Children’s Research Network News

Special Interest Group on Child Health Research

This Research Bulletin is a new initiative of the recently launched Special Interest Group on child health research, under the Children’s Research Network. The members of this Special Interest Group recognise the need to identify, better coordinate, share and disseminate research into children and young people’s health issues. One of the identified areas was transition from child to adult health services, which was therefore chosen as the second topic of a series of thematic research bulletins on different aspects of children’s health.

The new Special Interest Group on Children’s Health is open to all members of the Children’s Research Network. The Group is interested in both academic and practice based research into Children’s Health. To join the Special Interest Group on Children’s Health, please contact David Kenefick (dkenefick.crn@effectiveservices.org).

Recent Research and Reports from Ireland

Improving Transition to Adult Healthcare for Young People with Cystic Fibrosis: A Systematic Review.

As survival increases worldwide, large numbers of young people will need to transition from child to adult cystic fibrosis (CF) services. Little is known about the best method for transitioning patients with CF and which transition programmes yield better outcomes. In this systematic review, outcomes and experiences data for young people with CF transitioning to adult care were subject to a narrative synthesis and a thematic synthesis of experiences data.

Structured transition programmes were associated with increased satisfaction, discussions about transition, self-care and self-advocacy skills, more independence, lower anxiety, and increased self-management and parent management of physiotherapy and nutritional supplementation. Four themes emerged from the synthesis concerns about transition, transition readiness, psychosocial needs and variations in care. Concerns about transition varied across studies with some participants having few concerns while others expressed many.

The limited evidence suggests that transition did not appear to result in adverse health outcomes which contrasts with reviews of transition outcomes for other chronic conditions. Concerns about transfer varied across studies, with parents having higher levels of concern than young people with parents being concerned about their child’s self-caring abilities and their own diminished involvement. While young people were concerned about leaving familiar caregivers and potential infections, they wanted to be the focus of information sharing albeit valuing their parents’ practical and financial support. Factors that enhanced transition experiences included structured transition programmes, developmental maturity and a positive attitude towards adult oriented care, while inadequate preparation, severance of trusted relationships, professionals’ negative attitudes towards adult services, and insufficient communication and self-management skills hindered transition.

The authors of this review conclude that although detailed policy statements and guidelines currently exist, these appear to be based on expert clinical experience and a best practice approach rather than strong evidence from empirical studies. Furthermore, the contribution of the different transition programme components to desired outcomes are unclear. Future studies should include standardized operational definitions, rigorous sampling involving multi-centre studies, use of validated instruments to facilitate
comparability and adherence to reporting guidelines to permit study replication. Since transitional issues for young people with CF are similar across other chronic conditions.

There is a clear need for high-quality studies to inform the development of transition programmes so that all young people with Cystic Fibrosis experience successful transitions and can maximize their health potential.

For full article go here

**Transforming Transition for Paediatric IBD Patients in Northern Ireland - R Little, A Szabo, L McLaughlin. Archives of Disease in Childhood 2017; 102: A62**

Continuous efforts have been made by the Paediatric Gastroenterology team in Belfast’s Royal Hospital for Sick Children, to develop their services to facilitate a more efficient transfer of adolescent care to Adult Gastroenterology. Initially this process was by referral letter only however, in view of the increasing prevalence of Inflammatory Bowel Disease (IBD), establishing a well-structured transition clinic has been essential.

The Paediatric Gastroenterology Team in the Royal Hospital has sought to elucidate the level of preparedness for, and experience at, transition from adolescent attendees. The research team devised a questionnaire seeking information about all aspects of their management including; experience of Paediatric services, their future needs and apprehensions regarding adult care. This was distributed to all adolescent patients (n=22) attending transition clinic over a six-month period, which they completed anonymously. Data was then collated.

All the young people rated the quality of care at transition clinic as excellent or good and felt they were well supported by the medical and nursing staff present. The majority (80%) agreed the clinic adequately prepared them for moving to Adult Gastroenterology care. However, only 50% of patients knew their medication names and doses. 32% wanted more advice regarding investigations and symptom management while 75% of respondents stated they would prefer improved online advice through social media rather than the CCUK website or local support groups.

Some concern was expressed regarding the loss of a supportive relationship with the children’s nurse specialist which was a source of stress. Over the last eight years the Paediatric Gastroenterology team has successfully established transition clinics with all five healthcare trusts across Northern Ireland. Collaboration between the Paediatric and Adult Gastroenterology teams in Northern Ireland has transformed the continuity, safety and patient experience for young people with IBD transitioning between expert services. Further work to equip adolescents with knowledge regarding their medication and symptoms, in conjunction with increased provision of allied health care professionals to adult services, will enhance wellbeing and improve clinic engagement.

For full article go here

**The Perceptions of Patients, Their Parents and Healthcare Providers on the Transition of Young Adults with Type 1 Diabetes to Adult Services in The West of Ireland**


This report was of a qualitative study which describes young adults’, parents of young adults’ and health care professionals’ (HCP) perceptions of the transition process from child to adult diabetes services, and barriers to and facilitators of this process in the West of Ireland.

Semi-structured interviews were conducted with 3 stakeholder groups; young adults (n=6), parents of young adults (n= 7) within 2 years of transitioning and diabetic service health care professionals (n=7). Thematic analysis of these interviews was undertaken to assess how existing transition processes meet current international guidelines.

In relation to their experiences of the transition process; Young adults hardly noticed the transition, and they felt in control of their diabetes. However, resource limitations and a lack of structured education were identified as barriers to a smooth transition by parents. Health care professionals reported experiencing problems in the areas of achieving consistent attendance, and the lack of a psychology service to accompany treatment. This study identified perceived barriers to and facilitators of the transition process for young adults with type 1 diabetes. A young adult’s ability to self-manage had a significant effect on their and their parent’s perceptions of transition, whilst a key navigator
who transitions with the family was identified as an effective facilitator of the process.

For full article go here

The Temple Star Transitional Model of Care for epilepsy; the outcome of a quality improvement project.


This study was to engage parents and get their opinions on transition and the design of a multidisciplinary epilepsy transitional programme. A mixed method study design was used to gain parents (n=34) knowledge and views in order to inform a transitional and adolescent program for epilepsy.

The majority of parents wished for children to be transitioned at the age of 18. The majority also wished for a structured programme to be introduced between the age of 12 and 16. Issues to be included in the programme were independent health behaviour, educational and vocational planning, sexual health topics and lifestyle issues (alcohol, substance misuse, sleep, stress management and disclosure to peers). The Temple Star Transitional Model of Care was developed from the information gathered in the study. One of the main issues was that adolescents did not disclose their disease to peers so part of the programme was to meet peers who also had epilepsy.

To date transitional programmes have focussed on the actual time and logistics of transition from child to adult services. Engaging parents in the development of an epilepsy transitional and adolescent care clinic meant that a detailed structured preparation multidisciplinary programme is now available to young people with epilepsy.

Focus on a St Clare’s Unit, and Transitions in Therapy

By Maura O Sullivan (Principal Social Worker)

The therapy service in St Clare’s Unit offers therapy to children and young people up to the age of 18 who have experienced sexual abuse. As a young person approaches the age of 18, thought and planning takes place with regard to a young person’s on-going therapeutic needs and whether or not transitioning onto an adult service may be required. A variety of issues are considered by the therapist and explored with the young person and their parents in advance of this time. Many young people crave independence and will welcome the prospect of moving from a paediatric service to an adult one, where their attendance will be on their own terms. It is important that this is respected. Others may find themselves reluctant to leave the familiar setting and express anxiety about this. However, with the passage of time most eventually come to a personal realisation, that their growing maturity and external commitments be it to college or work, mean that they are outgrowing the child based service. In certain circumstances, it can often make sense to continue the therapy while the young person is still attending secondary school to allow for continued support in this critical period. Where there are no perceivable outstanding or on-going therapeutic needs, the therapist and young person work towards an ending date.

In St Clare’s, parents are frequently involved in transporting and accompanying their child to and from their appointments. When attending a child service, there is regular linking with parents via review sessions about their child’s progress. At times, parents may also become actively involved in the therapy work, engaging in family therapy, parent/child work or parent support work. Additionally, in cases where particular concerns arise about the child or another individual need to be shared, parents are alerted to ensure the child’s immediate and ongoing safety is provided for. In contrast, a young person attending an adult service will be viewed as independent and contact with any other person in relation to a safety concern arising will be a decision for the young person and/ or the therapist. If the young person does not attend an appointment, normal policies regarding non- attendance will apply (e.g. discharge following two non-attendances), whereas in a child service, a parent or allocated social worker may be contacted in order to encourage attendance. This new responsibility for attendance and deciding who, if anyone should be made aware of anything concerning arising in therapy, will require consideration by the young person. Similarly, parents will face the challenge of stepping back and allowing the young person to assume this responsibility. Planning for
the transition in therapy can assist in negotiating these issues.

In St. Clare’s, the administrative systems in place are tailored towards serving minors and therefore involve parents/carers and or referrers to take account of their on-going role in the child’s life. For example, communications regarding appointments and on-going matters relating to accessing therapy are managed between the service and the parent. Services’ policies and procedures around consent and assent issues must take account of the age of the client to ensure that they meet their obligations regarding these issues. When a child client turns 18, the child based service can find its systems, including IT ones, stretched to try and accommodate the new set of circumstances. On a psychological level, once a young person turns eighteen, they become legally mature and with this they are entitled to be treated as an adult. Giving this fact some focused attention can become a useful part of the therapy work and can assist in smoothing the transition from child to young adult.

It is important that St Clare’s Unit ensure that the timing of the transition is carefully considered and any potential safety issues are identified and taken into account. For example, where there are specific mental health needs, safety planning must take place in order to ensure the welfare of the young person. This may involve negotiating with other services that may be on the brink of ceasing their involvement with the young person, due to their own referral criteria. It is possible that a young person may be straddling two services for a time, as they attend adult services for mental health needs and child services for therapy. It is useful for these complexities to be considered in the therapy so that joint planning with the young person and/or their parents/carers can take place.

In situations where a young person decides to continue to avail of therapy elsewhere, discussion will take place regarding whether or not any information should be shared with the new service and how best to do this. Introductory meetings may take place, and it may be the case that the adult service will carry out a therapeutic assessment when they commence working with the young person. St Clare’s Unit have created links with Laragh Counselling Service, the local branch of National Counselling Service. An arrangement has been established whereby an adult therapist representing Laragh can meet with the young person in St Clare’s initially to provide information on the new service and hopefully ease the transition for the young person. Planning is important in order to minimise waiting times. Adult services frequently have longer waiting lists so it is important that consideration is given to the point at which the therapy is transitioned from one service to another.

This area presents a significant challenge to services and would benefit from further research. How can we best facilitate the progression of young people from child to adult services while accommodating their unique needs at this transitioning stage?

**Development in Services – Epilepsy Transition Coordinator**

As can be seen above there are various studies being done with young people, parents and healthcare providers both before and after transition. Challenges, facilitators and barriers have been identified. The main aim of a structured transition is to maintain young people’s good health and avoid them disengaging with the adult health services or ‘falling through the gap’. A lack of a suitable transition programme means that this is more likely to occur.

An epilepsy transition coordinator post was created under the governance of the National Children’s Hospital Group and funded by Epilepsy Ireland and Yvonne Owen was appointed to the post. This is the first of its kind in Ireland dedicated to transition and its function is to improve preparation and engagement of young people with epilepsy for transition and to engage with epilepsy services to develop an evidence based standardized approach to transition.

To date a needs analysis of existing services was conducted and research in Temple St (Crowley et al. 2018) and RCSI (Epilepsy Partnership in Care EPiC) was consulted to get the views of young people and their families. Systems based issues and clinician’s views were also ascertained.

10 key objectives have been identified. These are:

1. Agreed transition pathway and model for young people that is equitable and sustainable.
2. Improved access to services at children and adult sites.

3. Development of a transition registry (database) to track and monitor young people and to see how many young people are anticipated to transition each year in the future.

4. Development of a standardised pack for the referral process and transfer documentation.

5. Development of information resources.

6. Develop transition interventions for paediatric, adult and community settings.

7. Develop staff education and support.

8. Explore Epilepsy Electronic Patient Record (EPR) integration and development.

9. Engage with Clinical Care Programme to develop national transition guidelines.

10. Ongoing research and audit of transition service.

Thus the role of the epilepsy transition coordinator will enable transition services to develop and grow in a systematic way across sites. It would be anticipated that if some of the resources developed could be adapted to other medical conditions it would improve the journey of young people from child to adult healthcare services across a range of services and facilitate integration of services in the future.

Working Group on Transition

The National Clinical Care Programme for Paediatric and Neonates has established a transition working group to draft a national guiding principles document to outline the priorities for transition. The group have representation across children, adult and community services and cover a large spectrum of specialities that deal with chronic conditions including diabetes, rheumatology, renal conditions epilepsy and mental health services.

The guiding principles document aims to provide generic advice to services who are delivering transition services across the country. It is hoped that the completed document will be circulated to the wider clinical community for consultation and feedback in the coming months.

Child Health Interest Group

This bulletin is produced by the Special Interest Group in Child Health of the Children’s Research Network for Ireland and Northern Ireland. The group, established in early 2017 is made up of members of the Network with a special interest in child health to identify, better coordinate, share and disseminate research into children and young people’s health issues. One of the ways in which this is achieved is through the dissemination of research reports, events, training opportunities and policy/practice updates to wide audience. The new Special Interest Group on Children’s Health is open to all members of the Children’s Research Network. The Group is interested in both academic and practice based research into Children’s Health.

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If you have items you would like included in the next bulletin or have any comments or questions, please contact Denise Scully (Project Support) on dscully@effectiveservices.org