

Transition planning and health literacy in teens with special health care needs



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Children with Special Health Care Needs (CSHCN)

- Nearly a quarter of Ohio (23%) youths have chronic conditions requiring enhanced health-related services
- CSHCN are more likely to live in socio-economically disadvantaged families
- CSHCN are more likely to have unmet medical, dental, and prescription medication needs

Chisolm DJ, Steinman K, Asti L, Earley E. Emerging challenges of serving Ohio's children with special health care needs: Final Report. June 2013



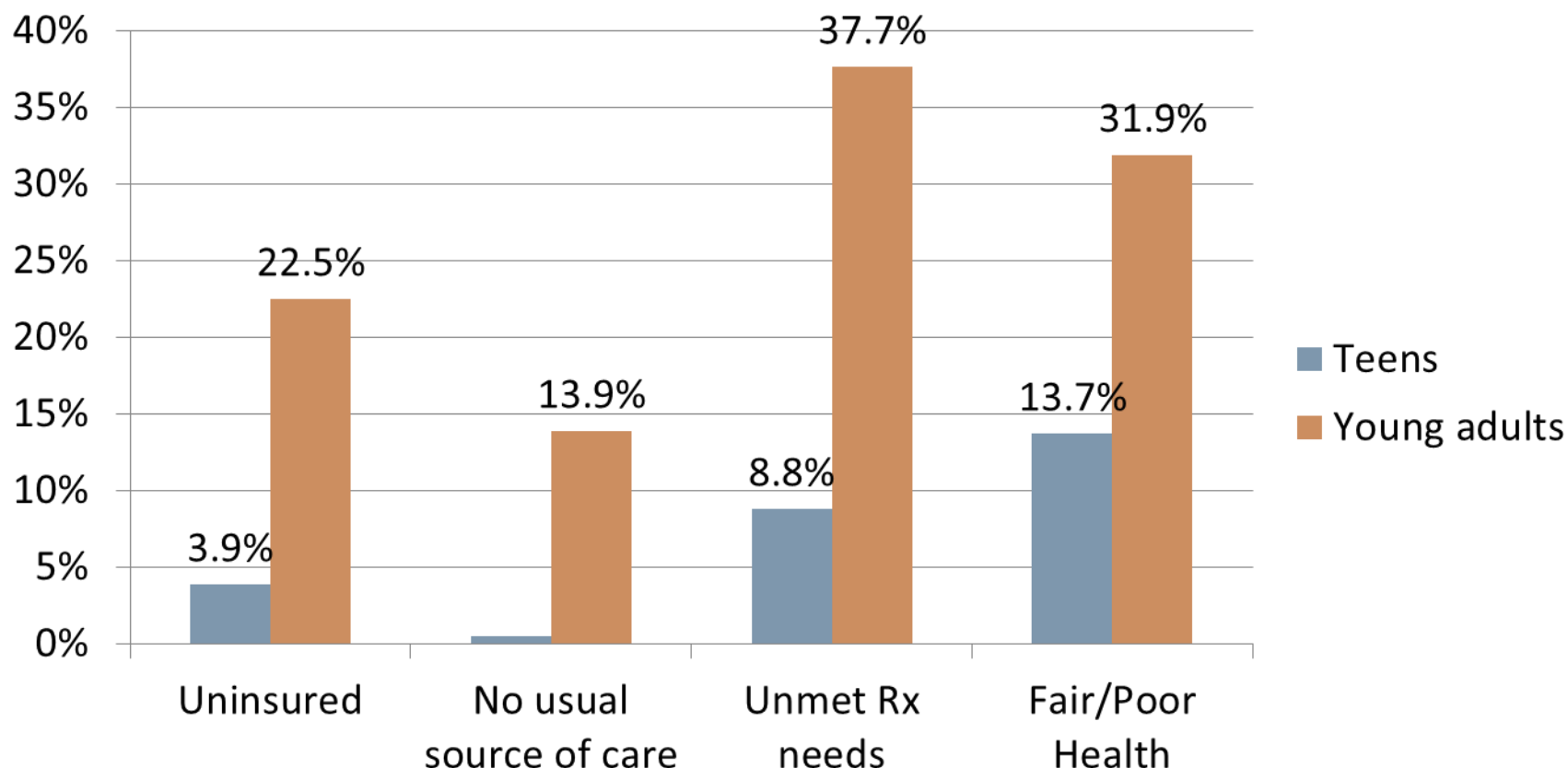
Transition to adult care

- During transition families must prepare for changes in providers, disease management responsibility, insurance, and more
- Nationally, only 40% of parents received desired, comprehensive counseling on preparation for transition
- Communication is less likely to occur when children live in poverty, when they are publically insured or uninsured, and when they have more complex conditions
- Nothing is known about whether such communication is occurring with the youths directly or how parent and child health literacy are associated with transition communication



Source: www.childhealthdata.org

Teens with SHCN face special challenges in transition and **transitions are failing**



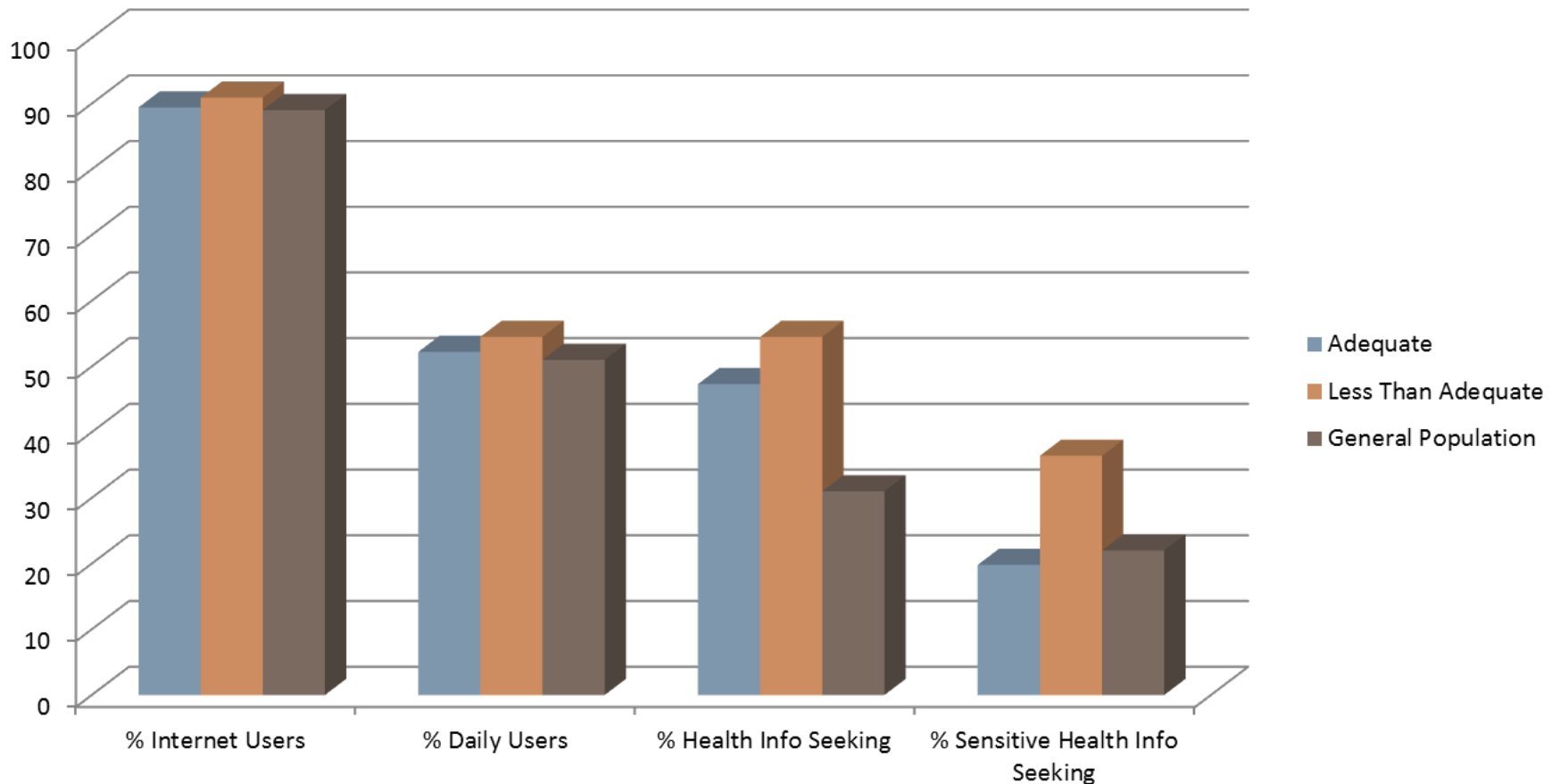
Source: 2012 OMAS preliminary data

The Big Question



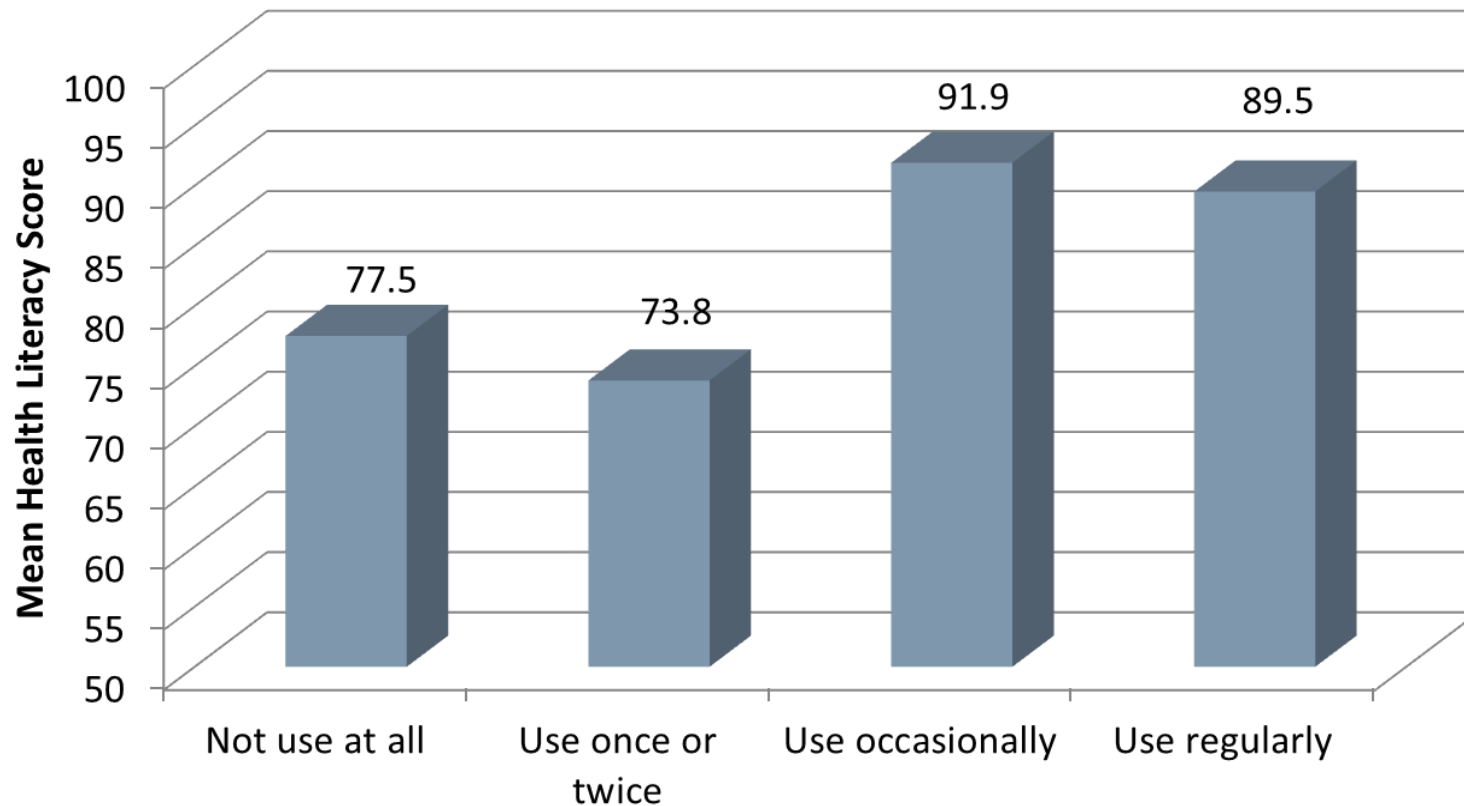
How might health literacy play a role in effective transition planning?

Health literacy and Internet use



Chisolm DJ, Hardin DS, McCoy KS, Johnson LD, McAlearney AS, Gardner, W. (2011) Health literacy and use of online health resources in teens with chronic disease. *Telemedicine and E-health* 17(9):676-82

Intent to use recommended eHealth resources by health literacy score



Chisolm DJ, Johnson LD, McAlearney AS. (2011) What makes teens start using and keep using health information websites? A mixed model analysis of teen with chronic illnesses. *Telemedicine and E-health*. 17(5):324-8

Teen Literacy in Transition (TeenLIT)

Specific aims

- Assess the relationship between adolescent health literacy, parent health literacy, and effective planning for the healthcare transition from adolescence to adulthood.
- Assess the relationship between adolescent health literacy, parent health literacy, and adolescent health indicators including health-related quality of life and healthcare utilization.
- Identify mediators and moderators of racial disparity in health literacy in a large, diverse Medicaid managed care population of adolescents with special health care needs.

Study population

- Initial Screening - Medicaid Claims data
 - Ages 15-18
 - Diagnosed with at least one of twenty diagnoses found in over 90 percent of CSHCN
 - Enrolled in Medicaid for 12 previous months
- Secondary screening - Telephone
 - Questionnaire for Identifying Children with Chronic health Conditions-Revised (QUICCC-R)
 - English proficiency
 - No significant developmental delay
 - Functional Limitation classification

Baseline data collection

- Health Literacy Assessment
 - REALM/REALM-Teen
 - Newest Vital Signs
 - Health Literacy Screening Items
 - eHEALS
- Tablet administered Red Cap questionnaire
 - Transition Readiness Assessment Questionnaire
 - NS-CSHCN Transition core indicators
 - eHealth Use (Adapted from Pew Internet Survey)
 - Quality of life and satisfaction with care (PedsQL)

Follow-up data collection

- Claims data for 12 months before and following interview date to assess
 - Well-care/Ambulatory visits
 - ED visits
 - Ambulatory care sensitive ED visits
 - Hospitalizations
 - Charges

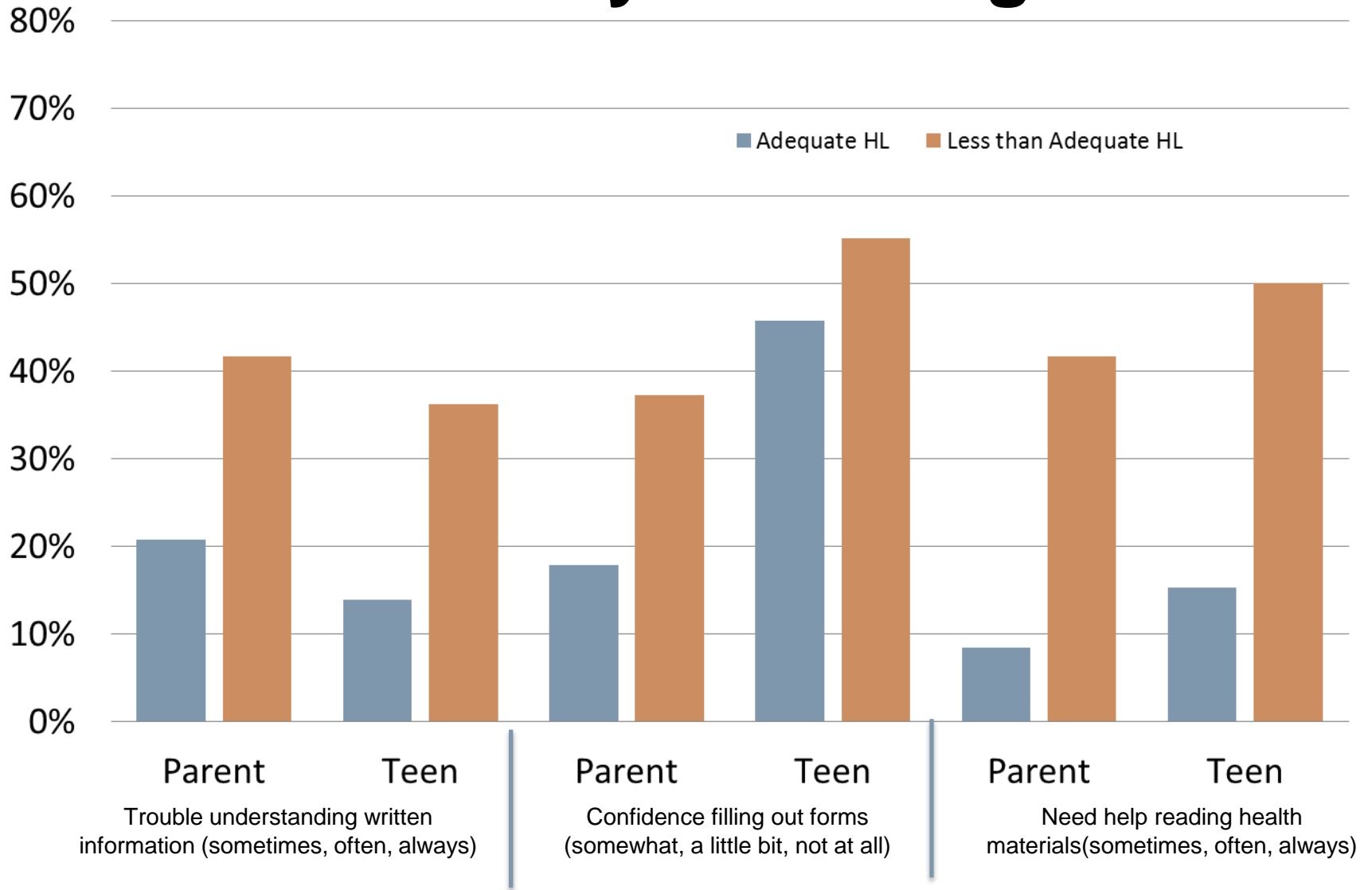
Participant characteristics (N=130)

Characteristic	Parent	Teen
Age Mean (range)	30-40 years (40%)	17.2 years
Gender		
Male	5 (3.9%)	64 (49.2%)
Female	125 (96.2%)	66 (50.8%)
Race		
White	80 (61.6%)	73 (56.2%)
Black	38 (29.2%)	40 (30.8%)
Other	12 (9.2%)	17 (13.1%)
Level of Limitation		
None		39 (30.0%)
Some		55 (42.3%)
Severe		36 (27.7%)

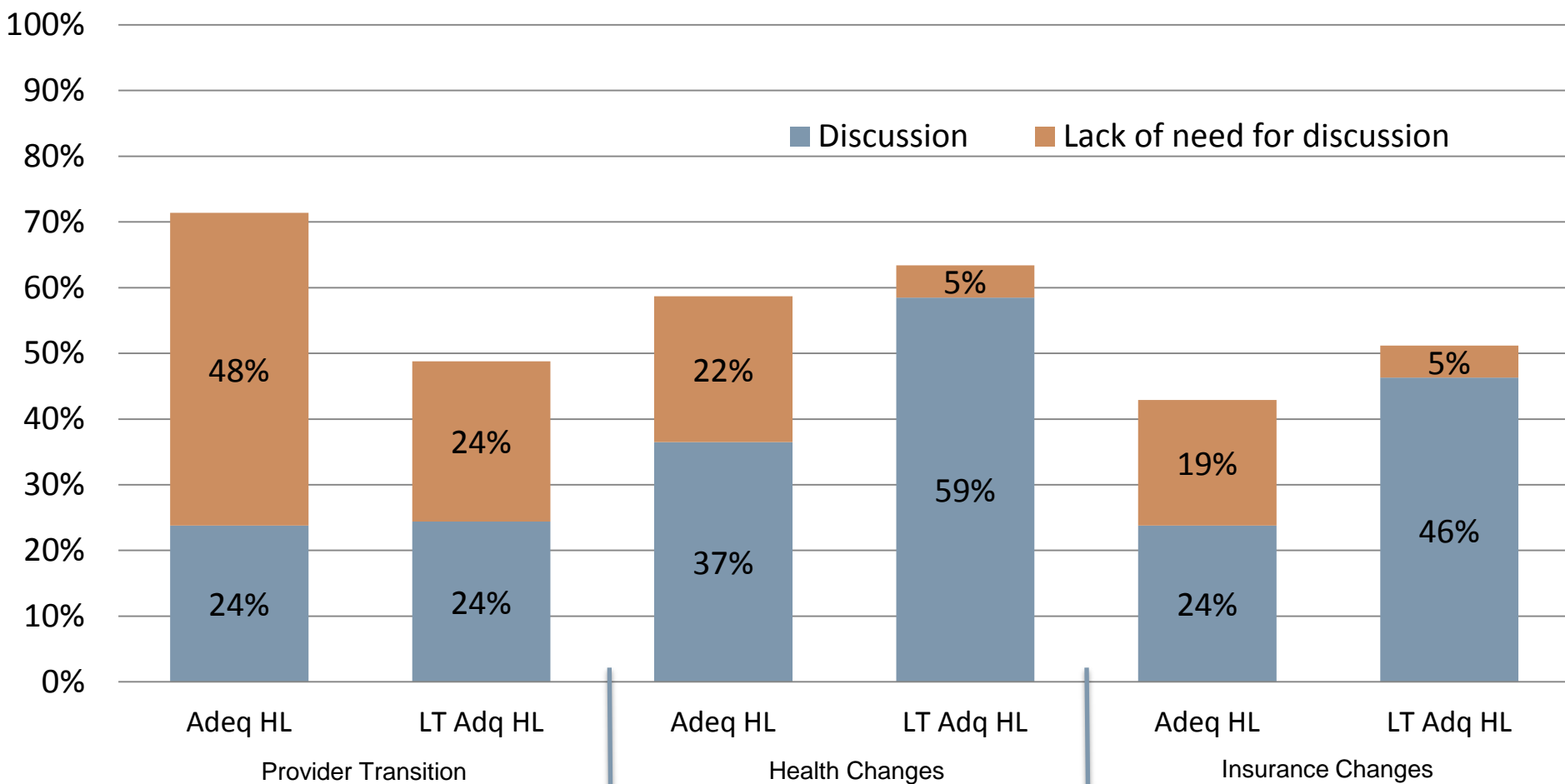
Health literacy levels

	Parent	Teen
REALM/REALM-Teen		
Adequate	106 (81.5%)	71 (54.6%)
Marginal	18 (13.9%)	49 (37.7%)
Inadequate	6 (4.6%)	9 (6.9%)
NVS		
Adequate	76 (58.5%)	63 (48.5%)
Marginal	15 (11.5%)	53 (40.8%)
Inadequate	39 (30.0%)	14 (10.8%)

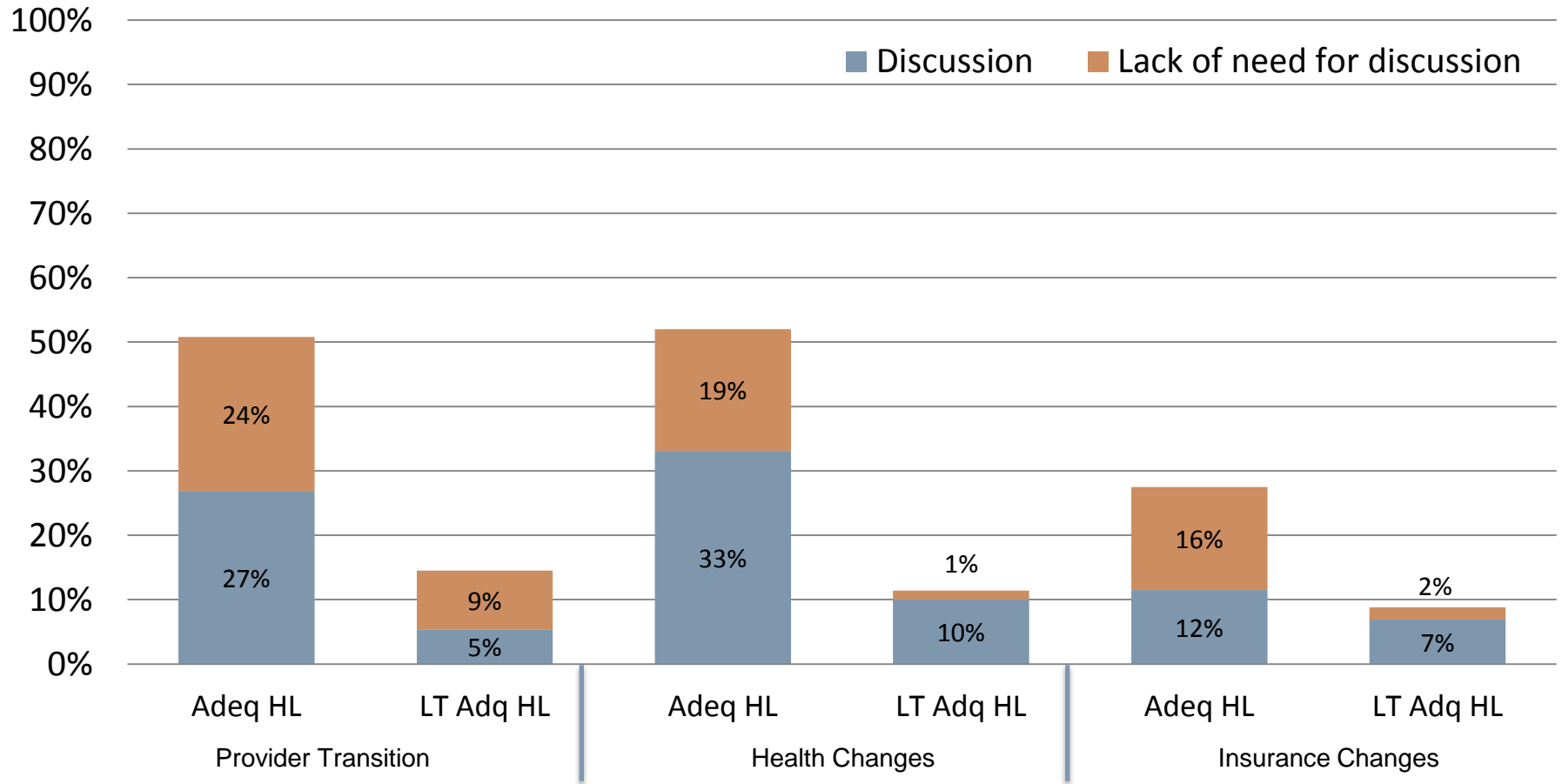
Health literacy screening items



Teen health literacy and transition communication with teens



Parental health literacy and transition communication with parents



Conclusions

- Transition planning for teens with special health care needs is poor across health literacy levels
- Overall, teens report more transition communication than their parents
- Teens with lower health literacy were more likely to report communication regarding changing health and insurance needs
- Parents with lower literacy were less likely to report any communication regarding their child's transition needs
- Recruitment is ongoing...More to come!!

Thank You!

