





Health Care Transition at UC UCEDD

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Transition Readiness Study



Health Care Transition Readiness Across Five Groups of Youth: Looking At What Matters



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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



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



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)



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



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



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



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






Measures

Table 1: Study Measures and Examples of Measure Items



Construct	Item(s)	Scale
Participant Demographics	Date of birth, gender, race/ethnicity, parent education, individualized education plan at school	n/a
Transition Readiness Assessment Questionnaire (TRAQ)	Do you fill a prescription if you need to? Do you take medications correctly and on your own?	1 = No, I don't know how 5 = Yes, I always do this when I need to
Medical Term Recognition Test (METER) Health Literacy Measure	Medical terms: Antibiotic, Exercise Non-words: Boweling, Irrity	Number of words identified correctly

[Graphic caption: Listing of measures used to get demographic information, assess transition readiness and assess health literacy]

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






Overall Results (preliminary analysis)

Table 1. Descriptives and Significant Mean Differences in Transition Readiness Assessment Questionnaire Sum Scores for youth with Spina Bifida (B), Autism Spectrum Disorder (C), Type 1 Diabetes (D), and Turner Syndrome (E) compared to youth without chronic medical conditions (A).

	A	B	C	D	E
N	35	23	35	35	35
Age	19	16	17	18	17
% Men	14%	45%	89%	54%	0%
% Minority	83%	13%	3%	11%	12%
% Mother college graduate	9%	48%	50%	43%	37%
% Reported has Individualized Education Plan (IEP) in school	9%	61%	89%	47%	57%
Health Literacy	11	11	11	12	12
Transition Readiness Assessment Questionnaire (TRAQ) Sum Score	79	55**	50**	65	61**



[Graphic caption: Descriptive information on participants; listing of health literacy scores and readiness assessment sum scores]

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 ($p = 0.04$)

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, $p < 0.01$
- For the entire cohort, lower participant age and lower health literacy also predicted lower TRAQ scores, $p < 0.01$

Overall Results (preliminary analysis)

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**

Table 2. The impact of age, health literacy, disease group, and key covariates on transition readiness assessment scores.

** $p < 0.01$

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

Item-Specific Results (preliminary analysis)

- Some items in the measures detected differences among groups better than other items
- Youth with Spina Bifida, ASD, and Turner Syndrome performed lower than youth with Type 1 Diabetes and youth without chronic medical conditions on 8 items:

Arranging transportation	Calling about acute health needs
Medical history	Preparing questions to ask provider
Health insurance coverage	Knowing what insurance covers
Asking for financial assistance	Accessing neighborhood services



Item-Specific Results (preliminary analysis)

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

Item-Specific Results



Figure 1. Differences in response rates for some items on the TRAQ. Some items show a consistent pattern contributing to lower overall transition readiness scores observed here.

NOTE. E = Youth with Turner Syndrome, D = Youth with Type 1 Diabetes, C = Youth with Autism Spectrum Disorder, B = Youth with Spina Bifida, and A = Youth without chronic medical conditions.



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.”



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”



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”

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



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

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.”



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

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 self-care for youth with developmental disabilities

Emphasis on healthcare and insurance navigation for all youth





Next Steps

- Data analysis of finalized dataset
- Manuscript for publication
- Determine follow-up study and funding

Questions










Transition Bootcamp








Transition Bootcamp

- One-day conference in the fall, providing a overview of transition-related topics:
 - Keynote Speakers
 - Education & Post-Secondary Options
 - Employment
 - Health Care
 - Housing, Transportation & Recreation
 - Guardianship & Alternatives
 - Financial Planning






Transition Bootcamp

- Collaborative effort of UC UCEDD, parents and community organizations
- 15-member planning committee







[Photo caption: Presenters smile at the conference; bootcamp materials detail agenda and presenters]





Transition Bootcamp

- Over 200 attendees
- Attendees received a resource binder
- Evaluations very positive
- Planning for 2015 conference




[Photo caption: Resource binder]

Transition Bootcamp

- Vendor Fair with over 36 vendors
- Funded through Rubinstein Foundation Funding
- Target Audience:
 - Parents/caregivers new to the transition process
 - Parents/caregivers
 - Educators & service providers





[Photo caption: Vendors at the Bootcamp Fair]







Transition Booster Sessions Series

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



[Image caption: Booster Session schedule]




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
 - Already 47 registrants



[Photo caption: Attendees sitting in employment booster session]

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DDBP Transition Clinic



[Photo caption for three photos: Transition-age youth interacting with healthcare providers]



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DDBP Transition Clinic


- Focus on transition-age youth with developmental disabilities (16+)
- Team of MDs, APN and nurses
- Volume of ~650 scheduled visits
- Support from VocRehab counselor
- Medical transition as well as life transition support
- Resource sharing with youth and families



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Transition Taskforce



Questions





Thank you!
