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Research Making a Difference

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Transition to Adulthood with Cyber Guide Evaluation Study:

Emergent Transition Profiles Among Youth with Chronic Health Conditions

Jan Willem Gorter, Andrea Morrison, and Oksana Hlyva

Objectives

- Review current transition guidelines and practices
- Illustrate the application of the Rotterdam Transition Profile to studies on transition
- Learn about the transition resources that are part of the TRACE study
- Learn from lived experiences of youth and caregivers
- Appreciate the multi-dimensional nature of transition processes for youth with chronic health conditions

Overview

- Transition: Research and Guidelines
- Rotterdam Transition Profile

  Jan Willem Gorter, MD, PhD, TRACE study Co-PI

- TRACE study and resources

  Andrea Morrison, OT Reg. (Ont.), TRACE study Co-I

- TRACE study: Qualitative interviews

  Oksana Hlyva, MSc, TRACE study coordinator

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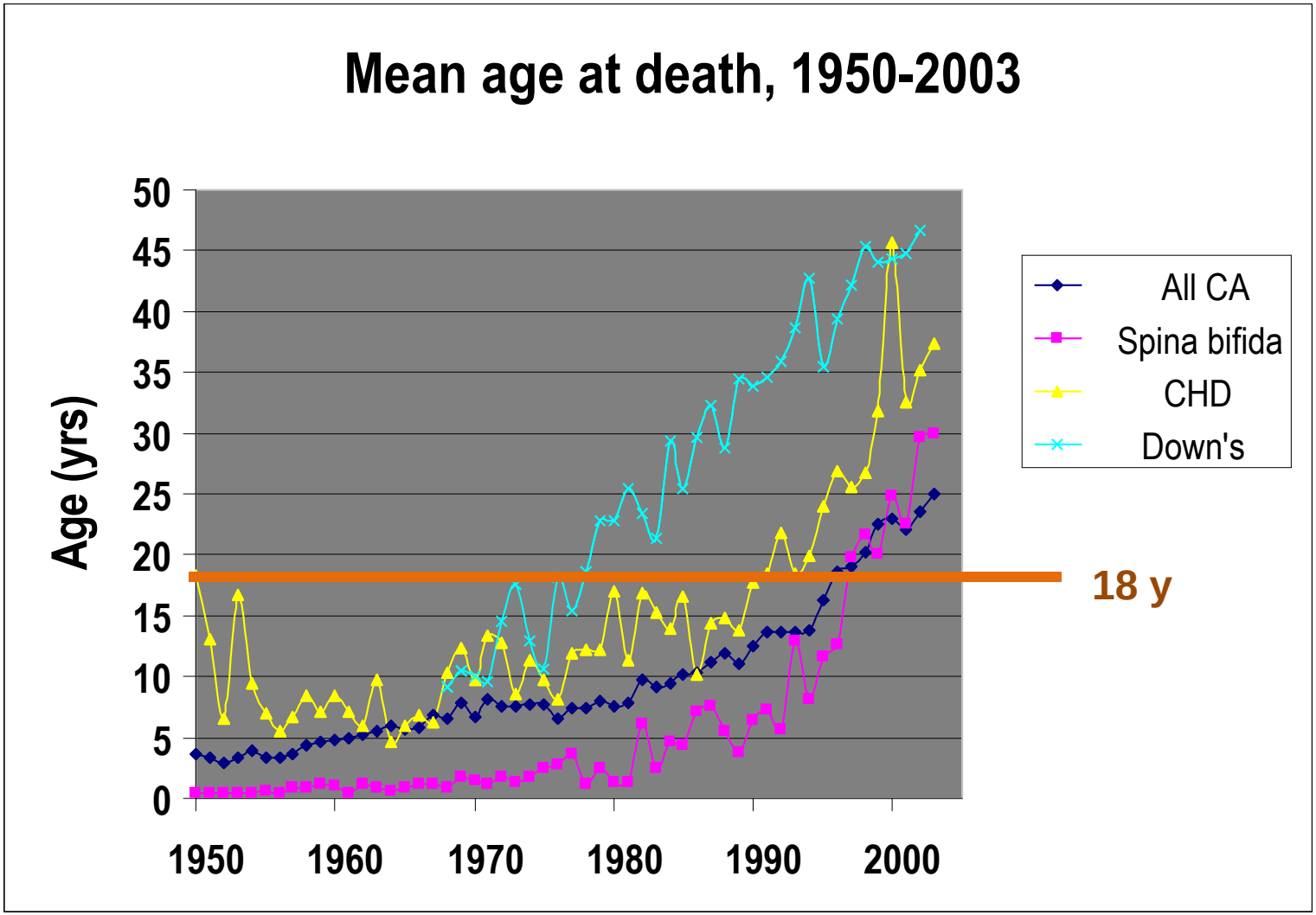
More youth with chronic disease survive to adulthood



CA=Congenital Anomalies CHD= Congenital Heart Disease

Source: R. Wilkens, Health Canada, 2007

Anecdote

- Ontario Federation for Cerebral Palsy (OFCP) – medical committee
- Adult with CP
- Pain / spasticity
- In need of medication (Diazepam)
- Family physician refused medication
- Ended up in emergency department

What happens to adults with CP?

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Data

- Health care utilization patterns for
  - youth (n= 587, age 13-17)
  - young adults (n= 477, age 23-32)
  - with CP across GMFCS levels

- Limited to physician services and hospitalizations in Ontario, Canada

Young et al. Arch Phys Med Rehab. 2007;88:696-702.

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Key findings

Compared to youth, adults have:

- Higher use of outpatient physician services
- Lower rates of specialist services
- Higher rates of emergency department visits

Conclusions (Young et al.)

- Similar high utilization rates (9 times) were found for spina bifida and acquired brain injury (Young et al. 2005)
- Similar hospital length of stay data were found in the US (Murphy et al. 2006)

- In Canada, few adult-oriented health services available to support adults with CP
- GP's can play a central role, but need resources
- Access to specialist consultation appears to be lacking

Meeting the needs

- Health care needs
  - Routine health care
  - Specialized medical care
  - Specialized rehab care
  - Rehab technology, including bracing, seating, communication devices etc
  - Therapy

- Developmental needs
  - Educational
  - Psychosocial

Guidelines

The Best Journey to Adult Life" for Youth with Disabilities: An Evidence-based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities.

Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, F. et al. (2009). Hamilton, ON: McMaster University and *CanChild* Centre for Childhood Disability Research. www.canchild.ca.

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CPS & SAMH Transition Principles	ON TRAC	Good2Go Shared Management Model	The Maestro System Navigator
Provide Developmentally Appropriate Care	+	+	
Enhance Patient Autonomy	+	+	+
Ensure Collaboration between Health Care Providers	+	+	+
Teach skills of Negotiation	+	+	+
Gradation of responsibility to the Adolescent	+	+	
Provide Community Resources	+	+	+
Designated Professional who takes responsibility for Transition	+	+	+
Provide Patient a portable summary of their Health Care Needs	+	+	
Have current transition plan documented	+	+	

Grant & Pan, 2011 Child Care Health Dev Special issue on Transition

Transition in 2011

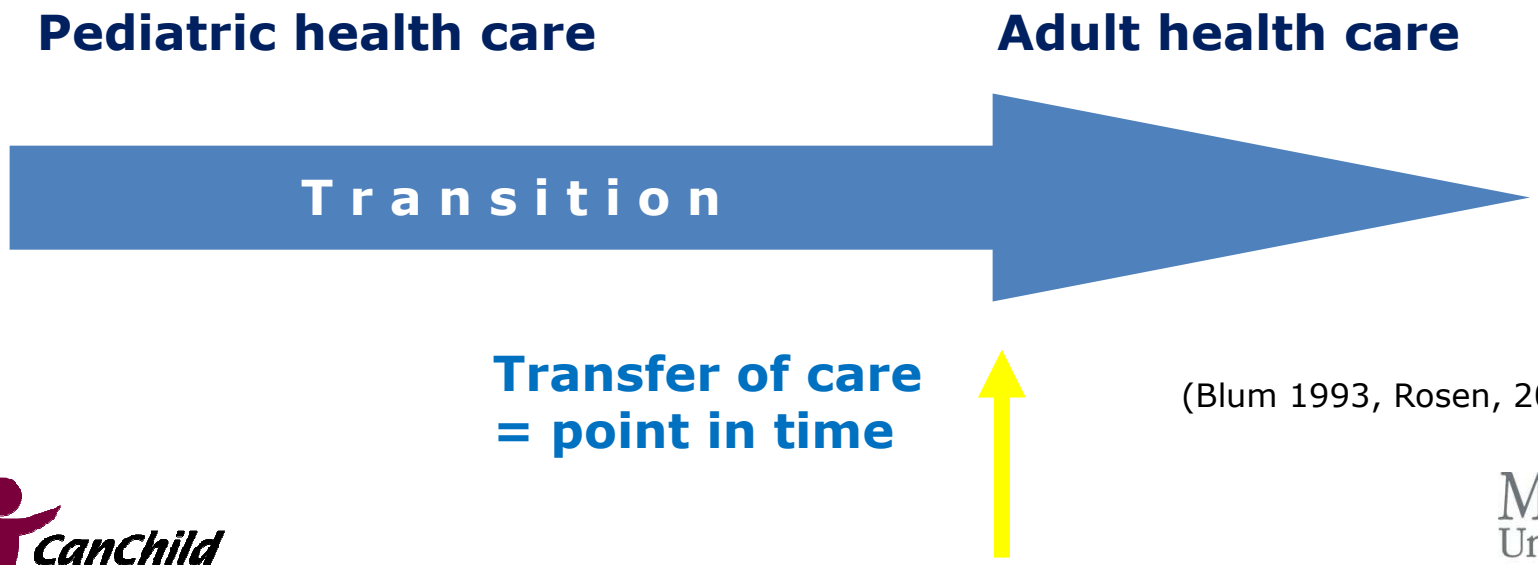
- June 2011: in a report from the American Academy of Paediatrics it was concluded that after nearly a decade of effort, wide-spread implementation of health transition supports as a basic standard of care has not been realized.

- November 2011: In a special issue on transition it is concluded that it is alarming to see the lack of evidence of effectiveness of programs and models of care.

AAP et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Paediatrics, 2011; 128: 182.*
Gorter, Stewart & Woodbury-Smith. Youth in transition: care, health and development. *Child: Care Health & Development* 2011

Transition and Transfer

- **Transition** is a process of growing up ready for adult life.
- A purposeful, planned movement of youth with complex lives from child-centered to adult-oriented services



(Blum 1993, Rosen, 2006)

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Life is a *transition*

Many *transfer* moments

- Start high school
- Start college/university
- First job
- Move away from home

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Lifespan approach required

- Comprehensive care plan
- Transitions (leaving the paediatric system!) are key markers in developmental trajectories
- The diagnosis/health condition is only one factor that determines outcome

Gorter JW, Stewart D, Woodbury Smith M, et al. Pathways Toward Positive Psychosocial Outcomes and Mental Health for Youth with Disabilities: A Knowledge Synthesis of Information on Developmental Trajectories. Canadian Journal of Community Mental Health (CJCMH). (Accepted 2012)

ABC of transition

- Awareness
- Be prepared
- Collaboration

Gorter JW. Making links across the lifespan in neurology. Can J Neurol Sci.2012 Jan;39(1):1-2.

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Awareness

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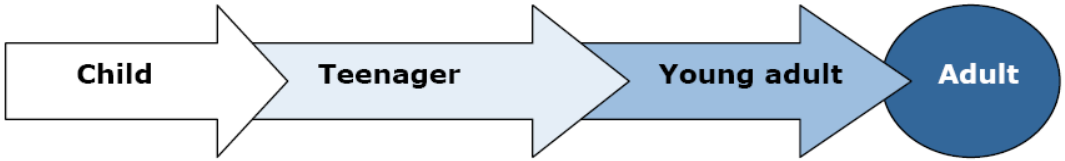
Getting ready for adult care

Information for teens at the Spasticity Clinic

As a teenager, you are starting to learn how to take care of yourself. Over the next few years you will gradually take on more responsibility for your health. This process, called transition, is part of growing up.



As a child, your parents and the health care team took care of you.

During your teenage years, parents and the health care team help you learn what you need to know and do to take care of yourself.

You gradually take on more responsibility for your care.

As a young adult, you will transfer from McMaster Children's Hospital to adult care.

As an adult, you are responsible for yourself, including the health care you need for spasticity problems.

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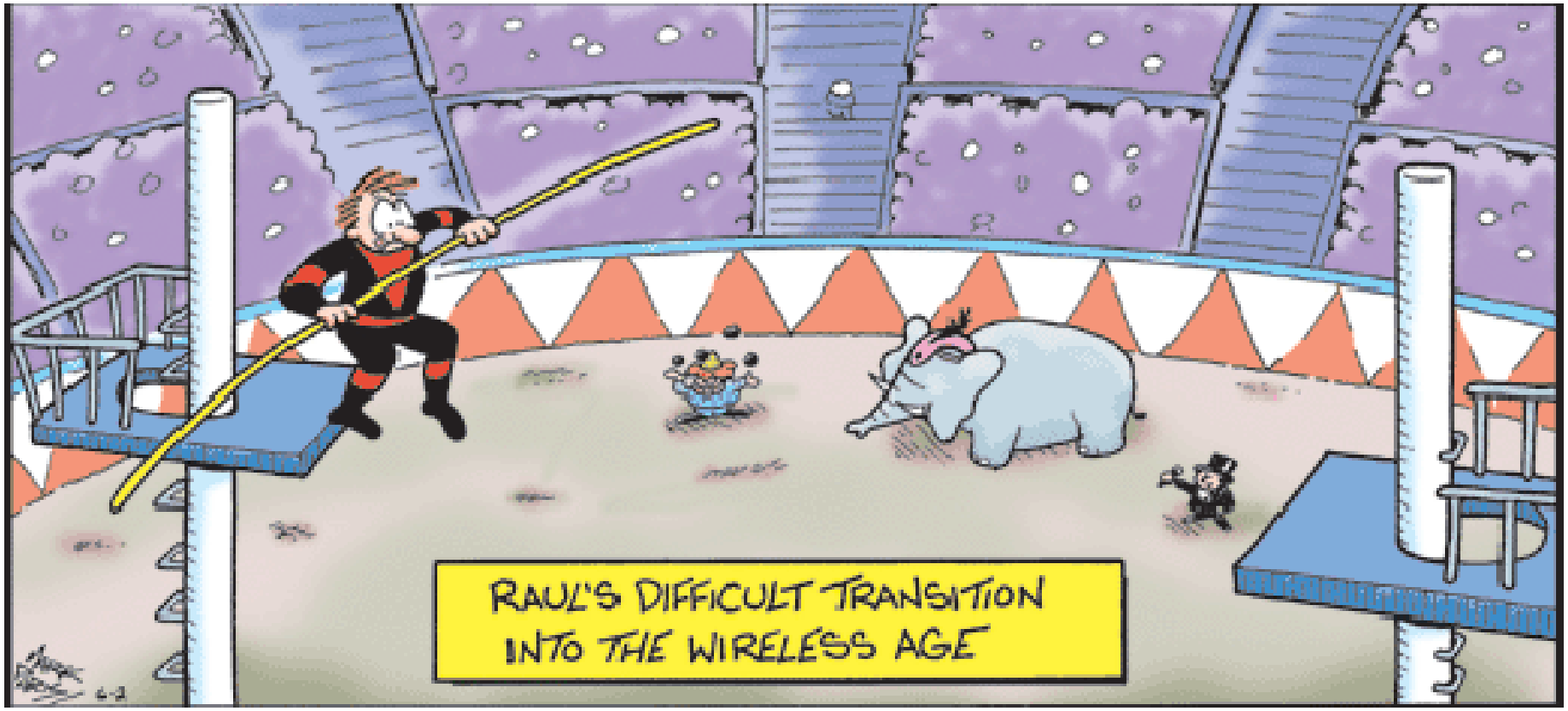
Be Prepared

- Pediatric Care
  - Family-centred
  - Protective/nurturing
  - Prescriptive
  - Focus on development and growth

- Adult Care
  - Independence (emotional and financial)
  - Autonomy for health
  - Collaborative
  - Empowering

Collaboration:
Transition can be challenging!



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Developmentally Appropriate Care

Transition Clinics

- Very popular for youth
- Shows promise-assists in getting to adult system
- Alleviates fear
- Opportunity for adult providers to attend

Teen-Transition Clinic

Teen Transition Clinic at CDRP

Children's Developmental and Rehabilitation Programme, McMaster Children's Hospital

As you may recall, your therapist at CDRP has suggested that you attend an appointment at CDRP's Teen Transition This is to confirm your appointment

When:

Where: **Holbrook Building** – Please check in at the main floor reception desk.

Why : To discuss topics related to your everyday life and to plan for your future and your eventual discharge from CDRP.

What happens at Teen Clinic

The Teen Transition Clinic at CDRP **assists teens in doing things NOW that will prepare them for their future and discharge from CDRP.**

Appointments give teens a chance to meet with Dr. Gorter and a CDRP social worker and/or occupational therapist to talk about things like ...

-medical questions and concerns
-transferring to adult-based health care services
-plans for after high school
-questions about health and/or diagnosis
-services/groups that can help you get what you want now and after discharge from CDRP
- setting goals for your future, eg becoming more involved in your health care decisions , learning how to get around in the community ... or becoming more independent in an activity.
-setting up an action plan in place to help you reach your goals.

Listening to Teens

We usually begin the appointment with teens and their parents and then encourage teens to have part of the clinic visit on their own with the doctor or clinic team. This gives you **a chance to speak for yourself** during the appointment which you will be doing more as an adult.

Privacy and Confidentiality

Meeting privately with the doctor or therapist may make it easier for you to talk about topics that might be hard for you to discuss with other people around. Information can be kept confidential between you and the team or we can discuss sharing some of that information with your parents. If you wish, you can also request that your CDRP therapist attend part of the clinic visit.

Information for Parents

Parents sometimes find it helpful to talk on their own to a health care professional if they have questions or concerns about "letting go" of their teens.

Caregivers who have teenagers with a developmental disability can also request an appointment at Adolescent Clinic to discuss how to coordinate their teen's medical care and transition from high school.

We are happy to meet with teens and their parents together and/or separately during clinic time.

Changes to your appointment

Please notify CDRP at 905-521-2100 ext 77031 as soon as possible if you are unable to attend the appointment due to illness or a scheduling problem. We appreciate your cooperation in keeping your scheduled appointment and look forward to meeting you.

Phases & Actions

	Phase	Actions
Early Adolescence (10-13)	**Awareness**	**Identifying kids** **Information (written and oral)**
Middle Adolescence (14-15)	**Experience**	**1:1 chat Teen & Dr.** **Parent support (Therapists/SW)**
Late Adolescence (16-19)	**Preparation for transfer to adult services**	**Information package** **Capacity building** **(health care & community)**

Opportunities & experiences

- Introduction to the clinic and privacy issues

- The ‘F-words’:
  - Family: values and beliefs (e.g. independence)
  - Function: Rotterdam Transition Profile
  - Friends: peer relationships – dating & sexuality
  - Future: perspective and information
  - Fun: positive experiences

- Medical issues (knowledge, need for follow-up)

Rosenbaum P, Gorter JW. The 'F-words' in childhood disability: I swear this is how we should think! Child Care Health Dev. 2012 Jul;38(4):457-63.

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Confidentiality

Here is an example of a confidentially statement (Grant et al., 2008):

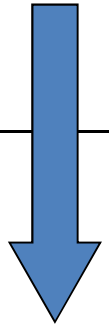
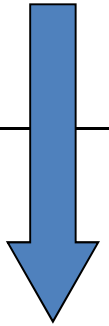
> *"'Everything we are going to talk about is confidential – that is we do not need to talk about it with your parents unless you would like to.*
>
> *There are a couple things, however, that I cannot keep secret and you need to know about:*
> - *If you tell me you are going to hurt yourself or someone else, I have to let others know.*
> - *If you are under x years, and you tell me that someone has hurt or abuse you in anyway, I have to let someone know as well.*
> - *Does this make sense?*
> - *Any questions?"*

Legal and Ethical Considerations

- The most common circumstances for a breech in confidentiality are those in which the young person:
    - Discloses **suicidal** or **homicidal intent**
    - Discloses **abuse** or **neglect** of themselves or their siblings

- **Remember**...It is our responsibility to inform families and teenagers about the scope and limitations of confidentiality **before** beginning an interview

Autonomy = Self-regulation

	Dependency	Relationship
Early Adolescence (10-13)	Largely dependent	Hierarchical
Middle Adolescence (14-15)		
Late Adolescence (16-19)	Relatively independent	Equivalent relationship

Be prepared

The shared management model encourages a shift in knowledge and responsibility from the service provider to the parent and finally to the young person.

Age & Time ↓	Provider →	Parent/Family →	Young Person →
	Major responsibility	Provides care	Receives care
	Support to Parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manager
	Resource	Consultant	Supervisor/CEO

*Kieckhefer GM., & Trahms CM, 2000

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Function: Transition Profile (Donkervoort et al. 2008)

Appendix Ia: Descriptions of the phases and domains of the Rotterdam Transition Profile

	Phase 1 (Childhood)	Phase 2 (Transition)	Phase 3 (Adulthood)
Participation			
Finances	Pocket money	Job on the side	Benefits
	Clothing allowance	Student grants	Job income
Education and	General education	Vocational training	Paid job
Employment		Work placement	Volunteer work
Housing	Living with parents	Seeking housing	Living independently
		Domestic training	
Intimate relationships	No partner	Dating, beginning	Sexual relationship
	No sexual activity	of sexual activity	with intercourse
Transportation	Parents' or carers'	Parents' or carers'	Young adult arranges
	transport	arrange transportation	transportation
Leisure	Leisure activities	Leisure activities	Going out in
(social activities)	at home	outside the home	the evening
Health care			
Rehabilitation	Child rehabilitation	No rehabilitation	Rehabilitation,
Services		visits in the past year	adult department
Services & Aids	Parents apply for	Young adult learns	Young adult applies
	services & aids	the procedures	for services & aids
Care demands	Parents formulate	Parents & young adult	Young adult
	care demands	formulate care	formulates
		demands together	care demands

Rotterdam Transition profile

www.erasmusmc.nl/revalidatie/research/transition

For each item below, please check off the <u>one statement</u> that best describes your current situation.

1. Education and employment
2. Finances
3. Housing
4. Intimate Relationships
5. Transportation
6. Leisure / social activities

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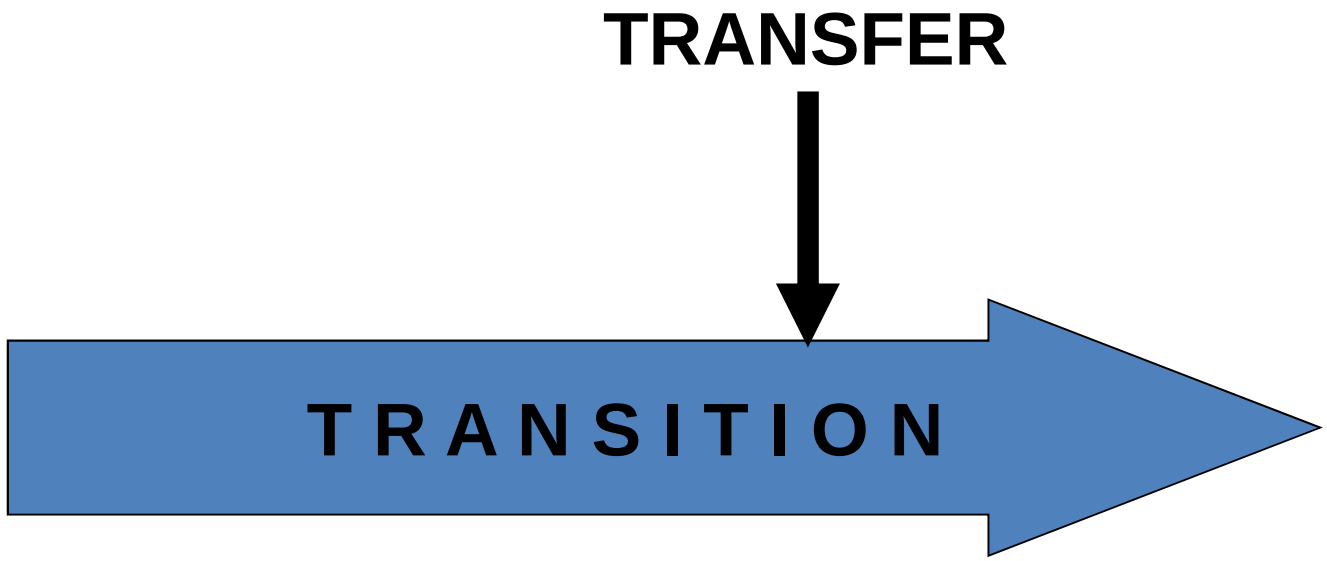
Transition vs. Transfer

- Transfer
  - the movement to a new health care setting, provider, or both.



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Blum J Adolesc Health 1993;
Callahan Current Opin Ped 2001

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TRACE STUDY

TRANSITION TO ADULTHOOD WITH CYBER GUIDE EVALUATION

Population at baseline

Site	N	Gender	Mean Age (SD)	Range	"Youngest " (by clinic)	"Oldest " (by clinic)
McMaster	41	53% F	18.0 (.9)	15.8-21.2	IBD 17.2 (.6)	DP 18.6 (1.2)
SickKids	11	73% F	17.6 (.4)	17.0-18.4	IBD 17.4 (.4)	Good2Go 17.8 (.)
Both sites	52	58% F	17.9 (.8)	15.8-21.2		

IBD=Inflammatory Bowel Disease/Disorder
DP=Developmental Pediatrics (Spasticity clinic, spina bifida clinic, teen transition clinic combined)

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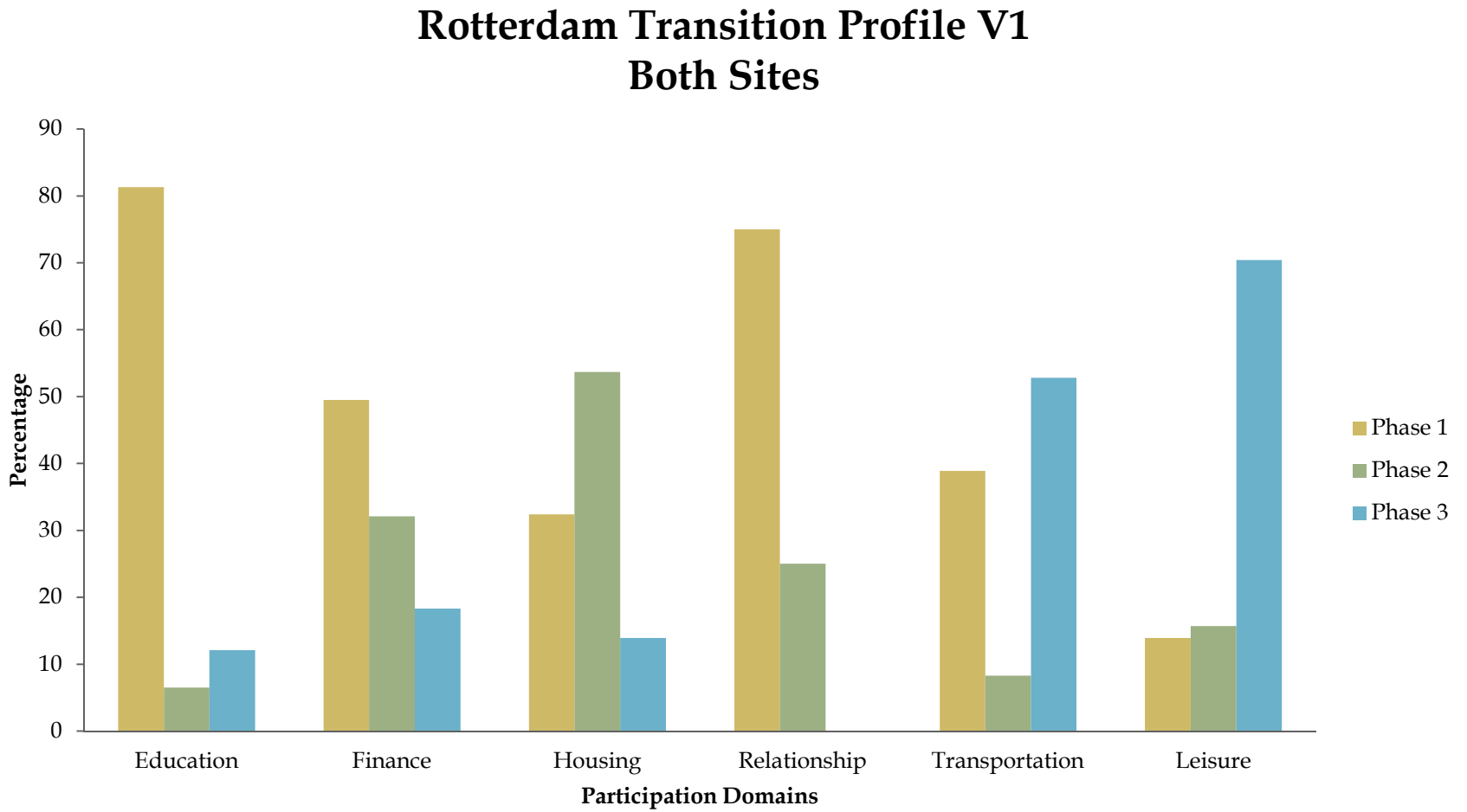
Population at baseline: (in)dependence stages



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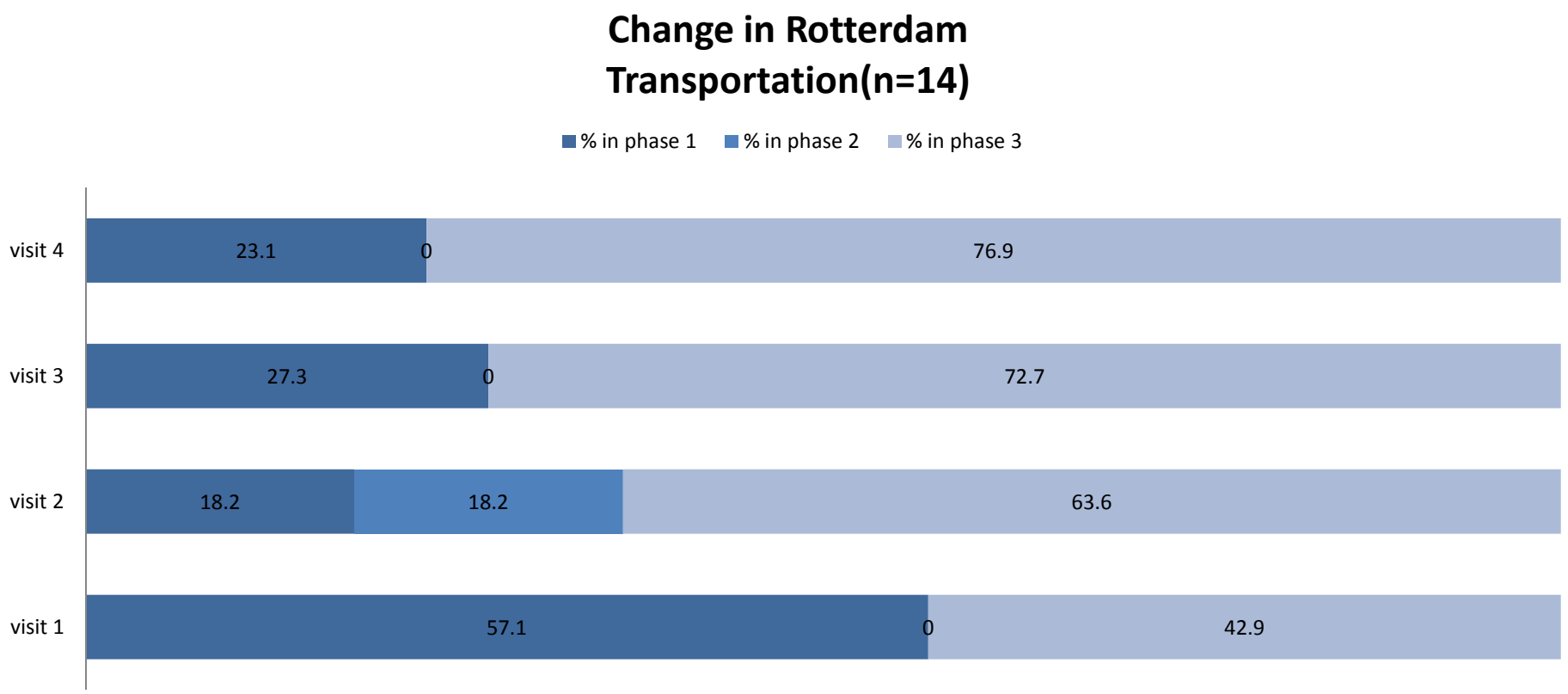
Change in Profile



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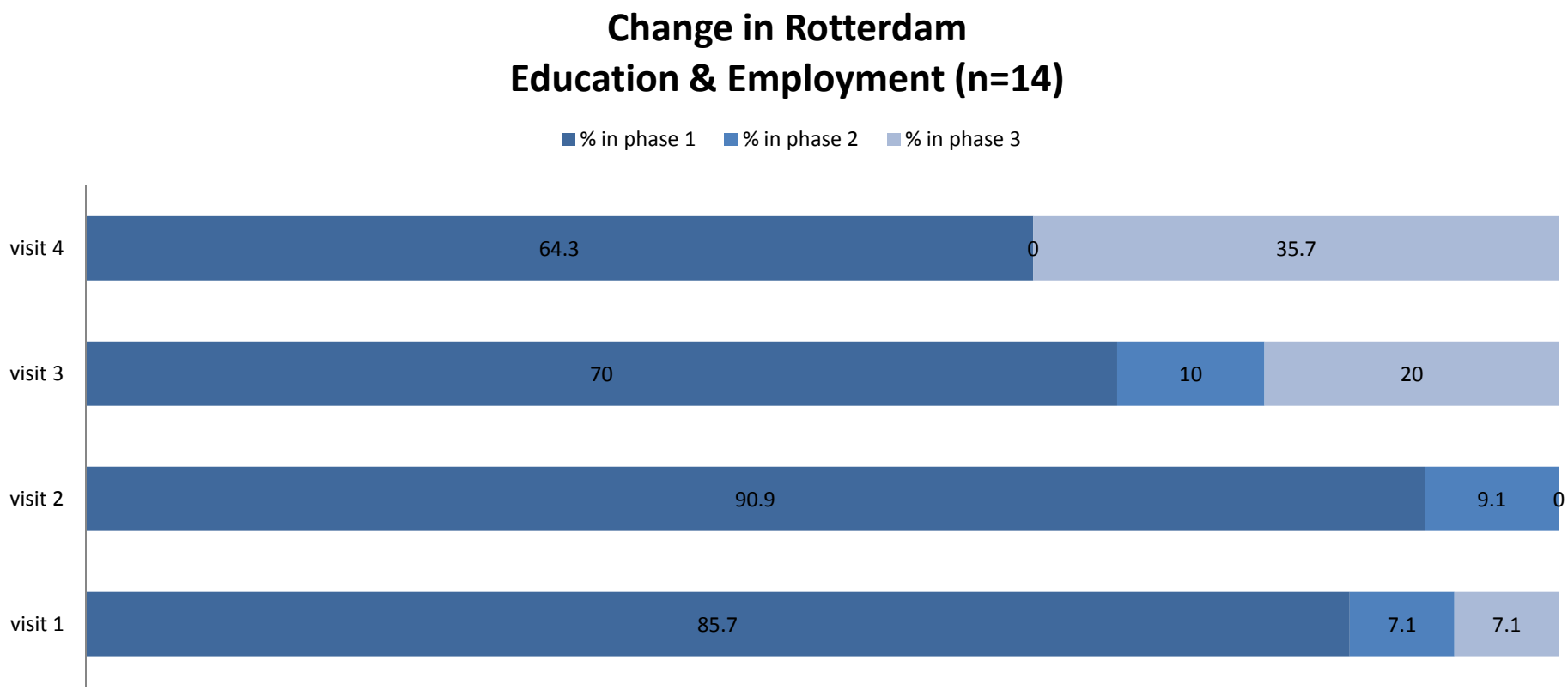

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Intervention Tools used in TRACE

- Youth KIT tool
  - Binder contains worksheets which assist with record keeping and transition planning

- "Trace" Online Transition Mentor
  - Available by e-mail, chat through abilityonline.org
  - Discuss teens' questions related to transition (*medical)
  - Assist with Youth Kit, goal setting

YOUTH KIT ©

- Personal Information
- Social Information
- Social Activities
- School Information
- Work Information
- Budget Information
- Personal Care and Life Skills
- Medical and Health Information
- Obtaining and Sharing Information

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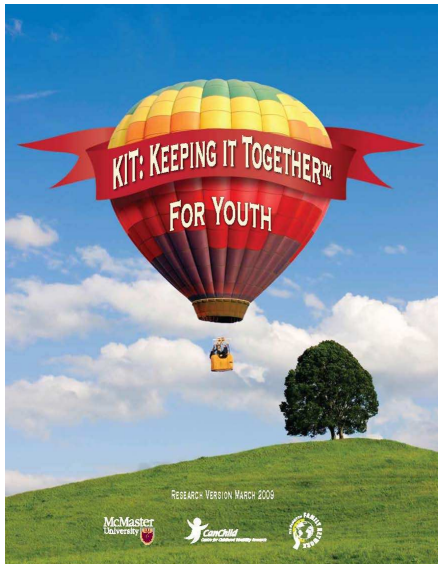
Purpose of Youth Kit

- Engage youth in planning for transition
  - Organizing information
  - Sharing information



- KIT Information allows you to
  - Do what you want
  - Get what you want
  - Share information with other people

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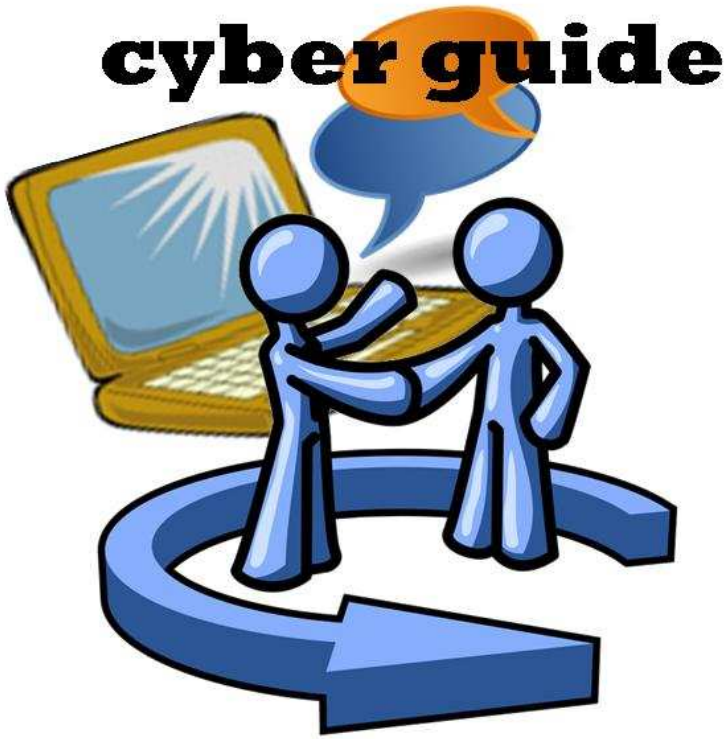
TRACE

ONLINE TRANSITION MENTOR



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AbilityOnline
Shine On

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Kids & Teens Homepage | Friendship Builder | Young Adult/Alumni Homepage | Members' Corner | Foru

Fun Stuff | Volunteer | TRACE Research (Private) | Transitions Plus | Find a Mentor

Member Menu

- Private Messages (13 new)
- My Account
- My Friends
- Logout

Home > Kids & Teens Homepage

Kids & Teens Homepage

Let your ability Shine On.

For things you would like added to this section please send a message to Michelle. Thanks!

Check out the "Express Yourself" module for ways to get active in your community. Are you an athlete or artist and want to be profiled? Send Michelle a message and we will post your inspirational story.

- Forums Exchange messages with youth from around the world!
- Homework Help -read the neat stuff the tutors are posting and ask any questions you might have.
- Bully Bouncers- confidential help with any type of bullying.

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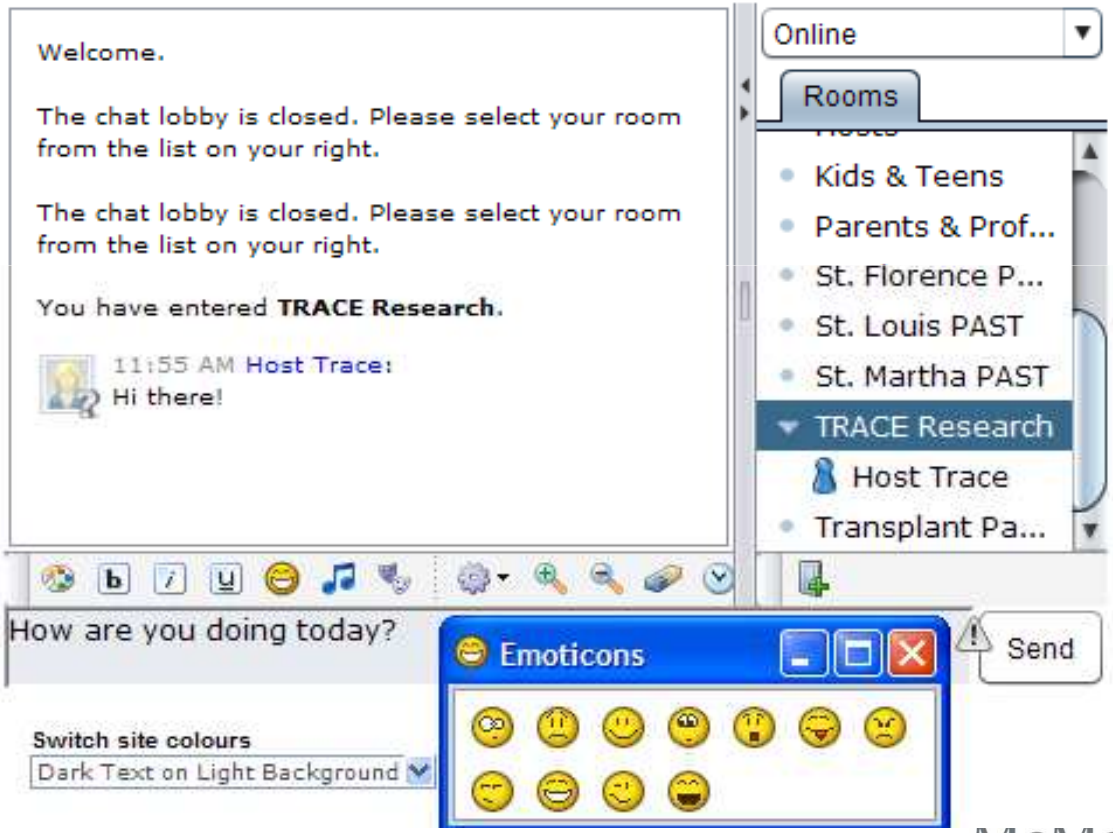
Chat Room

- Be friendly and respect other members in the chat room.
- Welcome people who join even if you are chatting with a group of your friends -tha chat rooms are shared spaces
- Some people are slower typers than others so please be patient
- No swearing or bullying allowed. Chat rooms are monitored. If you break the rules you will lose access to the site.
- Have fun!



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Transitions Plus Discussions

Transitions Plus is new program module being developed on Ability Online to facilitate the journey for youth of all abilities who are in transition - transition into and from highschool, pediatric to adult care, or from school to employment opportunities. Here you will be able to connect with Mentors, Employment Specialists, and other youth facing similar challenges.

We will also help you make the most of all our program modules (Homework Help, Express Yourself etc.) as you work on the skills you need to move into adulthood!

This is very much a collaborative work in progress, so check back often to see new content as it is added or let us know your ideas for things we can add. In the meantime, feel free to ask questions or read what others are saying in the following forums:

Under 20:

- Which subjects should I choose?
- Get Motivated and De-stress
- Transitions

Young Adult/Alumni:

- Employment Tips
- Living on Your Own
- College/University Life

Transitions Guide (Courtesy of NBACL and The Sandbox Project)

Medical and other helpful information courtesy of kidshealth.org

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Snapshot of TRACE participants

- Lives of adolescents/young adults
- Typical concerns
- Coaching conversations

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Conversations

- My mother won't let me …
- I need to tell "X" about my disability. I am worried about what they'll think.
- The counselor wasn't very helpful…
- Thanks Trace … I guess I never really looked at it that way before.

TRACE Study Qualitative Interviews: Background

- Question:

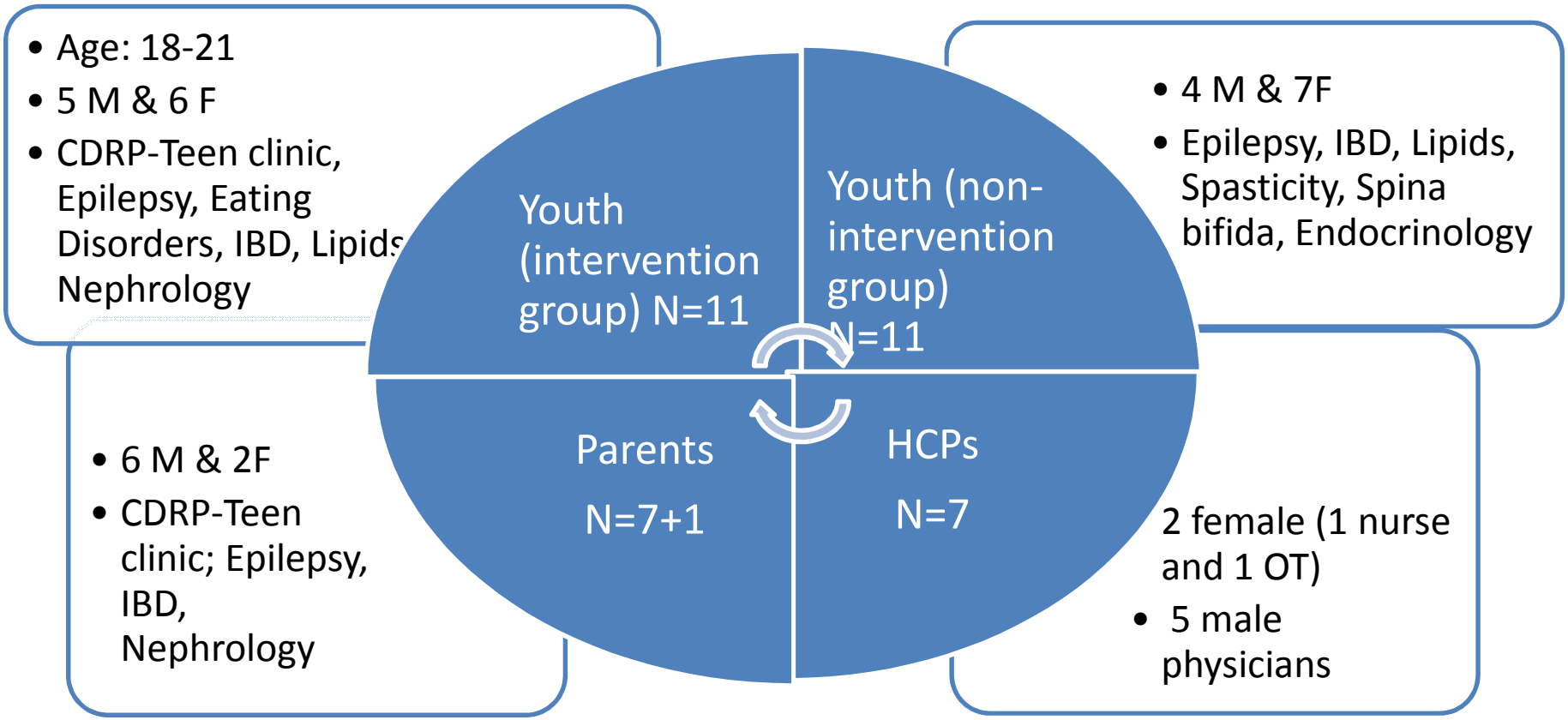
  What are the experiences and perceptions about the Youth KIT, TRACE mentor, and healthcare transition for youth with chronic medical conditions and their caregivers?

- Qualitative phenomenological approach.

- Post-transition interviews.

- Exclusion criteria: fully dependent youth.

Qualitative Interviews: Participants



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Youth and health care transitions: Theme 1: Self-management

- The majority of youth reported they were independent in managing their medical needs.

  "I see myself being more independent all the time. I am pretty independent as it is. I attend most of my appointments by myself, and I already direct my own care pretty well."

however…..

Theme 1: Self-management and parent role

- Many youth still rely on parents' behind-the-scenes support (e.g., scheduling, driven to appointments, accompanied by parents) :

Theme 1: Perceived independence

P: I have like a fair amount of independence. Like they [parents] don't control *all* of my stuff for me.

I: In what areas do you feel you are more independent?

P: In what area?... I don't know. Like in all areas I guess. …

They come with me so they can stay - they like to know what's going on. But it's *not because I need the support of what's going on or because I am having trouble going from a kid's doctor to an adult doctor*. They have gone with me from the kid's doctor until now. They have always gone with me to every appointment.

Theme 1: ”Real” independence?

“I like it [transition experience] but it was a lot easier when you would go to the appointment at McMaster, you would go and then as you were leaving you would make another appointment. It kind of seemed more structured. I feel like now I can just not go… and it's probably not a good thing. Like I haven't gone since January.”

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Theme 1: Towards the interdependent dance

- Parents recognized the need to step back and allow their youth to become more independent.
- Parents continue to provide support when needed.

  "At this point, there's really not much that is really required of me because he is full grown. I can just encourage him to stay on track and, you know, not go out every single night. Just keep a general eye over him to make sure that he is getting his sleep."

Theme 2: Health care providers' experiences

- Paediatric and adult systems: Two different systems:

  "So we have to bridge the divide. In a way, we created the divide between pediatric and adult services. Now we have to bridge it. "

  "…we have to let go but they also have to pick up"

- Working towards self-management of youth

  "One of the things I have been deliberate about in my practice is to really address myself to the kids… I try to make the child the focus of the visit."

Theme 3: Impact of TRACE Study and resources

- Youth were "too busy" to fully engage in the study and its resources.

  "He's been busy and he's not into that…I think we have a good support network so I think it's for that reason more than anything that we never really felt – you know."

- Health care transition was only one small part of their busy lives

Theme 3: Impact of TRACE study on Health Care Providers (HCPs)

- Raised awareness and resulted in a more formalized and systematic transition process:

"I guess I have seen a little bit more awareness of transition issues and the need to be prepared for transitions among clinic staff…it's become a little more formalized since the study started."

Theme 3: More Impact of study on HCPs

- Starting transition planning earlier

"…and with increased awareness I think we shifted the average age that they now start in clinic is more close to age 14 or 15 (physician).

Theme 4: Recommendations from HCPs

- Enable youth AND parents to work towards self-management:
  "Engaging the parents more could be helpful, and engaging the parents in a way that shows them how to empower their teens."

- Bridge the divide between two systems/Start transition planning early:

  "Some sort of continuity, overlap or introduction early on with the adult counterpart on my side, or the other way around."

  "For clinic staff, it's having an awareness in mind that transition will be taking place and that we need to begin it a lot sooner than we do and we need to do a much better job of being deliberate in our transition instead of doing it accidently and after the fact…"

Conclusions?

TRACE study reminded us that we need to recognize:

- Complex and multi-dimensional nature of transition experience
- Great variability in participants' progression towards self-management and independence
- Need to start transition planning early
- Need to involve parents and youth

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“ We cannot always build the future for our youth but we can build our youth for the future”

Franklin D Roosevelt
1882-1945