Crossing the “medical void”: health transition in young adults with special health care needs

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*This presentation, analyses, discussion & conclusions do not necessarily represent the official views of CDC/NCHS or the survey funding agency, HRSA/MCHB

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Agenda

- Tell a tale of two surveys
  - define “children with special health care needs” & “health care transition”
  - describe main & follow-back surveys
    - 2001 National Survey of Children with Special Health Care Needs (NSCSHCN)
    - 2007 Survey of Adult Transition and Health (SATH)
- How can these follow-back SATH data be used?
  - Describe select bivariate findings
  - Describe exploratory longitudinal analyses
- How to access SATH data & documentation

What do “health care transition” & “children with special health care needs” mean?

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Definition of Children with Special Health Care Needs (CSHCN)

Maternal & Child Health Bureau (MCHB) definition

Children aged 0-17 who:

(1) have ~~or are at increased risk~~ for a chronic physical, developmental, behavioral, or emotional condition

AND

(2) also require health and related services of a type or amount beyond that required by children generally

Definition & goals of health care transition

- Moving from health care providers who only treat children to those that only treat adults (vs general transition to adulthood)
- Patient-centered
- Flexible
- Responsive
- Continuous
- Comprehensive
- Coordinated

*American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians – American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002;110:1304-1306

“**Young adults often fall into a medical void after they leave their pediatrician** and don’t have a primary care doctor until their 30s or 40s, which worries many health care experts”.

Melinda Beck, “Can’t part with the pediatrician”, *Wall Street Journal*, August 10, 2010, health journal section

“We’ve **now realized that young adults are a special group**, just as we realized with adolescents 30 or 40 years ago...”.

Charles Wibbelsman, MD, chief of adolescent medicine, Kaiser Permanente

An emerging & interesting trend to follow

“The **growing medical specialty** known as **med-peds** (for doctors certified in both internal medicine and pediatrics) also **helps provide more continuity as patients outgrow their pediatricians – particularly those who have special needs**”.

A tale of two surveys

A tale of two surveys: key design differences

Design feature	2001 NS-CSCHN	2007 SATH
Population target	CSHCN aged 0 - 17 years at the time of the interview	Young adults (YA) aged 19-23 years who were subjects of the 2001 interview & from English-speaking households (HH)
Survey design	List-assisted Random-Digit-Dial (RDD) sample of landline telephone households	Follow-back survey targeting YASHCN who were 14 - 17 years old in 2001
Respondent	Most knowledgeable parent or guardian	Young adult
Sample size (person-level public use file)	38,866 completed CSHCN interviews	1,865 completed interviews out of 10,933 total eligible SATH cases, of which we located 2001 R for 3,524 cases (32% of overall eligible) Very high YA cooperation rate

SATH:
select bivariate findings

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Primary outcome variable

"About 6 years ago, your parent or guardian told us about your health. Compared with 6 years ago, would you say your health now is better, worse, or about the same?"

YA's self-reported change in health status over time, 2007

Change in health status six years later	Sample size	% (SE)
Improved	561	29.1 (1.7)
Same	1,101	59.9 (1.8)
Worse	197	11.1 (1.2)
Total	1,859	100.0

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.

Association between meeting conditions of MCHB Core Outcome 1 in 2001 with self-reported change in health status, 2007*

Change in health status six years later	CSHCNs' families WERE satisfied with services & care received, partnered in decision-making, 2001 n = 470 % (SE)	CSHCNs' families WERE NOT satisfied with services & care received, partnered in decision-making, 2001 n=328 % (SE)
Health status Improved	31.2 (3.3)	24.5 (3.6)
Same	56.7 (3.5)	68.8 (3.8)
Worse	12.2 (2.4)	6.8 (1.6)
Total	100.0	100.0

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.
*Differences are significant at the 0.05 level.

Association between meeting conditions of MCHB Core Outcome 2 in 2001 with self-reported change in health status, 2007*

Change in health status six years later	CSHCN received coordinated ongoing comprehensive care within a medical home, 2001 n=1,006 % (SE)	CSHCN DID NOT receive coordinated ongoing comprehensive care within a medical home, 2001 n=753 % (SE)
Health status Improved	29.9 (2.3)	28.8 (2.6)
Same	61.7 (2.4)	57.3 (2.9)
Worse	8.4 (1.4)	13.9 (2.1)
Total	100.0	100.0

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.
*Differences are significant at the 0.10 level.

Association between health care provider discussion with self-reported change in health status, 2007*

Change in health status six years later	YAs’ doctors discussed how YA health care needs might change as he/she aged n=1,016 % (SE)	YAs’ doctors DID NOT discuss how YA health care needs might change as he/she aged n=829 % (SE)
Health status Improved	32.8 (2.4)	24.1 (2.3)
Same	57.7 (2.5)	62.8 (2.7)
Worse	9.5 (1.4)	13.1 (2.1)
Total	100.0	100.0

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.
*Differences are significant at the 0.05 level.

Association between health care provider discussion with self-reported change in health status, 2007*

Change in health status six years later	YAs' doctors discussed w/YA - eventually see doctors who treat adults n=243 % (SE)	YAs' doctors DID NOT discuss w/YA - eventually see doctors who treat adults n=178 % (SE)
Health status Improved	36.2 (5.1)	20.9 (3.8)
Same	56.2 (5.1)	61.4 (5.3)
Worse	**	17.7 (4.2)
Total	100.0	100.0

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.
*Differences are significant at the 0.05 level.
**Figure does not meet NCHS standards for reliability or precision and cannot be reported.

YAs - any of their doctors/HCP only treat children, teens, or young adults, 2007

Any of YAs' MD/HCP only treat children, teens, YA	Sample size	% (SE)
Yes	430	26.7 (1.7)
No	1,397	73.3 (1.7)
Total	1,827	100.0

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.

YAs - any of their doctors/HCP only treat children, teens, or young adults by age, 2007

YA age in years	Yes n=430 % (SE)	No n=1,397 % (SE)
20	33.0 (3.5)	23.1 (1.8)
21	32.9 (3.7)	26.2 (1.9)
22	21.3 (2.9)	28.3 (2.0)
23	12.9 (2.4)	17.3 (3.2)
Total	100%	100%

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.

*Differences are significant at the 0.05 level.

Select preliminary longitudinal finding(s)

Methods

- Identified identical constructs & variables available in both data files (2001 & 2007)
- Created four groups to assess change in these variables over time
- Preliminary analyses

Summary of 4 groups created to assess change over time

X = health event, status, outcome, or characteristic that is desirable to have or experience

Features	Group 1	Group 2	Group 3	Group 4
In 2001	Did not have X	Had X	Did not have X	Had X
In 2007	Did not have X	Did not have X	Had X	Had X
Description SC/YA	Bad 2001 Bad 2007	Good 2001 Bad 2007	Bad 2001 Good 2007	Good 2001 Good 2007
WORST (Gr 1) → CONTINUUM → BEST (Gr 4)				

Association of changes in usual source of care (USC) over time with changes in health status: 2001, 2007*

Change in health status six years later	2001 no USC ↓ 2007 no USC % (SE) n=40	2001 had USC ↓ 2007 no USC % (SE) n=322	2001 no USC ↓ 2007 had USC % (SE) n=103	2001 had USC ↓ 2007 had USC % (SE) n=1,386
Health status Improved	**	31.2 (4.3)	**	29.4 (1.9)
Same	38.8 (10.9)	53.5 (4.7)	66.8 (7.3)	61.8 (2.1)
Worse	**	15.3 (3.4)	**	8.9 (1.2)
Total	100.0%	100.0%	100.0%	100.0%

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.

*Differences are significant at the 0.05 level (based on p-value of a single chi square test of association).

**Figure does not meet NCHS standards for reliability or precision and cannot be reported.

Association of changes in getting timely care with changes in health status: 2001, 2007*
(e.g., care was not delayed or foregone)

Change in health status six years later	2001 no timely care ↓ 2007 no timely care % (SE) n=61	2001 had timely care ↓ 2007 no timely care % (SE) n=441	2001 no timely care ↓ 2007 had timely care % (SE) n=75	2001 had timely care ↓ 2007 had timely care % (SE) n=1,271
Health status Improved	**	34.4 (3.7)	37.2 (9.2)	27.8 (1.9)
Same	53.8 (10.4)	46.7 (3.8)	50.1 (9.3)	65.6 (2.0)
Worse	**	18.9 (3.1)	**	6.7 (0.9)
Total	100.0%	100.0%	100.0%	100.0%

DATA SOURCE: CDC/NCHS, SLAITS Survey of Adult Transition and Health, 2007 public use file.
*Differences are significant at the 0.05 level (based on p-value of a single chi square test of association).
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How to access SATH data

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Survey of Adult Transition and Health

This nationwide survey looks at the health of young people who were 19 to 23 years old in 2007, whose parents were originally interviewed in 2001 when the subjects were 14 to 17 years old. The primary goals of this follow-up survey are to examine their current health care needs and transition from pediatric health care providers to adult health care providers.

Quick Facts

- Sponsor(s): Department of Health and Human Services, Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA)

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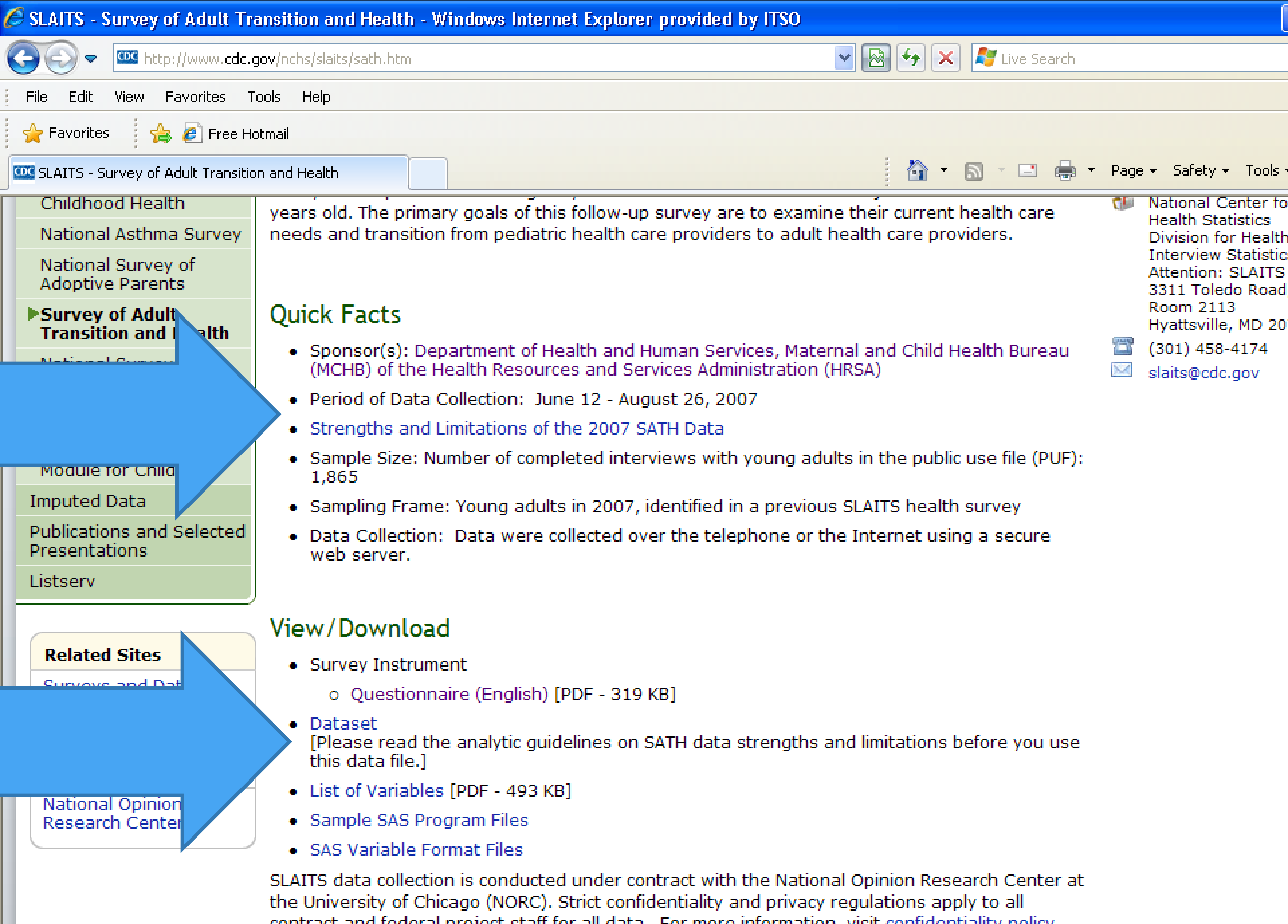

years old. The primary goals of this follow-up survey are to examine their current health care needs and transition from pediatric health care providers to adult health care providers.

Quick Facts

- Sponsor(s): Department of Health and Human Services, Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA)
- Period of Data Collection: June 12 - August 26, 2007
- Strengths and Limitations of the 2007 SATH Data
- Sample Size: Number of completed interviews with young adults in the public use file (PUF): 1,865
- Sampling Frame: Young adults in 2007, identified in a previous SLAITS health survey
- Data Collection: Data were collected over the telephone or the Internet using a secure web server.

View/Download

- Survey Instrument
    - Questionnaire (English) [PDF - 319 KB]
- Dataset
  [Please read the analytic guidelines on SATH data strengths and limitations before you use this data file.]
- List of Variables [PDF - 493 KB]
- Sample SAS Program Files
- SAS Variable Format Files

SLAITS data collection is conducted under contract with the National Opinion Research Center at the University of Chicago (NORC). Strict confidentiality and privacy regulations apply to all contract and federal project staff for all data. For more information, visit confidentiality policy

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Conclusions

IN THIS SAMPLE OF YASHCN:

- pairwise comparisons, modeling (to extent possible give sample sizes)
- Change in health status over time is associated with provision of timely care & having a usual source of care
- Over 1 in 10 YA at 23 YO still saw at least one type of pediatric care provider; continue to focus on actual transition for these youth
- identified areas of improvement for health care provider discussion with YA:
  - need to eventually see HCP treat adults
  - health changes over time

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