

**Victorian Travelling Fellowship**

**Travel report:**

Identifying best practice models of care for adolescent transition

**Sarah Macnee**

**15 November 2009**



## Table of contents

<b>Project information</b>	<b>3</b>
<b>Acknowledgements</b>	<b>3</b>
<b>Project summary</b>	<b>4</b>
<b>Background</b>	<b>4</b>
<b>Purpose of the project</b>	<b>4</b>
<b>Top three outcomes of the travel phase</b>	<b>4</b>
<b>Main activities undertaken</b>	<b>5</b>
<b>Synopsis</b>	<b>6</b>
<b>Lessons for the Victorian healthcare system</b>	<b>7</b>
<b>Lessons for The Royal Children’s Hospital, Melbourne</b>	<b>7</b>
<b>Outline of the study itinerary</b>	<b>9</b>
London, United Kingdom	12
<b>University College London Hospital [UCLH]</b>	<b>12</b>
<b>Great Ormond Street Hospital [GOSH]</b>	<b>19</b>
<b>Evelina Children’s Hospital [Guys &amp; St Thomas’ NHS Foundation Trust]</b>	<b>21</b>
Glasgow, Scotland	22
<b>Hospital Services for Young People Conference</b>	<b>22</b>
Sweden	23
<b>Associate Professor Kristina Berg-Kelly</b>	<b>23</b>
Birmingham, United Kingdom	24
<b>Birmingham Children’s Hospital [BCH]</b>	<b>24</b>
Vancouver, Canada	32
<b>British Columbia (BC) Children’s Hospital</b>	<b>32</b>
Calgary, Canada	35
<b>Alberta Health Services – Alberta Children’s Hospital, Calgary Area [AHS]</b>	<b>35</b>
Minneapolis, United States of America	41
<b>University of Minnesota, Division of General Paediatrics &amp; Adolescent Health Medicine</b>	<b>41</b>
<b>Gillette Lifetime Specialty Healthcare</b>	<b>44</b>
Toronto, Canada	46
<b>Bloorview LIFEsan Program</b>	<b>46</b>
<b>Good 2 Go Transition Program, Hospital for Sick Children [SickKids]</b>	<b>52</b>
Florida, United States of America	55
<b>JaxHATS - Jacksonville Health and Transition Services</b>	<b>55</b>
<b>Shands Children’s Hospital, University Of Florida</b>	<b>57</b>
<b>Sharing and promoting the project</b>	<b>60</b>
<b>Websites</b>	<b>60</b>

## Project information

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<b>Title</b>	Identifying best practice models of care for adolescent transition**
<b>Study area</b>	Chronic disease/ Quality and safety in healthcare
<b>Institution</b>	The Royal Children's Hospital, Melbourne
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<b>Date of report</b>	15 November, 2009

\*\* The initial title for this fellowship was 'Identifying best practice models of care for adolescent transition in a rheumatology setting'. Soon after receiving this fellowship, my role at The Royal Children's Hospital (RCH) changed to Transition Program Coordinator and hence the scope for this fellowship broadened to include an organisation-wide perspective for transition practice and research.

## Acknowledgements

Firstly I would like to acknowledge and thank both the Victorian Department of Health and the Victorian Quality Council for providing me with this extraordinary opportunity. Their generous funding of this travelling fellowship allowed me to meet and observe the practice of leading clinicians and researchers in my chosen field of practice. It was invaluable in collecting relevant information and providing professional networking opportunities. In particular, I would like to thank Paula Marsh, who managed the process from orientation to the delivery of this travel report with sound advice and good humour. I appreciate also, the support of my own organisation, The Royal Children's Hospital in supporting substantial study leave for the travel phase of this project.

I would also like to acknowledge the warmth and enthusiasm with which the sites I visited and the individual clinicians and researchers I interviewed, received me without exception. Despite having somewhat limited flexibility due to a tight itinerary, my interviewees accommodated me very generously, sharing their resources and expertise and even on occasion welcoming me into their homes. To those [and you know who you are] who coordinated a number of appointments for me at their sites, a special thank you. I sincerely hope that many of you will return the visit by coming to Melbourne, so I can repay your considerable hospitality.

I would also like to acknowledge the innovative transition practice that is occurring in my own backyard, particularly with the GMCT Transition Network in NSW and in Western Australia with the recent development of a Paediatric and Adolescent Chronic Disease Transition Framework. This fellowship was for international travel only, so in discussing my findings and referring to a global perspective, it is without as yet, the benefit of observing the transition work being done within Australia.

## **Project summary**

### **Background**

The concept of adolescent transition and its importance in improving long term health outcomes is relatively unfledged and poorly recognised in the health care arena, with a dearth of solid data to support expert opinion. Despite that, or perhaps because of it, clinicians working in developing transition programs and tools and carrying out research are in general well networked, well informed about current practice and research, and generous in collaborating and sharing their resources. They are also committed and passionate about the importance and value of their work and the need and opportunity for much more to be done.

A plethora of published articles discuss the need for changes in adolescent health care practice, clearly articulating the key issues for transitioning adolescents such as feeling under prepared, a lack of consultation, non-compliance and the ensuing 'drop out' rates between paediatric and adult health services. Clinicians themselves experience issues around letting go, a lack of collaboration and communication between paediatric and adult health care teams and a need for the principles of adolescent medicine and transition to be incorporated into education and training programs. I found that despite plenty of discussion about the need for change, both in the relevant literature and in discussing the topic with experts in the field locally and overseas, there is a lack of well researched and evaluated models of care as well as planning and resource allocation for transition practice.

In Victoria, we have just begun to explore the opportunities for a state-wide and coordinated approach, with transition on the agenda of the paediatric clinical networks. The set up in 2004-2005 through a Department of Health funded pilot of four adult complex disability clinics across Victoria, their evaluation and ongoing collaboration between the Department of Health and the clinic coordinators has reinforced the benefits of strategically planning and funding these services on at a state level.

The goals of this fellowship – to research, design, implement and comprehensively evaluate an evidence based, world-class transition program and assess, in collaboration with other chronic illness clinicians, its transferability – will have profound benefits and possibilities on an organisational and regional level.

### **Purpose of the project**

The RCH first commenced project work in adolescent transition in 2003. At the end of 2008, a permanent position was created for a transition coordinator to oversee transition planning and a transition program for the organisation.

Key goals achieved for 2009 have been the establishment of the Transition Advisory Council, a two-year strategic plan for the transition program, the drafting of a transition procedure to overarch all hospital specialties, and the commencement of a consultative process around redefining our age definitions for access, to embrace more developmentally appropriate age criteria. The recent report on The RCH Adolescent Model of Care demonstrated the crucial need to underpin our treatment and interactions with all young people in our care with the fundamentals of adolescent health care and transition. Research opportunities to evaluate past patient's engagement in adult health services and their and their parents' transition experiences are also being explored.

The purpose and opportunity of this project was to scope transition practice, research, tools, trends and future directions on a global level to inform the development of a transition model of care for the organisation. This model of care will be piloted in two specialties in 2010 with a quality improvement focus, with an array of evaluation tools and educational resources developed.

### **Top three outcomes of the travel phase**

- Confirmation of the strategic need to take a state-wide planning and resourcing approach, and on an organisational level to implement a hospital wide program approach to transition rather than fostering pockets of practice within an institution.
- An overview of a global perspective of current transition practice, tools, research and future directions.
- Establishing a network of the leading clinicians and researchers in the field of adolescent transition.

## Main activities undertaken

The travel phase consisted of two blocks of three weeks of travel. In May 2009 I visited six sites in four cities in Europe, meeting with nineteen clinicians and researchers. In August 2009, I visited eight sites, in five cities in Canada and the USA, meeting with thirty-three clinicians and researchers. Sites and clinicians visited were selected through a literature search and recommendations from peer acknowledged leading programs and clinicians in the transition field.

The following template was used in information gathering at the visited sites.

### **Fellowship Information Gathering Template**

#### **Policy/procedure**

- ❖ Does your dept have a transition policy/procedure?

#### **Model of care**

- ❖ What is your transition model of care?
- ❖ Where does transition sit in your organisational structure?
- ❖ What are the reporting lines for transition?
- ❖ How would you describe the state of transition in your division/department and on an organisational level?
- ❖ Who is responsible for facilitating transition in your department?
- ❖ What are the facilities for transition?
- ❖ What are your annual transition numbers?
- ❖ What is your definition of overage presentations?
- ❖ How are these monitored?
- ❖ How are the principles of adolescent health and self-management worked into your model of care?

#### **Evidence base**

- ❖ Is there any particular research that informs your practice?
- ❖ Is your department engaged in any transition research?

#### **Transfer pathways**

- ❖ What are the transfer pathways for your patient cohort?

#### **Gap analysis**

- ❖ What adult services gaps have been identified?
- ❖ What internal gaps in services, funding, and work force have been identified?

### **Enablers/barriers**

- ❖ What are the key barriers to effective transition in your division/department?
- ❖ What/who are the key enablers for effective transition in your division department?
- ❖ What is the level of executive support for transition?

### **Key challenges**

- ❖ What are the key challenges for you and your department in transition?

### **Responsibility/accountability**

- ❖ Do you have any transition key performance indicators for your department/division?
- ❖ What staff position funding does your department have dedicated to transition?
- ❖ Who are the champions for transition in your department?
- ❖ Is transition written into your institutions and department's business plan?
- ❖ Is transition included in staff's position descriptions?

### **Tools**

- ❖ What transition or transfer tools do you use such as, checklists, handouts?

### **Evaluation/stakeholder feedback**

- ❖ What transition evaluation is undertaken?
- ❖ What are the evaluation/reporting tools used?
- ❖ What opportunities are there for stakeholder feedback?
- ❖ What is done with customer feedback?

### **Strategic planning**

- ❖ What key strategies, implementations do you believe would enhance transition practice in your area?
- ❖ What are your immediate and long term goals for transition in your division/department?

## **Synopsis**

In summarising the learning's of this travelling fellowship, it is firstly important to acknowledge that there are a number of passionate, determined and highly skilled transition practitioners globally. It is these practitioners who are taking the lead in advocating for and driving the development of innovative small programs and models of care for

transition. This includes the development of a number of tools and resources that are being implemented and, in a small number of cases, evaluated within health care services.

However, what is critically missing within all services visited is the strategic planning and policy construct on both an organisational and state-wide or national level. The intrinsic frustrations and barriers experienced by the vast majority of clinicians interviewed was fundamentally due to a lack of investment in both service planning and resourcing by governing health departments, organisational executive and clinical leadership. Without this concrete commitment to, and valuing of transition practice as an intrinsic element of quality care for adolescents, most transition clinicians and programs worldwide will continue to struggle or indeed fail to implement effective transition processes beyond small pockets of innovative practice.

The following specific recommendations are informed by the travelling phase of this fellowship:

## **Lessons for the Victorian healthcare system**

### **Policy:**

- the Department of Health, at both a national and state level, to prioritise transition service planning on their agenda and commit resources to support expert recommendations and state-wide programming
- transition planning in a state-wide context to be identified as a distinct working group for the paediatric clinical network group.

### **Change management:**

- recognition that transition planning and resourcing needs to apply across the paediatric and adult services continuum
- transition to be part of health services accreditation processes
- paediatric and adult health care services striving to be 'youth friendly health services' as defined by the World Health Organisation.

### **Workforce redesign:**

- the development and implementation of a comprehensive adolescent health education package for all clinicians working with adolescents, for example, E-Learning Adolescent Health in the United Kingdom and 'No Man's Land' in Sweden
- evaluation of funding models for outpatient services to allow longer consultations for adolescent clinics.

### **Engagement/collaborations:**

- health service and Department of Health collaboration in service planning for adolescents and transition both across the state of Victoria and at RCH
- identify and strengthen key pathways and relationships between the paediatric and adult setting and within primary care and the community
- develop innovative programs and services for adolescents both within the community and in tertiary health services, for example, Streetlight – Shands, Florida, Youth Facilitators and The Independence Program – Bloorview
- internal and external collaborations to identify, support and conduct crucial and timely research to validate current data, anecdotal evidence and expert opinion and provide a foundation for future service planning and resource development
- develop a state and national network for transition practitioners and researchers to share expertise and encourage collaborative endeavours.

## **Lessons for The Royal Children's Hospital, Melbourne**

### **Policy:**

- support the continued development of an organisational framework and procedure for transition
- support a consultative process to assess the developmental appropriateness of our age criteria and other policies that support the management of adolescents at The RCH

- accountability and reporting measures to be written into policy/procedure for the organisation

**Change management:**

- a cultural change is required from the top down regarding the care and value we provide to adolescents in general, and transition practice in particular
- recognition that transition practice is a quality and essential service matter for our organisation and not a desirable extra, for example, Alberta Health Services Accreditation Review
- embedding adolescent health care and transition principles into the practice of all clinicians working with young people and ensuring their knowledge and skill level is adequate for excellent service delivery. For example, the RCH Adolescent Model of Care Recommendations
- a commitment to being a 'youth friendly health service'
- the move to the new hospital in 2011 being an opportunity to be proactive in developing transition and adolescent health resources and facilities.

**Workforce redesign:**

- a specific transition budget, including a small team approach to transition, to enhance planning, strategy, resources and the implementation and evaluation of an organisational approach for transition
- sustainability; building transition practice and accountability into all clinician position descriptions and departmental business plans, so it is greater than one person.

**Engagement/collaborations:**

- the RCH Executive and clinical leadership in crafting policy and future directions
- the RCH Transition Advisory Council – the only one of its type globally and crucial in providing leadership and expertise on transition matters
- the Centre for Adolescent Health in leading the process of implementing the recommendations of the RCH Adolescent Model of Care Report, including in regards to transition.

## Outline of the study itinerary

May 2009

### London, United Kingdom

#### University College London Hospital [UCLH]

Dr Debajit Sen, Consultant Rheumatologist
Christine Rawcliffe, Clinical Nurse Specialist, Adolescent Rheumatology
Dr Russell Viner, Consultant of Adolescent Medicine
Karen Walker, Adolescent Unit, Ward Sister
Dr Simon Lewis, Consultant Psychiatrist
Michelle Schofield, Respiratory Clinical Nurse Specialist
Kim Robinson, Urology Clinical Nurse Specialist
Vicky Riley, Cancer Unit Clinical Nurse Consultant

#### Great Ormond Street Hospital [GOSH]

Nigel Mills, Adolescent Nurse Specialist
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#### Evelina Children's Hospital

Cathy Gill, Senior Play Specialist, Paediatric Renal Unit
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### Birmingham, United Kingdom

#### Birmingham Children's Hospital [BCH], 'The Dream Team' Transition Program

Dr Janet McDonagh, Rheumatology Consultant
Amanda Daniels, Cardiology Nurse Specialist
Graham Gordon, Liver Nurse Specialist
Moirra Bradwell, Oncology Nurse Specialist
Dr Lizzie Rankin, Chair, Young Adult Strategy at UHB
Dr Clive Ryder, Clinical Lead Rheumatology
Charlotte Frith, Youth Worker
Maree McGee, Transition Nurse, Rheumatology

### Glasgow, Scotland

'Hospital Services for Young People' Conference – National Health Service [NHS] Scotland
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## Sweden

Associate Professor Kristina Berg-Kelly – ‘No Man’s Land - The young person with insulin dependent diabetes leaving paediatric care, entering adult facilities’
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August 2009

## Vancouver, Canada

### British Columbia Children’s Hospital

Dr Curran Warf, Director of the Division of Adolescent Health
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Dr Lynn Streetman, Paediatric Cardiologist
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Anna Graville, Cystic Fibrosis Clinic [via email]
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## Calgary, Canada

### Alberta Health Services – ‘Well on your way – youth in transition program’

Catherine Dunseith, Adolescent Transition Coordinator
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Dr Jorge Pinzon, Adolescent Consultant
--

Lindsay Bristow, Neurosciences Department
---

Sandy Baggot, Art Therapy
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Patty Knox, Paediatric Cardiology Nurse
---

Yvonne Balon, Adult Congenital Heart Program
--

Maureen McNaul, Manager of New Programs
---

## Minneapolis, United States of America

### University of Minnesota, Division of General Paediatrics & Adolescent Health Medicine

Dr Peter Scal, Associate Professor, Division of General Paediatrics & Adolescent Health Medicine
--

Dr Abraham Jacob, Director of the Paediatric Hospitalist Program
--

Dr Chris Boys, PhD, Paediatric Neuro psychologist
---

Betty Bishop, Nurse Coordinator, Rheumatology
---

## **Gillette Lifetime Specialty Healthcare**

Ronna Linroth, Manager, Adult Outpatient Services
Beck Nelson, Social Worker
Suzanne Constantini, Manager, Outpatient Clinic Services
Dr Robert Wagner, Program Medical Director

## **Toronto, Canada**

### **Bloorview LIFEsan Program**

Shauna Kingsnorth, Evaluation of LIFEsan Project
Dolly Menna-Dack, Youth Advisory Council, Youth Facilitator
Cross appointed staff; Andrea, Christine, Dolly
Bronwen, Occupational Therapist
Carie Gall, Occupational Therapist
Joanne Maxwell, Coordinator LIFEsan Project
Dawn Lunan, DOOR 2 Adulthood Website [phone]

### **The Hospital for Sick Children [SickKids]**

Geraldine Cullen-Dean, Clinical Nurse Specialist, Good 2 Go Transition Program
Dr Miriam Kauffman, Consultant of Adolescent Health
Elizabeth Dettmer, Psychologist, Program Lead [via email]
Tricia Williams, Clinical Psychologist, Stroke Unit

## **Florida, United States of America**

### **JaxHATS Health and Transition Service**

Dr David Wood, Director of JaxHATS
Ramonia Diallo, CMS Care Coordinator

### **University Of Florida, Gainesville**

Dr John Reiss, Associate Professor of Paediatrics
Rebecca Brown, Director of Streetlight

## Study site details

May 2009

### London, United Kingdom

#### University College London Hospital [UCLH]

##### 1. Russell Viner – Consultant, Department of Adolescent Medicine

###### Overview:

Russell Viner is an academic paediatrician and adolescent physician at the UCL Institute of Child Health in London. He set up the first adolescent medicine service in the United Kingdom (UK) jointly with Great Ormond Street Hospital (GOSH) Children and University College London Hospitals. He is a consultant on adolescent health for the Department of Health and of Education in the UK, and for the WHO internationally. He has over 100 published papers in international journals and is recognised as one of the leaders in transition and adolescent health literature.

###### Model of care:

In the UK there have been significant improvements in adolescent health with a lot of planning and resource development at a national level. Through the work of the Department of Health Transition Program, guidance documents and DVDs have been produced with the focus on how to get good transition practice into the community.

The UCLH adolescent model is that at the age of 12 years, the young person transfers from the paediatric setting to a UCLH specialty. Certain specialties at GOSH keep patients until the age of 18/19 years. Others, such as rheumatology, keep their patients in the paediatric setting until 14 years of age which is possibly too late to transfer to the adolescent setting. In the above model the rheumatologist sees the patient in both the paediatric and the adult setting.

Oncology at UCLH has half adult and half paediatric oncologists. The Young Adult Cancer Unit sees patients until they are 25 years of age.

Diabetes at UCLH has a formal transition track commenced in 2008. It involves:

- annual review
- competency framework
- self management focus
- skill set monitored
- meeting arranged with new adult team.

Four appointments are held with the adolescent physician and adolescent CNS per year. Currently seven young people are involved in the program.

###### Overview:

- Appointment 1 - meeting with the adolescent physician, clinical nurse specialist [CNS] and young person with a joint presentation of medical history and a discussion of the adult service
- Appointment 2 - meeting as above with joint management suggestions discussed
- Appointment 3 - visit to young adult clinic as a group [four visits conducted annually]
- Appointment 4 - final visit to the adolescent physician.

###### Transfer pathways:

GOSH have a struggle with the mapping of transition due to 'super specialism'. They have tried joint young adult clinics in the past with the adult consultant and young people 18-25 years. The main issues with these clinics that need to be considered are:

- reliance on a good working relationship between consultants
- double resources with both teams meaning expensive medicine that needs funding
- who is in charge?

**Gap analysis:**

GOSH see their core business as paediatric and hence will not have an adolescent unit.

**Enablers/barriers:**

GOSH has demonstrated support for transition for some years.

**Key challenges:**

18 years of age is a watershed for child protection issues. A young person under 18 years cannot be nursed in the same unit as an over 19 year old.

**Responsibility/accountability:**

There have been discussions about putting transition accountability into business plans.

There have been primary practitioners signing up to be 'champions of transition' but it is difficult to maintain practice.

## 2. Adolescent Rheumatology Team

**Interviews:**

Dr Debajit Sen, Consultant Rheumatologist  
Christine Rawcliffe, Clinical Nurse Specialist

**Overview:**

The department uses an adolescent team model. The team works across both the paediatric and adult setting [UCLH and GOSH]. This involves working across two Hospital Trusts.

**Policy/procedure:**

A transition policy is in draft form from GOSH. This is a generic document that a number of units are piloting.

**Model of care:**

Annually the clinic receives about ten transfers from GOSH and transfers about five to UCLH.

The Royal College of Nursing [RCN] Adolescent Transition Care – Guidance for Nursing Staff 2004, is the foundation document for the programs care and practice. Young people transfer into the program at the age of 13/14 years.

Transition is ideally mentioned from their first appointment. The GOSH access policy is that new patients <16 years and existing patients < 18 years are eligible for treatment.

At 17 years, transition is discussed including where the patient will transfer. In their final year in the service they are seen in a young adult rheumatology clinic. One adolescent clinic is held per week involving:

- two consultants
- two registrars
- nurse coordinator [large component of the role is psychological and social work]
- occupational therapist
- physiotherapist
- social worker
- psychologist by referral [mainly for chronic pain/rehab].

A team meeting is held prior to each clinic. Young people are seen until 19 years and then transferred to the adult service. All contact with patients is underpinned by transition and the focus is on the long term not a quick fix. The nurse coordinator also runs a weekly clinic to cover education, psychological issues, and medication management, usually four patients attend per clinic.

**Evidence base:**

The program is predominantly informed by the research of Russell Viner [UCLH] and Janet McDonagh [Birmingham].

**Transfer pathways:**

The transfer options include UCLH or a local service. Most adult hospitals have an adult rheumatologist.

**Gap analysis:**

Due to limited availability of a psychologist and social worker, psychosocial issues take up a lot of the nurse coordinators role.

**Enablers/barriers:**

Logistics is the main barrier. The late transfer on occasions from GOSH can result in limited time to engage the young person. Additionally, the lack of clerical support is a barrier

The NHS supports the transition program and funds the nurse coordinator role.

**Responsibility/accountability**

Currently there are no key performance indicators for transition and it is not specified in the organisational business plan.

**Tools:**

The following tools are used as part of the program:

- transition documentation
- pathway documents
- Royal College of Nursing Transition Checklist Adolescent Transition Care – Guidance for Nursing Staff, 2004
- questionnaire/checklists for the young person and parents are done pre transfer at GOSH at the age of about 11/12 years. They are repeated when they transfer to the adolescent team.

**Evaluation/stakeholder feedback:**

In 2006 approximately 30 patients participated in a questionnaire evaluation. The team are planning to develop questionnaires to further evaluate care.

**Strategic planning:**

The adolescent CNS is working to build relationships with the CNS in the adult sector. Planning is also focused on achieving across the board transition policy sign off from the adolescent team and wards at UCLH and GOSH.

### 3. Adolescent Unit, UCLH

**Interviews:**

Karen Walker, Ward Sister

**Overview:**

The adolescent unit at UCLH opened 11 years ago. It has 16 inpatient beds and five day care beds. The population includes most surgical and medical specialties except cystic fibrosis, renal dialysis, cardiac, neurosurgery and oncology.

**Policy/procedure:**

The access policy defines the age range from 13 to 19 years and is fairly strict. 60 per cent of the unit's nursing staff has paediatric qualifications and 40 per cent have adult qualifications. An adult trained nurse must staff all 16-19 year olds. The ward sister who follows up with clinicians does gate keeping at weekly meetings. The Royal College of Nursing [RCN] transition guidelines are followed but there is no specific written transition policy for the unit.

**Model of care:**

The nursing staff discusses transition with the patients. A meeting is arranged with the adult team to arrange an orientation to the new unit. Annual transfer numbers for inpatients are approximately 20 per year.

Key aspects of the transition model of care:

- ensuring good knowledge, including information about adult services

- change management
- independence and empowerment as part of the adolescent ethos
- not losing confidence
- young persons group run by a psychologist
- orientation of all new staff around the adolescent process
- two adolescent modules available as part of the degree pathway
- senior nurse initiated discussions with young person and family
- not a documented model of care but solid knowledge base
- multi disciplinary team staffing including social worker and activity coordinator.

**Evidence base:**

The programs evidence base is mainly research by Russell Viner [UCLH]. New staff are given details of the relevant literature.

**Transfer pathways:**

The simplest pathways are gastroenterology, rheumatology and diabetes that all transfer within UCLH so the transfer works well.

**Gap analysis:**

Gaps in service include endocrine testing, which cannot be done in the adult setting, and the day treatment is also not adequate in the adult setting for the endocrine group. In addition, with chronic pain and chronic fatigue patients, it is a struggle to find adult services to refer to.

**Enablers/barriers:**

The main barriers are due to service gaps, and more work is required in ensuring the young persons engagement with the adult health teams.

The main enablers are the ward sisters and senior staff. Strong relationships exist between the consultants and the CNS. Another enabler is having the same consultants working across both the adolescent and adult units. There is very good recognition from the executive, with the CEO supportive of the adolescent service.

**Key challenges:**

A key challenge is the 18-week government targets from the time of referral. There is a current evaluation of the whole regions services being conducted, with a redesign focus to centralise and streamline services. The service has yet to see what, if any, impact this will have on the adolescent unit/service.

**Responsibility/accountability:**

No key performance indicators are set within the unit for transition. The whole team are champions for transition. The adolescent CNS has a major role in transition practice but not sure if it is in her position description.

**Tools:**

Key tools for transition practice include:

- e-learning for health [new on-line education tool from the Department of Health], which is well used
- Royal College of Nursing checklist
- the program had a transition form in the medical notes about one year ago but it needs reintroducing.

**Evaluation/stakeholder feedback:**

No evaluation or audit has been conducted as yet. There has been some feedback from the inpatient group during the transition process and informal feedback post transfer. Action has been taken on all tangible recommendations.

**Strategic planning:**

Further planning is in place for education, awareness and skills of staff on the unit, including teaching from experienced staff. Work needs to be done on dispelling myths about the adult services.

The team are considering building transition into staff performance objectives and appraisals. Plans are to improve on the current service and formalise and map it.

#### **4. Adolescent Psychiatric Unit [Simmons House]**

##### **Interviews:**

Dr Simon Lewis, Consultant Child & Adolescent Psychiatrist

##### **Overview:**

Simmons House Adolescent Unit is an in-patient and day-patient psychiatric unit for young people between 13 and 18 years of age. The unit has places for a maximum of 12 young people. Young people who attend as day-patients receive the same range of treatments and education as those attending as residents. The average length of admissions is between six and nine months, but can be up to a year. The length of stay at Simmons House depends on the young persons needs.

##### **Policy/procedure:**

The unit has policies and procedures but they don't always work so well. No specific transition policy is in place.

##### **Model of care:**

Adolescents and their families/carers receive an individually planned and structured treatment package combining as appropriate: psychiatric assessment and medication, family therapy [which is often video taped], individual therapy, occupational therapy, group work and education. The inpatient multi disciplinary team have the time and space to orientate young people to the adult setting. There is also Connexions Workers UK who can individualise transfer arrangements.

##### **Transfer pathways:**

There is a government intervention service for 15-35 years for the treatment of psychosis. Inpatient units serve a number of regions within London and occasionally the UK. Social service groups provide young adult units covering approximately 30 Burroughs. Contact is made with the local service six months before the young person's 18<sup>th</sup> Birthday but the service will only receive transfer information just prior to transfer.

##### **Gap analysis:**

Adult services won't take on developing personality disorders. Also cases of abuse and risk behaviours are not well recognised in regard to transition.

##### **Enablers/barriers:**

A significant barrier is the lack of recognition of the importance of good transition; however, the NHS Islington supports the philosophy of transition.

##### **Key challenges:**

Key challenges include:

- the differences between child/adolescent mental health and adult mental health
- resource Issues
- definition of mental illness.

##### **Responsibility/accountability:**

Case managers drive the process of transition. All inpatients have case managers.

##### **Tools:**

No checklists or tools have been developed for transition as yet.

##### **Evaluation/stakeholder feedback:**

Simon is not aware of any evaluation post transfer.

## 5. Respiratory Unit, UCLH

### Interview:

Michelle Schofield, Respiratory Clinical Nurse Specialist [CNS]

### Policy/procedure:

Michelle is not aware of any generic hospital transition policy and there is no respiratory unit policy for transition.

### Model of care:

Two transition clinics are run, a six monthly adolescent clinic and a six monthly transition clinic:

- The Transition Clinic – the population age group is 13 to 18 year olds. The adolescent/ paediatric consultant and the CNS see the young person. Paediatrics sometimes keep the patients who have psychosocial issues for longer in the hope that they won't require an adult physician. A pre transfer appointment is held, with the CNS from the adult setting attending. At the first adult appointment, the paediatric CNS also attends. The unit's model of care is changing with more focus on 'getting into adolescent heads'.
- The Adolescent Clinic – at the first appointment the young person is seen with their parents, then after that they are seen on their own with their parents joining at the end of the appointment. The focus is on self-management. Information about the clinic is sent to both the young person and parent. A discussion is held before the clinic about where the transition process is at for each attendee.

### Clinic objectives:

- the opportunity to speak on their own [test their knowledge, revisit 'assumed' knowledge]
- decide whether to transfer to adult service or primary care
- gain a greater understanding of their illness
- the main goal is to evaluate and sustain the transition clinic.

### Evidence base:

The main influence for the program is the RCN transition model.

### Transfer pathways:

Cystic fibrosis patients at GOSH go to one of two adult hospitals in London.

### Gap analysis:

Adult services won't see patients unless they are physically quite unwell. There are issues with provision of psychosocial care.

### Enablers/barriers:

Having adult clinics within the same building as the adolescent unit for the last three years has enabled strong links. Michelle is not sure about the level of executive support for transition.

### Key challenges:

Most challenging issues are related to behavioural/non compliance issues.

### Responsibility/accountability:

Nothing is written into the CNS job description about transition, but they have a key role in monitoring and driving the process.

### Tools:

The main tool used is a proforma checklist for self-management.

### Evaluation/stakeholder feedback:

There is no transition research being conducted in the unit at present. The NHS will be conducting a 'rapid improvement scheme' looking at the wheezy child from home to discharge planning. This will include an evaluation of the transition process including the three transition clinic appointments.

**Strategic planning:**

Planning is underway for an adolescent clinic in outpatients. There are also plans to design an audit tool for the clinics.

**Documents obtained:**

- key questions/trigger questions for health professionals assessing and managing adolescent patients with chronic illnesses
- the purpose of the adolescent clinic for young people
- summary of the adolescent asthma clinic
- adolescent asthma clinic clinical summary.

**6. Urology Unit, UCLH****Interviews:**

Kim Robinson, Urology, Clinical Nurse Specialist [CNS]

**Overview:**

The population of the urology unit is 13-19 year olds. Bed blocks occur due to the highly specialised inpatient group such as post liver transplant. This unit services the UK for the urology specialty.

**Model of care:**

The urology transition clinic commenced in December 2008 and is held monthly with the consultant neurologist and the CNS. A GOSH clinician is involved as well. Complex cases generally have a psychological component. Attendance at the transition clinic can be anytime from their 13<sup>th</sup> birthday but a large proportion slip through without a transition process.

**Key challenges:**

The transfer from the paediatric setting can often be too late, such as, at 20 years of age or later. Currently there is no formal preparation prior to the first appointment at UCLH. The urology CNS has an honorary appointment at GOSH so she can arrange to meet them prior to transfer.

**Tools:**

The adult team have a 'welcome package' but the team are not sure if it is given out in the outpatient or inpatient setting.

**7. Teenage Cancer Unit – UCLH****Interviews:**

Vicky Riley, Clinical Nurse Consultant [CNC] Oncology

**Overview:**

The Teenage Cancer Unit holds the philosophy of empowerment of the patient. The unit's current population is 13-20 year olds.

**Model of care:**

Adolescents undergo two transfer events, from GOSH to UCLH Adolescent Unit, then a transfer to the Adult Unit. It is similar to the school model. Meetings are held between senior nursing staff at GOSH and the Cancer Unit at UCLH. The transfer ideally occurs at a point of stability not crisis. Transfer is ultimately not a choice but can involve empowerment of the young person.

**Evidence base:**

The main document that informs the unit's practice is Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer – NHS 2002

**Transfer pathways:**

The main transfer pathway is from GOSH. It doesn't work as a natural pathway as the two units don't speak the same language.

**Enablers/barriers:**

A barrier that has been identified is late transfer to the unit at 16 years. This can mean that they are late in their development of health care. An important enabler is having key people at each end with the focus on empowering the young person and with the paediatric team knowing when to step back.

**Responsibility/accountability:**

'Specialist care brings specialist responsibility'.

**Evaluation/stakeholder feedback:**

No evaluation of the unit's model of care has been done yet. The unit is currently looking for the best model to formally evaluate the service. Services do get peer reviewed and there is a formal accreditation process.

**Strategic planning:**

The unit may expand the population group in line with some other units to 16-24 year olds but this will depend on the facilities. There are plans to pilot a formal transition program with young people's input in design and a formal evaluation as part of the program. There is also a current proposal to have a transition meeting. The unit may introduce peer mentoring and support networks to promote the benefits and concepts of adolescent units.

## Great Ormond Street Hospital [GOSH]

**Interviews:**

Nigel Mills, Adolescent Clinical Nurse Specialist

**Overview:**

Great Ormond Street Hospital has 350 inpatient beds, of which up to 50 are occupied by adolescents. GOSH wards are defined by specialty not by the age of patients. Its reputation is as a paediatric facility rather than a child and adolescent facility. There are very limited adolescent facilities despite a growing population. There is no dedicated adolescent unit.

**Policy/procedure:**

There is an overall transition policy for GOSH, but individual specialties are responsible for transition. A generic transition integrated care pathway is being piloted across several specialties [renal, cardiology, HIV]. The pilot commenced in December 2008.

The GOSH age policy is 0-18 years with the reality being that significantly over-age patients are treated at times.

**Model of care:**

Individual specialties are responsible for transition. There are some pockets of good work but the general picture of transition is far behind where they would like it to be. Some specialties arrange regular joint clinics with the adult service prior to transfer [renal transplant, cardiac, urology]. Where numbers are low, transition is organised on an individual basis.

**Evidence base:**

The main research base for transition practice at GOSH is that done by Russell Viner [previous Consultant in Adolescent Health at GOSH]. The Department of Health has also published guidance documents.

**Transfer pathways:**

The transfer pathway varies according to specialties; cystic fibrosis and renal have clear pathways.

**Gap analysis:**

The main gap identified is in the lack of overall transition strategy and the lack of staff training in adolescent health and transition matters. A significant issue exists around a lack of adolescent identify demonstrated by a lack of signage for adolescent services in the new hospital.

**Enablers/barriers:**

A key enabler is the adolescent CNS role in advocating and promoting adolescent issues through out the trust. A significant barrier is the reliance on individual specialties having a clinician with an interest in transition to help drive the process. The specialties have also developed their own transition policies in isolation, which has implications for organisational policy and procedure. A further barrier is that GOSH is very 'medicalised' with super specialties and in some cases very small numbers of chronic illness cohorts.

**Key challenges:**

A major challenge is a lack of recognition of adolescent medicine ethos and principles by some key clinicians. There is a need to encourage specialties to organise their clinics jointly with adult services and to arrange clinics into age – groups to assist the adolescent CNS to provide services to these clinics. There is reluctance by the specialties to sign up to a generic trust-wide tool as they feel their patient groups have particular issues.

**Responsibility/accountability:**

There is still a reliance on individuals to drive the process. The adolescent CNS is the hospital lead for transition. Transition is written into this position description. Transition is also written into the adolescent department business plan.

**Tools:**

- a six-month pilot of an integrated care pathway is being conducted across the trust. This pilot will assess the paperwork only, with evaluation of the benefit on quality of transition to be evaluated at a later date
- web-based information and tools on the GOSH website
- cystic fibrosis has taken the lead in developing educational material for young people and their families
- nursing assessment checklist used in the outpatients department has a tick box to identify whether transition has been discussed from the age of 12 years.

**Evaluation/stakeholder feedback:**

Previous mapping has been done of Trust-wide transition practice. No current evaluation or feedback is being conducted.

**Strategic planning:**

Key strategies that would enhance transition practice are:

- all-embracing Trust-wide policy instead of individual policy
- development of a Trust-wide transition tool
- staff training
- hard copies of transition documents [currently all web based]
- development of a Trust-wide patient held record.

Current strategies being worked on are:

- transition integrated care pathway
- development of more accessible transition information
- development of a transition checklist/passport
- expert patient program with young people trained as facilitators.

**Documentation collected:**

- draft copy of 'Transition to Adult Health Services Integrated Care Pathway'
- transition policy for young people at Great Ormond Street Hospital [specialty]

- information sheets for child and family 'Transition: getting ready to move on to adult health services'
- transition checklist
- 'transition from paediatric to adult cystic fibrosis services' – information for families

## **Evelina Children's Hospital [Guys & St Thomas' NHS Foundation Trust]**

### **Interviews:**

Cathy Gill, Senior Play Specialist, Renal Unit

### **Overview:**

The Evelina Children's Hospital at Guy's and St Thomas' moved to a new purpose built hospital at St Thomas' in 2005. Everything from the menus and furnishings to the design of the building itself is chosen and designed by children. It is London's first new children's hospital for more than 100 years.

The Evelina Children's Hospital includes\*:

- 140 inpatient beds, including 20 intensive care beds
- three operating theatres
- full children's imaging service - includes MRI scanner, general x-ray and ultrasound
- kidney dialysis unit
- outpatients department
- medical day care unit
- hospital school

\* taken from the hospital's website

25-30 per cent of the hospital population are adolescents. The general environment is paediatric focused. There is a 'chill out' area with table tennis, computer games etc.

Patients are not admitted after 18 years of age.

### **Policy/procedure:**

A transition policy for the Trust is currently being drafted, as is a patient charter. The National Service Framework [NSF] also has recommendations that include transition.

There are two organisational-wide committees that are developing policy/recommendations for transition – the Adolescent Committee and the Transition Committee. Both committees include staff and input from the young people's focus group.

### **Model of care:**

Teenage activities evenings are held fortnightly for inpatients.

Most chronic specialties wait until the young person is 16/17 years to transfer to adult services. The renal department has the most advanced transition process. The model differs depending on the adult service destination:

#### Guys & St Thomas Hospital:

The Young Adult Clinic is run for patients 16-22 years. The adult and paediatric consultant and surgeon attend. Lunch is provided and the young person rotates between group sessions, the consultant appointment and any clinical testing required. At 16-18 years, they see the paediatric team but in the adult setting. From 18 years on they see the adult team following two or three joint team appointments.

#### Oxford Hospital:

From 14-16 years the adult consultant attends at Evelina Children's Hospital but takes a back seat. At 16-18 years the adult consultant takes the lead and a transfer to the Young Adult Clinic at Oxford is arranged. The clinics encourage autonomy, self-management, ownership.

Parents are not included in the young adult clinics but can join at the end of the joint clinic appointments. Wine and cheese evenings are held for parents to help explain the transition process and answer questions. If a patient transfers to a regional service a CNS goes for the first few appointments. The cardiac department has held a 'transition day' for patients and families. An annual adolescent day is held with topics including adolescent issues, medications, non-compliance.

#### **Transfer pathways:**

There are two main documented pathways as outlined above.

#### **Tools:**

The main tools used are checklists and information leaflets.

#### **Strategic planning:**

Group sessions are planned for young people with sponsorship. An education day was held by the charity GIFT in 2009 for representatives of transplant centres to discuss a national approach for transition. Further discussion is to take place.

#### **Documentation collected:**

- Evelina/Oxford Transition Pathway
- Evelina/Guy's & St Thomas Transition Pathway

## **Glasgow, Scotland**

### **Hospital Services for Young People Conference**

This was a one-day conference with the key presentations being:

- 'Essentially Different – The Nature of Adolescence', Dr. Russell Viner, Consultant in Adolescent Medicine, UCLH
- 'What does good hospital care look like – key criteria for inpatient services', Dr Janet McDonagh, Consultant Rheumatologist, Birmingham
- 'Motivating or Manipulating – How to make young people want to change', Dr Deborah Christie, Consultant Clinical Psychologist, UCLH
- 'Specialist care in an adolescent unit or age appropriate care in a specialist unit', panel consisting of a consultant in respiratory medicine, consultant surgeon and a representative from a youth panel
- 'Creating an age appropriate environment', Richard Mazuch, Healthcare Architect
- 'Moving On – The Importance of Good Transition', Dr Brian Kennon, Consultant in Diabetes, Glasgow
- 'Personal reflections – the future for adolescent hospital care', Dr Russell Viner, Consultant in Adolescent Medicine, UCLH

#### **Parallel sessions included:**

- lessons from experience
- sustaining education
- respecting autonomy
- support and protection.

## Sweden

### Associate Professor Kristina Berg-Kelly

#### 'No Man's Land' The young person with insulin dependent diabetes leaving paediatric care, entering adult facilities'

##### Program overview:

This innovative program was developed by Associate Professor Kristina Berg-Kelly who, prior to her retirement, was the Medical Director of the Internal Medicine Department at the Queen Silvia Child and Adolescent Hospital in Sweden.

The program started in 2006, and was developed as a means of educating health care professionals across Sweden about adolescent health care and transition. It has had great buy in from both the paediatric and adult sectors. The program is run over two days and uses a combination of teaching modules, case studies, role-play scenarios, and interactive sessions. Although the program is based on young people with diabetes, there are generic learning's for any clinician working with young people with any type of chronic illness.

At the end of 2007, IPULS [the official Swedish Institute for postgraduate education] passed it as accredited, giving it a quality marker. Since 2006, there have been ten Step 1 programs each with about 20 attendees and five Step 2 programs with a similar number of attendees. The Swedish Medical Association has recently asked Kristina to hold a seminar on transition at the National Assembly.

It is not clear how to evaluate this program, as it is much more about changing attitudes and developing skills. The outcome is a gradual process, with the view 'What is it like ten years from after the program started?' It does appear that people who participate in the program seem to really change their attitude towards transition and engage with young people in a gradual education process from 12-23 years of age.

##### Program content:

Key objectives for the program include educating the participants about tools and methods that facilitate communication with young people and the fundamental concepts of adolescent health.

The program uses three case studies to facilitate discussions and a more in-depth exploration of issues for the adolescent. The same case studies are discussed at 12, 15 and 18 years of age with pertinent issues for each age group.

##### Day 1:

Reflection session that includes questions such as:

- Is this patient ready for transfer?
- How would the paediatric service handle the situation?
- How would the adult service handle the situation?

Discussed themes include: family dynamics, psychology and trust.

Core topics are:

- definitions of adolescence
- historical context
- psychosocial data
- goals: knowledge, skills, attitude, psychosocial
- specific difficulties: early, middle and late adolescence
- parenting styles, caretaker role
- clinician tools: knowledge, engagement with young people tools
- Youth Friendly Health Service [YFHS] definition
- history taking: VAS, HEADSS, 24 hour recall.

In depth discussions on topics such as 'Why do young people not ask for help?' explore adolescent specific psychosocial issues. The advantages and disadvantages for change in health care behaviours are discussed. Working

with the young person and their families in developing health care plans are role-played. Key factors for success are also explored and options when the process is not working are discussed.

### Day 2:

Discussions are based on key questions including:

- When should a young person transfer?
- When is a young person ready for adult care?
- How should a referral be done?
- What are the steps for transition?

## **Birmingham, United Kingdom**

### **Birmingham Children's Hospital [BCH]**

BCH is a stand-alone children's hospital.

#### **1. Rheumatology Department**

The rheumatology team consists of:

- consultants: one professor, one senior lecturer, 1.6 NHS consultants
- up to two trainees, one foundation doctor
- two full time CNSs
- 2.5 physiotherapists
- one occupational therapist
- adolescent transitional care co-ordinator 0.6 [charitable funding]
- two secretaries.

#### **2. Dr Janet McDonagh – Consultant Rheumatologist**

Janet is a senior lecturer in Paediatric and Adolescent Rheumatology at the University of Birmingham and Birmingham Children's Hospital NHS Foundation Trust. She is one of the most prolific researchers and published authors in the field of adolescent transition.

#### **Policy/procedure:**

BCH has a generic hospital policy for transition that was due for revision in 2005 and has yet to be revised. The rheumatology department has a transition policy that requires reviewing.

There is currently no adolescent strategy for the hospital, no adolescent senior lead [although a one year post, two days/week is to be appointed soon] and no committee with specific responsibility for adolescent care. There are also no dedicated adolescent facilities in the hospital, either for inpatients or outpatients. The reporting lines for transition are not clear but all patients over 16 years of age must have a written transition plan to continue treatment in the hospital.

#### **Model of care:**

The rheumatology model for transition is a developmental one with individualised transition planning starting at 11 years of age followed by mid and late adolescence transition plans. The hospital transfer policy is transfer by the age of 16 years but rheumatology is more flexible with transfer usually happening at 16-18 years. It does become increasingly difficult to admit patients after 17 years of age due to hospital policy. An overage form must be completed for over 16 year olds who are inpatients. Outpatients are less well monitored. There are two Young Adult Clinics for 16-18 year olds in neighbouring adult hospitals, attended by a consultant and a nurse. Funding for a part time transition coordinator in the rheumatology department [three days a week, initially for two years] was obtained from a charity recently.

Other initiatives include:

- a residential summer camp planned by the young people including the use of public transport, meal preparation, and other activities [Hackett et al, 2005]
- 'Get a Grip Group' led by an occupational therapist
- transition to secondary school – occupational therapist led
- wellbeing days
- pamper days with local college hair and beauty staff – for body image and career information
- The Dream Team website

There are approximately 200 adolescents being seen in the adolescent clinic, with 30-40 of these transferred to adult services per year. The principles of adolescent health and self-management are worked into the transition planning structure and the promotion of routine use of screening tools such as HEADSS. Use of these tools varies between team members. Currently disease education and self-management happen at an individual level but Janet would like this to be more formalised. Potential resources that could be used include the Staying Positive Programme.

### **Evidence base:**

Janet has published prolifically on the subject of transition and adolescent health. Key research studies include:

1. Development of an evidence based transitional care program:
  - an audit of rheumatology services for adolescents and young adults in the UK
  - developing a program of transitional care: a postal survey
  - a study of unmet adolescent health training needs for rheumatology health professionals
  - a Delphi study of transitional care for adolescents with juvenile idiopathic arthritis
  - 'Growing Up and moving on in Rheumatology' – a multi centre cohort study
  - an evaluation of an innovative residential self-management program
  - parents as proxies of adolescents
  - the development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care
  - audit of transition readiness of 16 year olds attending rheumatology clinics.
2. Evaluation of the program
3. Identification of adolescent health training needs:
  - of rheumatology professionals
  - of general paediatric hospital staff
4. Evaluation of a peer support initiative:
  - an evaluation of an innovative residential self-management program
5. Vocational issues and chronic illness during adolescence

And many more!

### **Transfer pathways:**

Patients are transferred to over 30 different adult rheumatologists in a variety of clinic types. Although none have formal adolescent training, there are several adult rheumatologists that are interested in treating young adults. There are the two young adult clinics that are held quarterly.

### **Gap analysis:**

There is a lack of trained staff in the adult sector to transfer 16-18 year olds to. There is also a lack of trained staff within the BCH rheumatology team and 60 per cent of hospital staff have had no formal adolescent health training [McDonagh 2006].

There is no successful tracking mechanism to ensure successful transfer, with an audit last year revealing that a third of recently transferred patients had no follow up letter sent from the adult rheumatologist to the paediatric team. There is also suboptimal shared documentation of transition planning by team members, particularly with respect to educational/psychosocial aspects of transition as shown by a recent audit.

**Enablers/barriers:**

The key barriers to effective transition are:

- professional attitude
- lack of recognition of adolescents and institutional support within the hospital generally
- a lack of dedicated space for rheumatology in general and adolescent clinics in particular
- recent loss of two key 'enabling' senior adolescent team members with significant adolescent expertise [occupational therapy and physiotherapy]. Their successors have no adolescent expertise or specific interest.

Key enablers include members of staff who see the importance of transition practice and are committed to being involved.

**Key challenges:**

Key challenges include convincing all team members that:

- adolescent health care differs from paediatric health care
- all young people deserve adolescent rheumatology care even if they are not going to be transferred to adult rheumatology
- transition is not just an optional extra that happens if certain team members are present
- continuity of care is important to teenagers. Currently patients do not have a named consultant and potentially may see anyone including visiting consultants who are fairly ad hoc
- documentation is important for a planning process for consistency and continuity.

**Responsibility/accountability:**

There are no transition key performance indicators in the department. Transition is not yet written into the institutions or department's business plans but it is on the agenda to do so. The recent staff appointments, such as a nursing role and the transition coordinator position, have transition written into their position descriptions.

**Tools:**

A number of tools have been developed for the program including checklists, leaflets, multi disciplinary team proforma, and a transfer summary template. [[www.dreamteam-uk.org](http://www.dreamteam-uk.org)]

**Evaluation/stakeholder feedback:**

Patient and parent satisfaction evaluation is done. The tool used is the 'Mind the Gap' scale [Shaw KL et al 2007], there is also a feedback book kept in the clinic setting but rarely used. More work will be done on feedback and evaluation with the recent appointment of a transition coordinator to the department.

Lead specialty of Trust-wide 'Mind the Gap' study of patient and parent satisfaction at BCH and neighbouring adult hospital [University Hospital Birmingham].

**Strategic planning:**

The key strategies and implementations that would enhance transition practice in the department include:

- institutional support
- recognition of individual expertise
- space for an adolescent outpatient area with storage of resources
- administrative support to ensure the use of the tracing mechanisms, updating resources
- a permanent transition coordinator to facilitate paediatric-adult interface.

Immediate and long-term transition goals for the department include:

- a permanent adolescent transition coordinator position
- the development of transitional care for parents
- the development of transitional care planning for young people with learning disabilities
- involvement in developing hospital-wide adolescent strategy.

## Documentation obtained:

- Standards for the care of adolescents, Birmingham Children's Hospital [BCH]
- Policy for acceptance and treatment of patients over 16 years at Birmingham Children's Hospital
- Transition for young people at Birmingham Children's Hospital: Rheumatology Policy, Sept 2006
- Transition for young people at Birmingham Children's Hospital: [specialty] Policy
- Rheumatology Transition Plan – BCH
- Adolescence and Transition – the UK experience: a presentation by Dr Janet McDonagh.
- Transition - getting it right – DVD UK Department of Health, 2007
- Nothing About Us Without Us – DVD Dream Team, BCH
- Key Data on Adolescence 2009 UK– J Coleman, F Brooks
- Draft terms of reference for the Adolescent Strategy Steering Group
- Application for a BUPA Foundation Clinical Excellence Award – 2005 [awarded]
- Rheumatology Transitional Care Coordinator Position Description – Jan 2009
- Adolescent Resource Newsletter – May 2009
- Getting the right start: National Service Framework for Children, UK Department of Health April 2003
- Bridging the Gaps: Health Care for Adolescents – June 2003
- Under their skins: Tackling the health of the teenage nation, CMO Annual Report 2007
- Growing Up Matters: Better transition planning for young people with complex needs, Commission for Social Care Inspection Jan 2007
- Transition: moving on well, UK Department of Health, 2008
- Making Every Young Person with Diabetes Matter, NHS. 2007
- Healthy lives, brighter futures: The strategy for children and young people's health, UK Department of Health, 2009
- Better Health, Better Care: Hospital Services for Young People in Scotland, NHS Scotland 2009
- Think transition: Developing the essential link between paediatric and adult care, RCPE, 2008
- Transition: getting it right for young people, UK Department of Health, 2006
- You're Welcome quality criteria: Making health services young people friendly, UK Department of Health, 2007
- You're Welcome: quality criteria self-assessment tool, UK Department of Health, 2007
- The Birmingham 'Mind the Gap' Project, satisfaction questionnaires for young people and parents
- The Transition Care Pathway: A framework for the development of integrated multi-agency care pathways for young people with life-threatening and life-limiting conditions, The Association for Children's Palliative Care UK, 2007
- BCH Adolescent Rheumatology Summary, 2009
- Final Transition Plan [early] Rheumatology, BCH 2006
- Final Transition Plan [mid] Rheumatology, BCH 2006
- Final Transition Plan [late] Rheumatology, BCH 2006
- Parent Transition Plan Rheumatology, BCH 2008
- Parent Transition Resource List, Rheumatology BCH 2009
- Transferring Young People to Adult Care, Administration Issues, Rheumatology BCH
- Staying Positive: Young People's Workshops, Information sheet, Pamphlet and Program DVD.
- Preparing for the Adolescent Clinic Questionnaire
- Questions to ask – NHS, 2007
- Arthritis: a guide to teenagers, ARC 2006
- D[dedicated]R[rheumatology]E[expert]A[adolescent]M[multidisciplinary] TEAM -laminated cards
- Adolescent Rheumatology Clinic Guide, BCH - pamphlet
- The Rheumatology Team, BCH – pamphlet
- Consent – what you have a right to know, UK Department of Health, 2001 – booklet

- Break-Out: the complete lifestyle guide for young people with arthritis, Arthritis Care 2008
- Get Healthy, Feel Great [adolescent health issues], Dairy Council 2005 – booklet
- The Source: free information and support for young people with arthritis – card
- Transition: Guidance for young people [Inflammatory Bowel Disease] NACC, CICRA 2008
- Transition: Guidance for parents [Inflammatory Bowel Disease] NACC, CICRA 2008

### 3. Dr Clive Ryder - Clinical Lead Rheumatology, Cardiology Department

The following is a summary of a discussion about the barriers to transition practice at BHS.

The National Service Framework [NSF] from the Department of Health has a chapter on young people's services. Ischaemic heart disease and oncology both had funding attached to their recommendations that made them mandatory and ensured effectiveness. The Child and Adolescent NSF have no funding attached to the recommendations and there are no penalties for non-compliance. The outcomes are also not as concrete as the oncology targets and there is no measuring of targets. The initial feedback regarding the NSF is that the recommendations are not addressed unless there is a financial penalty for non compliance.

In the NHS there are two main ways that change is implemented:

- a slow evolution, clinic led and usually medically driven
- a target dictated from above.

Currently, transition and adolescent health practice is driven purely by individuals from a small group, resulting in a small knowledge base. There are long standing, entrenched views about treating a medical condition rather than a holistic viewpoint. Paediatricians practice involvement in families, school etc but usually without formal documentation. A major barrier to change is the perceived issue of needing more time and a bigger workload. Also there is the issue of capacity and clinics competing for limited space. Other barriers include institutional ageism and society's perception of adolescents.

The question is how to bring about cultural change and accountability? One recommendation would be NSF mandating adolescent targets requiring across the board compliance with funding attached. In regards to an adolescent inpatient unit, there is a perception that patients may not receive adequate specialist care and the skill base required for staffing. Either the whole hospital needs to be adolescent friendly with specialty areas or an adolescent area with specialist knowledge.

### 4. Cardiology Department

#### **Interview:**

Amanda Daniels – Cardiology Nurse Specialist

#### **Policy/procedure:**

Current age cut off for treatment at BCH is 16 years.

#### **Model of care:**

A 2003 working group was set up specific to cardiology transition, but the designed framework has yet to be adopted. A number of educational pamphlets for young people and parents have been developed.

#### **Transfer pathways:**

In 2001 the Grown Up Congenital Heart [GUCH] service commenced in the adult sector.

#### **Gap analysis:**

Once patients are referred to adult service, they have to wait a year until their first appointment resulting in non-compliance issues.

#### **Enablers/barriers:**

Key enablers are that the transition nurse works across both the adult and paediatric services.

Also the GUCH Association has supported transition development.

**Key challenges:**

A key challenge is raising the awareness of clinicians regarding the difference between ‘transfer’ and ‘transition’.

**Tools:**

Excellent tools, such as pamphlets and letters of introduction, have been developed but are yet to be introduced due in part to a lack of awareness of transition concepts by some members of the team.

**Evaluation/stakeholder feedback:**

Involved in the Trust-wide ‘Mind the Gap’ study of patient and parent satisfaction at BCH and the neighbouring adult hospital [University Hospital Birmingham].

**Documentation obtained:**

- Grown Up Congenital Heart [GUCH] moving on to adult hospital care, Cardiology BCH 2004 – information booklet
- Moving On to Adult Cardiac Care, Cardiology BCH 2005 – information booklet
- Young Persons Cardiology Clinic, Cardiology, BCH 2004 – information booklet
- Adolescent Transition Operational Pathway, Cardiac BCH
- Young Person’s Cardiology Clinic information letter to young people
- Hearts for Life – Transition to Adult Care for Adolescents with Heart Disease – a collaborative approach - poster presentation
- Young Person’s Clinic Outpatient Consultation Sheet, Cardiac BCH
- Guidance for the Young Person’s Clinic Document for clinicians, Cardiology BCH

## 5. Liver Unit

**Interviews:**

Graham Gordon – Nurse Specialist, Liver Unit

**Model of care:**

The model of care is dependent on the specialist condition.

- Viral Hepatitis: many are discharged to primary care. The majority of others go to the University Hospital Birmingham [UHB]. Specialty nurses go to the paediatric setting for periodic ‘meet and greets’.
- Hepatology/transplant services which include mainly the cystic fibrosis cohort: transferred to Young Person’s Liver Disease Clinic at the UHB. Clinics were set up in 2001. Patients are seen in clinic from 11 years of age.
- Transplant Services: the second largest service in Europe. The catchment area is the whole of the UK. The adult service is in Oxford. Graham is currently working with the adult team to design a transition process. They are running joint clinics at the adult setting twice a year. Patients are seen in the joint clinic from 13 years of age. Ideally patients have three clinic visits prior to transfer.
- A telephone help line operating since 2001 is available for parents and young people. This includes email support.

**Evidence base:**

A follow up questionnaire to evaluate the initiative of 13 year olds seeing their doctor on their own demonstrated a sense of more control on the part of the young person. A number of research projects are currently underway including one on the ‘Transplant Journey’.

**Gap analysis:**

No adult service gaps for hepatology have been identified.

**Enablers/barriers:**

The CNS role is a major driver for transition initiatives but the capacity of the role is an issue. The newly created role of 'young persons nurse specialist' is expected to help drive many transition initiatives.

**Tools:**

There is currently work being done with the Children's Liver Disease Foundation in developing literature for the young person and their families. <http://www.cldf-focus.org/>

A collaborative project being done is 'Taking your liver disease into adulthood'. This involves consultation of young people around subjects such as puberty, sex, smoking, alcohol, medications, and recreational drugs.

The 'Reflection Series' is about to be published. This will include worksheets to be used by the young person.

The new website is to be launched in May 2009. It is currently designed for use by 11-15 year olds. The older age group portion of the website is to be developed later in 2009.

**Evaluation/stakeholder feedback:**

Focus groups have been held by the CNS and the psychologist resulting in some restructuring in 2005, as well as extra activity and support groups. Also involved in the Trust-wide 'Mind the Gap' study of patient and parent satisfaction at BCH and the neighbouring adult hospital [University Hospital Birmingham].

**Strategic planning:**

There have been discussions since 2003 about the increasing numbers of patients post transplant. The 2008 funding stream was directed to develop services for young people. There is funding in adult services but they are working closely with the paediatric service. A young peoples' specialist nurse position is imminent, and this role will work across both the adult and paediatric services and be supported by a youth worker position and possibly, a sessional psychologist and administration support.

There are also plans for the development of an on-line message board and 'facebook' type site.

**Documentation obtained:**

- Moving to adult services, some thoughts...Children's Liver Disease Foundation booklet
- Flying the nest, some thoughts...Children's Liver Disease Foundation booklet
- Supporting your child as they grow up, some thoughts...Children's Liver Disease Foundation booklet
- Parenthood, some thoughts...Children's Liver Disease Foundation booklet
- Going to school, some thoughts...Children's Liver Disease Foundation booklet
- a number of booklets and flash cards with disease specific information - Children's Liver Disease Foundation
- Liver Disease Information Pack - Children's Liver Disease Foundation
- an assessment of psychological well-being and adherence during transition of paediatric Hepatology patients to adult services - Draft copy of expressions for interest

**6. Oncology Unit****Interviews:**

Moira Bradwell – Oncology Nurse Specialist

**Model of care:**

There is an emphasis on moving the young person at the right time, when they are informed enough and ensuring independence in health care.

The transition program was developed in 2005. In the early days of post treatment surveillance [first 2-3 years] they are seen by consultants. Once they are about 15 years of age and at least three years post treatment, they are seen in the Transition Clinic and under the Long Term Follow Up Program. They are then seen in the Transition Clinic until 18 years of age.

The clinic staff include the paediatric consultant, adult consultant and the clinic coordinator. The low risk follow up is nurse led. The Transition Clinic is held in the oncology outpatients area in regular hours.

The transition program is stage based – early, mid and late adolescence. Transition care plans are completed. Topics covered include: psychosocial issues, education, independence, understanding of their illness, monitoring, and late effects. The clinic nurse completes a medical summary as per a template. A letter is sent to primary care and the adult health service.

**Transfer pathways:**

The Late Effects Clinic is for patients 18 years and older and is held at the adult service. Paediatric oncology doesn't necessarily refer patients to an adult oncology service. The main referral pathway is endocrine. Referrals can also involve oncology, a fertility specialist, and cardiology.

**Key challenges:**

Currently the key challenge is the development of a nurse led follow up program.

**Tools:**

A treatment summary card is used for the young person at the time of transfer. A questionnaire is completed by the young person at approximately 11 years of age.

**Evaluation/stakeholder feedback:**

There are issues with evaluation as follow up is on an annual basis. There is the possibility of an exit questionnaire.

**Strategic planning:**

A nurse led leukaemia clinic is proposed for follow up for the younger age group when off treatment for more than two years. There will be surveys of staff, families and young people in the transition clinic about the Follow Up Clinic being a nurse led program. Funding has just been received for a permanent follow up nurse role.

**Documentation obtained:**

- Late Effects Clinic, Selly Oaks Hospital, BCH 2006 – information brochure
- What's the point of coming to the clinic [a guide for young people with cancer] – CCLG 2006 – booklet
- After Cure – CCLG 2007 – booklet
- Transition Partnership – Newsletter 1, November 2008

## **7. Dr Lizzie Rankin – Chair, Young Adult Strategy at UHB**

Lizzie approached the executive at University Hospital Birmingham 12 months ago regarding transition. As a result, a 'strategic working party for adult care' that she now chairs, was established. Strong buy in has been achieved from specialties in a short space of time.

The main goals of the working group are:

- transition – in particular the collection of data to evaluate wide-spread practice
- the promotion of good adult care
- initiate transition experience for senior nurses leading to generic transition staff as a resource
- provide educational opportunities for clinicians in adolescent health.

**Key opportunities:**

- consideration of the commonalities between specialties and the possibility of sharing resources, such as a youth worker
- the building of a new hospital being an opportunity to reconsider practice
- a meeting room for transition teams to 'meet and greet' transferring young people
- generic adolescent workers including an adolescent psychologist who could be paged for on the spot referrals

- encourage the concept of youth workers for health
- adolescent health e-learning tool recently launched that all primary health clinician must complete
- Euteach: Adolescent Summer School for Europe for adolescent health training -www.euteach.com

The working party report to the clinical redesign team, and then presents a paper to the Strategic Redevelopment Board.

## **8. Charlotte Frith – Youth Worker**

Birmingham Children’s Hospital has approximately 200 inpatient beds, a third of which are occupied by adolescents. There are issues for young people who are isolated from their support systems and friends and have very little non-clinical contact. The youth worker role is part of the child and adolescent mental health service [CAMHS]. Youth workers have completed a specific three year degree course offered in a number of UK universities. Patients are referred on a voluntary basis. Medical notes are kept of contact with the young person. The term ‘youth worker’ is non-threatening. Currently there are two youth workers with another position being advertised at BCH. There is also one adolescent hospital play specialist position. These four positions make up the Adolescent Support Service.

Key initiatives:

- forum for adolescent awareness.
- generic leaflet for departments to distribute to young people with links for anti bullying, depression etc in a credit card fold out size
- youth club held twice a week for inpatients
- themed sessions, such as, safety, relationships
- hospital youth workers network just established to provide training and support

August 2009

## **Vancouver, Canada**

### **British Columbia (BC) Children’s Hospital**

#### **1. Dr Curran Warf, Director of the Division of Adolescent Medicine**

I very much appreciated the opportunity to meet with Curran who had only commenced his new role a week previous and had flown in from California that evening. His insights into the differences between the American and Canadian health care systems and their funding, was an invaluable foundation to inform the discussions that followed with clinicians across those two continents. In Australia we are fortunate not to have the barrier of lack of medical insurance as a reason why young people don’t engage in adult health care. From our discussions it became very apparent that the cost of health care for young people with a chronic disease, who are funded up to the age of 18 years on Medicaid and then may be left without any insurance, is a major contributor to drop out rates in America among young people with chronic illness. This group are less likely to have the types of jobs that provide health cover and face prohibitive premiums due to their pre-existing conditions, if they can get insurance cover at all. Funding of transition programs is also a major issue with specific disease groups receiving funding but without clear health system policy or strategy.

#### **2. Dr Lynn Straatman – Paediatric Cardiologist, Providence Health, BC**

**Policy/procedure:**

British Columbia Hospital has no overarching hospital transition policy. It is left to the specialties to manage transition. There are currently no written policies with certain individuals driving transition research and practice.

**Model of care:**

Cystic fibrosis has a strong adolescent transition program. Young people who are 16-17 years of age have two transition appointments. Information covered is mainly based on sourcing funding, equipment, housing etc. Social work is involved in these appointments. There is also an adult congenital heart disease transfer clinic; the diabetes unit have some transition process and the metabolic unit have a straight referral from one paediatrician to one adult specialist at British Columbia Hospital [BCH].

There is no adolescent program at British Columbia Children's [BCC]; treatment of adolescents is mainly done through the psychology department and there are no reporting lines for transition. Individual paediatricians drive transition and no data is kept on hospital transfer numbers.

Regarding definitions of overage they are quite strict:

- 16 years – cut off for new patients
- 18 years - cut off for existing patients
- existing patients transfer age dependent on specialties.

Theoretically, any request for an exemption process needs to go to the hospital board. Some specialties keep patients for longer, sometimes into their 20s. No one really monitors this, particularly the chronic illness overage group. Age criteria is generally only scrutinised on admission. Some specialties use the 'On Trac' transition program and tools developed in Vancouver, but the utilisation of these is piecemeal.

**Evidence base:**

Transition research projects currently being undertaken to inform practice are:

1. Delphi research study – a longitudinal study in specialty groups that have no transition program, 42 participants in Round 1.  
Currently awaiting an application for Adolescent Health Outcome Network funding. Collaboration on the project is part of HART – Healthcare Transitions Adolescent Research Team. A paper is to be published shortly.
2. Caregiver stress study – participants are carers of children aged 0-25 yrs with a chronic illness that may limit life expectancy.  
They received 300+ applications to be in study. 320 participants have returned questionnaires. Interviews will be held two years later with similar questionnaires.
3. A longitudinal study of patients with metabolic conditions from the age of 18 years.
4. USA NIS Self-help and Coping Study – large funding has been allocated for this study, including for a transition aspect.

**Gap analysis:**

- there is a big difference between the paediatric and adult world. The adult services are autonomy focused
- there is a problem with adult clinicians who have no training and are reluctant
- neuromuscular has no adult service so patients are transferred to see a general neurologist
- metabolic has only one adult specialist
- spina bifida and cerebral palsy have no adult complex disability clinic, so may not see a neurologist
- no cohorts continue to be treated long term in the paediatric setting so are transferred to whatever level of service is available
- young adult patients with complex disabilities often end up in a group home and may go from paediatric care to an aged care facility due to a lack of appropriate services.

**Enablers/barriers:**

The main barriers are adult clinicians who are reluctant to see adolescents due to the length of appointments and not feeling comfortable dealing with adolescent issues.

**Key challenges:**

The main challenge is to have a dedicated adolescent health service. There is the need to separate and broaden adolescent health from the eating disorders cohort. There are currently no clinical appointments [Lynn's team are all researchers based at the University of British Columbia].

**Responsibility/accountability:**

- there are no transition key performance indicators
- there is one dedicated transition staff member who has funding for one day/week
- certain staff take responsibility for transfer, but not really for transition
- transfer processes are mainly nursing driven by paediatric nurses in the clinics
- transition may be written in the business plan for paediatrics, but certainly not in any adult business plans
- transition is not currently written in any staff position descriptions.

**Tools:**

Some components of the 'On Trac' transition program are used in various clinics.

**Evaluation/stakeholder feedback:**

- there is not a lot of evaluation done as yet
- transition workshops have commenced. There were 25 clinicians + Lynn + four researchers from across Canada at the last workshop
- the next workshop will include a panel discussion with adolescents.

**Strategic Planning:**

- a longitudinal study is planned to provide concrete evidence of the need for transition [mortality, morbidity, cost effect]
- aiming to get buy in from the adult services.
- the American Society of Internal Medicine statement had no adult perspective
- there is limited cross over from the paediatric to adult trainees.

**Research plans:**

- Define what is successful transition? How is it accomplished?
- What are young people dying of before their life expectancy?
- to strengthen the links between the university and hospital to allow funding for evaluation activities
- Café Scientifique – women and heart disease, stroke and palliative care. Coffee shop booked for evening with coffee and cookies provided. Well advertised. Questions are submitted at the beginning of night, followed by a brief presentation on a particular health issue then earlier submitted questions are answered.

**Documentation obtained:**

- Draft of abstract - Healthcare Transitions for Adolescents with Chronic Life-Threatening Conditions Using a Delphi Method to Identify Research Priorities

**3. Anna Gravelle, Cystic Fibrosis Nurse Clinician [via email]**

The clinic starts their cystic fibrosis [CF] patients on a transition pathway around the age of 10-11 years. The clinic pathway has been adapted from the 'On Trac' Transition Clinical Care Pathway created by the youth health team several years ago. In the past the team have hosted a 'pre-graduation' workshop for the young person at around age 17 years as a means of providing further CF education and preparation for the adult CF clinic. However for the first time the graduation workshop will not occur this year, due to increasing concerns regarding infection control in their CF population.

A 'readiness to graduate' questionnaire has also been developed. At some point in their 18<sup>th</sup> year, a CF graduation clinic is held at the hospital. The adult team come from St. Pauls' Hospital in downtown Vancouver and a joint clinic is

held. After this, the young person is considered transferred to the adult CF clinic. There are generally no exceptions to transfer at the age of 18 years.

Some 'light' research [surveys and retrospective chart review] has been done by Anna and plans are for the next project to develop a questionnaire for recently transferred cystic fibrosis patients, to review how their transition process went and how best to evaluate successful transition.

**Documentation obtained:**

- Adolescent Transition Care Clinical Pathway – Cystic Fibrosis BC Children's Hospital
- Cystic Fibrosis Readiness to 'graduate' to Adult CF Clinic Questionnaire – 2007
- Adult CF Clinic Information Sheet
- The CF Graduation Clinic at BC Children's Hospital

## Calgary, Canada

### Alberta Health Services – Alberta Children's Hospital, Calgary Area [AHS]

#### 1. Catherine Dunseith – Adolescent Transition Coordinator, Well on your way – Youth in Transition Program

**Policy/procedure:**

Alberta Health Services [Calgary area: population 1.2 million] do not have a specific, service wide transition policy, however there has been a policy for many years that is imbedded in the paediatric admissions policy and clearly defines the parameters of who has access to hospital services based on age and the expectations of transition.

Individual departments are encouraged to draft their own transition procedure to accommodate the unique characteristics of their patient population and their staff/patient ratio. These procedures are expected to fit within the parameters of the system wide transition care guidelines. The transition coordinator is available to support departments and provide general transition services for their patient population. In addition, the transition coordinator is currently drafting a clinical pathway which summarises the principles of the policy in regards to serving over age patients.

**Model of care:**

The overage definition for new patients at AHS[C] is 18 years. For existing patients it is 18 years and three months where a transition plan is in place. There are exceptional groups where the paediatric protocol has proven to have better medical outcomes or where there is no adult counterpart to take over care. Overage admissions require approval from the director. Currently there are approximately 5,000 overage patients in ambulatory care. There are no private clinics on site.

In 2004 a Transition Committee at the Alberta Children's Hospital was formed to identify gaps in service and establish a strategic plan for comprehensive transition service. A survey of paediatric clinicians confirmed concerns about the level of transition practice across paediatric services. The recommendation was made that a youth in transition program be established.

In 2006, the position of adolescent transition coordinator was created to comprehensively assess the supports available for adolescents to transition to adult services. Transition was on the agenda of the 2006/2007 Canadian Council on Health Services Accreditation [CCHSA] process. The new transition coordinator's first task was to chair the accreditation committee, made up of adult, paediatric and community representatives. They surveyed youth, parents and staff, ran focus groups and interviewed key stakeholders. The results delivered information demonstrating that further resourcing of the transition program was required. This became the leverage to put transition on the radar and some accountability around transition resulted. Transition went from being perceived as an enhancement to becoming an essential service.

This information was then the basis for a pilot program, titled 'Youth in Transition'. This pilot study has encouraged involvement and feedback from specialty departments as a means of gaining credibility for the program. Initially the transition coordinator's role was evaluation and development but this has moved more to implementation. The program was piloted in five specialty clinics in 2008 and rolled out to all clinics in 2009/10.

Youth in Transition pilot program: the vision of the program is 'to provide and maintain a high standard of care for youth as they safely transition from the paediatric system to adult services within the Calgary Area'. The three key objectives are:

- to support health care providers as they partner with youth/families to develop self-management skills that will prepare them for the more autonomous environment of the adult medical system
- to provide patients/families with education and support according to the child's developmental stage and level of functioning
- to enhance services within both the paediatric and adult health systems to support continuity of care, smooth and safe transition.

Young people who are aged 12-25 years with special health care needs and who will require ongoing medical care in the adult sector are eligible for the program. The guiding principles for the program are:

- family centred
- respect needs defined by the youth/family
- promotes self-management
- collaborative and builds on existing strengths
- evidence based
- values diversity.

The pilot program is divided into three phases and is currently in the first phase: Transition Readiness: The Paediatric Implementation Stage. To follow will be Phase 2 – The Transfer Process: From Paediatrics to Adult Care, and then Phase 3 – Youth Adaptation: The Adult Care Implementation Stage.

Other hospital programs for young people include:

- The Youth Connection Program – following on from the Family Connection Program that is run by the Family Resource Centre in collaboration with the transition program. Dependent on the adolescents needs, there can be group or individual sessions.
- The Inflammatory Bowel Disease Clinic has joint transition clinics with a slideshow of the adult facilities and staff.

#### **Evidence base:**

The Stanford Self Management Course was evaluated for possible use. It is a peer led model with trained facilitators. Edmonton, Chronic Disease Management adapted the program to be more youth friendly and is doing a randomised study. It has also been trialled in the UK at one site. It is a licensed program and whilst it has many strengths and the evaluation to date has delivered some very useful information, it was felt to be too structured for many participants. It will be offered as one of a battery of options for youth to develop their skills.

The Youth Advisory Council was consulted in the development of the model, particularly on confidentiality issues. The 'On Trac' Program was evaluated and whilst it has the strengths of being comprehensive, developmentally appropriate, adaptable and young person and family centred, it was evaluated by staff in this setting too cumbersome, requiring multiple visits and not clear how it would fit into the specialty clinics time expectations.

The paper 'Problems and pitfalls of transition from paediatric to adult renal care' – Watson 2004, demonstrated that most young people are at risk of dropping out of care in their first year in the adult service. This knowledge has informed the development of the phased approach to the transition program.

#### **Enablers/barriers:**

Transition is championed at an executive level but resourcing is an issue.

#### **Key challenges:**

The biggest challenge is change management and fostering a 'curious approach'.

**Responsibility/accountability:**

There has been some reporting on transition on the organisational scorecard but with the recent appointment of a new CEO it is not yet clear what ongoing reporting will take place.

**Tools:**

The program has developed global resources that can be used by the specialty clinics. These include:

- a youth transition care summary [currently in draft form]
- youth in transition staff orientation [Learning modules]
- transition practice guidelines
- multiple handouts, brochures and posters for services and to promote key messages
- readiness assessment tools for the young person, parents and clinicians to use
- templates for transfer summary, referral letters and letters of introduction
- a transition resources database.

A series of transition experiences of young people, a parent and the transition coordinator have been delightfully captured on the DVD 'Well on Your Way Transition Stories'.

Another initiative that is currently under consideration is whether a 'Transition Tab' in the medical records is feasible. This would allow copies of results that will later be useful for transfer to be filed and readily available.

**Evaluation/stakeholder feedback:**

Extensive evaluation has been undertaken on the transition program since its inception. A key evaluation was the accreditation process in 2006/ 2007 that highlighted the need for further resources for the program and recognised the expertise and enthusiasm of the transition team. It identified the need for a 'more formal approach, which has common language and tools with flexibility to adapt to patients needs; and an approach that builds on existing community partnerships and strengths of other children's services'.

In June 2008, a comprehensive program evaluation of the Child Health Youth in Transition pilot was done. This included background to the program, an overview of the program structure including the three phases, an evaluation of phase one, proposed timelines, and a comprehensive list of tools and resources developed for the transition program. A fundamental component of the program itself and its evaluation is stakeholder feedback including young people, their families, clinicians, pilot clinic staff and community organisations.

**Strategic planning:**

The transition team under the lead of the transition coordinator are continuing to identify collaborative partnerships, program development opportunities, and program modifications as informed by evaluation data. Further tools and resources for the program are currently being developed.

**Documentation obtained:**

- Youth Transition Care Summary [draft] – Well on Your Way Program, Alberta Health Services, 2009
- Youth in Transition Pilot Program Overview, January 2008
- Alberta Children's Hospital Admission Guidelines: Patients over 18 Years, 2009
- Canadian Council on Health Sciences Accreditation [CCHSA] report, Adolescent Transition – Well on Your Way Program, Alberta Health Services 2007
- Child Health Youth in Transition Pilot Program Evaluation – Alberta Health Services, 2008. This report contains the following tools and resources:
  - Youth Transition Care Guidelines
  - Participant Information Letter
    - Transition Introductory Letters
    - Self Management Skills Assessment Check In for Patients
    - Self Management Skills Assessment Check In for Parent/Guardian
    - Self Management Skills Assessment Check In for Patient Advocates

- Individual Transition Plan
- Transition Resource List
- Transfer Summary
- Evaluation Workplan
- Existing Transition Services Interview
- Perception of Adolescent Issues and Resources Survey
- Orientation Feedback Form
- Staff Readiness Survey
- Pre-Pilot Survey for Patients
- Pre-Pilot Survey for Parents/Guardians
- Pre-Pilot Survey for Staff
- Post-Pilot Survey for Patients
- Post-Pilot Survey for Parents/Guardians
- Post-Pilot Survey for Staff
- Staff Satisfaction with transition Readiness Orientation and Tools
- Patient/Parent/Guardian Satisfaction with Transition Tool-kit

- Well on Your Way Transition Stories - DVD

## 2. Dr Jorge Pinzon, Paediatrician, Adolescent Medicine

Dr Jorge Pinzon has established a Youth Health Program the specialty clinics can refer patients. There are other specialty young adult clinics for 16-24 year olds; the Young Adult with Rheumatic Disease [YARD] and the Neuroscience Department, run by a podiatrists, both located at an adult facility. Jorge also runs a clinic in the Eating Disorder Clinic for youth and adults in the paediatric hospital. Chronic disease management is facilitated in the community and at the Chronic Complex Disease Clinic at one of the adult hospitals. Calgary has a population of 1.2 million and is divided into four geographical quadrants. There is a shortage of primary care practitioners.

Transition discussions in Canada go back to 1995 when Miriam Kaufman wrote the book 'Easy for you to say'. In 1996 in Vancouver at the British Columbia Children's Hospital, the 'On Trac' [Taking Responsibility for Adolescent /Adult Care] resource started to be developed. At that time the organisations emphasis was on pathways. Mary Paone, Sandra Whitehouse and Jorge worked with them to develop this framework for transition.

The 'On Trac' model was conceptualised using the normal adolescent developmental stages of early, middle and late transition stages. Within this framework six main developmentally – appropriate strategies were used for content areas: self advocacy, independent health care behaviours, sexual health, psychosocial supports, education/vocation and financial planning, and health and lifestyle choices. Three main tools support this model:

- Setting the Trac: A Resource for Health Care. This is a manual of 250 pages written for health care providers who are working with young people with chronic health conditions. It includes worksheets, tools, evaluation tools and a literature review.
- Year Plan – It: A youth health planner to assist in education about their health condition and its management. The planner is designed for young people aged 10-18 years to record and store their health information for clinic visits and emergency care.
- Getting On Trac: A Workbook for Youth. This workbook contains over 70 exercises aimed at assisting in developing self-management and transition planning skills.

## 3. Lyndsey Bristow, Paediatric Neurosciences Program

### Policy/procedure:

The Neurosciences Department doesn't have a written transition policy.

### Model of care:

The program model of care is based on a family centred and client centred approach. The PEO model is used: person, environment and meaningful occupation. The Neuroscience Adolescent Transition Program is one of the services offered to youth [aged 12-19] who are involved in one or more of the neurosciences clinics.

The preferred method of referral is for families or preferably youth to contact the team directly via email or phone, clinician's referrals are not often accepted as the preference is for the young person or family to drive the process. The team will then talk with the main contact from the clinic as well as the involved youth's social worker, therapists to gather additional information on what the youth's needs are. Copies of written documentation are sent to clinic and placed in health records. If the young person is close to the stage of transfer to adult services, copies of the programs documentation are included in the referral package to the adult health care clinics. If additional adult services are needed, such as referral to an adult therapy service, referrals and information can be sent to the appropriate adult provider with family permission.

All direct health care providers [doctor, nurse, social worker, and allied health care staff] are responsible for letting families know that there will be a transfer of care when the child turns 18 years of age and let them know about the Neuroscience Adolescent Transition Program.

There is no formal space for the transition program but there are facilities within the neurosciences area including a kitchen and space for life skills training.

The neurosciences program sees 1800 youth between the ages of 12-18 years. The service sees 200-300 families currently, mainly due to marketing and family referrals. Transition funding for staff positions has covered Lyndsey's role for two days per week with an additional day per week funding shared by a psychologist and a social worker. There is no permanent clerical support but there has been some temporary support over the summer months.

A clinic called the Milo Clinic is run for patients with spina bifida. There are about 200 patients attending the clinic and Lyndsey has funding to discuss transition with every patient. There is also more generic education across the province. In addition, disease specific education sessions on topics such as driving, scholarships are being run with small groups of adolescents. Information packages are also being developed. Small social skills group are another group that is being run. There are also resources online for all clinicians to use.

If the young person is highly independent they often have a one-off consult, with possible follow up via email. Patients with developmental delay have extra funding that provides for community resources. The PDD [person's with developmental disabilities] provides ongoing funding as long as the onset of the disability is before 18 years of age and the youth has an IQ below 70. At 14 years of age a competency assessment regarding the making of decisions is made in British Columbia and at 16 years of age in Alberta.

#### **Evidence base:**

The neurosciences department is participating in the 'Well on Your Way Transition Pilot'. At this time there is no additional research being conducted within the program. Some pockets of the hospital used the 'On Trac' resources from Vancouver, but it was only used in a piecemeal fashion in neurosciences three years ago.

#### **Transfer pathways:**

The transition program is available to follow youth until 19 years of age. Often if youth present with sexually transmitted diseases, pregnancy or drug concerns the youth health program rather than the transition program follows them. The Youth health program follows youth aged 12-25 years.

#### **Gap analysis:**

Large catchment areas can be an issue in running programs. The geographical catchment area for specialty care in the province is shared between Edmonton's Stollery Children's Hospital [the North] and Alberta Children's Hospital [the South].

#### **Tools:**

Information and brochures are provided by the clinics at approximately 12 years of age. Information is given out to young people and families giving contact details for the transition team. A sheet is being developed to be given out by clerical staff regarding what the young person wants to cover.

The program started with the question 'What are we doing individually that could be done in groups'. Eight packages are to be developed for families and young people with the answers to the questions that get asked the most to the social workers and allied health care team. Hopefully these education packages will in time go online.

#### **Strategic planning:**

Planning for more tools to be developed including a transfer booklet.

## Documentation obtained:

- Neurosciences Department diagram of programs and services

## 4. Sandy Baggot, Art Therapy

Art therapy is supported by child life specialists and recreational therapists. They hold a child and youth development degree and masters. Music therapists also have a masters degree. Part of their role is involvement in a program for young people. This includes meetings with Youth Connection and an orientation program for peer support. They are currently collaborating on a pilot program with 50 young people. This is a peer support model with the involvement of art and music staff. The staff have informally been using art and music tools to prepare and celebrate the young person's transfer to the adult health care system. They are now developing a formal partnership with the transition program. Based on the understanding that different people get information from a range of mediums, this program has a breadth of information delivering methods available.

Although it is planned that this program will in time be available for 13 year olds plus, at the moment it is currently for older adolescents. All participants will be facilitating the program with some past 'transitioners' returning to be involved. There will be group and individual support for participants based on a therapeutic model. There will be the potential to develop psychotherapeutic support. The program is commencing in November 2009 and will run three times a year.

## 5. Cardiology Department

### Interviews:

Patty Knox, Paediatric Cardiology Nurse and Yvonne Balon, Adult Congenital Heart Program

### Policy/procedure:

There is no written transition policy for the cardiology department.

### Model of care:

The cardiology department are part of the transition program pilot study that came about through information from the 2006/2007 accreditation. In 2009 the staff have been looking at how to identify and track young people who will be transferring to an adult service rather than waiting until they are 17 years old. They are also considering the practicalities of finding time for transition.

A large proportion of cardiology patients are only seen annually making their appointments very busy and reducing the time for transition education and discussion opportunities. Four or five patients have been in the pilot study. The young person is given the choice to have the parents in the room or not. They have found that parents are supportive of young people having some time on their own with their clinician. When they are transferred to the adult sector, staff ensures that the treatment plan is not changed on the first visit. It is very important to manage change and build trust. It is also a significant cultural change between the paediatric and adult sector. The goal is not to 'have them ready'. It is viewed as a progression, where what can be done is done, and the adult team is then informed about outstanding issues.

There is an annual orientation to the adult setting once per year. 'Off Beats' - a peer support group for cardiology was set up. It is now run by the social worker but has small numbers attending.

### Enablers/barriers:

There is a definite advantage in having a counterpart in the adult setting. It creates the opportunity for good information exchange, with information filed in the paediatric setting more readily available if it becomes relevant in the adult setting. One key question is who will drive the transition process?

### Tools:

The cardiology team utilise the available tools created by the hospital transition program.

# Minneapolis, United States of America

## University of Minnesota, Division of General Paediatrics & Adolescent Health Medicine

### 1. Peter Scal, Associate Professor – ‘Rheum to Grow’ web-based intervention

#### Policy/procedure:

Transition has been on the radar for the organisation for about 10-15 years but despite talk about policy and best practice there have been no interventions until now.

This pilot intervention is titled – ‘Rheum to Grow’

#### Overview of a web-based intervention

Peter has talked to colleagues about web-based interventions for some time. He attended a course on e-Public health intervention in 2006 in Minneapolis.

The ‘Rheum to Grow’ intervention is based on participatory action research. A key component of design was youth team consultation. Twelve teens were enrolled in the advisory panel and six attended regularly. Focus groups were held with adolescents, young adults, and parents.

The content is quite structured, based on self-management and advocacy. The content is also based on the previous findings that young people are interested in practical life questions not just medical care. They want information about self-management, skills that are relevant to their life. Hence the intervention is about ‘living with arthritis’. Key to the content is the self-determination theory:

- competence
- autonomy
- relatedness.

There is a balance of adult expert and peer delivered information. Delivery is based on young people using the web material in their own time. Key aims:

- get educated
- take control
- stay healthy
- connect and share.

Shortly they will commence a six-week tracker [pilot].

Some tools in the intervention are audio recordings:

- teen speak – peer response to standard questions, five various fictional characters, answers given in character
- nurse response to standard questions – 20 most common questions with the option to add more questions
- ‘poll of the day/week’ – with a question related to their condition or general wellbeing
- section to role-play and practice difficult situations, such as a young person and their doctor, young person and their peer or teacher
- scripting – script important conversations, such as visit to the doctor, discussion about physical limitations with a teacher
- the young person can create a personal profile to populate letters for doctor’s visits etc. and these can be printed off and taken with them to appointments
- sections: know your documentation; know your healthcare [insurance, team]. This is particularly important as a third of young adults are uninsured.

#### Evidence base:

‘Talking about Health Care, Transition: they’re not getting it’ 2005 data.

#### Evaluation/stakeholder feedback:

Evaluation will include:

- illness intrusiveness scale [Stanford]
- paediatric QL [Quality of Life]
- evaluation of healthy device in managing disease
- a complex monitoring system of page usage
- pilot evaluation – usability, feasibility and outcome measures.

**Strategic planning:**

Expansion of the web tool to parent and provider is planned. The pilot will have 30 young people as participants. It will then go to a full randomised trial.

## **2. Dr Abraham Jacob, MD, Director of the Paediatric Hospitalist Program**

The following is a summary of our discussions about transition practice at University Children’s Hospital:

- The University Children’s Hospital is in the same building as the adult hospital. It has about 220 beds and sees a fairly complex patient mix. The other children’s hospital in the region is Minneapolis/St Paul Children’s Hospital, which is a private practice group.
- University Children’s Hospital has no adolescent unit. Patients are cohorted by disease process in line with where the nursing skill set is perceived to be. There is a teen room that is well utilised. Primary care does have an adolescent specialty.
- There is no transition policy but there are guidelines for overage patients, with 18 years being the nominated cut off.
- The cystic fibrosis [CF] team transfer their patients well and follow a procedure. This hospital is ranked number one for life expectancy in this group of patients. The CF Foundation has insisted that transition planning be part of practice. Both diabetes and cystic fibrosis are good at developing self-management practice.
- Cardiology run an adult and paediatric combined clinic from about 18 years plus.
- A major issue is health insurance where young people remain on their family plan until 18 years of age, or if they are in college until 21 years. They are then in the position of trying to obtain health insurance with a pre-existing condition.
- One goal is to create a medical home clinic that cares for immunisation, transition etc
- Current ‘transition’ practice is focused on input to output.

## **3. Dr Chris Boys, PhD, Paediatric Neuropsychologist**

Chris works between a number of departments with chronic illness groups including rheumatology, diabetes and cystic fibrosis.

**Model of care:**

- The cystic fibrosis handoff is good as there is strong communication between the adult and paediatric services.
- Diabetes has minimal linkages with very little preparation.
- In general, self-management practice is seen as the adolescent medicine scope.
- Currently there are no transition goals established by the department but the transfer information is good as adult services have access to the same electronic medical records system and hence all medical information.

**Evidence base:**

**Research project 1:**

A shared care model: to increase self-management, with a gradual increase in responsibility, includes preparation for parents.

Part of the model encourages regular meetings between the young person and parents on Sunday/Thursday to plan week's care. The aim is that the meeting will be less than 15 minutes. The program would commence at 11/12 years of age. This sort of model is happening already in diabetes and cystic fibrosis.

**Research project 2:**

Perceived parent vulnerability: using a vulnerability scale to determine how fragile a parent perceives their child/infant to be. The scale will be administered at diagnosis, three months, six months, one year. Medical markers will be used in the analysis of results and the aim is to have 60-70 participants per year.

**Research project 3:**

An illness uncertainty model and quality of life [QOL] assessment in adolescence: There will be 100 participants [half male, half female] aged 13-18 years and diagnosed for more than two years. It is documented that adolescents have more knowledge, but do less with it, than at any other time in their lives. Have they thought about outcomes? Is it related to illness uncertainty? Are they overwhelmed by illness and regimen expectations? The study will use the Mischel Illness Uncertainty Scale.

**Transfer pathways:**

Transfer for most patients is from the paediatric setting to the adult setting within the same hospital.

**Gap analysis:**

Chris is the only paediatric psychologist.

**Tools:**

None currently used.

**Evaluation/stakeholder feedback:**

There is no evaluation that Chris is aware of.

#### **4. Betty Bishop, BSN, Nurse Coordinator, Rheumatology**

Betty has worked in the rheumatology department for 14 years.

**Policy/procedure:**

There is no hospital policy or procedure for transition. Each specialty does what they want.

**Model of care:**

The rheumatology team includes:

- rheumatologists and one fellow [two further rheumatologists in Minneapolis]
- physiotherapist
- occupational therapist
- social worker [outpatient]
- psychologist [Chris Boyes].

When the patient reaches 18 years of age the expectation is they will commence self-management. They may continue to be treated by the team until 22 years of age. Education is given regarding medications and insurance. The patients are referred by the rheumatologists to Betty.

Currently, young people are still treated even if they are at a college in another state.

Generally have a back up plan with a local rheumatologist but this relies on them being stable. From 18 years of age a release needs to be signed by patient for staff to speak to parents. Usually from about 18 years of age the patient starts to be seen on his or her own.

The transfer to the new paediatric hospital [currently being built] may mean that the young person may feel more ready to leave paediatric care as they may feel the setting is inappropriate for their age.

There may be an advantage to transitioning within the same environment from a paediatric ward to an adult as is currently the case. Unfortunately there is very little contact between the paediatrics and adult rheumatologists. There are very few patients that don't have a family physician and they can have bloods done by the family physician with less specialist visits than required. With abnormal results, the results and recommendations are first sent to the primary physician for them to follow up.

**Transfer pathways:**

There is a rheumatology fellow who is doing her fellowship in paediatrics and adult training with the thought that she could manage the 16-22 year olds separately.

**Gap analysis:**

There is no hospital funding for transition.

**Key challenges:**

Medicaid health cover is available for only some conditions such as Lupus and most pts with juvenile idiopathic arthritis. Medicaid covers most of the medications including biologics. Lots of paperwork is required for Medicaid, which is resource intensive for Betty's role. It is not easy to get a young adult clinic going; it took the cystic fibrosis team 'forever' to get an adult clinic going.

**Responsibility/accountability:**

The hospital administration has transition somewhat, in a small part, on their radar.

**Tools:**

There are currently none used, but tools and checklists may be useful if they are not too onerous/tedious.

**Evaluation/stakeholder feedback:**

There is currently no evaluation or stakeholder feedback.

**Strategic planning:**

The team have plans to develop a timeline around transition. In an ideal world there would be commencement of an earlier transition timeline such as, start transition at 14 years, then by 18 years be independent, and then supported in independence until transferred to adult care.

## **Gillette Lifetime Specialty Healthcare**

**Interviews:**

Ronna Linroth, Manager, Adult Outpatient Services  
Becky Nelson, Social Worker  
Suzanne Constantini, Manager, Outpatient Clinic Services  
Robert Wagner, Program Medical Director

**Background:**

Gillette Lifetime Specialty Healthcare [Gillette] was established in 2001 to meet the needs of young people from the age of 16 years and adults who have conditions that limit their abilities, in particular cerebral palsy, neuromuscular conditions and spina bifida. The St. Paul-Phalen Clinic that I visited was opened in 2007. Gillette Lifetime Specialty Healthcare is part of Gillette Children's Specialty Healthcare that was founded over 110 years ago to provide care for children with complex needs and disabilities.

**Mission statement:**

The mission statement of Gillette is 'to meet the special health-care needs of people – primarily children and teens – who have disabilities and to help those they serve realise greater well-being, independence and enjoyment in life'. Gillette has eight centres of excellence for cerebral palsy, craniofacial services, gait and motion analysis, paediatric neurosciences, paediatric orthopaedics, paediatric rehabilitation, paediatric rheumatology and spina bifida.

**Model of care:**

Gillette have an integrated care model where clinic visits are coordinated to offer a multidisciplinary team approach including specialty physicians, nursing, social work, occupational therapy, physical therapy and assistive-technology practitioners. In addition, services such as diet and nutrition, chaplaincy, psychology, radiology, seating and speech pathology are available.

**Facilities:**

The facilities at Gillette are excellent with a therapy gym, therapy kitchen and treatment bathroom. Examination chairs, radiology equipment and lifting and weighing equipment are all designed to accommodate young people and adults with complex needs including wheelchair access.

**Transition program:**

Gillette has developed a transition program focusing on issues for young people with disabilities and complex needs such as legal, medial and independent living. The program commences at the age of 14 years with staff engaging the young person and their family in planning their transition from adolescent to adult care. If the young person is medically stable, they move to an adult model of care at the age of 16 years. All patients over the age of 18 years transition to adult care.

**Policy/procedure:**

An administrative policy for transition to adult services was developed in 2004. The transition procedure includes:

- an initial discussion about transition
- a transition resource folder 'Make your Move' for the young person from the age of 14 years that includes: an introduction to transition, health information, independence, relationships and sexuality, checklists, goal setting, resources and Gillette's transition philosophy
- assessment at the age of 16 years for readiness to transition to adult care
- staff are encouraged to have regular dialogue with transitioning patients.

**Tools:**

Transition matters also feature in Gillette newsletters for young people and families and 'A Paediatric Perspective', a Gillette publication for clinicians that focuses on specialised topics in paediatrics, orthopaedics, neurology and rehabilitation medicine.

**Evaluation/stakeholder feedback:**

The evaluation process at Gillette includes a satisfaction survey that is conducted in the outpatient clinic.

**Documentation obtained:**

- Gillette Lifetime Specialty Healthcare: St Paul-Phalen Clinic - booklet
- Growing Older: For adults with a History of Polio – booklet
- Growing Older: For adults with Cerebral Palsy – booklet
- Growing Older: For adults with a Neuromuscular Condition – booklet
- Growing Older: For patients with Spina Bifida – booklet
- Pain Management: a patients guide – booklet
- Family Focus: A newsletter for Gillette Patients and Families
- Assisting in the Transition to Adult - Focused Health Care: What Paediatric Providers Can Do, Wagner 2007
- Make Your Move! A transition Guide for Teens
- Outpatient Clinic Survey
- Staff Competency Checklist; Lower Body and Foot Evaluation
- Independent Living Evaluation
- Social Services Request Form
- Administrative Policy: Transition to Adult Services – Gillette Children's Specialty Healthcare

## Toronto, Canada

### Bloorview LIFEsan Program

Special thanks to Carie Gall for facilitating my visit and despite her hectic schedule as part of the Independence Program, finding time for an informal chat over lunch.

#### **Bloorview Kids Rehab:**

Bloorview Rehab is Canada's largest children's rehab hospital and is a specialised hospital for children and young adults with disabilities and acquired brain injury. It is a teaching hospital that is affiliated with the University of Toronto. It treats more than 7000 children with more than 600 inpatients per year.

#### **Toronto Rehab:**

Toronto Rehab is Canada's largest academic hospital specialising in adult rehabilitation. It has five sites across Toronto and has 575 inpatient beds and nearly 150,000 outpatient visits annually.

#### **The LIFEsan service model [as summarised from the program's literature]:**

- **partnerships** with the client, family and other health care and community providers – increasing the capacity of the client, caregivers and the community with respect to the management of childhood onset disability
- **age appropriate services** that focus on preparation for, access to, coordination of, and continuity of service across the Lifespan for persons with chronic disabilities with onset in childhood [congenital and acquired]
- **developing and sharing expertise** in the management of the chronic health care needs of persons with disabilities of childhood onset.

The LIFEsan service model has three main aspects:

1. **Growing up ready:** evidence-based, auditable framework that ensures all youth and families have access to comprehensive supports that starts early to help youth grow up ready for transition to adult life. It provides a coordinated pathway developed through evidence based practice by introducing tools such as timetables for growing up to families, and working with Bloorview staff to integrate a shared management approach and to put resources into practice.
2. **Transfer services:** a transfer clinic for 16-18 year olds with the long-term goal of improving readiness of clients and their families for transfer to adult programs, services and supports. The transfer clinic process is supported by the philosophy of shared management [Wagner 1998].
3. **Adult services:** this model is a shift in practice from acute management to the chronic care model. The chronic care model focuses on: improved patient self-management, planned visits, strong links with the community, care coordination between facilities, development of expertise in the client and improvement of primary care.

### 1. Shauna Kingsnorth – Evaluation of LIFEsan Project

#### **Background:**

A few years ago, there was an opportunity to submit a research proposal for an evaluation of the LIFEsan Project. The evaluation would mainly look at process and outcomes. The proposed evaluation project received funding in September 2008. Prior to that there was a pilot and partial clinic leading to transfer at 18 years but not a full program in place.

The previous pathway for these patients prior to the LIFEsan Project was transfer to Sunnybrook [Adult Health Service]. This service is not multidisciplinary and has a year waiting list. Patients also saw their family physician for management. Bloorview Children's Rehab has been in the new building for three years.

#### **Research outline:**

The research outline is:

- to follow a cohort of 16 year olds from September 2008 for three years until one year post transfer
- the cohort will be taken from young people with cerebral palsy and acquired brain injury and will be a prospective study

- spina bifida is the condition used as comparison as well as forming a retrospective group
- the main focus will be the LIFEsplan model
- the main outcome measure will be continuity of care.

Plans are for traumatic brain injury and spina bifida as the next group to be rolled out. The evaluation will be looking at a two-year window and will include topics such as self-efficacy, advocacy, health status, and quality of life, number of emergency visits. Tools utilised will be surveys and qualitative interviews with the young person and their parents at one-year post.

There will be a number who will not be able to self-report. Currently there are no statistics on the numbers engaged in adult services who have been transferred from Bloorview. The evaluation projects commenced in September 2009.

#### **Cohort:**

The cohort will be one year into the LIFEsplan Program and will consist of:

- 60 patients with cerebral palsy
- 40 patients with acquired brain injury
- 25 patients with spina bifida.

The cohort will have normal attend annual visits but one additional visit of three to four hours will be required for project.

#### **Data:**

There will be multiple baselines. Process evaluations will include checks as to whether patients received program specifics. Work will be done with the team about their experience in running the program and perceived enablers and barriers.

#### **Project specifics:**

The evaluation project is funded by the Ontario Neuro Foundation. The principal investigators are Mark Bailey [Physician] and Colin McCarthur [Director]. There will be a team of five scientists and a research assistant has been hired. Shauna is the Research Coordinator [part-time]. Further resources are available for a biostatistician, qualitative interviews, transcription etc. Recruitment period will be 12 months.

## **2. Dolly Menna- Dack- YAC, Youth Facilitator**

### **Family and youth facilitator roles**

The family facilitator role was set up in 2004 and is partially funded by the occupational therapy budget. A discussion about the role of a youth facilitator was first held at the transition conference in 2004. It is the shared experience between the youth facilitator and the young person not the disability/condition that makes the connection. This role is now part of the clinic. The mentorship program is a separate program.

The youth facilitators come from two departments:

- two days per week from the Lifespan Program
- one day per week from the Lifeskills & Wellness Institute.

The role is available to all Bloorview clients, families, and staff as a resource. It is a resource to help, and give opinion. It is a paid role in recognition that it requires professional understanding of the organisations resources. It also requires putting ones own needs aside. It is a role valued by the organisation.

Dolly has also served on the Youth Advisory Council for 13 years as a volunteer and also has a role as a clinical facilitator.

### **Resource desk**

Set up one day per month – information clinics run with Dolly. It is paid for by the Lifeskills budget. The resource desk is set up in the waiting area, and allows Dolly to talk to clients, families, staff etc. Dolly introduces herself by asking about Lifeskills topics and whether they have seen them. An opportunity for role modelling that employment is obtainable. Consultations can be long – up to 40 minutes.

### **Other initiatives:**

- lifeskills training, camps etc
- competency training – 'Do they understand the consequences of the decision they are going to make'. Accreditation required by every researcher. On-line course requirement of approximately one hour. Test with certificate given
- 'Your life as an adult' – mailed to every 16 year old seen in the last two years. Not sent to autism patients, as there is no intervention at Bloorview for autism, only diagnostic
- poster presentation 'Can adults decide?'

### **Youth at Work**

Sessions held during orientation, such as transferable skills. Mentorship provided including private discussion with 'Youth at Work' participants. Dolly engages them from their first visit. They must consent to the program and have an explanation of the risks and benefits. The participants give verbal consent. The program was set up five or six years ago.

### **Youth Advisory Council [YAC]**

There are 15 members on the YAC. Generally eight to twelve members attend each meeting. Members are current/past clients of Bloorview [16-29 year olds] and meetings are held September to June on a monthly basis on a Saturday for 2½ hours. One staff member attends to the minutes [non-voting]. The staff member can also provide clarification when necessary. The executive are a chair, vice chair, treasurer, public relations x two [one goes to the Family Advisory Council]. Membership is voluntary. The YAC acts as a sounding board to staff, clients and the community. Guests can come for 30 mins to present their project then the YAC provides feedback. There is no charge for this service. For larger projects and more consultation, there is a fee of \$10 per hour and public transport costs charged, per member of the focus group.

The YAC is very well respected and utilised at Bloorview. It has provided representation on the new building project, the Branding Committee, the Awards Committee, the Evaluation and External Review Committee, the Family Advisory Council, Accessibility Committee, and the Patient Safety Committee. To vote, members have to attend seven out of ten meetings and pay \$2.00 per meeting. Snacks are supplied. The chair is voted in annually and Dolly is the youth link between the organisation and the YAC. There is a set agenda, signed off by the chair and the staff support member. Speakers are also booked.

## **3. Cross appointed staff [Bloorview Rehab and Toronto Rehab] - Andrea, Christine, and Dolly [Nurse Practitioner, Social Worker and Youth Facilitator]**

The team see an inpatient group of 75 patients from the dental and orthotics/prosthetics departments [fee for service] and provide communication and writing aids. The team has a one-year cross appointment between Bloorview Rehab and Toronto Rehab. The two services are situated on the same campus. The partnership with Toronto Rehab has been in place for one year.

The Child Development Program [CDP] involves a director and two managers. The three staff are involved in LIFEspan, in the neuromuscular and specialty clinics [such as Botox] and they also participate in the LIFEskills and Wellness Institute, which has activities such as creative art, aquatic and therapeutic recreation. There is a school program onsite that is fitted around the therapeutic program. Respite care is also provided for newborns to 18 years of age.

All Bloorview referrals are already engaged with a physician and have had a consultation regarding practical changes across health, education, and the funding spectrum. At Toronto Rehab there are individual clinic assessments and follow up regarding needs. Some patients don't have primary healthcare due to lack of resources and/or complexity. Education is provided for the young person and their families. Currently there is a hypertoniaspasticity clinic being established.

The main differences between the two programs are age, legality [privacy] and funding.

- Legality: in Ontario, consent is based on an assessment of capacity and capability to consent for each intervention. Issues also include consent to discharge and referral options. The issue of consent is confronting for families.
- Age criteria: Bloorview Rehab provides services 0-18 years of age. The LIFEskills Program is up to 29 years of age. Students are treated up to 21 years of age.

- The Hospital for Sick Children [SickKids] is very strict about age criteria.

There has been an evaluation of the gaps in adult services.

### **LIFEsplan**

LIFEsplan acts as a clinic. There is an adjustment from routine clinic practice around psychosocial aspects. LIFEsplan works around the routine clinics that the young person attends. Engagement begins at 16 years of age. There are four visits between the ages of 16-18 years at LIFEsplan and they then transition to the rehab team, which includes a coordinator, doctor, physiotherapist and occupational therapist.

Cross appointment mainly means a geographical change within the campus. LIFEsplan clinic patients are engaged at Toronto Rehab for life. They have annual visits.

The clinical teams include:

- Bloorview team – four in the team; coordinator, three cross appointed staff
- Toronto Rehab team – four in team; doctor, physiotherapist, occupational therapist and one cross appointed staff member.

There are pre-clinic meetings held where all patients are discussed and planning takes place.

## **4. Bronwen – Occupational Therapist**

### **LIFEsplan**

Young people transfer three months after their last paediatric appointment. The first appointment is approximately three hours long. It includes:

- introduction
- explanation of the service
- establishing of goals
- engagement.

After this initial appointment they then have annual appointments. The total number in the program is 90-100. Approximately ten are currently actively engaged.

### **My Health – transition to adult health care**

A seven week program with one appointment per week for two hours. Young people are offered the program from the age of 16 years. The program includes:

- consent
- advocacy
- appointment
- documentation
- describe condition.

Bronwyn and Christina set up the program and currently run it. They hope to get some role modelling with young people's involvements that have been through the program.

### **General program issues:**

- recognising that although the client's medical/system knowledge is extensive, their life/social knowledge may be low
- the diversity of clients leads to a generalist approach
- recognising that there is time for goal achievement, not everything needs to be accomplished in the first appointment
- the team approach – monthly process meetings for the whole team.

## 5. Joanne Maxwell – Coordinator LIFEsan Project

### Policy/procedure:

There is no hospital wide transition policy at Bloorview Rehab or Toronto Rehab.

### Model of care:

A key advantage of the program is the geographical proximity between Bloorview Rehab and Toronto Rehab. The two facilities share common values. The program has CEO and senior clinical team support. The LIFEsan program started as a transition project. It is based on a chronic model of service provision that is provided to the client when they are not in the acute phase. There is starting to be a shift to planned care. Referrals have to come from Bloorview.

### History of the program:

- November/December 2006 – demonstration model with approximately 30 clients
- January 2008 – some funds provided to make physical changes.
- April 2008 – full funding granted
- August 2008 – team in place
- November 2009 – proposal for expansion to spina bifida and neuromuscular conditions.

### Key challenges:

It may be difficult to prove the cost effectiveness of proactive planning.

### Key enablers:

- executive support
- patience
- consultation
- a committed team
- knowledge of the key elements of the model of care
- opportunity sourced in finding an institution to collaborate with
- new opportunity for funding.

### Unique elements:

- some borrowing from Gillette Lifetime Specialty Healthcare
- preparation piece around ‘Growing Up Ready’
- education of all staff
- one hour staff orientation around ‘Growing Up Ready’.

### Barriers:

- perception around level of disability
- adjust services to make age appropriate
- concerns around expertise.

### Strategic Planning:

- capacity build to accept community referrals [currently must come from Bloorview]
- ability to refer to community occupational therapist and physiotherapist to ease capacity issues
- use of a phone consultant.

### Documentation obtained:

- Welcome Letter to LIFEsan Services
- Information sheet for clients and families at Bloorview Kids Rehab
- Measure of Processes of Care for Parents

- Feedback Form for LIFEsan Services
- Youth Facilitators – poster presentation
- Toronto Central LHIN LIFEsan Progress Report 2009
- The LIFEsan Service – PowerPoint presentation
- LIFEsan Clinic Visit Questionnaire – draft
- LIFEsan Project Charter, 2009
- The Development of a LIFEsan Model of Care overview
- Orientation Package – Neuro Rehab Program
- Transition to Adult Services Project Business Plan Proposal for LIFEsan Services, 2007
- The Independence Program – brochure
- Living Independently Fully Engaged – brochure
- Consensus on best practices for transition to adult services – summary of pre-conference workshop, 2006
- Your Life As An Adult – Think About It ... - brochure
- A Timetable for Growing Up – brochure
- Developing the Skills for Growing Up – Getting Started
- Developing the Skills for Growing Up – On My Way
- Developing the Skills for Growing Up – Almost There
- Guidelines for Service providers in using the Skills for Growing Up Checklists
- Across the LIFEsan – The Canadian Experience of Developing A Lifespan Model of Care – presentation paper
- Health Professional Checklist – Developing the Skills for Growing Up
- Growing Up Ready: A Shared Management Approach – Gall, Kingsnorth, Healey 2006

## **6. Dawn Lunan – D.O.O.R [Disability Ontario Online Resource] 2 Adulthood Website [phone conversation]**

Dawn is a parent of a 13 year old child with a disability. She has volunteered as a Family Facilitator as part of the LIFEskills Program and created a company related to disability services. The Door 2 Adulthood website started as a research project a number of years ago. In 2007 the project restarted with a great deal of work being done on the content. Further work is needed, in particular an overhaul of the graphics, technology and search mechanisms.

The resources on the website are designed as a starting point for anyone with a disability. It is also a resource for families and health providers. It is currently independent so the content can be a little more 'out there' and allowing more scope to tackle sensitive and real issues around sexuality, body image, dependencies, frustrations.

<http://www.door2adulthood.com>

## **7. Door 2 Door Program**

### **Program level 1**

This program gives young people with disabilities the opportunity to have work placements in Bloorview and Toronto Rehab in areas such as transport, reception, finance, and security. There are around ten participants in the program. Eligibility is from the age of 15+. Two groups run over summer; July/August and August/September. Meetings are held after placement for evaluation and social contact. Then, over spring break, they have a one-week placement that can be outside Bloorview. A phone interview is used as part of the selection criteria. Wages are provided by funding from Capital 1 [Finance Bank].

### **Program level 2**

A six-week program with a focus on greater independence. Currently there are only a small number of participants.

## 8. The Independence Program – Kim Jones – Galley and Carrie Gall

### The Independence Program [TIP]

This innovative program is a three-week live in program for young people with any type of physical disability. An interview is required to secure a place in the program. The aim is to learn the skills necessary for independent living such as shopping, public transport.

Participants must be [as taken from the program brochure]:

- aged 17-21 years
- willing to work on goals related to independence
- able to identify personal care needs
- motivated to participate
- making a transition to college, university, employment or an independent living opportunity.

Participants live in a university residence in downtown Toronto. Topics covered include:

- Sessions:
  - goal setting
  - street smarts
  - city survival
  - attendant services.
- Activities:
  - dinner out
  - reunion
  - wheelchair sports
  - exploring Toronto.
- Practicals:
  - grocery shopping
  - cooking
  - laundry
  - banking.

'...for three weeks, we essentially live our lives as able-bodied people. We are relatively unsheltered for all that time. The program really goes far beyond teaching us how to book attendant care; it teaches us that it is possible to live like ordinary people, despite our disability.' – Dan DiPoce, program participant 2006.

A graduation participant/parent brunch is held as well as an evaluation at the end of the program.

## Good 2 Go Transition Program, Hospital for Sick Children [SickKids]

### Interviews:

Geraldine Cullen-Dean, Clinical Nurse Specialist  
Miriam Kaufman, Adolescent Paediatrician  
Elizabeth Dettmer, Psychologist, Program Lead [via email]

### Policy/procedure:

SickKids does not have a generic hospital transition policy. The Good 2 Go Program works with individual departments to develop transition procedures and programs. The Good 2 Go transition team has developed a set of tools that can be used by the different hospital clinics/programs. The team often consult with them on setting up a procedure and how to customise the tools for their particular patient population.

**Model of care:**

The Good 2 Go Team was put together to facilitate transition in the adolescent medicine department and the hospital as a whole. The team is comprised of providers from psychology (0.8), nursing (1.6), social work (no dedicated time), and medicine (no dedicated time).

Most programs use their regular clinic space. The Good 2 Go Team has office space and shared meeting space but no specific transition program space.

The program relies heavily on the theories of shared management and self (or optimal) management. All of the team members specialise in the care of adolescents and the tenets of self-management are woven into the base of all of our tools/procedures. It is a small transition team (housed within the Adolescent Medicine Department at the Hospital for Sick Children) dedicated to aiding teams throughout the hospital improve and increase transition interventions.

The team develop transition tools, consult with department teams, and engage in transition research. The Good 2 Go Team reports directly to their administrative director. Each of the programs/clinics reports to their department head and administrative managers. At the moment there are lots of differences in how the program functions within various specialties. The program is about identifying champions and bringing others on board, empowering teams with them driving and designing the transition process for their department.

The transition team is now looking at the more resistant departments and what the challenges are. They describe the state of transition in their organisation as growing rapidly. The definition of overage at SickKids is over 18 years of age. This policy is overseen via patient registration procedures, although this data is flawed as some programs check in parents that are most often above 18 years of age.

**Evidence base:**

The Good 2 Go Program is based on the shared management model developed in Seattle, Washington. The model describes the development of an early therapeutic alliance between the children/youth, families and health care providers as being essential to allow young people with chronic conditions to develop into independent, healthy, functioning adults [Kieckhefer and Trahms, 2000] – Good 2 Go website. In 2004 a planning day was held prior to the set up of the program.

A full list of research activities can be found on the program's website. They are collaborators and consultants on several projects throughout the hospital and are the principal investigators of a Kidney Foundation of Canada grant in which youth are being asked to aid the team in developing a youth friendly self-management program.

**Transfer pathways:**

The program is in the process of developing a transition (not just a transfer) pathway. They hope to employ a computer programmer to help them create a system that can be integrated with the hospital data system to allow for easy access to all health care providers.

**Gap analysis:**

There is a lack of adult health care providers for patients over the age of 18 who are living with conditions such as phenylketonuria [PKU], spina bifida, thalassemia, and genetic metabolic conditions. Other gaps are related to work force or dedicated staff time.

**Enablers/barriers:**

The key barrier to effective transition in the various departments is staff time. In the Good 2 Go Program the entire team are enablers for transition. In programs throughout the hospital it has mostly been a combination of medical doctors, nurses, and social workers. Physicians are, in general, very supportive of the philosophy of the transition program but may give issues around patient flow and clinic time. There is a high level of executive support, however financial resources are limited.

**Key challenges:**

The key challenge currently for the program is staff resources, primarily time.

**Responsibility/accountability:**

Performance indicators for the Good 2 Go Team include:

- number of teams consulted
- number of transition tools customised/developed

- family/patient satisfaction with the transition process
- health care provider satisfaction with the transition process
- number of new collaborations and improved transfer procedures with adult healthcare centres.

As far as the team are aware, transition is not written into their institution's and department's business plan. Transition is written into the Good 2 Go Team position descriptions.

#### **Tools:**

Tools that the program uses include:

- the Good 2 Go website – [www.sickkids.ca/good2go](http://www.sickkids.ca/good2go)
- graduation certificate
- clinic transition letter
- transition clinic evaluation form
- readiness checklist for parents
- readiness checklist for adolescents
- timeline
- timeline survey
- My Health Passport
- 3-Sentence Summary.

#### **Evaluation/stakeholder feedback:**

The program strongly encourages all hospital teams to evaluate all transition initiatives. The type of evaluation that is used varies. Some examples are: patient/family/provider satisfaction, attendance at the adult healthcare centre for the first or several appointments, health indicators, utilisation of self-management skills, and level of transition/self management knowledge. Evaluation/reporting tools used include: transition readiness questionnaire, satisfaction questionnaire, chart review of attendance at appointments and chart review of health indicators.

The opportunities for stakeholder feedback include a Youth Advisory Committee with whom the team meet with three to four times per year. They also work closely with healthcare providers from both the child and adult healthcare systems. Customer feedback is integrated into the improvement of transition tools and procedures.

#### **Strategic planning:**

The key strategies and implementations that would enhance transition practice in the hospital include: computerised pathways that could be integrated into the hospital patient records so that health care providers across the centre could access clear customised guidance on needed transition interventions for each patient visit. The immediate and long-term goals for transition for the program are to expand the number of programs within the hospital that are implementing high quality transition interventions. They are currently developing a transition certification system for individuals and teams within the hospital.

#### **Documentation obtained:**

- The Good 2 Go website – [www.sickkids.ca/good2go](http://www.sickkids.ca/good2go)
- Graduation Certificate
- Clinic Transition Letter
- Transition Clinic Evaluation Form
- Readiness Checklist for parents
- Readiness Checklist for adolescents
- Timeline
- Timeline Survey
- My Health Passport
- three-Sentence Summary
- Good 2 Go Resource Manual - 2009

\*\* Special thanks to Nelson Paiva from Public Affairs who gave me a very informative and extensive tour of SickKids. Thanks also to Tricia Williams, Clinical Psychologist, from the Stroke Unit, with whom I had a great chat over a lovely meal and who gave me a tour of Toronto.

## Florida, United States of America

### JaxHATS - Jacksonville Health and Transition Services

#### Interviews:

Dr David Wood, Director  
Ramonía Diallo, CMS Care Coordinator

The JaxHATS program was created in 2005 to establish a 'medical home' for all youth and emerging adults with physical and emotional health conditions or developmental or cognitive disabilities in Northeast Florida. JaxHATS provides primary care, health care, transition education and active learning experiences as well as support for transition in education, vocation and independent living [taken from the program information].

#### Vision:

It is the vision of the program that all youth 16-26 years of age, and especially those with chronic health conditions, have access to and receive high quality medical care, regardless of ability to pay, and that these health services, in coordination with the educational and vocational systems, help them achieve a successful transition to a productive adulthood [taken from the program information].

#### Model of care:

JaxHATS is based at the University of Florida Shands – Jacksonville Health Science Centre. The clinic is run on a Tuesday and Thursday. The members of the multidisciplinary team are: a primary care paediatrician, a primary care internist, a nurse coordinator, a social worker and a youth liaison. They also have AmeriCorp Volunteers, a role from the University of Florida for one year placements of on the job training for premed students who assist with the vocational/education care system, and advice on practical supports. The Children's Medical Services [CMS] fund the nurse role.

Referrals come from a range of hospitals not just from Shands [located next door]. The clinic referrals come from a large geographical spread and CMS and other paediatric services also refer.

Team meetings are held weekly or fortnightly to discuss transition readiness checklists, care plans etc. The age criterion currently for the service is 16-26 years, with plans to extend to 14 years. Patients with the following chronic conditions are seen at the clinic: spina bifida, cerebral palsy, muscular dystrophy, sickle cell, cystic fibrosis, down syndrome, autism, developmental disabilities, mental health disorders, diabetes, chronic endocrine conditions, congenital heart conditions and inflammatory bowel disease. Partnerships are slowly being built with adult services such as the spina bifida adult services.

Services provided by JaxHATS include:

- coordinated and comprehensive primary medical care
- referrals to adult sub-specialty physicians
- nurse care coordination
- transition readiness assessment, planning and education
- medical insurance assessment, education and referral
- assessment of and assistance with educational and vocational needs
- rehabilitation/independent living services linkage
- linkage with other community service providers.

Patients are booked in 30-minute blocks but may stay for two hours seeing the whole team. The time for each patient is not rigidly defined in advance but is based on the needs on the day. The clinic also has a high 'fail to attend' rate which makes resource planning difficult. The clinic may be moving to a larger space with more providers.

**Evidence base:**

The following papers help inform the practice of the clinic:

- Transition to Adult Health Care for Adolescents and Young Adults With Chronic Conditions-Position Paper of the Society for Adolescent Medicine 2003
- Implementing Transitions for Youth With Complex Chronic Conditions Using the Medical Home Model, Kelly et al 2002
- Between Two Worlds: Bridging the Cultures of Child Health and Adult Medicine, Rosen 1995
- Transition for Youth With Chronic Conditions: Primary Care Physicians' Approaches, Scal 2002
- A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs, American Academy of Paediatrics et al 2002
- Transition from paediatric to adult care: Bridging the gaps or passing the buck, Viner 1998

**Gap analysis:**

There is a big gap in the state, and nationally, for services and funding around complex needs such as cerebral palsy. There is a complete lack of resources on the adult side. The 'Primary Care Track' involves care in a group home for severe disabilities. There is no funding for psychology but there is funding for psychiatry. Most mental health patients end up in the juvenile justice system. The South Florida model 'Transition to Independence' is used with a visit to JaxHATS every three months.

**Key challenges:**

The clinics clients come from a low socioeconomic area. There are significant issues with school dropout, teenage pregnancies etc. A number of the patients have learning issues with resulting unemployment.

Funding is a huge issue with health care in Jacksonville, especially with limited resources in the poorer areas. Programs are run by a non profit/ private system but it is owned by the city. The city awards contracts for care that is for one year but can be renewed. Each state handles health gaps differently. It is important to know what funding patients have and as a result what services they can access. The non-insurance rate in Florida is 30 per cent in the general population and 60 per cent in the poor population. Florida rates last in most health care areas. There is extreme wealth in the retiree population, who do not want to pay taxes. The company Wal-Mart pays no taxes in Florida.

**Responsibility/accountability:**

It is a struggle to find the time to review the readiness checklists and update care plans.

**Tools:**

A systematic intake has been developed as well as checklists for readiness and questionnaires for the young person and their parent/carer.

**Evaluation/stakeholder feedback:**

An ongoing evaluation and quality improvement program is conducted using client outcome measures, such as enhancing skill development in disease self management and education/vocation and other transition activities.

**Strategic planning:**

One goal is to meet with the paediatric, adult and multidisciplinary teams to develop a regional plan.

**Documentation obtained:**

- Reasons to call your JaxHATS Nurse Care Coordinator and Emergency Room Procedure
- JaxHATS Program Information Leaflet
- Middle - Older Adolescent Questionnaire
- Parent/Guardian Questionnaire
- Agency for persons with disabilities Fact Sheet
- Transition Readiness Assessment Questionnaire 3.0
- Transition Readiness Assessment Questionnaire 4.0 [condensed]

## Shands Children's Hospital, University Of Florida

### 1. Professor John Reiss, Associate Professor of Paediatrics

John Reiss, PhD, is the Associate Professor of Paediatrics and Director of the Health Care Transition Initiative at the Institute for Child Health Policy at the University of Florida. Since 2002 he has served as PI on a contract from the Florida Children's Medical Services Program to develop a web-based health care transition training curriculum for CMS nurses, assess current health care transition practices in the state and develop transition training materials for youth and their families.

#### **Policy/procedure:**

There is currently no transition policy in place for the hospital. Inpatient Care has an access policy that addresses age criteria for treatment and admission.

#### **General overview:**

The Shands Children's Hospital, University of Florida is a paediatric hospital of 164 beds within the adult hospital.

Any model of care needs to recognise that transition doesn't end at transfer – the importance of transition continuing after the young person transfers. It is also important that the adult orientated physicians acknowledge the needs of the adolescent.

Family medicine care needs to be in an outpatient and in the acute setting for the inpatient.

Cystic fibrosis has a transition program and the CF Foundation requires a transition program to give accreditation. This is a peer review accreditation rather than having a monetary value per se. About ten years ago it was mandated that there must be an adult component in transition programs.

The Congenital Heart Disease – American College of Cardiology have guidelines from 2000 that include transition. In addition, the paediatrician for cardiology at Shands supports transition practice. Shands Children's Hospital is currently developing a formal overage policy:

- up to 18 years: paediatrics
- 18-21 years: paediatrics or internal medicine as deemed most appropriate for the patient's condition
- 21-23 years: not to go to paediatrics unless in rare circumstances.

There will also be a developed overage exemption process. The paediatric registrar is reluctant to look after patients over 21 years of age. Transition doesn't sit anywhere in the organisational structure. The Department of Paediatrics is not willing to fund a transition coordinator position. Children's Medical Services have prioritised transition in the last year.

#### **Evidence base:**

One example of a successful model of care is the Building Connections: The Maestro Program. The program was established in Manitoba, Winnipeg in 2002 for young people with Type 1 and 2 diabetes. Key aspects of the program are a helpline, giving young people the ability to talk to their peers, and monthly dinners with the provider and the young person. They had an increase in visit attendance as a result. Funding has been received for two pilot studies – one in Pensacola, the other using existing working groups. These studies will involve health planning councils and working to develop community based supports.

#### **Enablers/barriers:**

Communication between adult and paediatric clinicians and services has not gone on in any structured fashion. Paediatric clinicians like to know what happens to their patients. This could take the form of being copied in on letters post transfer.

Currently there is a push to set up a separate children's hospital. Shands Children's Hospital serves a 100-mile radius catchment area. There is some complexity around adult referrals and geographical location.

**Key challenges:**

Engaging adult physicians is a problem and presents a key challenge.

**Tools:**

CMS [Children's Medical Service] have funded a lot of material that John has developed. A report on transition was requested by the state legislature and they then mandated a taskforce [CMS and Medicaid]. John participated in drafting the recommendations, which he feels are very positive. The taskforce report came out in December and continues to work and meet. John is adapting some of his training material to allow continuing medical education credits for this material [CMS].

**Evaluation/stakeholder feedback:**

The 18-24 year old group have the highest rate of non-insurance. Anecdotally this is given as the leading reason for drop out but there is no data to quantitate this.

**Documentation obtained:**

- Health Care Transitions: Web, Video and Print Resources – John Reiss, PhD, Health Care Transition initiative, The Institute for Child Health Policy

## 2. Streetlight Program

**Interviews:**

Rebecca Brown – Streetlight Director

Rebecca Brown developed the Streetlight Program in 2006 for adolescents and young adults being treated at Shands with cancer, cystic fibrosis and sickle cell disease. The aim is to create a TEENZONE on each paediatric unit. There are six inpatient rooms that have been decorated with teen themes. There are two double rooms and a music room. The basis of the program is partnering and companioning. Rebecca's role is externally funded.

**The team:**

The Streetlight Team is a multi-ethnic group of more than 60 University of Florida students selected through interviews, recommendations, and eight hours of special orientation on adolescent psychosocial and health issues, palliative care, end-of-life care, and the three primary disease populations they serve. Team members are aged 18-22 years, and most are pre-med students. Each team has a captain and is closely supervised by the director with daily briefing, education, chart writing, monthly rounds and discussion. The expected commitment is three hours minimum per week. Some of the team visit every day.

Currently, there are approximately 50 on the waiting list to become part of the team. The volunteers have a lot of ownership of the program. The intention is for them to commit for the long term, not even for just a year. Applicants are sent an initial 'somewhat discouraging' letter to weed out those who are not serious. The volunteers have team nights, with their individual teams of six. As a group they are very bonded and take it very seriously. There is a two-page application letter and interview required and they must have a recommendation of someone who knows the program. The volunteers work afternoon or evening shift.

**Programs/services provided** [from Streetlight website]:

- Patients aged 13-22 years – we will try to find and offer you movies, video games, magazines, and an invitation to Teen Lounge (Monday through Thursday) regardless of your reason for being at Shands.
- Room Bound Patients – we will take the necessary gowning precautions and offer you movies, video games, and some companionship if you want it.
- Beyond movies and video games, we have books, magazines, beading and crafts, CDs, CD players, Puzzles, Sudoku, journals, posters, and Streetlight tee shirts.
- Patients who make more than four return visits to Shands – we consider you a frequent flyer, and make a special effort to get to know you, make a ShandsSpace with you (identity profile), and provide whatever support you need at the time.

- Patients treated for cancer – we hope you will find a few team members with whom you make a connection. It is great to have friends you look forward to seeing when you come in for chemo.
- At the end of your chemotherapy treatments, you have the option of having an END OF CHEMO [EOC] party where nurses, doctors, friends and family are invited to celebrate this marker in your health care journey. We also help you write a bio that tells your own story with cancer and has pictures you wish to include. Some EOC parties are all about playing Rock Band. Others are all about the food and cake. It is whatever you want it to be. We are beginning an association with the organisation i2y - which will provide added support for teens 15-years-old and older with cancer.
- Patients with a sickle cell pain crisis – we will make sure you are visited by some Streetlight members on our Sickle Cell Team. This team has a greater understanding of and empathy for the sickle cell young person and the obstacles they encounter.
- This team is headed by Fariza Alendy, who works closely with Dr. Levette Dunbar, to raise awareness, to assist in Sickle Cell transition to adult care and to help provide a supportive outpatient community for get-togethers. Our vision for supporting Sickle Cell patients is just beginning. We know we need to raise awareness, but also to raise hopes and spirit in the SCD population. We're working on it.
- We encourage sickle cell patients to visit the Stop the Sickle Cell Cycle YouTube channel to view inspirational videos.
- Cystic fibrosis patients at the hospital for a 'tune-Up' – we know this can sometimes mean a couple of weeks being room bound. We feel for you and will make every effort to visit you and help make the time pass faster. We will, of course, observe the precautions for infection control. With your doctors permission you are welcome in the Teen Lounge with a mask/gown. We also have created a special invitation only CF website to allow CF teens to interact while room bound or at home.
- Cystic Fibrosis Patients Transitioning to Adult Care – you will want to be a part of our CF transition program. Thanks to a generous donor we are developing a transition program that celebrates the move from paediatrics to adult care, with a graduation dinner, a yearbook and a personal video that walks you through the adult care system at Shands. This donation also enabled us to develop the CF website, which will feature transition patients, among other things.
- Transplant patients – sometimes transplant patients wait a long time for their transplant to come through and then more time for post transplant recovery. We usually have a few team members that focus on our transplant patients, so you get used to just a few team members.
- Patients in the hospital for long term care – we will be sure to support you. Long term admissions can lead to depression and despair. We will help keep your spirits up, and provide company and diversion - whatever it is you need.
- Patients in the Paediatric Intensive Care Unit – we will visit you if we have known you from previous visits, or if we are asked to see you by a doctor, nurse or social worker.
- Patients on other floors – if you are located on other floors because there is not room on the paediatric floor, or because you are in the process of transitioning to adult care, you can call us, or we may find you and will provide what we can to make your stay better. Some of the TVs on the adult floor do not take movies or video games. But hey, we can always watch American Idol with you!

The team have also developed 'Voicebox' – a cystic fibrosis Facebook type site. The background of the site changes according to the weather. The team engaged college-age students to help develop the website. The program has also initiated 'Yearbooks – transitioning online'. This includes photos of the clinicians from the adult setting which are non-clinical, such as scuba diving, holiday, with a few words about themselves. They have a graduation dinner with their favourite paediatric clinician and a clinician from the adult service. The restaurant due to a personal connection funds half of the dinner.

Identity posters can also be created by the young person and displayed outside the room. The medical staff appreciates that they can talk about something of interest with the young person. It also importantly helps to preserve their non-medical identity. 'SHAND Space' involves a plan to have nurse and doctor profiles updated and available to the young person to know who their staff is. A suggested project for paediatrics is to have baseball cards with the doctor's pictures and names.

Streetlight continues to engage the young people after transfer. The length of time that they are engaged in the future has not yet been decided. Rebecca, as Director, supports the volunteers, and keeps social work and the clinicians in the loop. There are no major concerns from the hospital administration as to responsibility/legalities. The legal department gave the program a 'need to know' status so they can know the patients diagnosis and discuss issues

within the group for support. There has been limited evaluation of the program with qualitative interviews conducted with five of the pre med students conducted so far.

## Sharing and promoting the project

This report will be used to disseminate and share detailed site information and recommendations with interested parties at the Victorian Department of Health, The Royal Children's Hospital, state-wide health services, and to the many clinicians and researchers I visited during the travel phase.

It is my hope that this report will inform those in the field of transition of the current transition landscape and highlight some of the innovative and exciting programs and research initiatives that I was fortunate enough to visit and observe. An overview of my travel experiences and findings has been presented to The RCH Transition Advisory Council and on a less formal basis in interactions and discussions with my fellow clinicians in the course of my work.

## Websites

### **Simmons House:**

[www.simmonshouse.org](http://www.simmonshouse.org)

### **UK Department of Health:**

[www.dh.gov.uk/en/index.htm](http://www.dh.gov.uk/en/index.htm)

### **University College London Hospital:**

[www.uclh.nhs.uk](http://www.uclh.nhs.uk)

### **Great Ormond Street Hospital:**

[www.ich.ucl.ac.uk/health\\_professionals](http://www.ich.ucl.ac.uk/health_professionals)

**Evelina Children's Hospital:** [www.guysandstthomas.nhs.uk/services/managednetworks/childrens/evelina](http://www.guysandstthomas.nhs.uk/services/managednetworks/childrens/evelina)

### **Adolescent Health e-learning UK:**

[www.e-lfh.org.uk/projects/ah/index.html](http://www.e-lfh.org.uk/projects/ah/index.html)

### **Birmingham Dream Team:**

[www.dreamteam-uk.org](http://www.dreamteam-uk.org)

### **Door2Adulthood:**

[www.door2adulthood.com](http://www.door2adulthood.com)

### **Gillette Specialty Healthcare:**

[www.gillettechildrens.org/](http://www.gillettechildrens.org/)

### **University Children's Hospital, Minnesota:**

[www.uofmchildrenshospital.org/](http://www.uofmchildrenshospital.org/)

### **Streetlight:**

[www.shands.org/public/programs/streetlight/default.asp](http://www.shands.org/public/programs/streetlight/default.asp)

### **Bloorview LIFEspan Program:**

[www.bloorview.ca/resourcecentre/transitions/lifespanprof.php](http://www.bloorview.ca/resourcecentre/transitions/lifespanprof.php)

**SickKids Good 2 Go Transition Program:**

[www.sickkids.ca/good2go](http://www.sickkids.ca/good2go)

**Alberta Children's Hospital, Well on Your Way:**

[www.calgaryhealthregion.ca/ACH/programs\\_services/services.html](http://www.calgaryhealthregion.ca/ACH/programs_services/services.html)

**JaxHATS:**

[www.jaxhats.ufl.edu](http://www.jaxhats.ufl.edu)

**British Columbia Children's Hospital:**

[www.bcchildrens.ca/Professionals/default.htm](http://www.bcchildrens.ca/Professionals/default.htm)

**The Independence Program:**

[www.tip.fmhi.usf.edu](http://www.tip.fmhi.usf.edu)

**Health Care Transition Initiative:**

[www.hctransitions.ichp.edu](http://www.hctransitions.ichp.edu)

**Child Liver Disease Focus:**

[www.cldf-focus.org](http://www.cldf-focus.org)

**Euteach:**

[www.euteach.com](http://www.euteach.com)

**Staying Positive:**

[www.staying-positive.co.uk](http://www.staying-positive.co.uk)

**The Royal College of Nursing, UK:**

[www.rcn.org.uk/development/publications/publicationsA-Z](http://www.rcn.org.uk/development/publications/publicationsA-Z)