

Development of an indicator of the impact of assistive devices in children and their families

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WORKSHOP

A Health Services Research Agenda: Building Capacity within the Maternal, Child, & Youth Sector

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Shriners Hospitals
for Children™

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Funding Support_Acknowledgements



Project Overview_Context

- ❑ 90,000 Canadian 5-14 year-olds need assistive technology (AT) devices to participate in everyday activities at home, at school, and in the community (Statistics Canada, 2008)
- ❑ 56% of parents reported that their children had unmet AT needs; device cost was the main barrier
- ❑ all provinces have special programs to provide funding to help families buy 'essential' AT devices
- ❑ ADP co-payments to buy/lease AT devices for residents = \$347 million in 2008/09 (Office of Auditor General, 2009)



Project Overview_Context

- ❑ AT devices are environmental resources that improve child functioning, but empirical evidence is weak
- ❑ sound measures of AT impact of children and their families are unavailable
- ❑ Family Impact of Assistive Technology Scale (FIATS) is a new measure that detects the effect of AT device use on the lives of children with disabilities and their families
- ❑ the FIATS has acceptable scale properties for measuring the effect of special seating devices in children with CP



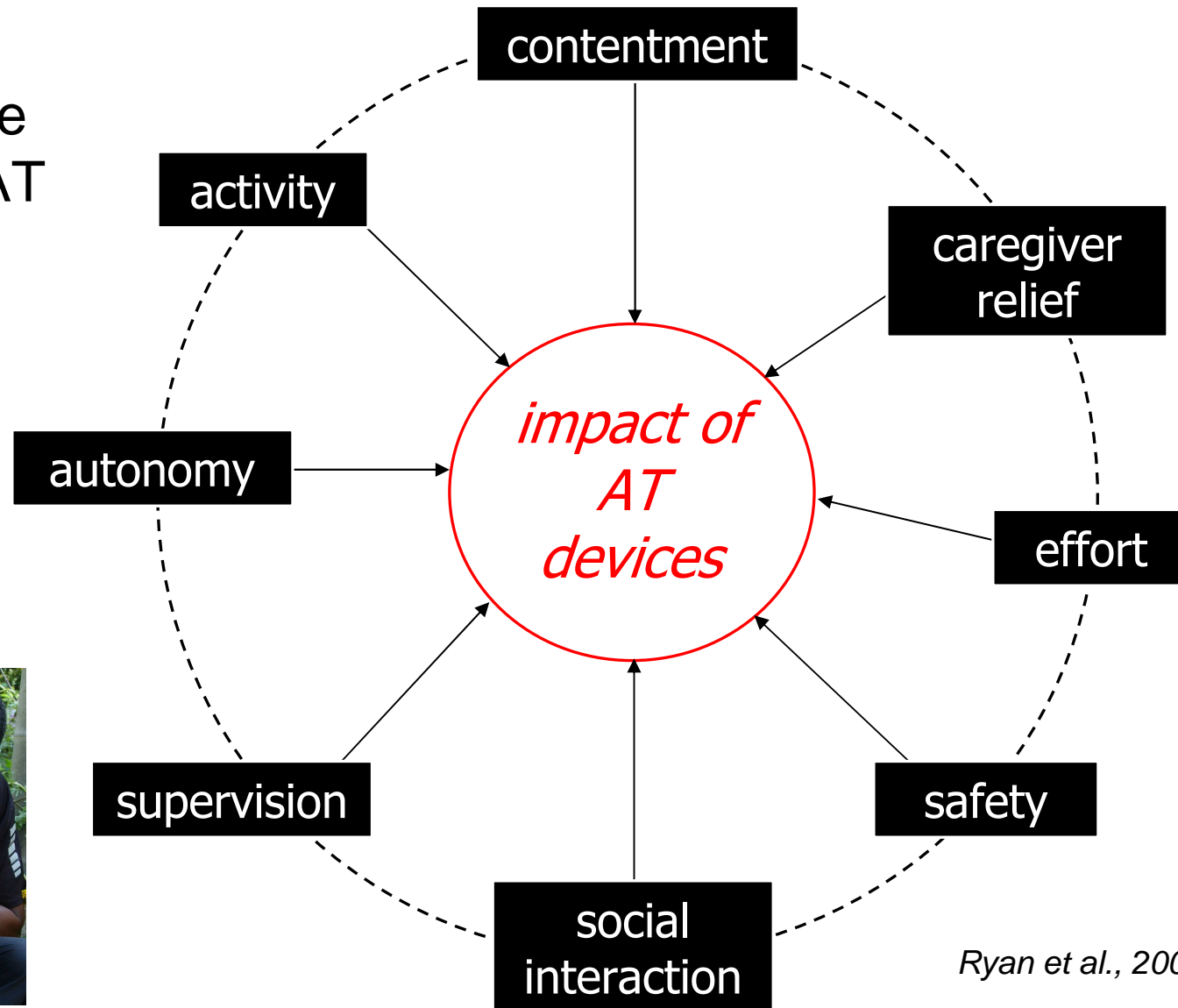
Project Overview_Context

- FIATS has 55 items assigned to one of 8 subscales (4 to 9 items per scale)

Item	Strongly Agree Strongly Disagree						
I find it easy to play with my child.	7	6	5	4	3	2	1

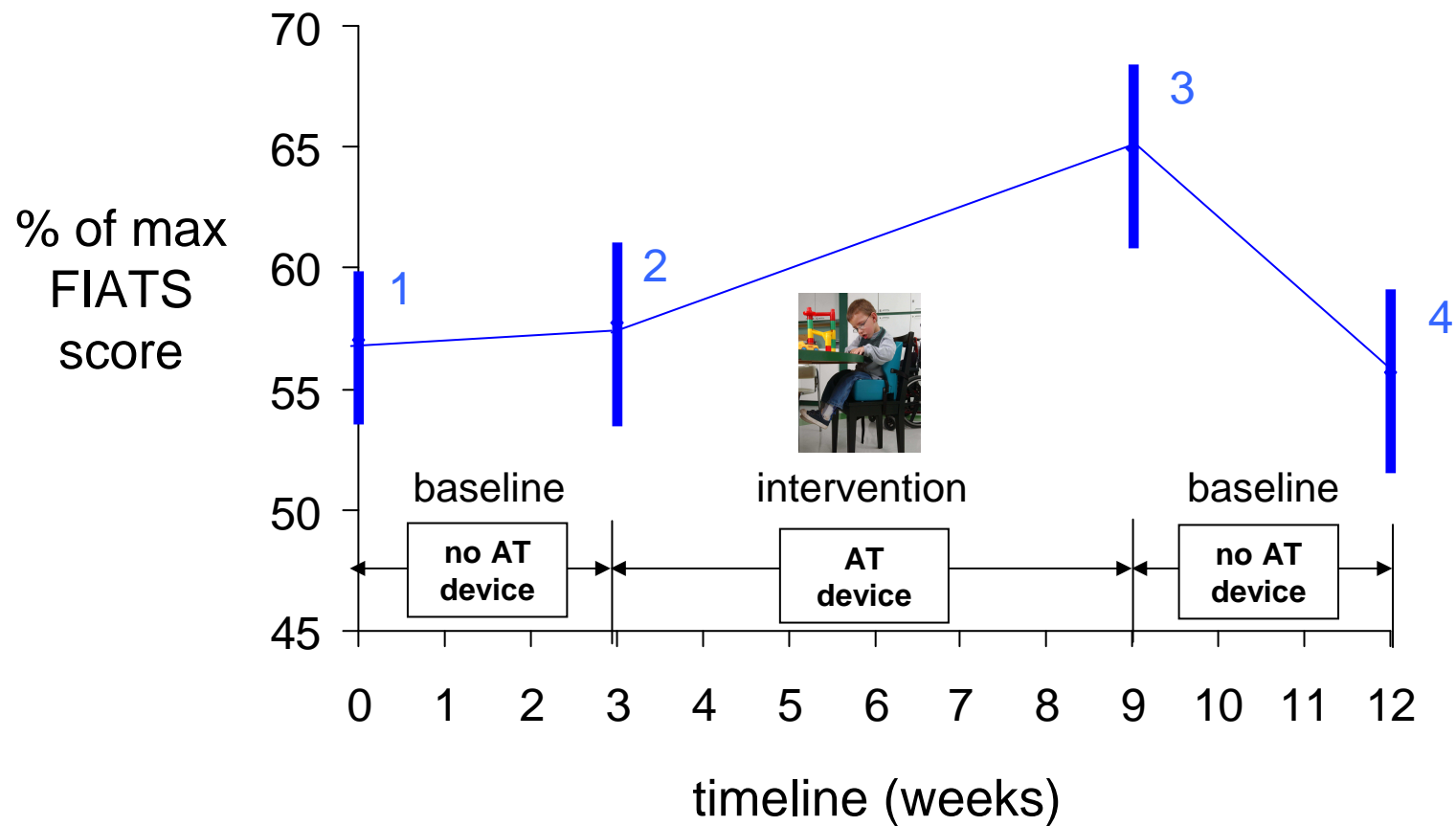
Project Overview_Indicator Development

Measuring the influence of AT devices in children & families

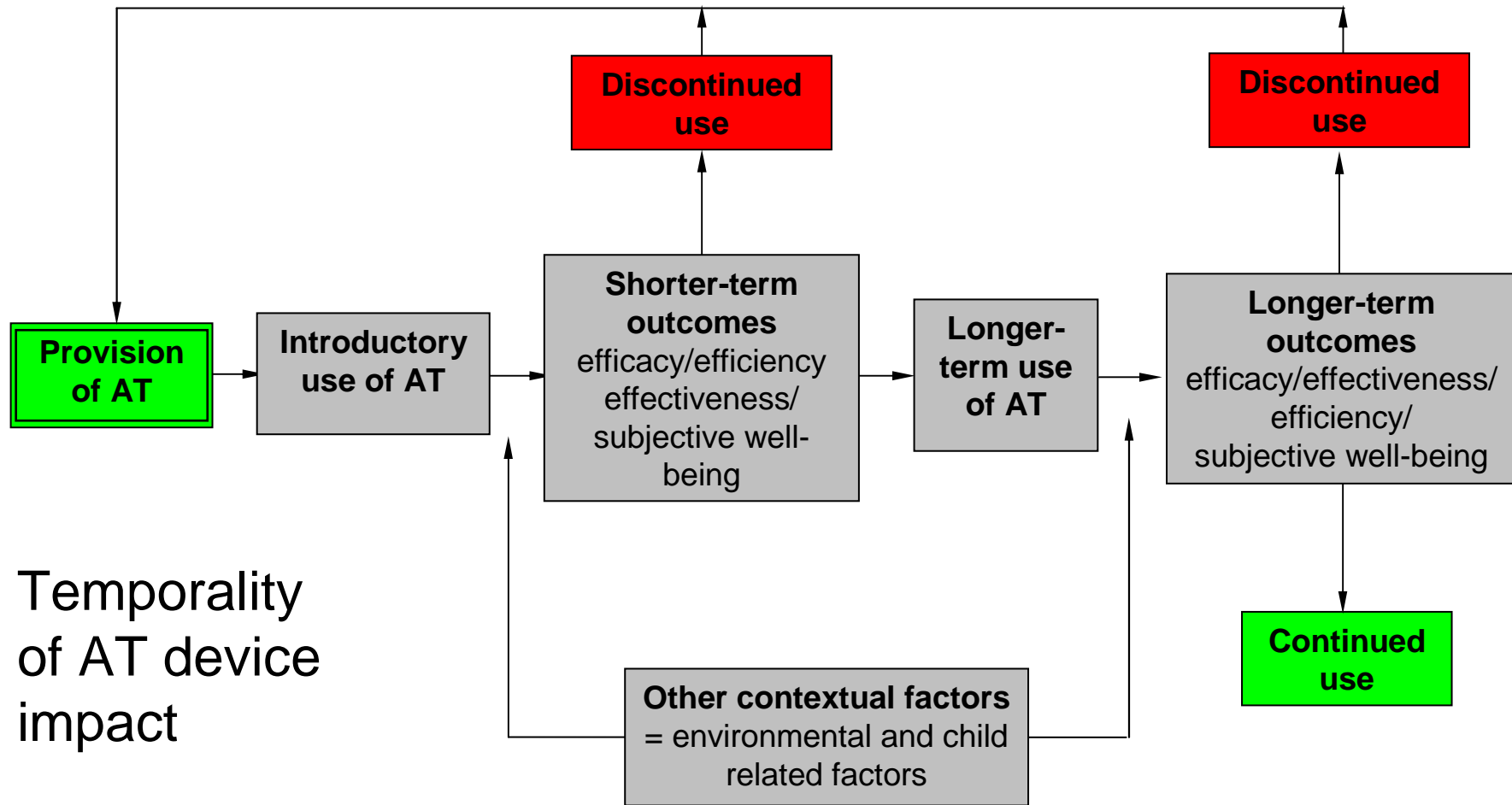


Ryan et al., 2007

Project Overview_Indicator Development



Project Overview_Indicator Development



Temporality
of AT device
impact

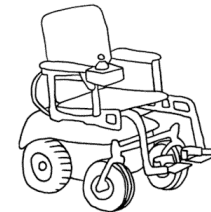
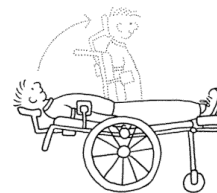
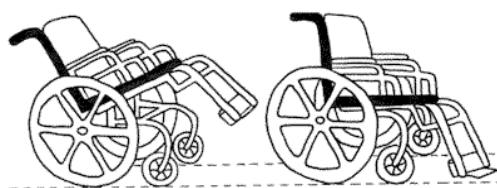
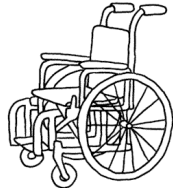
Project Overview_Research Question

Is the FIATS responsive to important changes in the lives of children with physical disabilities, aged 1-18 years, and their families during the 6 months following the provision of a new wheelchair seating system?



Project Overview_Protocol

- ❑ longitudinal study of 100 Canadian parents of children and youth with mobility impairments in Ontario (50), Quebec (30), and BC (20)
- ❑ follow parents whose child is due to receive a 'new' seating system for a specialty stroller, manual wheelchair, or power wheelchair
- ❑ each parent interviewed 4x over 7-9 months
- ❑ contextual data gathered during the initial and final interviews



Project Overview_Protocol

Interview Number	1	2	3	4
Timing	More than 3 weeks before receipt of new w/c seating	2-3 weeks after first interview	6 weeks after receipt of new w/c seating	6 months after receipt of new w/c seating
Interview Type	In person	Phone	Phone	Phone
Outcome Measures	FIATS PEDI 2 PedsQL	FIATS	FIATS	FIATS PEDI 2 PedsQL



Project Overview_Analyses

- Primary analysis
 - RM ANOVA applied to determine if significant differences in mean difference scores are present among first, third and fourth FIATS administrations
- Secondary analyses
 - estimate test-retest reliabilities using ICCs and 95% CIs for FIATS and MIAT-F between first and second administrations
 - use correlational statistics between FIATS and other measures to study convergent construct validity

Achievements / Milestones

- Phase 1 (completed): did item equivalence testing and linguistic validation of French version of the FIATS
 - Mesure de l'Impact des Aides Techniques sur la famille (MIAT-F) use with parents in Montreal
 - Turkish and Chinese versions of the FIATS are under development by other research teams
- Phase 2 (in progress)
 - recruited 37/100 (37%) families from 6 clinical sites
 - will be recruiting parents from 15 clinical sites this year
 - maintained alliance of AT decision makers in Ontario and BC

Achievements / Milestones

- ❑ Trainee activities
 - 6 MScOT and 2 undergraduate students have participated in the scale development of 2 new communication modules for the FIATS
 - FIATS-WD to measure the impact of creative writing technologies (e.g., word prediction software)
 - FIATS-AAC to measure the impact of augmentative and alternative communication systems (e.g., speech generating devices for face-to-face communication)



Key KT Challenges_Mind the Gap

- ❑ *knowledge to action* gap will lessen with the availability of the FIATS as a measurement tool
- ❑ AT decision makers need to learn to appreciate the research process, how to use indicators, how to interpret change; we (researchers) need to learn more about how to influence change in AT policy`
- ❑ multicultural environments challenge the development and application of national indicators



Key KT Challenges_Mind the Gap

- ❑ need commitment to measure AT outcomes and the effect of other contextual factors longitudinally to understand the influence of AT devices
- ❑ need support for research teams to develop other AT impact indicators that integrate the perspectives of children, youth, young adults, clinicians, educators
- ❑more to come!



Next Steps

- Short-term
 - complete data collection and analyses
 - organize interactive forum with provincial decision makers, clinicians, other researchers to discuss outcomes and plan strategies for indicator uptake
- Medium-term
 - promote the FIATS through ministry venues, clinical and academic fora, and consumer media
- Long-term
 - build capacity to advance FIATS-WD, FIATS-AAC & other modules to create a battery of AT effect indicators for funded and unfunded devices
 - prioritize AT research needs, develop better indicators, inform policy/clinical/family decision makers

