

Oral presentation

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Preparation for adult participation, starting at the beginning Judy Thibadeau* and CDC's Partnership for Transition

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Background

Improvements in medical care have dramatically improved the survival rate to adulthood of children born with spina bifida (SB). In the United States, many of these adolescents and young adults encounter the following challenges: difficulties in transitioning from pediatric to adult health care and enrolment in health insurance plans as well as self management of their special health needs; reduced sensitivity to learning differences and psychosocial needs; changes in the type and level of formal supports and access to services; changes in individual decision making; a change in the role of parents; obstacles in establishing adult relationships; and finding vocational success.

SB-specific guidelines to make this journey from diagnosis at birth to a maximized level of independence and participation as an adult have not been clearly delineated. This presentation will describe a lifespan approach to foster the successful transition to adulthood.

Materials and methods

Centers for Disease Control and Prevention professionals, U.S. clinicians, researchers, and individuals living with SB have collaborated in structured work-groups to identify crucial areas of preparation for adult independence and participation. Three domains of a transition pathway model from early childhood to adulthood were targeted: Self Management/Health, Personal and Social Relationships, and Employment/Income Support. Components of the transition pathway model include: identification of

key developmental milestones and measures, and the use of assessment tools intervention strategies and referral resources. The resulting Transition Pathway Model serves as a lifespan template for professionals and families to better prepare children and youth for adulthood in the three domains and serves as a record of progress in these domains.

Results

Preparation for Adult Participation" logic model

- Key developmental milestones and associated indicators in the areas of:
 - Self Management/Health
 - Personal and Social Relationships
 - Employment/Income Support
- Interventions recommended to assist in milestone achievement

Conclusion

Much work has been done in the area of transition for young people with chronic disabling conditions such as SB. Many individuals with SB are less likely to finish high school, pursue secondary education, get and keep jobs, and live independently. This presentation describes a lifespan oriented framework to potentially improve these outcomes for youth with SB.