2016

GROWING UP IN THE YARD

A MODEL FOR TRANSITIONING YOUNG ADULTS WITH CHRONIC DISEASE

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Hosted by BC Transplant and the BC Renal Agency

DISCLOSURES

- Neither I nor any of my family are employees or own shares of any pharmaceutical company
- I have received honoraria from Abbvie, Amgen, Bristol-Myers Squibb, and others for giving lectures and sitting on advisory boards

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LEARNING OBJECTIVES

- Learn about the challenges facing youth with chronic disease who are transitioning to adulthood
- Learn about ways the health profession can support youth as they proceed through this transition

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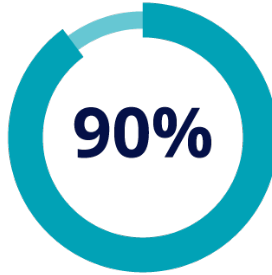
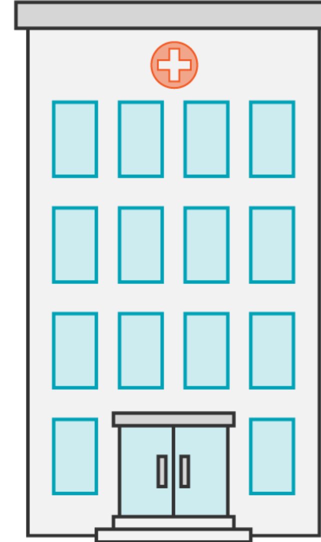
WHAT'S AT ISSUE

- A generation ago, most children with chronic health conditions/disabilities (CHC/D) died before their teen years
- Now 90% will survive into adulthood
- Results in new demands on family physicians and adult specialists



of children with CHCs age out of pediatric care

Pediatric Care



Adult Care

Young adults with pediatric onset make up only 2% of adult patients

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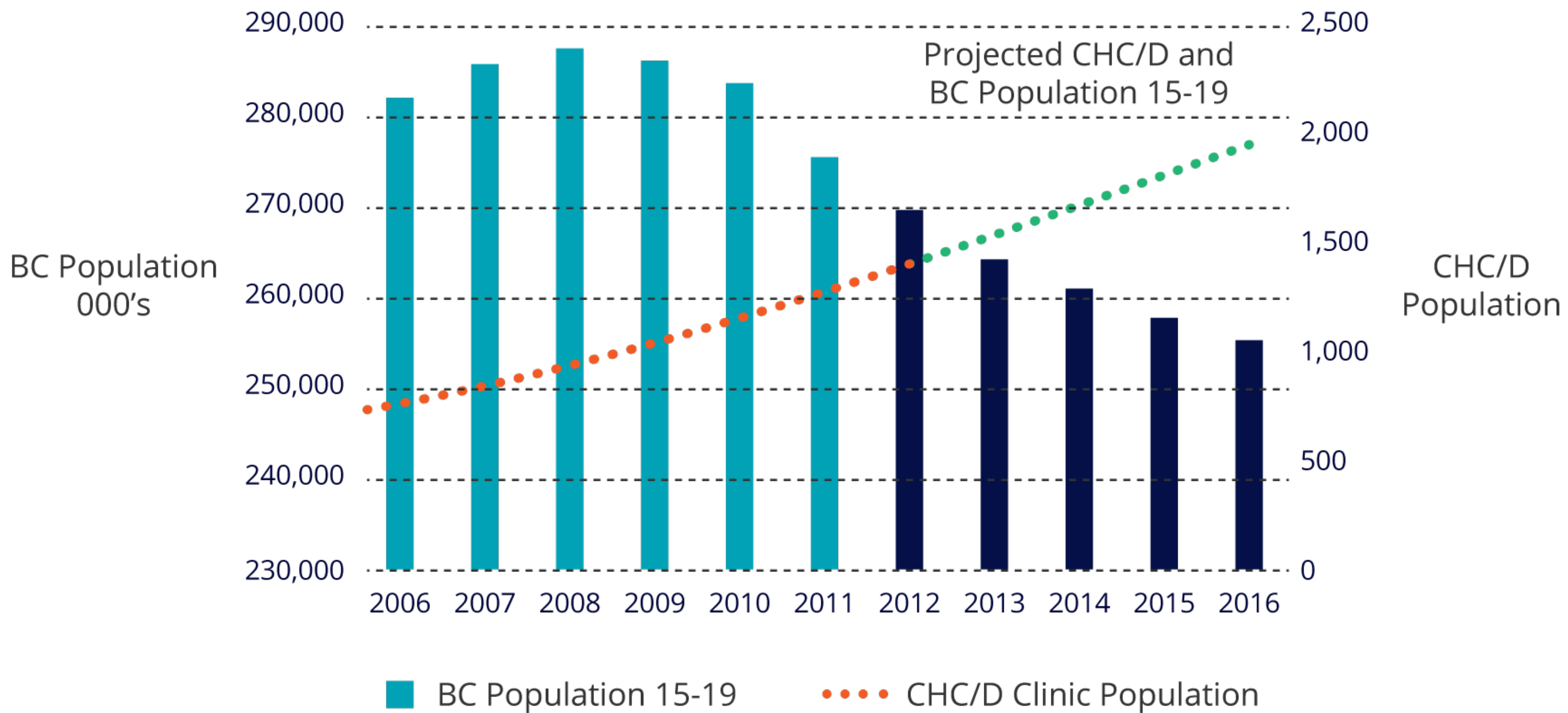

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Successful transition is the successful planning, preparation, and transfer of youth with chronic health conditions and/or disabilities (CHC/D) from pediatric care to the adult care system, with attachment to primary care and specialist services.

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WHAT IF TRANSITION FAILS?

- Deterioration in health status
- Poor adherence and engagement
- Increased use of emergency services
- Increased mortality

2010 Canadian study of 100 youth transitioned to adult rheumatology; Hazel, et al, Pediatric Rheumatology, 2010

52/100 were unsuccessfully transitioned

- 17 did not contact the adult rheumatologist for an initial appointment
- 35 attended initially but were lost to follow up 2 years after transfer

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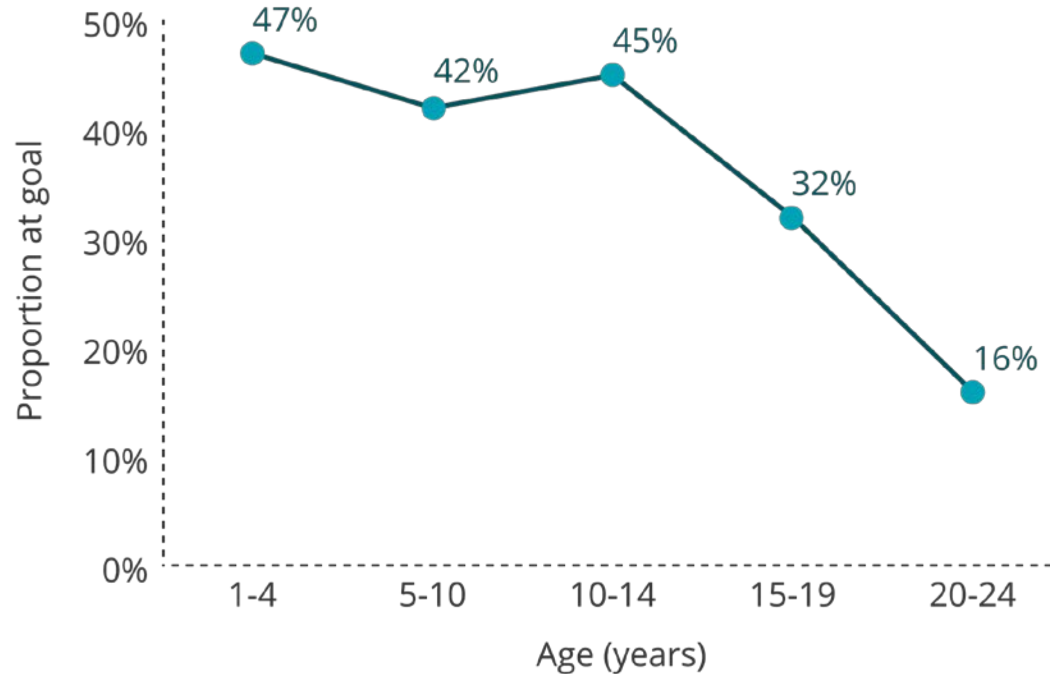

Proportion of diabetes patients meeting guideline goals in B.C.

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WITHOUT TRANSITION PROGRAM (n=33)

3 deaths
7 allograft losses
all unanticipated

WITH TRANSITION PROGRAM (n=12)

NO deaths
NO allograft losses

Two years after renal transplant patients transfer

OLD MODEL OF CARE

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IDEAL MODEL OF CARE

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TRANSITION IS THE "IT" THING

- In the early 2000's, reports were published on the inadequacy of the transition processes then current
- 2011 the American academy of Pediatrics, Amereican Cllege of Physicians, and the American Association of Family Physicians published guidelines on transition supports

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- In 2011, Got Transition, a national Health Care Transition center, developed a structured approach, Six Core Elements of Health Care Transition. In 2014, these were updated http://gottransition.org/index.cfm
- 2013 Dr. Lori Tucker gave a presentation at the Pediatric Rheumatology European Society on transition issues.

- In 2015, there were at least 5 articles published on transition of pediatric rheumatology patients to adult care
- Joint project beween the Special Services Committee (SSC) and UBC CPD (Continuing Professional Development) to develop learning modules on transition for FPs: in final stages of development

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- Sept/16 BCMJ: Ensuring a successful transition and transfer from pediatric to adult care in patients with congenital heart disease
- Oct/16 BC Kidney Days

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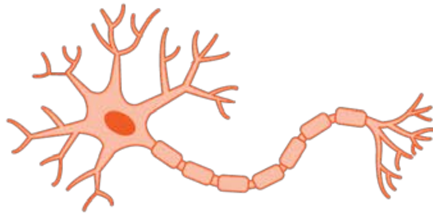
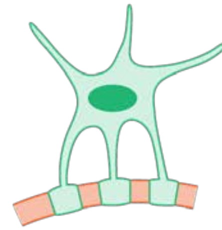
DEVELOPMENTAL TRAJECTORY

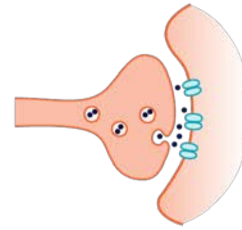
- The completion of earlier developmental stages sets the trajectory for successful completion of later stages
- Adolescence is a stage during which identity development is the central task



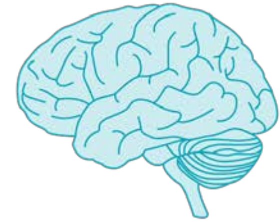
10 billion
neurons



100 billion
support cells



100 trillion
connections

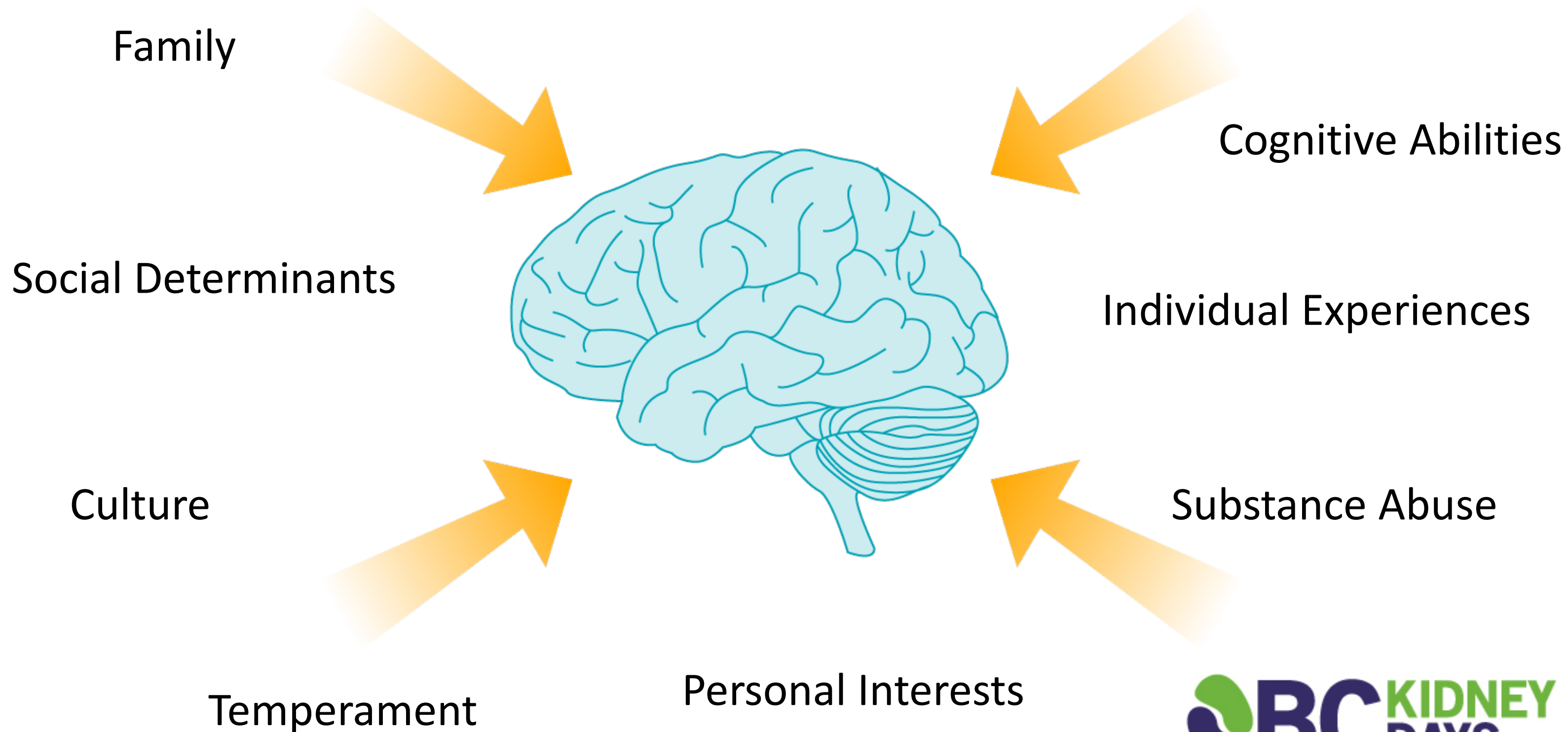


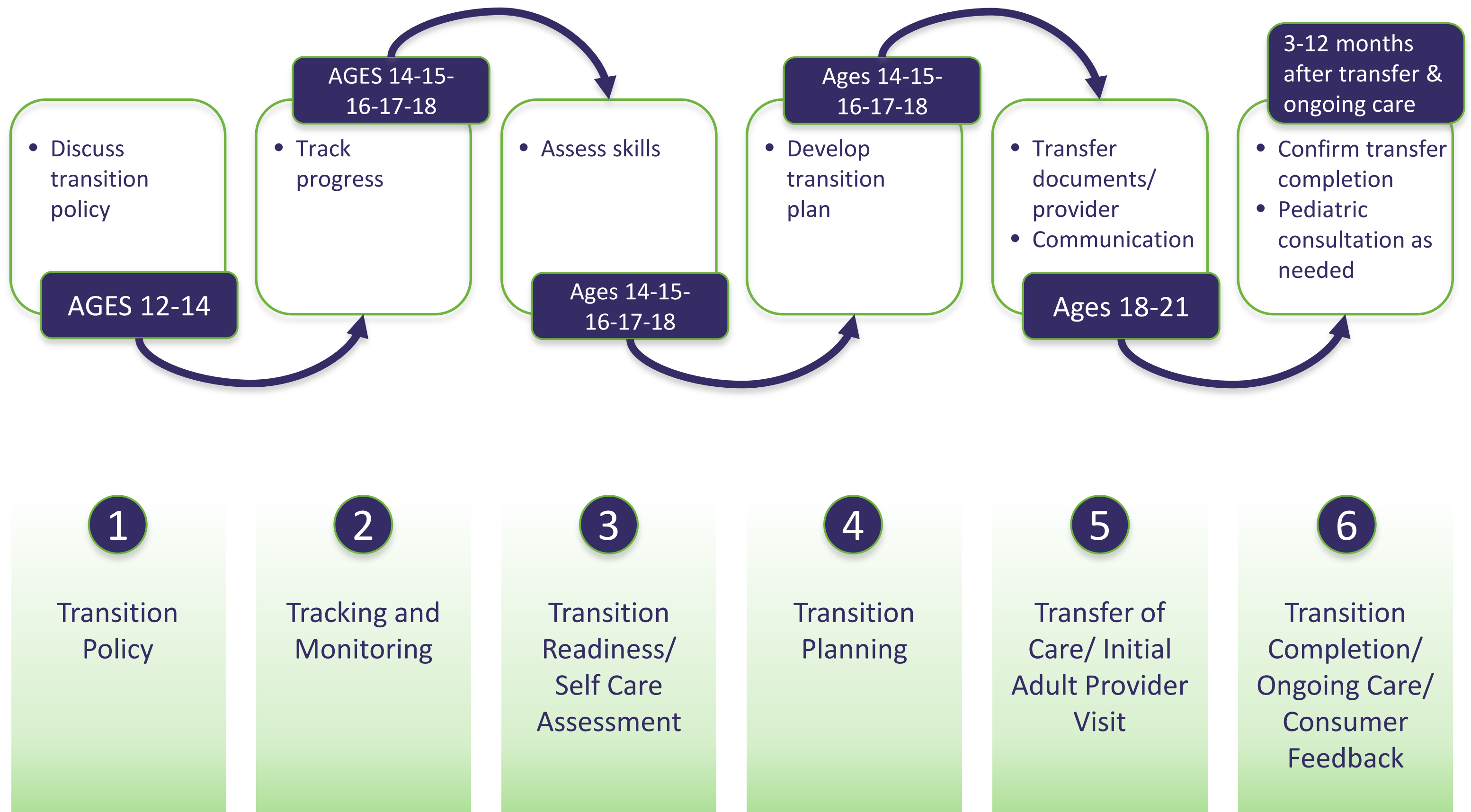
3 pounds
(1360 grams)

Human brain at birth

- During the learning years, there is proliferation of new connections between and myelination of neurons
- Throughout childhood, adolescence and young adulthood, there is enhanced myelination of used pathways and synaptic pruning of unstimulated pathways
- Adolescence is a unique period of building on the learning of childhood to build new skills and learning through young adulthood

Influences on Brain Development





Six Core Elements of transition

Graph adapted from Got Transition/Center for Health Care Transition Improvement

Transition Issues in Youth with CHC/D

- Need for independence conflicts with level of medical limitation and need for clinical care
- Youth with cognitive disabilities often exhibit poor judgement with regard to risky behaviors
- The adult health care system is often shockingly different than the pediatric environment.

Pediatric rheumatology	Adult rheumatology
Family centered	Patient centered
Parents responsible	Patient autonomy
Developmentally guided	Self-advocacy

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WHAT IS YOUTH FRIENDLY CARE?

- Positive relationship with the physician and other staff
- Overall result will be improved health outcomes through the development of positive health practices such as adherence to treatment

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EXAMPLES OF YOUTH FRIENDLY CARE

- Make youth feel welcome on first contact, starting with the front office staff
- Allow for flexible appointment times to accommodate school, work, mobility issues
- Use of neutral and accepting tone: avoid shaming and blaming, lecturing. This is especially important around adherence issues

- Use of open-ended questions; avoid a barrage of questions
- Use language that the youth (especially those with cognitive impairments) can understand
- Explicitly emphasize the importance of patient confidentiality and respect that commitment
- Include parents when appropriate

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GROWING UP IN THE YARD

Yard Adult Rheumatic Disease clinic

- First established in 1993
- The primary raison d'etre is to help guide adolescents through the process of transitioning from pediatric to adult care
- Pediatric patients transition to the YARD clinic at age 17 or 18.

The team is made up of:

- Pediatric rheumatologist(s)
- Adult rheumatologist
- Nurse
- Social worker
- Physiotherapist
- Occupational therapist
- Trainees, research assistants

GOALS AND ASPIRATIONS

- Encourage and facilitate development of independence: from parents, from the pediatric milieu
- Education or re-education about their disease and the treatment of the disease
- Promote adherence to the treatment

- Discuss adolescent needs: THREADS

  T: transition; developing skills, any barriers, have adequate support

  H: home; support, stability, transition out of the family home

  Rx: medication and treatment; adherence; adverse reactions

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- E: education, employment, eating; barriers, accommodations, nutritional education
- A: activity and affect; physical limitations, social isolation, mood disorders
- D: drugs; substance abuse, peer pressure
- S: sexuality; contraception, reproduction, sexual orientation/gender identity

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- Ensure that each patient has a family physician (medical home)
- Facilitate transition to adult health care givers: medical specialists, allied health care
- Facilitate access to medication and services: Pharmacare, disability insurance,
- Provide a learning environment for trainees
- Provide a milieu for research

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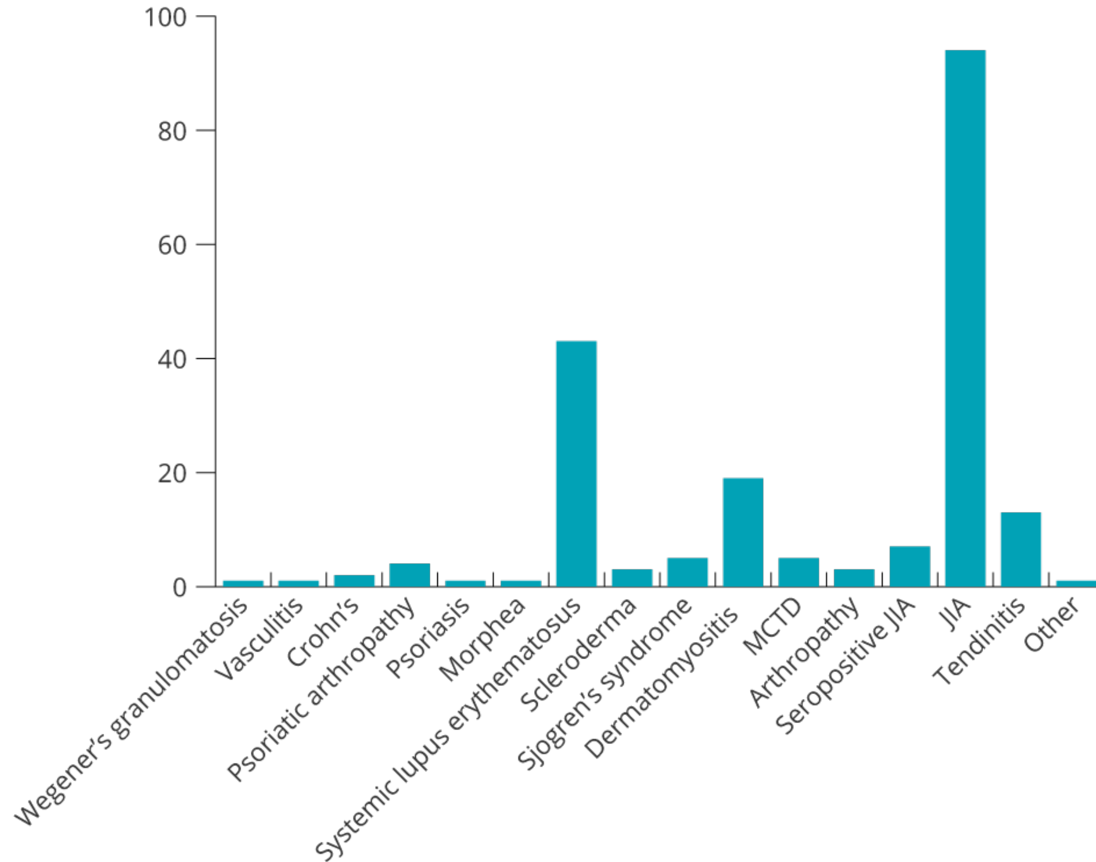
Yard Patients

Fiscal year Apr 1 2014- Mar 312015: 203 patients visits/year



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HOW YARD FUNCTIONS DAY TO DAY

- Young adults are referred to YARD at age 17-18, usually on graduation from high school
- There is preparation of the youth for transitioning while still in the pediatric program.
- On the first visit to YARD, he/she is seen without his/her parent in the room.

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- He/she is introduced to the program by the nurse coordinator who administers an 'admitting questionnaire' to determine the youth's knowledge, psychosocioeconomic situation, readiness for transitioning, etc.
- She will be their primary contact throughout their time in YARD

- At the first visit, the youth will be seen by the adult rheumatologist and a comprehensive history and physical exam detailing the course of the illness from onset will form a stand-alone chart
- Also at the first visit, the social worker will be introduced and the need for further sessions will be established.

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- Prescriptions are renewed as necessary
- Monitoring blood tests will be re-requisitioned so that YARD receives the results
- Special authority requests for coverage of restricted drugs will be made (different types of coverage for ‘adults’ as compared to the pediatric population)

- Return appointments are made as necessary, usually every 3 to 4 months
- Patients learn how the costs of their meds are covered, when to renew their prescriptions, who to contact with health concerns, etc
- Patients are expected to be adherent to attending appointments, taking their meds, going for blood tests and investigations, etc.

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- Parental concerns are to be addressed through their children. This teaches their children to care for their health independently and to learn to advocate for themselves
- When this process is successful, the young adult will be ready to transition to adult care, usually around age 21

WHAT HAVE WE LEARNED?

- In the early days of YARD, patients would remain in the clinic until as old as age 28
- It has become clear that, if he/she has not completed the transition process successfully by age 22 or 23, he/she would likely not benefit further from an extended stay in the program

- It is important to develop relationships with a cadre of subspecialists eg nephrologists, gastroenterologist, opthalmologists who are aware of and sympathetic to the challenges faced by young adults with CHC/Ds while transitioning to adult care.
- It is equally important to foster a good relationship between the young adult and their family physician.

WHAT CAN WE DO BETTER?

- Quality assurance eg questionaires at the first and last visits to get patient feedback and measure outcomes
- Better follow up after YARD eg registries
- Publish data to further knowledge of transition issues

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Transition Websites

1. On Trac – Transitioning Responsibly to Adult Care ontracbc.ca Made in BC involving multiple partners including BCCH
2. Gottransition www.gottransition.org USA

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PSYCHOSOCIAL CHALLENGES SEEN IN A YOUNG ADULT TRANSITION CLINIC

GREG TAYLOR, MSW, RCSW

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Developmental Challenges

1. Identity formation
2. Autonomy from parents
3. Establishment of peer relationships
4. Gender roles, sexuality and reproductive health
5. Vocational planning

Environmental Challenges

1. Financial constraints imposed by a volatile global economy
2. Rise of social media to influence adherence to treatment
3. Emergence of medicinal marijuana for pain management

Individual Differences in Coping Challenges

1. Adjustment to changes in quality of life
2. Motivation to engage in self-management strategies

Tips for Clinicians

1. Respectful relating
2. Direct and authentic feedback

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UBC CPD ELEARNING

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