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SCHOOL OF NURSING AND MIDWIFERY

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Addressing the 'transition issue'

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4th International Children's Palliative Care Conference

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Overview of presentation

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➢The 'transition issue'

- What interventions may help transition in your area of work?
- What needs to be in place organisationally to support transition?
- How do the transition interventions work?

➢A personal perspective of transition

➢Reflections from conference delegates

➢Moving forward

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What is transition?

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- Transition is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems" (Blum *et al.,* 1993, p. 570).

➢ It is process rather than an event

➢ It is multidimensional

➢ It is multifaceted

➢ An effective transition from children to adult services provides high quality, coordinated, uninterrupted health care that is patient centred, age and developmentally appropriate, culturally competent, flexible, responsive and comprehensive (McDonagh and Kelly, 2003).

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'Transition issue'

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- Improvements in care and treatment have led to an increasing number of young adults with life-limiting conditions living beyond childhood, which means they must make the transition to adult services.

- There are reports of unmet needs for young adults such as;

➢ Lack of emotional support (Kirk and Fraser, 2014)

➢ Deficiency of information (Kirk, 2008)

➢ Challenging issues related to inpatient experiences (Beresford and Stuttard, 2014)

➢ Loss of services such as respite breaks when in adult care (Noyes *et al.,* 2014)

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'Transition issue'

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Poorly managed transitions are associated with;

- Increased risk of non-adherence to treatments
- Loss to follow-up
- Unmet needs in a range of medical conditions

(Sloper *et al.,* 2010; Annunziato *et al.,* 2007; DoH, 2006, Van Walleghem *et al.,* 2006)

The transition issue is…… the potential gap

(image from St Oswalds Hospice, 2012)

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'Transition issue'

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- There is emerging evidence to suggest good transition programmes can improve outcomes such as;

- Developed self-management skills
- Adolescent transition readiness
- Improved perceived health status
- Meeting disease specific educational needs

(Mackie *et al.,* 2014; Chaudhry *et al.,* 2013; Robertson *et al.,* 2006)

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Considerations

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Consider the area in which you work.

- What can feasibly be done to improve transition to adult services in the area in which you work?
- Could any of the interventions being outlined be introduced or developed in your area of work?
- What can be changed in the context in which you work to give the interventions a better chance of succeeding?

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What interventions may help transition?

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- Realist review of the literature (Kerr *et al.,* 2017)
- All-Ireland research (Kerr *et al.,* 2018)
- All-Ireland survey (Kerr *et al.,* 2019)
- Transition workshop (Kerr and O'Halloran, 2017)
- International comparison with Canada (Kerr *et al.,* under review)

Realistic review of the literature (Kerr *et al.,* 2017)

- Four electronic databases searched, supplemented with a search in Google Scholar and articles from reference lists of included papers.
- January 1995-April 2016.
- 78 papers included in review.
- Six interventions identified related to an effective transition to adult services.
- Key review question: What range of interventions are associated with a successful transition from children's to adult services for young adults with life-limiting conditions?

Kerr, H., Price, J., Nicholl, H. and O'Halloran, P. (2017) Transition from children's to adult services for young adults with life-limiting conditions: A realist review of the literature. *International Journal of Nursing Studies,* 76, pp. 1-27.

Realistic review of the literature

1. Early start to the transition process.
2. Effective communication and collaboration between children's and adult service providers.
3. Orientating the young adult to adult services and optimizing relationships with children's and adult service providers who demonstrate a person-centred and individualised approach.
4. The engagement of a key worker.
5. Interdisciplinary and interagency joint working.
6. Development of an autonomous young adult throughout the transition process.

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All-Ireland research

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Aim of the research:

To identify the organisational factors, and interactions between factors, involved in promoting or hindering a successful transition to adult services for young adults with life-limiting conditions.

Context:

Island of Ireland

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Methods

Realist evaluation approach using a mixed methods design with four phases of data collection;

1. Survey questionnaire to the statutory and non-statutory sector which included health and social, education and voluntary organisations
2. Interviews with young adults with life-limiting conditions
3. Focus groups with parents/carers of young adults with life-limiting conditions
4. Interviews with service providers from statutory and non-statutory organisations

Phase one: survey questionnaire (Kerr *et al.*, 2019)

- 20 item questionnaire survey developed to map availability of transition services on the island of Ireland.
- Dublin North East Health Services Executive area in the Republic of Ireland (RoI) and all of Northern Ireland (NI).
- Inclusion criteria: statutory and non-statutory organisations providing services to young adults with life-limiting conditions falling with the four categories of the ACT classification of illness trajectories.
- Purposive sampling.
- Gatekeepers distributed survey questionnaire in larger organisations.

Kerr, H., Price, J. and O'Halloran, P. (2019) A cross-sectional survey of services for young adults with life-limiting conditions making the transition from children's to adult services in Ireland. *Irish Journal of Medical Sciences, 188(9), pp. 1-10*.

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Phase one: survey responses

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Country	Number of organisational invitations	Number of organisations responded (percentage response rate)
RoI	20	13 (65%)
NI	35	16 (46%)
Total	55	29 (53%)

Country	Number of individual invitations	Number of individual responses (percentage response rate)
RoI	165	31 (19%)
NI	237	73 (31%)
Total	402	104 (26%)

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Phase one: survey responses

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Role	Number (percentage of participants)
Nurses	30 (29%)
Medical staff	26 (25%)
Managers/Directors/Head of Service	16 (15%)
Allied Health Professionals	13 (12%)
Social workers	5 (5%)
Transition coordinators	5 (5%)
Psychologist	2 (2%)
Teacher	1 (1%)
Other	6 (6%)
Total	104 (100%)

Phase one: organisational responses (Kerr *et al.,* 2019)

- Transition policy: 45% responded yes: 46% in RoI and 44% in NI.
- Developing transition strategies: 62% responded yes: 69% in RoI and 56% in NI.
- Evaluation on transition completed: 21% responded yes: 8% in RoI and 31% in NI.
- Most frequently reported age to commence the transition process was 16 years in RoI and 14 years in NI.
- Most frequently reported age to transfer the young adult to adult services was 18 years across the island of Ireland.
- 38% in RoI and 19% in NI reported having young adults in children's services beyond the age of 25 years.
- Most frequently used transition model on the island of Ireland was effective communication between children's and adult services and interagency collaboration.

Phase one: survey results (Kerr *et al.,* 2019)

- *Factors which promote a successful transition:* effective communication between children's and adult services and with the adolescent/young adult and their parents/carers.

- *Strengths of the services provided:* an early start to the transition process, adopting an interdisciplinary approach and availability of knowledgeable staff.

- *Weaknesses in the services identified:* loss of services when the young adult transferred to adult services and concerns about the ability of the young adult increasing their self-management skills.

- *Changes suggested:* children's services becoming more active in promoting the young adults' autonomy while they were in children's services and the availability of respite care in adult services.

All–Ireland research on transition to adult services

- Phase two: interviews with seven young adults with life-limiting conditions.
- Phase three: two focus groups with ten parents/carers of young adults with life-limiting conditions.
- Phase four: interviews with 17 service providers from statutory and non-statutory organisations.

Interventions associated with a successful transition

(Kerr *et al.,* 2018)

1. Early start to the transition process.
2. Effective communication, cooperation and commitment between children's and adult services.
3. Interdisciplinary and interagency joint working.
4. Developing the young adults' autonomy.
5. *Engagement of a transition coordinator.*
6. *Orientation of the young adult to adult services.*
7. *A person-centred approach to care being demonstrated by service providers.*
8. *Involvement of parents/carers.*

Kerr, H., Price, J., Nicholl, H. and O'Halloran, P. (2018) Facilitating Transition from Children's to Adult Services for Young Adults with Life-limiting conditions (TASYL). Programme Theory developed from a mixed methods realist evaluation. *International Journal of Nursing Studies,* 86, pp. 125-138.

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Contextual factors

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- Availability of time to implement the interventions.
- Availability of adequate resources and knowledgeable staff.
- Children's service providers identifying relevant adult service providers early.
- Children's service providers recognising need to develop the young adults autonomy.
- Adult service providers engaging in the transition process.
- Trained and motivated transition coordinators who understands both children's and adult services.
- Young adult who is capable and willing to engage in transition related activities.

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‘Mechanisms’ How interventions work

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- Adolescent/young adult experiencing a growing sense of self-efficacy, agency, empowerment and confidence in taking increasing responsibility for their own medical management and adopting a sense of ownership of their journey into adult services.

- Adult service providers feeling empowered as a result of being in possession of relevant information related to the young adults’ needs.

- Parents/carers feeling empowered as a result of continued involvement in the transition process.

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Transition workshop

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- All Ireland Transition Workshop in Newry in September 2016 led by Dr Helen Kerr and Dr Peter O'Halloran.
- Over 80 people attended including service users and service providers.
- Aim was to rank order the eight interventions associated with a successful transition in order of importance.

Ranked order of importance of factors

(Kerr and O'Halloran, 2017)

1. Effective communication, cooperation and commitment to joint working between children's and adult services.
1. Engagement of a transition coordinator.

3. Interdisciplinary and interagency joint working.
4. Person-centred approach to care being demonstrated by service providers.
5. Involvement of parents/carers.
6. Early start to the transition process.
7. Developing the young adults' autonomy throughout the transition process.
8. Orientation of young adults to adult services.

Kerr, H. and O'Halloran, P. (2017) Transition from children's to adult services for young adults with life-limiting conditions in Ireland: Recommendations from an All-Ireland Stakeholder Workshop.

International research: development of Transition Theory

- Cross-sectional survey focused on organisational approaches to transition distributed to three organisations providing services to adolescents with life-limiting conditions in Toronto, Canada.
- Data were mapped to the TASYL Transition Theory to identify corresponding and new theoretical elements.
- Invitations sent to 411 potentially eligible health care professionals with 56 responses.
- Very strong support for three of the eight interventions: early start to the transition process; developing adolescent/young adult autonomy throughout the transition process; and the crucial role of parents/carers.
- Results validated the eight key interventions and identified one new intervention.

Development of Transition Theory

1. Early start to the transition process.
2. Effective communication and collaboration to joint working between children's and adult services.
3. Orientation of the young adult to adult services.
4. The engagement of a transition coordinator.
5. Interdisciplinary and interagency joint working.
6. Developing the young adults' autonomy throughout the transition process.
7. Service providers demonstrating a person-centred approach to care.
8. Involvement of parents/carers.
9. Service providers communicate effectively with the adolescent/young adult and their parents/carers.

Kerr, H., Widger, K., Cullen-Dean, G., Price, J. and O'Halloran, P. Transition from children's to adult services for adolescents/young adults with life-limiting conditions: developing realist programme theory through an international comparison, under review.

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Personal perspective

Suzanne Glover

- Introduction - https://mediasite.qub.ac.uk/Mediasite/Play/a2524960f80b471e9d14dcd628f734a21d
- Factors for a successful transition - https://mediasite.qub.ac.uk/Mediasite/Play/e30123a49371425fbe8af8a88b19eac01d
- Steps for an improved transition - https://mediasite.qub.ac.uk/Mediasite/Play/b798fc9e42054d6cb4895404a3286c2b1d

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Feedback from conference delegates

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1. If relevant, briefly outline the services provided in your organisation to support adolescents/young adults with the transition from children's to adult services?

2. In your opinion/experience, how can the transition from children's to adult service be improved for adolescents/young adults with life-limiting conditions?

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Moving forward: considerations

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Consider the area in which you work.

- What can feasibly be done to improve transition to adult services in the area in which you work?
- Could any of the interventions outlined be introduced in your area of work?
- What can be changed in the context in which you work to give the interventions a better chance of succeeding?

What interventions may help transition in your clinical area?

1. Early start to the transition process.
2. Effective communication and collaboration to joint working between children's and adult services.
3. Orientation of the young adult to adult services.
4. The engagement of a transition coordinator.
5. Interdisciplinary and interagency joint working.
6. Developing the young adults' autonomy throughout the transition process.
7. Service providers demonstrating a person-centred approach to care.
8. Involvement of parents/carers.
9. Service providers communicate effectively with the adolescent/young adult and their parents/carers.

What needs to be in place organisationally to support transition?

- Availability of time to implement the interventions.
- Availability of adequate resources and knowledgeable staff.
- Children's service providers identifying relevant adult service providers early.
- Children's service providers recognising need to develop the young adults autonomy.
- Adult service providers engaging in the transition process.
- Trained and motivated transition coordinators who understands both children's and adult services.
- Young adult who is capable and willing to engage in transition related activities.

Final thoughts

- Successful transition should be seen as a core responsibility for *both* children's and adult services.

- Outcomes related to a successful transition from children's to adult services is a young adult who is integrating into adult services demonstrated by patient satisfaction, attendance at appointments and engagement with disease management strategies.

- However, the goals for transition should include those identified by adolescents/young adults and extend beyond their engagement with health services.

Thank you…

- Suzanne Glover for the participating in the video.
- Young adults, parents and carers, and service providers who participated in the research.
- To you, for completing the online questionnaire on transition.
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- School of Nursing and Midwifery, Queen's University Belfast who continue to support the research.

Thank you for listening

Research team (left-to-right)

- Dr Peter O'Halloran, Queen's University, Belfast
- Professor Jayne Price, Kingston and St George's University, London
- Dr Helen Kerr, Queen's University, Belfast
- Dr Honor Nicholl, Trinity College, Dublin

Questions