Lindsay et al, 2019)

- Engaging in a supported transition programme can provide young people with access to **information, options, confidence** and some of the **hard and soft skills** required for successful transition into education and employment contexts (Scanlon & Doyle, 2022)

- **Very few exist in Ireland** – funding often uncertain e.g. Ability, Rehabilitative Training, National Learning Network, Some Disability Agencies

Transition Preparation

- Quality of **transition preparation paramount** to individual and family's experience (Kuchenbuch et al., 2013)

- Transition is a **multidimensional, multiagency process** which needs to address all areas of adult functioning and account for interactions between multiple sectors (Bhaumik et al., 2011)

- Recommendations for effective transition planning **included early initiation** (Davies et al., 2011)

- **Improved information and education** for young people and families helps (Camfield & Camfield, 2011)

- Identifying a **lead team with clear defined responsibilities** to ensure procedures and pathways are followed can be useful – especially for those with complex needs (Davies et al., 2011)

- **Transition coordinator** can be beneficial in ensuring needs were met, essential information communicated, and a formal handover of care undertaken (Bindels-de Heus et al., 2013)

Transition Process Issues

- Young people with disabilities are **generally underprepared** for transition

- Some become **over-dependent on SNA assistance** for organising themselves and engaging in learning

- **Practical skills** needed for FE/HE generally not developed e.g. public transport use, self-care, goal-setting, self-management, study skills

- Focussed **career guidance with an expertise in additional opportunities** for people with disabilities not generally available

- **Little interaction** between schools and FE/HE institutions

(NDA-NCSE, 2017)

A qualitative study of how well young people with disabilities are prepared for life after school

June 2017

Transition Process Issues

- Study of transition from school to higher education among people with disabilities (McGuckin et al, 2013, NCSE) found:

    - **Little evidence of transition planning** at an early stage
    - **Lack of knowledge of FE/HE** supports available sometimes hampered School Guidance Counsellors in providing information and advice
    - When there was **direct contact with the FE/HE** ahead of move, this was a significant support for students
    - **Parents often required** to be very involved during the process

- Recently, concept of **Transition Passports** has been introduced by DES (based on work started in a number of disability agencies prior to that – notably Enable, SMH), but not obligatory for schools to participate

Policy & Legislation

Relevant Policy & Legislation (International)

- **Salamanca Statement (UNESCO, 1994)** – called for a move away from segregated special to mainstream education, except in cases where there are significant reasons for a child to be educated elsewhere

- **UN Convention on the Rights of Persons with Disabilities (UN, 2006)** – Art. 24 expanded this to the level of a right i.e. each individual has the right to equal opportunity and access to an appropriate education, regardless of disability

- **USA: Free Appropriate Public Education (FAPE)** established under Rehabilitation Act (1973) & Individuals with Disabilities Education Act (IDEA) (1975) – right to transition planning and supports for education up to 22 years

- **Canada: New Brunswick Policy 322** on inclusive education (DEECD, 2013) – primarily relates to under 18, but a driver for 18+ inclusion also
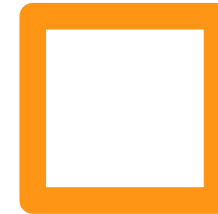
Relevant Policy & Legislation (UK)

- **ORACLE 1 (1983) & ORACLE 2 (2002)** promoted transition focus (UK)

- **Education Acts** 1944-1996 (especially Education Act 1981), **Children and Families Act** (2014) & **Special Educational Needs and Disability Act** (2001) – introduced obligation to engage in transition planning

- **"From the Pond Into the Sea:** Children's transition to adult health services" (Care Quality Commission, UK, 2014) – review, research and recommendations re best practice approach to healthcare transition
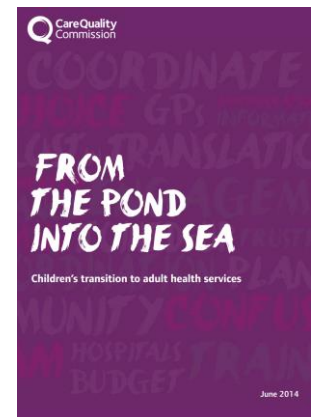
Relevant Legislation (Ireland)

- Report of the Special Education Review Committee **(SERC)** (DES, 1993) +

- **Seminal court cases** e.g. O'Donoghue Case (1993) +

- Education for Persons with Special Educational Needs **(EPSEN)** Act (GOI, 2004) – established NCSE, IEPs

$\Rightarrow$ Commitment, based on **rights**, that all children

would receive an **appropriate education up to 18**,

but no clear guidance on transition planning.

Relevant Legislation (Ireland)

- **Education Act** (GOI, 1998) – promoted equality of access & provided for expansion of **school guidance counsellor** services, with role envisaged to include transition planning and linkages with FE & HE for students with special educational needs

- **Disability Act** (GOI, 2005), gave children and their parents the right to an Assessment of Need (**AON**), outlining their support needs in all aspects of life (a review is currently underway to address waiting lists, disagreements on format of assessments etc)

Relevant Policy (Ireland)

- In 2019, a new **School Inclusion Model** was established (NCSE, 2020). Implementation progress relevant to transition includes:

  - New system for **allocating SNAs and Special Ed Teachers**, based on school profile (breaking link with individualised assessments & diagnostic requirements)
  - **"Certificate in Inclusive School"** online training being offered to SNAs
  - Some increase in **no. of Psychologists** (National Educational Psychology Service)
  - **Additional therapy and behavioural** supports (collaboration with HSE to employ – recruitment difficulties)
  - **Planned national nursing service** for children w/ complex needs
  - **Pilot** is continuing……

- **Cautious optimism** that the new model will result in positive outcomes for children (McCoy, Shevlin & Rose, 2020)

Relevant Policy (Ireland)

- **Comprehensive Employment Strategy (2015-2025)** (GOI, 2015): aims to enable persons with disabilities to have jobs, earn a living, make a contribution, have reduced poverty risk. Priorities relevant to transition include:

  - **Early career planning** commencing as young as 13 years
  - **Work experience** opportunities during 2ry school
  - Acknowledgement that **place & train models** often work better than train & place for people with disabilities
  - **Managed transitions**, with IEPs leading into **ITPs** (T = Transition)
  - **Different & individualised approaches** across the disability spectrum and persons – acknowledgement that one size does not fit all
  - **Obstacle of transport** to be addressed e.g. car-pooling schemes, door-to-door rural transport, universally designed public transport

https://assets.gov.ie/18906/1120bc6ad254489db9571c74e8572f44.pdf

Relevant Policy (Ireland)

- **NDA Review** of the progress of the Comprehensive Employment Strategy (2015-2025), at the midway point (NDA, 2020):

  - **Slow progress** overall but some good developments
  - **Employment gap** between people with and without disabilities remains stubbornly high (36.5% v. 72.8%)
  - People with disabilities still **exiting school earlier** than non-disabled peers
  - Low engagement with **training, FE, HE** continues (before age 21 is key)
  - Limited progress on **career guidance, work experience & TY access**
  - New **School Inclusion Model** launched by DES is promising
  - Promising **Pilot Transition Project** (NCSE & HSE, 2020)
  - Some progress re **transport infrastructure & systems** (no. of accessible taxis, bus fleets, bus/train stations, route planning information)

Relevant Policy (Ireland)

- The NCSE and HSE **Transition Project Group** was established in 2019 to explore a holistic approach to transition

- In collaboration, HSE and NCSE **established an oversight group** with representatives from Solas, Education and Training Board Ireland (ETBI) and Department of Education who met on several occasions in 2021

- A **plan to be progressed in 2022** to provide access to school leavers requiring transition supports

(NCSE, 2022)

Relevant Policy (Ireland)

- Study undertaken to explore **educational opportunities in disability day services** in Ire (NCSE, 2021). Stakeholders views relevant to transition:

  - **Policy and legislative context disjointed:** no legal basis for appropriate education provision post-18; inadequate funding of services & supports; opportunities for people with disabilities not consistent with that of others – inequality
  - **Silo approach across health and education:** day services & HSE don't typically regard themselves as providers of education
  - **Systemic links need to be reinforced and consolidated:** between statutory & voluntary and with FE/HE; shared language/typology/framework needed

- Recommendations include:
  - **Benchmarking tool** of criteria/standards to be met
  - More access to **accredited training** options in day services
  - **Better links** between day/FE/HE in regional areas
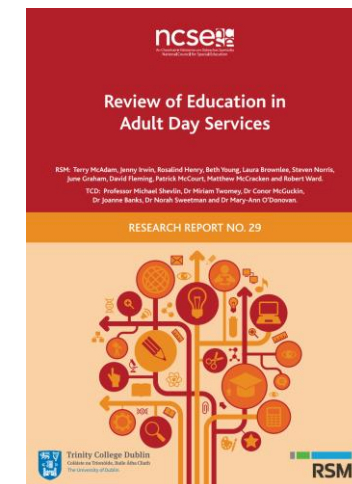
Relevant Policy (Ireland)

- **Progressing Disability Services (PDS)** (HSE, 2009) - reconfiguration of children's clinical services away from a diagnosis-dependent model to a geographical catchment-based service – transition protocols needed

- **National Plan for Equity of Access to Higher Education** 2015-2019 (HEA, 2015) file:///C:/Users/MainUser/Downloads/79102_af09b002-3258-4ff0-ab43-79d70db40417.pdf . Under this plan, the government aims for an **8% target** (proportion of all new entrants to HE who are students with disabilities) – proportion is currently 6%. **Priority goals** of the plan are:

1.	To mainstream the delivery of equity of access in HEIs.
2.	To assess the impact of current initiatives to support equity of access to higher education.
3.	To gather accurate data and evidence on access and participation and to base policy on what that data tells us.
4.	To build coherent pathways from further education and to foster other entry routes to higher education.
5.	To develop regional and community partnership strategies for increasing access to higher education with a particular focus on mentoring.

Governance & Funding (Ireland)

- The **Programme for Access to Higher Education (PATH**) is a dedicated fund, committed to increasing participation by under-represented groups in higher education

- Was established in 2017 **to support the National Plan for Equity of Access** to Higher Education 2015-2019

- In June 2022, **PATH Strand 4** was announced, which will be supported by funding of €12m over a four-year period starting in 2022:

  - Phase 1 (2022) – **Universal Design Fund** – Supporting inclusive universally designed HE environments (**specific focus on ASD and ID**)

  - Phase 2 (2023-2025) – Proposals for courses for **Students with ID**

https://hea.ie/policy/access-policy/path/

Governance & Funding (Ireland)

- https://hea.ie/funding-governance-performance/funding/student-finance/fund-for-students-with-disabilities/ - students with disabilities can apply to receive financial assistance for QQI Level 6+.

- **HSE Day Opportunities Offices** offer a single route to access Disability Day Services now (an improvement on referrals to separate agencies), but there is no single point of contact for other training/FE/HE for people with disabilities. Clinical teams for transition (in devt).

- **Disability Day Services** - Older service users are supported via **block funding** whereas support for school leavers is based on individual assessment of need as part of the **school leaver profiling** process. This makes a difference to staff ratios & model of service.

- **Towards Personalised Budgets** for People with a Disability (2018) file:///C:/Users/MainUser/Downloads/9935_2f07ddbc914b438280d5cc4036f2037c%20(1).pdf – demonstration pilot & evaluation underway.

Families & Transitions

Family-based social capital of emerging adults with and without mild intellectual disability

S. A. H. Giesbers,[1,2] A. H. C. Hendriks,[3] R. P. Hastings,[4,5] A. Jahoda,[6] T. Tournier[1,7]
& P. J. C. M. Embregts[1]

- Study re the **family-based social capital** of young people with Mild ID (Giesbers et al, 2020) compared with young people without disabilities found:

  - **Fewer family members** who they considered significant

  - Close network **less likely to include peers** (friends/partners/siblings)

  - Family support **relationships less reciprocal** in nature

  - Particularly **dependent on small no.** of significant family members

  - Had not made the transition to a **wider network** of close adult relationships

  - **Cuts in services and supports** increased over-reliance on small natural network and increased the vulnerability of individuals' positions

Families & Transitions

- Study of **barriers to family involvement in transition planning** by Hirano (2018) described school, adult service and family barriers to transition including:

  - Lack of **information** for families
  - Lack of **respect** for parents' knowledge
  - Disregard to **family values**
  - Not viewing **person as an individual**
  - Lack of a **strengths-focussed** approach
  - Family **work and day-to-day busyness**
  - Lack of **financial and practical** supports
  - Limited **support network**
  - **Stress** of providing day-to-day care
  - **Fear of change and letting go** as the young person approaches adulthood

REVIEW PAPER

CrossMark

Systemic Barriers to Family Involvement in Transition Planning for Youth with Disabilities: A Qualitative Metasynthesis

Kara A. Hirano[1] · Dawn Rowe[2] · Lauren Lindstrom[3] · Paula Chan[4]

Families & Transitions

Michael Brown PhD, MSc, RN, Professor[1] | Juliet Macarthur PhD, MSc, RN, Chief Nurse Research & Development[2] | Anna Higgins MRes, MA, Research Assistant[3] | Zoë Chouliara PhD, MSc, PsyDip, Professor of Mental Health[4]

- **Incomplete/Fractured transitions** common. When appropriate processes not in place, or discontinuity between services occurs, transition often relies on **parents' resourcefulness, family support and ability to establish new relationships** in adult setting

- Essential medical history and **information can be lost.** Parents regularly called on to be **'information gatherers'**

- Significant **gaps in ongoing follow-up** after their last paediatric appointments Parents often have to take on **role of advocate/organisers** of transitions, because of uncoordinated, inconsistent transition

- Emotional impact of transition often described as a **sense of loss, abandonment or rejection** by healthcare professionals - Transition **treated as 'ageing out'** rather than a proactive transfer and handover

- Families **rarely feel ready to move** to adult-oriented health systems and can enter the transition period with **little information**, which creates **uncertainty** with regards the process and future

(Brown, 2019)

- Parents **can feel "abandoned"** by health and social care services at this most difficult transition time. Families report little concern from health professionals as to their **roles as carers** and lack of or **explanation of choices and control** over the future (Care Quality Commission, 2014)

Emerging Adults with Spina Bifida

- Transition from child to adult healthcare needs to be **more than just transfer** of care.

- The goal of transition should be to **maximise lifelong functioning and potential** through the provision of **quality, appropriate health care** that continues **uninterrupted** as the individual moves into adulthood.

- A **complex response and approach** is required (see Figure on next slide)
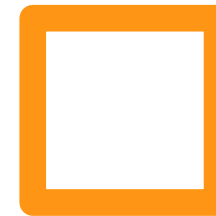
DEVELOPMENTAL DISABILITIES
RESEARCH REVIEWS *16: 60–65 (2010)*

TRANSITION TO ADULT HEALTH CARE FOR ADOLESCENTS WITH SPINA BIFIDA: RESEARCH ISSUES

Susan M. Sawyer[1]* and Sarah Macnee[2]

(Sawyer & Macnee, 2020)

Fig. 1. A schematic representation that shows transition (T) to adult health care placed at the intersection of the overlapping knowledge, skill sets and resources that constitute adolescent medicine, self-management of chronic disease and health care systems. Reprinted with permission from Kennedy A, Sawyer SM. 2008. Transition from pediatric to adult services: are we getting it right? Current Opinion in Pediatrics 20:403–309. ©2008 Lippincott, Williams & Wilkins.

As reproduced in Sawyer & Macnee, 2010

Emerging Adults with CP

- Transition to adult services experienced by **young people with CP** - survey of young people, families & staff (Ryan et al, 2022 – CRC, HSE, UCD)

- Differences in reported practices/experiences. Many **young people did not experience/report practices that may have improved** the experience and outcomes of transition, even if staff reported having provided these.

- Key Recommendation: **Young people should be involved in the development and delivery** of transition plans to ensure they meet their needs.

TABLE 4 Transition practices experienced by young people (n = 75)

Transition practice	n (%)
Named worker for transition	27 (36)
Parent involved in young person's care (from the young person's perspective)[a]	40 (89)
Parent involvement at an appropriate level (from the young person's perspective)[b]	36 (90)
Parent involved in young person's care (from a parent perspective)[c]	43 (78)
Parent involvement at an appropriate level (from a parent perspective)[d]	35 (81)
Information about transition	18 (24)
Written transition plan	10 (13)
Promotion of health self-efficacy	28 (37)
Self-management support (physical health)	27 (36)
Self-management support (mental health and emotional well-being)	13 (17)
Young person meeting the adult team	12 (16)
Discharge letter to GP[e]	4 (10)
Formal life-skills training	12 (16)

Emerging Adults with ASD

- Many young adults with ASD experience **poor transition outcomes** in relation to: postsecondary employment, higher education, health care, social connectedness, and independent living.

- Research on perspectives of youth and young adults with ASD, parents, services providers and other stakeholders were reviewed, to **identify barriers and facilitators** to optimal outcomes. Findings included:

  - **Poor transition outcomes are influenced by several factors**, inc. poor person-environment fit, uncertainty about roles of parents, and lack of comprehensive/integrated services

  - Stakeholders believe **supports should be individualised** and focused on the changing aspects of the young adult's **social and physical environment** rather than changing the person or their behaviour

(Anderson, 2017)

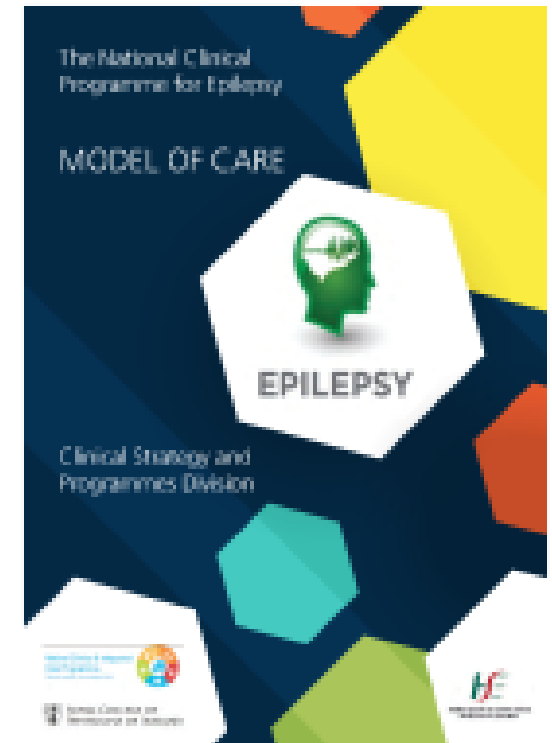Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies

Kristy A. Anderson, MSW,[a] Collette Sosnowy, PhD,[a] Alice A. Kuo, MD, PhD,[b] Paul T. Shattuck, PhD[a]

Emerging Adults with Epilepsy

- National Clinical Programme for Epilepsy (HSE, 2022) mentions transition:

  - Transition should be **a planned phased process** and should be introduced in **early adolescence**, with the young person becoming aware of their own health and care needs, and the full implications of their medical condition.

  - Progression through transition phases should be based on the assessment of the **young persons' understanding** and their confidence in their own autonomy.

  - **Six key areas should be addressed** during transition and these are: Self-advocacy; Independent health care behaviour; Sexual health; Psychosocial support; Educational and vocational planning; and Health and lifestyle.

  - By the final phase, the young person **should have a considerable degree of autonomy over their care.** They should be aware of their own health care needs and how best to access support or seek advice and further information/education if needed.

    https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/epilepsy-model-of-care.pdf

The National Clinical Programme for Epilepsy

MODEL OF CARE

EPILEPSY

Clinical Strategy and Programmes Division

Emerging Adults with ID

- In the NIDD Report of 2017, just 84 people with ID were recorded as attending "Third Level Education", out of a total of 57,872 people with an ID recorded as using day services i.e. **0.145%**. (Hourigan et al, 2018)

- **Inclusive settings at school** stage tend to be associated with **more inclusive settings in adulthood,** however **mainstream education** continues, internationally, to be **far less the norm for students with ID** than for other students with disabilities (Buchner et al, 2021)

- There is often **little multiagency/joint working** considering a wider spectrum of needs including employment, day activities, and social opportunities (Bindels-de Heus et al., 2013)

Emerging Adults with ID

- Those with **severe/profound levels of ID face particular challenges** accessing further education (Gauthier-Boudreault et al, 2019)

- Two main choices to occupy their days: **daily activity centres and/or leisure**

- **Few options to maintain capabilities** developed while they were at school or to work towards **new learning goals**

- Ongoing **dependency and vulnerability is assumed** - limited planning for their lives as adults

Outline of Planned Research Study

PhD Study: Transition from School to Adult Life:

perspectives, lived experiences & goals of persons with ID and family members

- There are three component parts to the study:

    1. **Systematic Scoping Review**: To find out what is already known from research literature about the views, experiences and goals of young people with ID and their family members about transition. (2022-23) (Protocol available to view at: https://osf.io/m94pq/)
    2. **Modified Delphi Survey**: Will involve gathering the views of a panel of experts (i.e. people with ID & family members), through an adapted Delphi Survey method. The aim will be to produce an agreed set of recommendations about transition: what helps and what makes things more difficult. (2023)
    3. **Survey of Service Managers & Leaders**: A survey of those involved in planning and providing services to people with ID in Ireland, to ask which recommendations they feel could be easily put into action and what difficulties there might be acting on others. (2024)

Relevance for Social Workers

Relevance to Social Work Practice: Some Ideas

- Advocacy for **rights and adulthood** of emerging adults

- **Emotional impact** of transition on family & person with disabilities

- **Other barriers** faced by families re transition (see above Hirano, 2018)

- Assessment & support of the **natural support network** (see above Giesbers et al, 2020)

- Support of family & young person through **difficult decisions and changes**

- **Communication planning** – what message, when, how, to whom

- **Bridging, multi-agency** teamwork e.g. CDNT – Adult Services

- **Culturally-sensitive approach** to transition planning - parental and child expectations vary under the influence of culture (Wilt & Morningstar, 2018)

- Over to you!

Thank you

For more information on Future Study Findings & Presentations, please contact:

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