

*Health Care Program for Children with Special Needs:*

## **Transition Interagency Group Envisioning Realization of Self (T.I.G.E.R.S.)**

Location: Colorado

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Category: **Emerging Practice**

### **BACKGROUND**

The 2009/2010 National Survey of Children with Special Health Care Needs data indicate that only 5.8 percent of youth, ages 13-17, with special health care needs receive the services necessary to make a successful transition to adult life.<sup>1</sup> Clearly, there is a need for interagency work to support and assist youth transitioning to adult life.

The Transition Interagency Group Envisioning Realization of Self (“T.I.G.E.R.S.”), located in rural Colorado, began in 2002 to address “transition to adult life” for youth with disabilities. T.I.G.E.R.S. has grown to include a diverse group of community partners representing various aspects of life including adult health care, school, work, recreation/leisure, and independent living.

### **PROGRAM OBJECTIVES**

The overall goal of T.I.G.E.R.S. is to advocate for persons with disabilities as they transition into adulthood by empowering youth, their families, and communities to their highest potential by promoting education, employment, creative opportunities, health literacy, and independent living skills. The core value of T.I.G.E.R.S is that the work of any one agency is enhanced and enriched through interagency collaboration and partnership.

The key objectives are to:

- Assist youth and their families to make informed decisions by identifying educational, vocational, recreational/leisure, and independent living opportunities;
- Assure a Medical Home with an adult provider;
- Guide families and youth as they seek appropriate guardianship choices; and
- As youth exit entitlement programs, educate families and youth on how to navigate the system of limited resources and services.

<b>TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED</b>
<b>#11:</b> Percent of children with and without special health care needs having a medical home.
<b>#12:</b> Percent of children with and without special health care needs who received services necessary to make transitions to adult health care.

Parent feedback indicates that the work of T.I.G.E.R.S. presents a myriad of resources and services available in the community from which parents and youth can pursue more information. Families feel empowered through this youth and family-centered approach to transition to adult life rather than having an agency member suggest or recommend a path to the family for the youth.

### **TARGET POPULATION SERVED**

T.I.G.E.R.S. serves a six-county, remote, rural/frontier area in south central Colorado, about the size of Connecticut, with a population of 40,000 and is bound on three sides by the Rocky Mountains. There are about 4,000 youth, ages 15-19 years, in this six county region.

Assuming that 13% of these youth have special needs, the approximate sample size is 720; however, the catchment population is probably greater than 1,000 because some agencies within T.I.G.E.R.S. serve youth up to age 25.

### **PROGRAM ACTIVITIES**

T.I.G.E.R.S. is an interagency group of 10 organizations assisting youth with special needs to transition into adult life. The work of T.I.G.E.R.S. is community-based with an emphasis on targeting youth with disabilities through the school systems. Based in the Life Course Theory, the youth’s whole life is the focus of T.I.G.E.R.S. rather than just the education or employment components of adult living. T.I.G.E.R.S. views transition as the successful movement from school to meaningful adult life, from pediatric to adult health care, and from living at home to independent living. Through effective transition to adult life planning protective factors can be maximized and the risk factors minimized to enhance the lifelong health and potential of youth with disabilities. The premise of T.I.G.E.R.S. is to assess the

strengths and needs of each youth and family and creatively match the services, resources, and opportunities available in the community for that youth.

Group commitment is formalized through a written Memorandum of Understanding (MOU) to ensure that community agencies remain committed to the group and its mission even if individual members change. This level of commitment has allowed the group to be a valuable resource to the community for ten years without a specific funding source. T.I.G.E.R.S. has developed numerous materials and tools useful to others in emulating this work.

T.I.G.E.R.S. provides education, consultation, and technical assistance not only to families and youth but also to community partners such as medical providers, employers, and school personnel. For example, T.I.G.E.R.S. provides ongoing training sessions to school personnel regarding transition to adult life issues and services that teachers can then share with families and youth. Special education teachers have become the champions for Transition to Adult Life by preparing youth and their families for post-public school education opportunities.

T.I.G.E.R.S. bases its practices on tools and resources gleaned from each of its constituent agencies. The T.I.G.E.R.S.' Vision and Mission Statements were developed by the team across agencies to provide the foundation for the practice, which addresses the various aspects of life including adult health care, school, work, recreation/leisure, and independent living. All of these tools and resources speak to the need to identify persons appropriately who need transition planning, begin the planning early, and provide a coordinated approach through communication among all team members.

Regular interagency communication was established by having regularly scheduled meetings, updated list of contact information for members, and several opportunities for informal gatherings so that members can get to know one another, exchange ideas, and learn from each other.

T.I.G.E.R.S. developed a list of [“Tips, Tricks, and Challenges to Successful Interagency Work”](#) to incorporate continuous quality improvement which addresses how group members can contribute, provide feedback, and continually learn how to better serve families and youth. Written and verbal feedback is also encouraged from each youth/family at the School-Based Transition to Adult Life Trainings that are provided in our six-county, 14-school district catchment area. This information is compiled and shared with the group on an ongoing basis so that the approach can be modified as needed.

### PROGRAM OUTCOMES/EVALUATION DATA

Since 2009, data collection has focused on the number of referrals made, services provided, and the outcomes of

those referrals and services across agencies. The referrals and services provided include those made to enhance outcomes for Health, Independent Living, Education, Employment, and Community Living. The data is collected on a monthly basis and is compiled and sorted by agency and date.

The results of the practices include:

- As they make difficult transition to adult life decisions, youth and parents are able to make more accurate, informed decisions.
- Youth and families have an opportunity to create relationships with post-secondary educators and staff members while the youth is in high school.
- Employment opportunities are increased for youth with disabilities as they transition to adult life as a result of the Employer Recognition activities provided by T.I.G.E.R.S.
- Employers throughout the program’s six-county region have become much more aware and comfortable about the ADA Law and providing employment opportunities for youth with disabilities.
- Team members have learned to represent and speak for each other, other agencies and their services adding value to our school-based presentations and trainings.
- To date, 16 families have received technical assistance in seeking guardianship for their youth with disabilities as a result of the work of T.I.G.E.R.S.
- There is greater visibility and use of services by the community because of our collaboration.
- The local Community-Centered Board relies much less on the Medical Proxy document for medical procedures and services and endorses the Guardianship process for its consumers, as appropriate.
- T.I.G.E.R.S.’ members from Adams State University (ASU) and Trinidad State Junior College (TSJC), both located in Alamosa, have reported increased numbers of students utilizing the ASU Office of Disability Services/Diversity and the TSJC Student Support Services for assistance as they transition to adult life. Anecdotally, it is surmised that these young adults have built relationships by connecting to these offices before they come to college as a result of the community-based work championed by T.I.G.E.R.S.

The written and verbal feedback from youth and parents to T.I.G.E.R.S. is overwhelmingly positive. However, one of the challenges in evaluating the T.I.G.E.R.S. program was differentiating the activities and results of the program from regular “agency” work. The program evaluation plan is to measure and determine the “value added” as a result of our interagency work through the application of the [PARTNER Tool](#). This tool, developed by Dr. Danielle Varda at the University of Colorado-Denver, is designed to collect, analyze, and interpret data to improve collaboration within



community networks. It is anticipated that this tool will demonstrate that the work of any one agency is enhanced and enriched through interagency collaboration and partnership. It is the intention of the program to explore grant opportunities during the 2013-2014 academic year to provide funds to support the adaptation of the Partner Tool to our local interagency needs.

### PROGRAM COST

The services and activities of T.I.G.E.R.S. are all provided in-kind by the participating agencies to allow for personnel time, travel, copies, and other supplies. Each year the group meets approximately 4-6 times, meeting minutes are maintained, 4-5 school-based trainings are provided, and Employer Recognition activities are planned. Each of the ten participating agencies allocates approximately 2-4 hours per month to the work of T.I.G.E.R.S.

Ten agencies x 4 hours/month x 12 months/year x \$25/hour = \$12,000 per year of in-kind transition services provided by participating T.I.G.E.R.S. agencies. Approximately 120 youth, ages 14-25 years, are served annually at an approximate cost of \$100 each.

### ASSETS & CHALLENGES

#### Assets

In 2002 the concept of transition to adult life was relatively new at the state and local levels within Colorado's Health Care Program for Children and Youth with Special Needs (HCP). At the time, there were some key leaders in the community whose rich experience with youth and children with special needs provided the impetus to the larger community to focus on transition to adult life services and opportunities. We were aware that there are many persons who were born and raised here, have disabilities, seek local opportunities, and wish to contribute meaningfully to the community.

#### Challenges

Challenges include the development of an effective Data Collection Tool, an "Interagency Authorization to Send, Receive, Exchange, Use or Disclose Information" Consent Form, and concerns about confidentiality which ultimately put an end to client-focused staffings. Each agency has its own HIPAA and/or other consent forms and we learned that we prefer to work per our particular agency's protocol rather than rely on the interagency consent form to release information. Thus, the staffings were felt to be beyond the scope of the interagency group as well.

#### Overcoming Challenges

There was a significant learning curve as a group regarding how to counsel or guide youth and their families to prepare

for the Age of Majority (age 18 in Colorado). There was confusion about when and how to implement a Medical Proxy vs. a full or partial Guardianship. A literature review and counsel with an attorney at the state level who has vast experience with such issues as they relate to persons with disabilities, underscored the profound seriousness of addressing individuals' civil rights. Each youth and family's situation is assessed carefully and referrals and services are provided as needed.

T.I.G.E.R.S. refers to the document on [Guardianship](#) in its work with youth and families. The team uses challenges, such as this guardianship issue, as learning opportunities to become more informed and to overcome differences of opinion/perspectives and to improve our practices.

### LESSONS LEARNED

The opportunity for T.I.G.E.R.S.' members to develop camaraderie across agencies and domains (i.e. education, employment, community life/recreation, independent living, and health) creates a synergy of understanding and expertise that is invaluable to youth with disabilities transitioning to adult life, their families, and the community.

The T.I.G.E.R.S.' webpage and numerous materials developed over the years streamline our work, testify to the depth of knowledge that members have gleaned in working with youth and families, and provide a means by which our services and resources can be shared with others.

People and agencies must have a heart for interagency work. There has to be some flexibility on the part of each agency to support the work of an interagency group. Tying interagency collaboration directly to funding opportunities at the local, state, and national levels could better assure a more seamless, comprehensive menu of services to youth with disabilities and their families.

### FUTURE STEPS

Annual activities include employer recognition; community outreach to raise awareness of persons with disabilities; youth/family trainings at all 14 school districts; and staff development opportunities for educators and other community groups. Memoranda of Understanding are being updated to assure that the work of the interagency group is incorporated into the work plan of a staff member within each community partner of the group. As noted in Program Outcomes, adaptation of the Partner Tool to our interagency work is expected in the next 2 years, pending grant funding. As individual interagency members face funding challenges, T.I.G.E.R.S. will determine means to maintain key supports for transitional success. Proactive considerations for supporting guardianship navigation in the legal system is one example.



## COLLABORATIONS

The T.I.G.E.R.S.' partners include:

- Blue Peaks Developmental Services (Community-Centered Board)
- Colorado Workforce Center
- Colorado Division of Vocational Rehabilitation (DVR)
- Health Care Program for Children with Special Needs (HCP)
- Rocky Mountain Service, Employment, and Redevelopment (SER)
- San Luis Valley Boards of Cooperative Educational Services (BOCES)
- San Luis Valley Community Behavioral Health Group
- School to Work Alliance Program (SWAP is administered through the BOCES)
- Social Security Administration
- Trinidad State Junior College (TSJC)

(Contributions to this document were made by: Kathy Mortensen, M.A.; Susan Foster, FNP; Patrick Rheume, M.S.; Kelli Robinson-Gonzales, RN; and Yvette Lujan, B.S.)

## PEER REVIEW & REPLICATION

In 2006, T.I.G.E.R.S. was recognized by the Colorado Division of Vocational Rehabilitation and the Department of Education for its work in Transition to Adult Life for youth with disabilities.

In 2007, the interagency group was commended by the "National Collaborative on Workforce and Disability for Youth" and "The National Center on Secondary Education and Transition" for its contributions to the transition process for youth with disabilities.

The work of T.I.G.E.R.S. was shared at the AMCHP Annual Conference in Washington, D.C. in February, 2012. Two presentations/discussions were provided as K-Café sessions at the conference entitled "Improving Maternal and Child Health Across the Life Span: Acting Today for Healthy Tomorrows".

While T.I.G.E.R.S. has received recognition for its work and has presented at statewide and national venues, it has not been formally replicated to date.

## RESOURCES PROVIDED

All of the T.I.G.E.R.S.' materials, including the brochure, Request for Follow-up Form, Action Plan, Resource List, and pertinent links are available on the [San Luis Valley Board of Cooperative Education Services](http://www.slvbooces.org/) webpage:

- [http://tigers.slvboeces.schoolfusion.us/modules/groups/integrated\\_home.phtml?&gid=3284295&sessionid=6e65411339695ee2bf2312aefc3542ac](http://tigers.slvboeces.schoolfusion.us/modules/groups/integrated_home.phtml?&gid=3284295&sessionid=6e65411339695ee2bf2312aefc3542ac)

**Key words: Adolescents, Children/Youth with Special Health Care Needs, Access to Health Care, Family/Consumer Involvement, Primary/Preventive Health Care, Reproductive Health, Specialized Care, Workforce & Leadership Development, Guardianship**

***\*\*For more information about programs included in AMCHP's Innovation Station database, contact [bp@amchp.org](mailto:bp@amchp.org). Please be sure to include the title of the program in the subject heading of your email\*\****

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<sup>1</sup> Retrieved 7 June 2012 from <http://childhealthdata.org/browse/survey/results?q=217>.

