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Promoting Optimal Health Outcomes in Adulthood for Youth with Disabilities: Evaluation of a Demonstration Model for School-Based Health Care Transition Education

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ABSTRACT

With the proportion of persons living with a disability on the rise, it is increasingly important to examine ways to promote optimal health outcomes in adulthood for youth with disabilities. Successful transition from pediatric to adult health care is recognized as a critical factor, yet there are few examples of effective, evidenced-based health care transition programs. Our study focuses on the evaluation of a new model that leverages the infrastructure of the public education system to help equip youth with the **health literacy** and **self-determination** skills that they need to become self-sufficient, healthy adults.

BACKGROUND

- Preliminary formative research guided program development
- Funded by the Florida Developmental Disabilities Council, Inc., Health Care Task Force
- Implemented in the School District of Hillsborough County (Tampa, FL) from February to June 2005

PROGRAM DESCRIPTION

Primary program components are:

Student Curriculum

- Targeted to high school students with varying disabilities
- Developed by special education teachers for low level readers, and reviewed by a multi-disciplinary team of health care professionals
- 8-unit module with practice activities, assignments, tests
- 40+ hours of instruction
- Topics: self-determination, rights and responsibilities at age 18, medication management, communicating with health care providers, finding adult providers, health insurance, and sexual health
- Includes personal health journal and medical summary

Educator Training

- Targeted to special education teachers, school nurses, social workers, transition specialists, and other school support staff
- Topics: health-related factors in students' Transition Individual Education Plan (IEP), strategies to help students prepare for health care transition, community resources

Information and Resource Guide

- Targeted to families and providers who serve youth with disabilities
- Printed in English, Spanish, Braille, and large print
- Topics: planning for health care transition, paying for health care in adulthood, finding adult providers, age 18 in legal terms, developing a medical summary, and how schools can support youth and families
- Includes listing of local, state, and national resources

EVALUATION QUESTIONS

1. To what extent did classroom instruction facilitate changes in knowledge and skills among students?
2. To what extent did training facilitate changes in knowledge and practice among educators/teachers?
3. What is the perceived value and relevance of the *Demonstration Model*?

METHODS

Student Performance Test

- Pre-test/Post-test research design
- Measured knowledge of curriculum content
- Self-report of health-related skills

Classroom Observation

Likert-type scale developed for:

- Teacher knowledge of curriculum content, fidelity of instruction, and enthusiasm in class
- Student interest, understanding, and participation in class

Focus Groups

Teachers and students provided qualitative assessment of curriculum value, relevance, readability, completeness, and interest

Family Survey

Measured parent perceptions and satisfaction with curriculum and resource guide

Educator Survey

- Pre-test/Post-test research design
- Measured knowledge and attitudes about health care transition, and frequency of health-related goals in Transition IEPs

RESULTS

Student Curriculum

- Piloted in 5 diverse high schools, 13 classrooms
- Of 137 student participants, 82 matched pre/post performance tests were completed (N=82)
- Observed instruction in 3 classrooms (N=3)
- Conducted 3 focus groups with 22 participants (N=3)
- Nineteen family surveys were completed (N=19)

Key findings:

- High level of interest, perceived relevance, value, and satisfaction among students, teachers, and families
- Statistically significant increase in student knowledge
- Consistent but small gains in frequency of performing health-related skills
- Degree of gains were similar among SLD, EMH, and PI students

Educator Training

- Of 332 educator participants, 27 matched pre/post surveys were completed (N=27)

Key findings:

- Statistically significant increase in educator knowledge
- Small overall increase in frequency of addressing health care transition issues in Transition IEPs

Information and Resource Guide

- Among parents of 137 students, 19 family surveys were completed (N=19)
- Informal feedback from service providers
- Key findings:
- Over 90% of families were "very" or "somewhat" satisfied with the resource guide
- Providers reported very high degree of satisfaction and usefulness

CONCLUSIONS

The consensus among all study subjects was that the curriculum is highly relevant and useful for students with disabilities. Small but statistically significant increases in post-test scores suggest that classroom instruction facilitated a positive change in student knowledge of health care transition and health-related skills that adults need in order to live independently. Data from classroom observation and focus groups suggest that that the curriculum was most immediately beneficial to PI students. In addition, an increase in educator post-survey scores indicate a positive program effect on knowledge, attitudes, and practice among teachers and school staff.

Importantly, the *Demonstration Model* was structured to be replicated in other school districts and communities. Recommendations from students and teachers for future implementation include:

- Develop a version of the curriculum for lower functioning students
- Develop a version for general education students
- Allow more time to implement the curriculum
- Add more interactive activities and color pictures
- Add a unit on high risk behaviors (alcohol, drugs)
- Provide concurrent training for parents

Study limitations to be considered are:

- Research design did not establish true causal effect
- Self-report measures raise questions about accuracy
- Low family response rate was not sufficiently representative to generalize findings
- Measured short-term impact only

This project demonstrates the feasibility of bridging systemic gaps between public health and the public education system to serve an underserved population in a very functional way. It also raises provocative questions about whether traditional health education programs are effectively preparing young people – with and without disabilities – to manage the complexities of our current health care system. By empowering students with self-determination and health literacy skills, this model provides a promising framework to better prepare youth with disabilities to be informed health care consumers.

REFERENCES

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Table 1. Student Demographic Summary Data

Student Demographics	N=82	
	Freq	Percent
Gender		
Male	46	57%
Female	35	43%
Grade		
9th	28	34%
10th	25	31%
11th	19	23%
12th	10	12%
Race/Ethnicity		
White or Caucasian	35	43%
Black or African American	24	29%
Hispanic or Latino	19	23%
Other	3	4%
Multiracial	1	1%
Special Education Program		
Educable Mentally Handicapped (EMH)	25	31%
Physically Impaired (PI)	22	28%
Specific Learning Disabilities (SLD)	21	26%
Other Health Impaired (OHI)	1	2%
Tramatic Brain Injury (TBI)	1	1%
Other	1	1%
Don't know	9	11%

* Lack of response to some items resulted in frequencies less than 82

Table 2. Student Pre/Post Performance on 29-Item Knowledge Test (N=82). This chart shows mean scores by topic subsection.

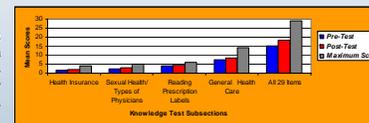


Table 3. Student Pre/Post Self-Report on Performing Health-Related Skills (N=82). This chart shows percentage of students who performed specified skills either "often" or "always."

