



State Efforts to Support Transition to Adult Life

Champions for Progress, the precursor to Champions for Inclusive Communities, awarded incentive mini-grants to 34 states and territories to support their efforts to achieve the six outcomes for children and youth with special health care needs. Eleven of the states used these funds to implement strategies to support transition to adult life. A summary of these strategies—and some keys to their success—are presented below. Reports and products from these incentive award recipients can be found at www.championsinc.org and clicking on “Champions products.”

What strategies were used to support transition?

1. Transition Advisory groups/Coalitions were formed.
 - Ad hoc groups were developed to guide the incentive award activities (AL, AZ, CO, NH, NM)
 - Long-term Title V advisory groups were established (DE, FL, HI, MI, NJ, OH)
 - Exclusive youth/young-adult groups were created (OH, MI, HI, FL)
 - Multiple-stakeholder groups were created (AL, CO, NH, NM, DE, HI, MI, NJ, OH)
2. Written Needs Assessments were conducted to understand consumer priorities and to guide implementation plans.
 - Written surveys were administered to families (OH, MI, DE)
 - Surveys were administered to providers (NJ)
3. Focus groups were conducted to determine transition challenges, needs, and priorities.
 - Focus groups with youth/young adults exclusively (DE, WI, NJ)
 - Focus groups with families exclusively (NJ)
 - Focus groups combining youth and families (MI, OH)
 - Focus groups combining youth, families and providers (CO, WY, NV)
4. Training sessions and resource materials were developed & distributed statewide.
 - Self-directed workbooks were developed for youth and families (NV, CO, NJ)
 - Workshops and “train the trainer” manuals were developed (WI, AZ, NM)

What priorities were identified?

- Youth want help, but they also want to be in control.
- CYSCHN need more experience, opportunities to manage their own health care.
- Self-advocacy skills that facilitate independence must be nurtured in youth.
- Investigate youth versus parent expectations for the future, which are often different.
- Easily-accessed educational and resource information for youth and families are needed.
- Health care providers need to be better informed about the transition process and resources.
- Stronger communication among pediatric and adult providers is needed.
- Transition is a process that begins early, not a one-time event.

What were the “keys to success?” across these efforts?

- Key stakeholders were brought to the table as partners from the very beginning.
- Numerous voices of youth and young adults leaders with a variety of needs were involved.
- A plan was developed based on stakeholder-identified needs.
- Strategies were implemented in ways to fit the needs of communities and stakeholders.
- Both short-term and long-term measures are needed to gauge success.
- If at first you don't succeed, try again – with feedback from stakeholders.

How can these efforts be sustained?

- Groups/coalitions can be institutionalized within Title V advisory infrastructure.
- Training efforts can be continued by family organizations.
- Family- and youth-friendly tools are in a format that can be easily updated.
- Provide dedicated Title V staff FTE to sustain efforts.

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