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Health Care Transition at UC UCEDD
Ilka Riddle, PhD Director, UC UCEDD
2014 AUCD Conference, Washington, D.C.
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Transition Readiness Study
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Health Care Transition Readiness Across Five Groups of Youth: Looking At What Matters
Riddle, I.; Duncan, A; Corathers, S.; Kichler, J.; Houchen, A; & Casnelli, L.
2014 AUCD Conference, Washington, D.C.

# Cincinnati Children's ucedd **Background** • Health care transition important topic for youth with disabilities; especially if medical condition(s)/need(s) is/are present • Increased research and practice focus on health care transition of youth with special health care needs **Background** • Little research on how transition readiness varies across conditions and contexts of youth · Little research on the role of health literacy for/in transition readiness across populations Cincinnati Children's **Background** • Emphasis on transition readiness has been either: - Disease-specific or - Aggregated across multiple conditions

# Background • Identifying differences in transition readiness by chronic conditions essential to: - Improve understanding about resource allocation - Determine the potential need for special

emphasis within specific populations

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Background

- Variability in transition readiness between populations could be attributable to differences in the:
  - Cognitive impact of diagnosis
  - Medical complexity of disease management
  - Combination of cognitive impact and medical complexity
  - Disparate organizational and systemic perspectives about transition within same organization

Purpose of Study

• Examine youth transition readiness and health literacy among five subgroups of youth

- Type 1 Diabetes; Turner Syndrome; ASD; Spina Bifida, no medical condition or disability

• Compare differences between groups

 Identify mechanisms that support successful transitions and test interventions for subgroups (future research) Cincinnati Children's ucedd **Study Aims** 

- Aim 1:
  - Examine differences in transition readiness among youth from four clinical groups (Type 1 Diabetes; Turner Syndrome; ASD and Spina Bifida from two divisions (Endocrinology and Developmental/Behavioral Peds) in comparison to youth without medical conditions or disabilities from Adolescent Medicine Teen Health Clinic

Cincinnati Children's **Study Aims** • Hypothesis Aim 1:

- - There will be differences between groups
  - Youth with developmental/behavioral diagnoses will demonstrate lower readiness than youth with chronic medical conditions
  - Youth without medical condition or disabilities will have highest level of readiness

Cincinnati Children **Study Aims** • Aim 2:

- Determine whether differences in the four groups with chronic medical condition and disabilities are attributable to demographic characteristics
- Hypothesis Aim 2:
  - Demographic characteristics would predict differences in transition readiness scores but would not fully account for differences between the groups

Study Participants

• Youth/young adults (12-21) from five different clinics at CCHMC:

- Type 1 Diabetes; Turner Syndrome; ASD; Spina Bifida, Teen Health

- Youth/young adults from Teen Health Clinic screened for chronic conditions and disabilities

• Target: 35 youth/young adults per group

• All participants IQ of 85 or higher

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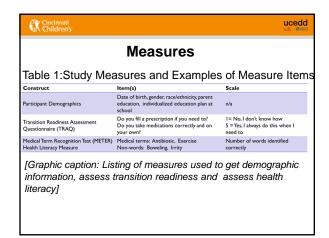
# **Study Participants**

- Participants recruited at time of clinic visit and via mailings and phone calls (ASD and Spina Bifida only)
- Participants signed assent (if under 18 years) or consent (if over 18 and own legal guardian)
- Parents/Legal guardians signed consent

Measures

• Validated tools

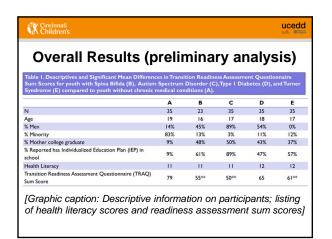
- Three questionnaires:
- Tillee questionnailes.
  - Participants Demographics
  - Transition Readiness Assessment Questionnaire (TRAQ)
  - Medical Term Recognition Test (METER) and Health Literacy Measure



# Measures • Disease-specific questions for youth from following clinics: - Type 1 Diabetes; Turner Syndrome; ASD and

Spina Bifida

- Questions about medications and medical self-management items



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### **Overall Results (preliminary analysis)**

#### **Health Literacy**

- Youth with Type 1 Diabetes had significantly higher health literacy than youth with Spina Bifida (p < 0.01) and youth without chronic medical conditions (p = 0.03)
- Youth with Turner Syndrome had significantly higher health literacy than youth with Spina Bifida (p = 0.04)

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# **Overall Results (preliminary analysis)**

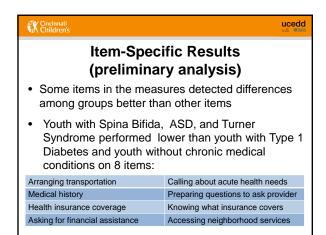
- Transition Readiness
- Youth with Spina Bifida, ASD, and Turner Syndrome had lower TRAQ sum scores than youth without chronic medical conditions, p < 0.01</li>
- For the entire cohort, lower participant age and lower health literacy also predicted lower TRAQ scores, p < 0.01</li>

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Overall Results (preliminary analys	sis)

#### • Transition Readiness

Variable	DF	Mean Square	F
Age	1	8040.88	59.81**
Gender	1	72.79	0.54
Race	1	19.91	0.14
Maternal education	1	63.61	0.47
IEP	1	0.073	0.001
Health literacy	1	1266.5	9.42**
Clinic Group	4	884.59	6.58**

[Graphic caption: Listing of significance of age, health literacy, group and key covariates on transition readiness assessment scores.]

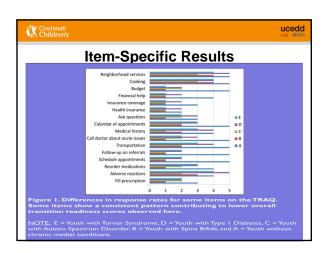


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# Item-Specific Results (preliminary analysis)

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 Groups demonstrated equivalent scores for items assessing medication management, talking to providers at appointments, and cleaning up (median score = 4 - 5)



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# Disease-specific Information of Youth who have ASD (preliminary analysis)

- Info for new doctor:
  - "Don't know"/"not sure": 6 responses
  - No response/blank: 4 responses
  - Study participants' answers:
    - "The issues that I have with my disability."
    - I might need the doctor to rephrase his/her question so I can understand."

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# Disease-specific Information of Youth who have ASD (preliminary analysis)

- · Medications:
  - 25/35 were able to list off specific medications or function of their medication
  - 7 did not answer question
  - 3 provided vague answers like, "pills"

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# Disease-specific Information of Youth who have ASD (preliminary analysis)

- Medication purpose:
  - 22/25 were able to accurately describe purpose of their medication, e.g. "Concerta keeps me focused"; "Celexa is for anxiety and depression"

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- Cathing:
  - -21 reported cathing, ranging from 3-8 times a
  - 18/21 indicated that they cath independently
- Knowing how to check for skin sores:
  - 16 said "yes"
  - 4 said "no"

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# **Disease-specific Information of** Youth who have Spina Bifida (preliminary analysis)

What information would you share with a new doctor:

- "My medical condition, what past doctors I've had, how many and what kind of surgeries I've had and what medications I have been taking."
- "Tell them about my background and name and stuff like that."

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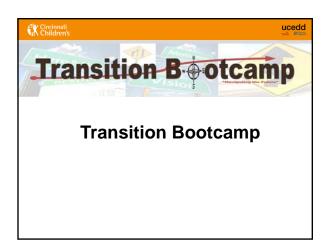
# **Disease-specific Information of** Youth who have Spina Bifida (preliminary analysis)

- · Medications:
  - 20 participants identified specific medications
- Purpose of Medications:
  - 18/20 who take medications indicated appropriate purpose for their medicines

# ucedd Cincinnati Children's **Preliminary Conclusions** 1) All groups would benefit from enhanced transition preparation. 2) Youth without chronic medical conditions and youth with Type 1 Diabetes showed higher transition readiness than the other groups, followed by youth with Turner Syndrome, Spina Bifida and ASD. **Conclusions** 3) Specific interventions that are tailored for each group may be indicated, including: Emphasis on community resources and selfcare for youth with developmental disabilities Emphasis on healthcare and insurance navigation for all youth

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Next Steps	
Data analysis of finalized dataset	
<ul> <li>Manuscript for publication</li> </ul>	
Determine follow-up study and funding	









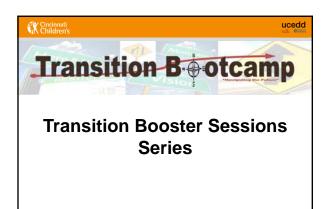


Planning for 2015 conference



Parents/caregivers

• Educators & service providers



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# **Transition Booster Sessions**

- 11 monthly, 2-hour-long in-depth sessions in the evening, dedicated to one transition topic
- · Target Audience:
  - · Parents and caregivers
  - Educators and other professionals

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[Image caption: Booster Session schedule]

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#### **Transition Booster Sessions**

- First Booster Session on Employment
  - 50 attendees
  - Panel presentation; Q&A
  - Very positive feedback
- Next Session on Post-Secondary Education in mid-November



[Photo caption: Attendees sitting in employment booster session]

• Already 47 registrants

