Transition:
From Pediatric and Adult Care

Simone Appenzeller MD, PhD

Associate Professor

Rheumatology Unit

State University of Campinas

PReS Latin American Pediatric Rheumatology Basic Course, BRAZIL - 2015

Conflict of Interest

- Research Grants
  - FAPESP
  - CNPq

Agenda

- Define transition
- Review how improved survival rates in childhood illnesses have changed how we practice medicine
- Understand the challenges of transition from multiple perspectives
- Present key elements to implementing a transition plan
- Our experience

No Longer Just a Childhood Illness

- ~ 11.2 million children (15% of all US children) 0-17 years have special health care needs

- Survival rates have increased for children with chronic illnesses
  - >90% survive beyond their 20th birthday

Rheumatic disease: fluctuating course

- Chronic diseases
- Fluctuating course
  - SLE flare rates:1.4-5%/year
  - JIA: 30-50% active disease

Transition

Pediatric Care → **Adult Care**

Transition

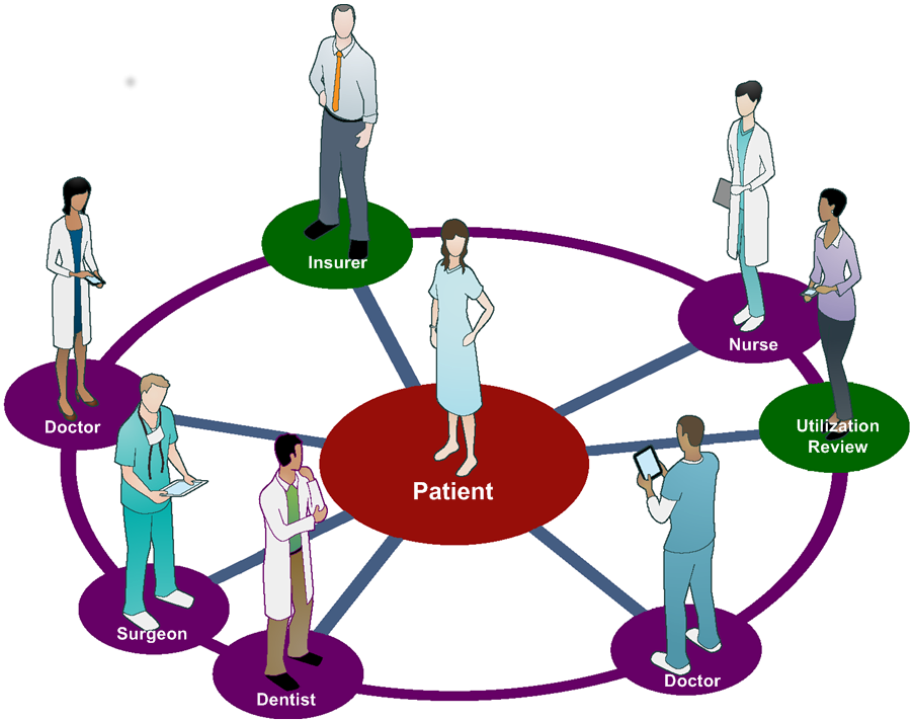
Pediatric Care → Adult Care

Child and family-centered health care → Patient-centered adult-oriented health care

Society for Adolescent Medicine, 1993

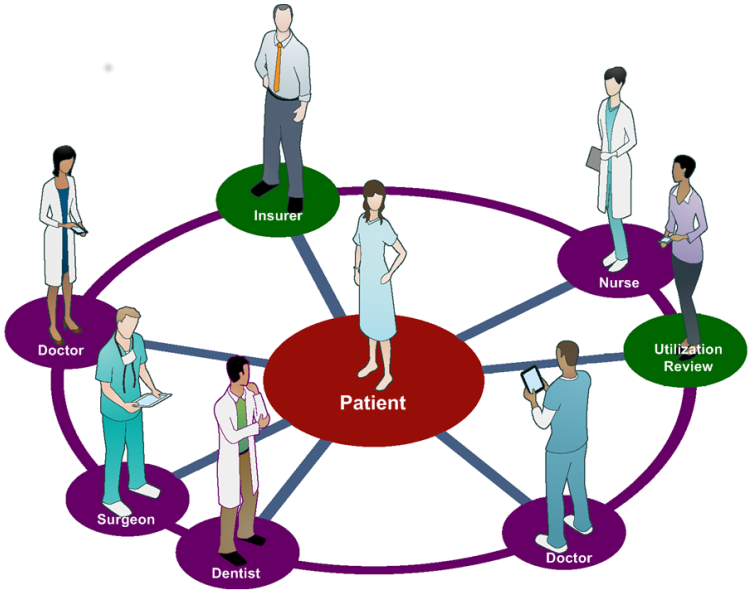
Child and family-centered health care

Patient-centered adult-oriented health care

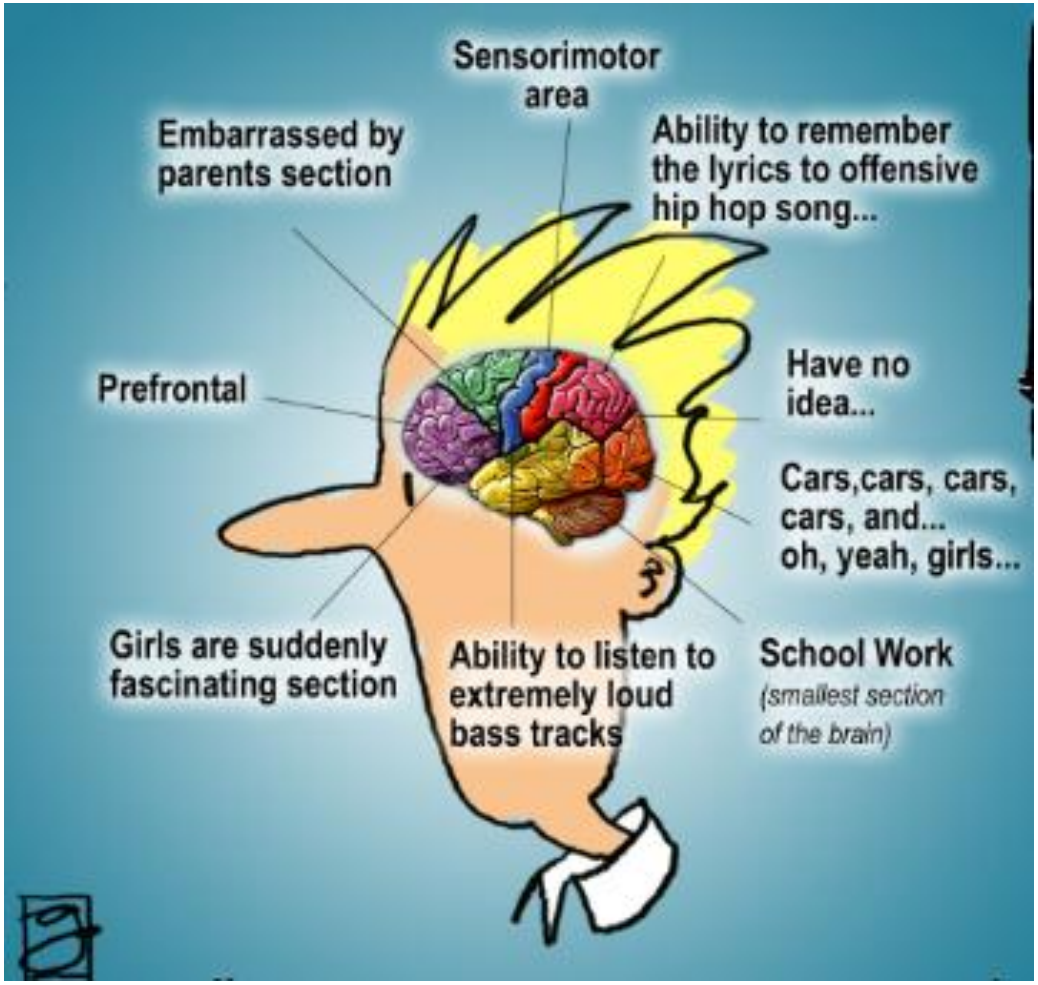


Transition


Optimal Health
Patient Experience
Health Equity
Patient Safety
COMMUNITY & HEALTH SYSTEM
CARE at SickKids
FAMILY
RESPECT
COMMUNICATION
CHILD
at the core
PARTNERSHIP


Insurer
Nurse
Doctor
Utilization Review
Patient
Surgeon
Dentist
Doctor

Adolescence



Adolescence

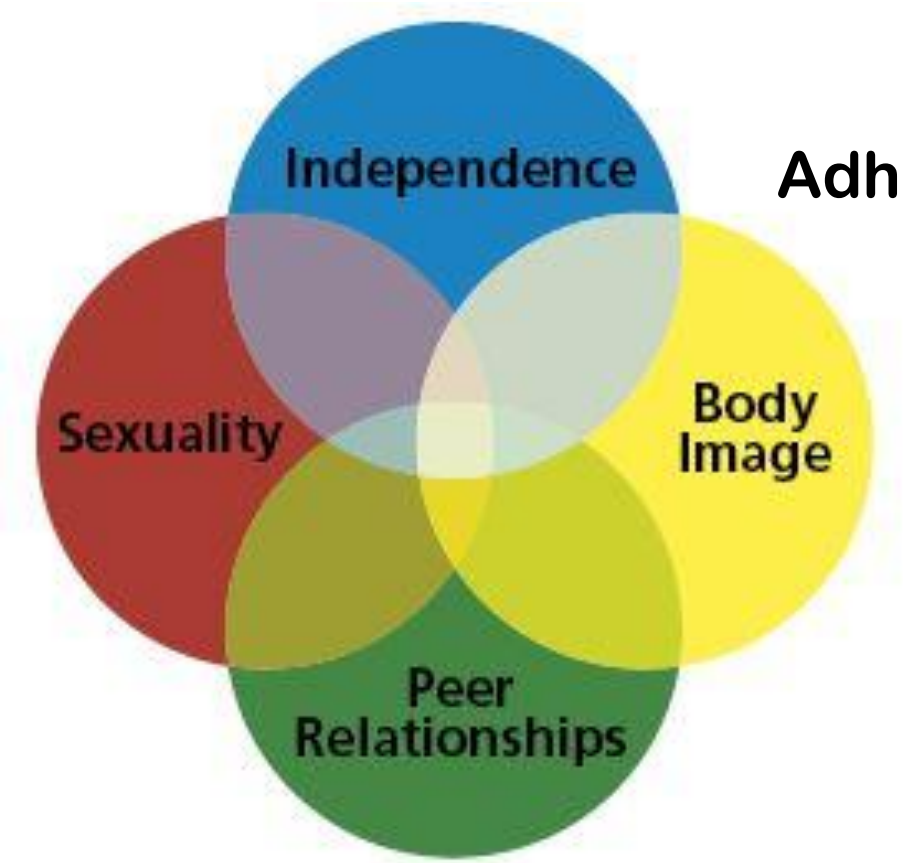
- Latin word “adolescere” = to grow, to mature
- They are no longer children yet not adults
- It is characterized by rapid physical growth, significant physical,emotional, psychological and spiritual changes.

Tattersall & McDonagh 2010
World Health Organization 2014
World Health Organization 2012

Problems of adolescents are multi- dimensional in nature

Adherence

STDs
Pregnancy



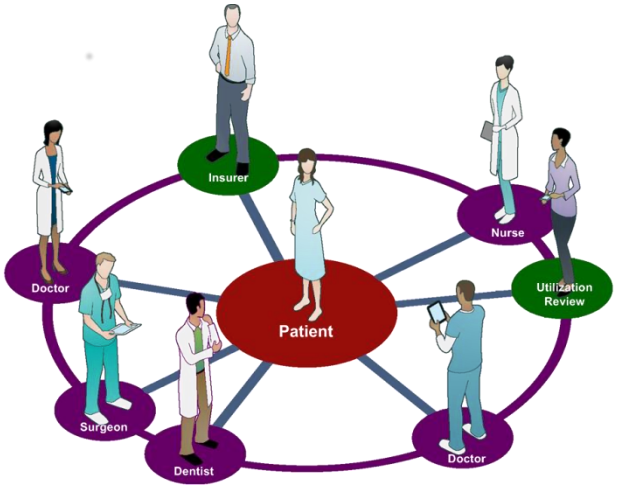
Alcohol, Tabacco, Drugs

Tattersall & McDonagh 2010
World Health Organization 2014
World Health Organization 2012

Transition


Optimal Health
Patient Experience
Health Equity
Patient Safety
COMMUNITY & HEALTH SYSTEM
CARE at SickKids
FAMILY
RESPECT
COMMUNICATION
CHILD
at the core
PARTNERSHIP


My life, my choice, my way
Welcome to Care Connect
Discuss my needs
Plan my future
Organise services and support
Receive services and support
Check my progress
My Life My Choice My Way™


Insurer
Nurse
Utilization Review
Doctor
Patient
Surgeon
Dentist
Doctor

Children and Youth with Special Health Care Needs (CYSHCN)

"Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally."

Department of Health and Human Services,
Health Resources and Services Administration
Maternal and Child Bureau

Skills needed for transition

Health maintenance skills

Life skills

management of the disease/ disability and general and sexual health

mobility, home management, time management, relationships, leisure, work and training

Ansel BM et al. Baillieres Clin Rheumatol 1998;12:363–374

Why Transition is Important

- Failure to recognize and plan transition may result in patients dropping out of care
- Poor transition processes are recognized to have a significant negative effect on morbidity and mortality in young adults with chronic health needs

Persistent morbidity into adulthood

- Reduced participation in school and social activities
  - Fatigue
  - Pain
  - Stiffness
- Increased risk for overall adjustment problems and internalising symptoms
- Unfavourable psychosocial outcome

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674

Life with JIA: from childhood to adulthood

Theme

Living with juvenile idiopathic arthritis involves struggle and adjustment to an insecure everyday life and an unpredictable life course

Categories

Bodily experiences of limitations or freedom
Being acknowledged or set aside in interpersonal relationships
Intrapersonal experiences of insecurity or confidence

Sub-categories

Unpredictable or stable course of disease
Suffering or well-functioning body
A sense of devotedness or abandonment
Experience of being believed or mistrusted
A sense of loneliness or belonging
The disease as loss or value
Struggling against or along with the disease
Loss of self-esteem or perceived positive self-image

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674

Rheumatological diseases: a more complex transition

Simpler Transition	More Complex Transition
Single health condition	Multiple health conditions
Low risk of future health problems	High risk of future health problems
No dependence on medical equipment	Reliance on life-sustaining medical equipment
Rare acute illness, medically stable	Frequent acute episodes, medically unstable
Few medications	Multiple medications, medication problems
No cognitive impairments	Profound mental retardation
No physical impairments	Serious physical impairments
Mentally healthy	Mentally ill
No behavioral concerns	Serious behavioral concerns

SOURCE: Adapted from Kelly et al. (2002).

What are the challenges?

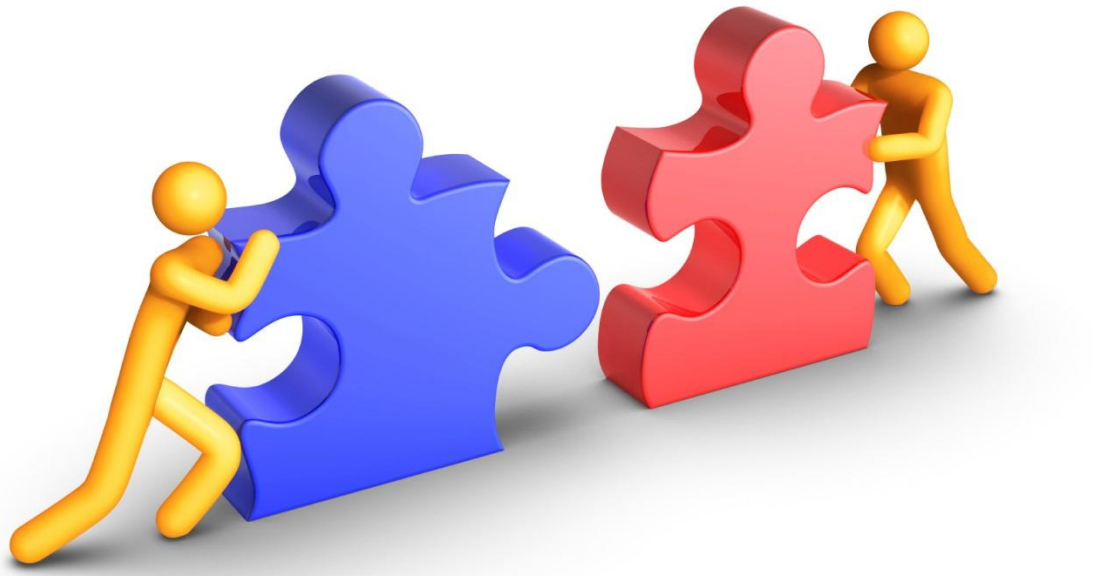
Patient Challenges: Many transitions at once

- Healthy peers:
  - Graduate, move away, new job
  - New relationships, new opinions about politics and religion
  - Choices about alcohol, tobacco, drugs, sexual activity
  - Focus on independence
- Addition:
  - Unpredictable disease course
  - Disease management
  - Expectation of the future?

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674

Biological, social and social changes

Variable and unpredictive disease



Transition process to adulthood

⇨ Control life

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674

Family Challenges

- Close ties with pediatric caregivers
- Considered an adult at 18 y.o. → privacy becomes an issue
  - Mistrust
- Lack of confidence in:
  - Young adult's ability to adequately provide self-care
  - Adult medical team

Landgraf et al. Disability and Rehabilitation, 2009; 31(8): 666–674

Pediatric Care Team Challenges

- Tight bond with patient and family
- Limited contact with adult providers and services
- Lack of trust in adult healthcare system/providers
- Lack of training on how or when to start transition

Adult Care Team Challenges

TABLE 2 Mean Likert Ratings and Wilcoxon Rank Order of Stage 2 Survey Items

Item	Mean Likert Rating	Category	Wilcoxon Rank[a]
1. Internists may not have the training in congenital and childhood chronic illnesses to prepare them to manage them beyond childhood.	2.86	Medical competency	1
2. It is difficult to care for patients with cerebral palsy or mental retardation if the family does not stay involved.	2.86	Family involvement	1
3. It can be difficult to meet psychosocial needs of young adults, especially those living with chronic illness.	2.77	Psychosocial needs	1
4. Some patients may need a superspecialist to manage complex problems (eg, complex congenital heart disease).	2.77	Medical competency	1
5. Internists often lack training in adolescent medicine, adolescent development, and adolescent behavior.	2.63	Medical competency	1
6. It is often difficult to face disability and end-of life issues at an early age and early in the doctor-patient relationship.	2.63	Medical competency, psychosocial needs	1
7. Managed care/financial considerations limit the time an internist is able to spend with transitioning young patients.	2.57	System issues	1
8. The families of transitioning patients have high expectations of the amount of time/attention needed for proper care.	2.55	Family involvement	1
9. Because patients with chronic illness are often less mature than their healthy counterparts, they may have increased adherence problems.	2.49	Maturity	2
10. Young patients are not always ready to assume decision-making responsibility.	2.47	Maturity	2
11. While insurance programs may cover sick children, coverage may not exist for young adults.	2.45	System issues	2
12. Internal medicine practices often lack adequate infrastructure and staff training to deal with these patients.	2.45	System issues	2
13. It is often challenging to make sure that the young patient does not get lost to follow-up.	2.44	Maturity, system issues	2
14. Young patients are often ignorant of morbidity/mortality and therefore may lack motivation for preventive care.	2.44	Maturity	2
15. Internists may be unfamiliar with local and regional services for chronically ill, young adult patients.	2.42	Medical competency	2
16. Caring for chronically ill young patients can be potentially very time-consuming.	2.42	System issues	2
17. It is difficult for young adult patients over 18 with chronic illness to obtain insurance because of their preexisting condition.	2.40	System issues	2
18. Parents are often reluctant to relinquish responsibility for health care/decision-making to young adult patients.	2.39	Family involvement	2
19. Young patients with chronic illness often have significant dependency needs.	2.37	Maturity	2
20. It is difficult to meet the expectations of care for chronic incurable problems; often family wants a full evaluation though one has already been completed.	2.37	Family involvement	2
21. The transition from pediatric caregivers is often poorly coordinated.	2.36	Transition coordination	2
22. Young patients often neglect to raise issues or ask questions that their parents previously would have asked.	2.35	Maturity	2
23. Young patients are often closed-minded to different approaches after living with their illness for so long.	2.32	Maturity	2
24. Parents and caregivers can remain excessively protective and may not understand privacy issues.	2.32	Family involvement	2
25. It is often difficult to obtain old records.	2.30	Transition coordination	2

Adult Care Team Concerns

Patient's maturity

Systems issues

Patient's psychosocial needs

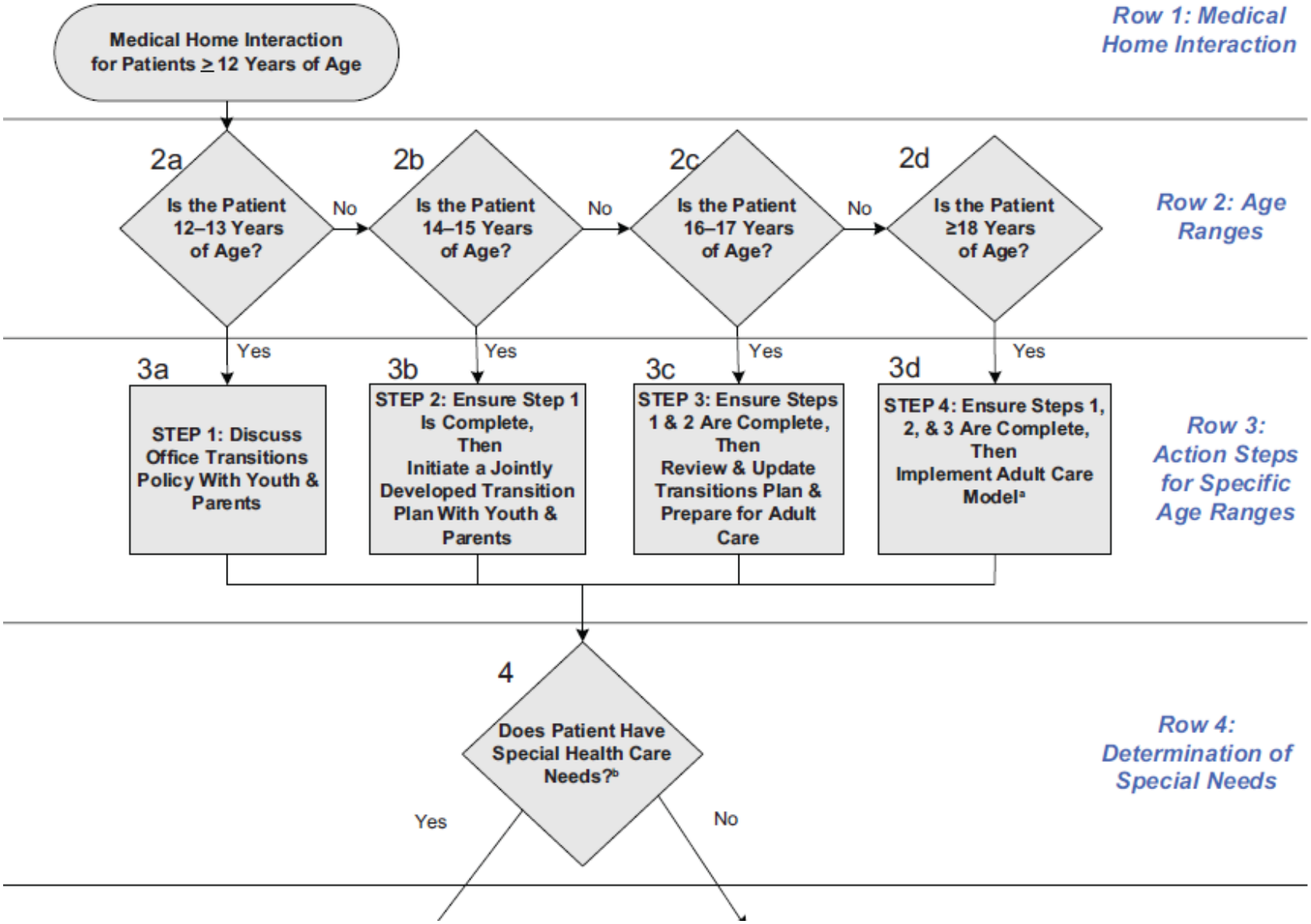
Family involvement

My medical Competency

Transition coordination

Institutional & System Challenges

- Aging out of treatment
- Insurance coverage/funding changes with age:
  - Limited options for personal health insurance
  - Discontinued from parents' health insurance
  - Change in eligibility requirements: Supplemental Security Income (SSI), Medicaid
  - Poor reimbursement for transition services


Medical Home Interaction for Patients ≥ 12 Years of Age
Row 1: Medical Home Interaction
2a
Is the Patient 12–13 Years of Age?
No
2b
Is the Patient 14–15 Years of Age?
No
2c
Is the Patient 16–17 Years of Age?
No
2d
Is the Patient ≥18 Years of Age?
Row 2: Age Ranges
Yes
Yes
Yes
Yes
3a
STEP 1: Discuss Office Transitions Policy With Youth & Parents
3b
STEP 2: Ensure Step 1 Is Complete, Then Initiate a Jointly Developed Transition Plan With Youth & Parents
3c
STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care
3d
STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model[a]
Row 3: Action Steps for Specific Age Ranges
4
Does Patient Have Special Health Care Needs?[b]
Yes
No
Row 4: Determination of Special Needs

Elements of Health Care Transition

1. Clinic Policies
2. Registry
3. Preparation
4. Planning
5. Transfer of care
6. Transition Completion

1. Clinic Policies

- **Pediatrics:**
  - **When will the transition process begin?**
  - **When is the transfer expected to happen?**
- **Adult Medicine:**
  - **What age will the clinic start seeing patient?**
  - **Outline of what to expect**

2.Registry

- **Pediatrics:**
  - **Identify transition-age youth, <u>especially</u> CYSHCN**
  - **Start by 12-14 y.o.**
- **Adult Medicine:**
  - **Identify young adults by level of complexity**
  - **Monitor health care needs**

3. Preparation – *Pediatric Team*

- **Prepare patients/family for success in adult care system & envision a future:**
  - **Visits without parents**
  - **Discuss illness, meds, troubleshooting**
  - **Self-management skills**
- **Assess Readiness:**
  - **Transition Readiness Assessment Questionnaire (TRAQ):**
    - **2 domains: self management and self advocacy**
    - **Identifies areas for more education**

Subject Number: _____ **Date** _____ **Person Completing Survey:** _____

Transition Readiness Assessment Questionnaire 4.1

Direction: We would like to know how you describe your skills in the areas that are important in your care. Your answers will help us provide services and education that will be important in preparing you to transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private. Please check the box ☑ that you feel best describes you.

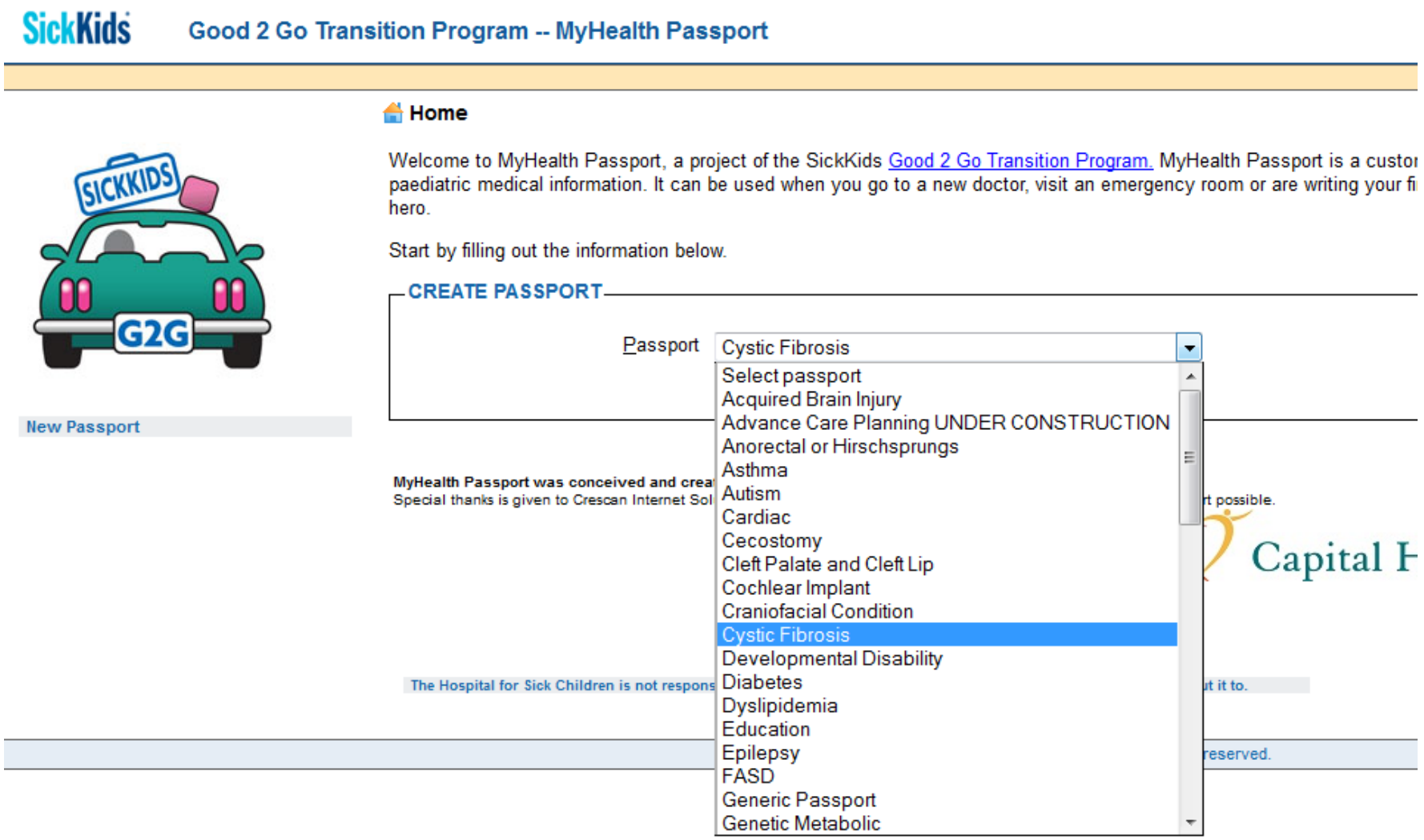
	Not needed for my care	**No, I do not know how**	**No, I do not know how but I want to learn**	**No, but I am learning to do this**	**Yes, I have started doing this**	**Yes, I always do this when I need to**
Skills for Chronic Condition Self-Management						
1. Do you fill a prescription if you need to?						
2. Do you know what to do if you are having a bad reaction to your medications?						
3. Do you pay or arrange payments for your medications?						
4. Do you take medications correctly and on your own?						
5. Do you reorder medications before they run out?						
6. Do you take care of your medical equipment and supplies?						
7. Do you call the suppliers when there is a problem with the equipment?						
8. Do you order medical equipment before they run out?						
9. Do you arrange payment for the medical equipment and supplies?						

3. Preparation – *Adult Team*

- Discuss how to use/access services in adult model of care
- Continue to assess and address gaps in knowledge and skills

4. Planning – *Pediatric Team*

- **Health Care Transition Action Plan:**
  - **Checklist of goals/expectations prior to transfer**
- **Portable Health Summary:**
  - **Chronological account of patient's past and current medical problems**
- **Emergency Plan:**
  - **Actions to be taken during urgent/emergent events**


SickKids
Good 2 Go Transition Program -- MyHealth Passport
Home
SICKKIDS
G2G
New Passport
Welcome to MyHealth Passport, a project of the SickKids Good 2 Go Transition Program. MyHealth Passport is a custor
paediatric medical information. It can be used when you go to a new doctor, visit an emergency room or are writing your fi
hero.
Start by filling out the information below.
CREATE PASSPORT
Passport
Cystic Fibrosis
Select passport
Acquired Brain Injury
Advance Care Planning UNDER CONSTRUCTION
Anorectal or Hirschsprungs
Asthma
Autism
Cardiac
Cecostomy
Cleft Palate and Cleft Lip
Cochlear Implant
Craniofacial Condition
Cystic Fibrosis
Developmental Disability
Diabetes
Dyslipidemia
Education
Epilepsy
FASD
Generic Passport
Genetic Metabolic
MyHealth Passport was conceived and crea
Special thanks is given to Crescan Internet Sol
rt possible.
Capital H
The Hospital for Sick Children is not respons
ut it to.
reserved.

4. Planning – *Adult Team*

- "Get acquainted" visit
  - Up to one year before transfer
- Continue to use and update:
  - HCT Action Plan
  - Portable medical summary
  - Emergency care plan

4. Planning – *Team Discussion*

- Insurance
- Guardianship
- Community resources

5. Transfer of Care – *What age?*

- For most, between 18-21 y.o.
- Other factors to consider:
  - Is the patient medically stable?
  - Is the illness terminal?
  - Has transition readiness been assessed?
  - What skills are still needed to make a successful transition?

5. Transfer of Care

- **Pediatrics:**
  - **Direct communication with adult PCP and team**
  - **Transition package:**
    - **Transfer letter**
    - **Health summary**
- **Adult Medicine:**
  - **Review history and talk to referring physician**
  - **Introduce patient to clinic**

6. Transition Completion

- Pediatric PCP and team remains a resource for adult PCP/team

…So, how are we doing?

…So, how are we doing?

- Different clinic code
  - Space issues: still at the pediatric ward
  - Access to Family planing clinic
  - Planning adult rheumatology fellows permanent rotation
- Admission at
  - Adult ER
  - Adult rheumatology ward

Transition: Bridging the Gap Between Pediatric and Adult Medicine

Questions?