TransitionInAction Clinic Proposal
Submitted by Sonoran UCEDD
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Introduction

Transition is a time of uncertainty when youth and families are navigating multiple systems to prepare for and plan the trajectory towards a quality, productive adult life. Within this particular time frame – characterized as *emerging adulthood* – individuals "acquire the physical, cognitive, emotional and economic resources that are the foundation for later life health and wellbeing" [2016, Patton, et al, p. 2423]. In addition to the critical nature of this phase of life, adolescents and emerging adults are "biologically, emotionally, and developmentally primed for engagement *beyond their families*" [emphasis added - Patton, et al, 2016, p. 2424]. This combined reality necessitates the need for new ways of thinking, access to new, additional information and a steady stream of genuine decision-making opportunities. Of equal importance, it also requires sharing examples of what's to be expected "downstream" and multiple, real-world chances for these emerging adults to practice, explore, change one's mind, and to grow from their new experiences. Families consistently report how unprepared and overwhelmed they feel during this complex period, how they need and want resources and information, and how transition planning meetings are often insufficient to address their questions and allow for future decision-making with all relevant persons.

Background

The TransitionInAction Clinic, developed at the University of South Dakota Center for Disabilities (https://www.usd.edu/medicine/center-for-disabilities/transitions-clinic) is a comprehensive, day long, multi-disciplinary team experience designed to assess a young adult's current status and future goals in the major life areas of health, education, employment, and independent living as they plan their transition to adulthood. Participants served by the clinic ranged in age from 16 to 21 and presented with a disability label of Autism, Intellectual Disability, Down Syndrome, Traumatic Brain Injury, Deaf Blindness, Fetal Alcohol Syndrome Disorder, and many with co-occurring mental health, behavioral, and health conditions.

The Clinic includes interviews, assessments, discussions, meetings with a family member and self-advocate peer mentor, a guided health care transition simulation, situational assessment mini work experiences, and one-on-one meetings with representatives from adult services (e.g., vocational rehabilitation, independent living, supported employment provider, family advocacy, mental health, benefits planning, and developmental disability resource coordinator). The *Transition Engagement Guide* (Parent-Johnson, Parent-Johnson, & Meier, 2017), a tool developed with a diverse group of stakeholders and pilot-tested with promising results, is used to guide youth with disabilities, families and health professionals in the development of an action plan that promotes assets, opportunities, and connections in preparation for transition from pediatric to adult healthcare.

Both the young adult and family participate in separate and together activities focused on allowing the team to get to know the young adult's strengths, interests and vision for the future. Together with the young adult and family member, the multidisciplinary Clinic team generates a comprehensive plan for transitions that is focused, coordinated and action oriented with specific recommendations for "next steps" as they relate to successful transitions. Resources and a clinic report highlighting recommendations are provided to enable sharing this information with other key people involved in the young person's transitions such as school, health care, and adult services. Clinic follow-up is conducted at regular intervals. Annual revisits as needed can be completed to update and address transition issues.

Of particular significance is the active role young adults with disabilities are reported to be taking in their health care and other transition planning and services. A component of the clinic focuses on self-efficacy and self-determination with emphasis on practicing goal setting and how to take steps to accomplish those goals. The youth themselves decide on something they would like to achieve in their life and receive help with identifyin the steps they need to take. The parent agrees to support the youth in working on their goal and follow-up contacts check on the status and progress. For many youth, this is the first time they have actively participated in decision-making and self0 direction in their lives. For many families, they never thought this was possible and began understanding how they might actually be restricting their son or daughter with taking part in these kinds of activities. For example, Elana and her family participated in the clinic. Elana was 18, had a diagnosis of deaf blindness, intellectual disability, and other health conditions. Elana and mom decided she would become independent in taking her meidciation and obtaining her prescription. Mom contacted the pharmacist to let them know Elana would be contacting him. Elana called, requested her refill, and rode her bike to pick it up. Mom said "I never realized hoe much I was holding her back until I attended this clinic".

TransitionInAction Clini data suggest positive gains in important indicators for transition as well as increases in social networks, increases in opportunities to be independent, and increases in perceptions of what's possible. Perhaps most compelling is anecdotal evidence from the families and youth who participated.

Family Feedback:

> "Now we have more resources than we ever could have imagined."
> "I feel more confident in the transition process."
> "The whole thing was very eye-opening."
> "I had no idea this stuff was out there. Oh my gosh, this is what I needed!"
> "….has become a different person since the Transition Clinic. He's doing more on his own, just more independent – he seems older."
> *"I hope…that other families will have this wonderful experience and to provide another young person the opportunity to use this great resource to assist them as they transition to the adult world. I highly recommend it! A++"*

Young Adult Feedback:

> "There were no low points to the day."
> "I'm actually really glad I went here. I learned a lot about myself today. I have great ideas and resources now."

"….I learned a lot of new things; now the fun part will be applying it."

Adult agency personnel indicated how helpful spending time with the family and youth was, how they wish they could do this with all of their clients, and stated "this is what we should be doing." Teachers conveyed an appreciation for all of the information shared and the usefulness of the recommendations in shaping the Individualized Education Plan (IEP) goals.

Case Study Example

Sophie is 17 years old and attends a local public high school where she is learning how to grocery shop and cook, use a cell phone, call in prescription refills and take medications on her own, ask a friend to go to the movies, and navigate her community. She is participating in work experiences in a variety of restaurants and related businesses throughout the school year to help her explore the environment, work culture, and job duties she is most interested in. Sophie's schedule includes classes in the general curriculum with her peers while many of her academic requirements are integrated throughout the individualized functional activities. Sophie is planning the move to a supported living situation to occur while she is in her senior year at school since an opening came up with the local community support provider. Her transition Individualized Education Plan (IEP) is driven by the needs Sophie has to fully participate in these settings, become competitively employed, and gain independent living skills to achieve the post-school outcomes that she and her parents would like.

A year ago, when Sophie was 16, her education program looked quite different. She was described as friendly, social, active, and impulsive; someone who exaggerates the truth, displays behavioral outbursts, requires prompting to complete a task, recognizes numbers only, and reads at a kindergarten level. Her IEP objectives reflected segregated, in class workbook and computer activities focused on preparing her for the long-term goal of moving to community-based vocational and independent living skills training. School personnel were unsure if Sophie could become employed and felt her aggressive behaviors, chronic health issues, and extensive support needs were prohibitive of her gaining any level of independence. Sophie expressed an interest in working at a restaurant and her parents said they would like to see her have a job, apartment, community involvement, and friends. Questions were raised by the transition IEP team about what the possibilities might be and what resources were available to assist with achieving them, creating the impetus for change.

What was the change creating the impetus for Sophie's "new life" at age 17. Sophie's physician believed she could do more and referred her the TransitionInAction Clinic when she was 16. The experience opened the family's eyes as to the possibilities and the clinic report offered new information and recommendations for school, adult service, and other transition-related personnel. As a result, the goals for Sophie's remaining year's in school are preparing her for a quality, productive life after she graduates.

1st Year Implementation Plan

Replication of the TransitionInAction Clinic in Arizona would be designed to meet the needs of families, youth with disabilities, educators and other professionals in the state. This project is proposed to support the development, implementation, evaluation, and dissemination of a sustainable innovative transition clinic designed to improve post-school outcomes related to employment, health, and independent living. The goals of the project are as follows:

1. Develop and pilot a Transition Clinic school-based model for high school and middle school students in Arizona together with stakeholder and ADDPC involvement to make any modifications and additions to best meet the needs of this community.

2. Make any Transition Engagement Guide revisions, determine metrics and evaluation measures, and collect data to assess impact and youth/family outcomes over the course of the project summarizing, analyzing, and reporting results.

<u>Year 1 Timeline and Action Plan</u>

Develop a Transition Clinic for high school and middle school students in the Tucson area.

January, February, March, 2020 – Start Up

- Make personnel arrangements.
- Engage school, employment, independent living, and health stakeholders.
- Complete start up planning activities.
- Determine location and make logistical arrangements.
- Identify 1 or 2 school districts to receive referrals from for pilot.
- Establish referral criteria, procedures, and materials.
- Obtain permissions and approvals.
- Contact and coordinate school, community, and medical clinic partners.
- Finalize workplace assessment sites.
- Design flyer and referral informational materials.
- Determine metrics and evaluation measures.
- Set up data collection and evaluation measures.

April, May, June, 2020 - Pilot

- Recruit clinic participants.
- Establish processes and procedures for conducting the clinic.
- Pilot the clinic with 6 youth and families.
- Review data and stakeholder feedback and make any revisions.
- Create any additional informational materials, tools, and products.
- Finalize implementation protocols.
- Submit report to ADDPC and present at Council meeting.

July, August, September, 2020 – Field Test

- Field test the Transition Clinic in Tucson twice a month for 6 youth and families.
- Collect impact and outcome evaluation data.
- Obtain stakeholder and participant feedback through interviews and focus groups.
- Make any revisions to the *Transition Engagement Guide* to be applicable for school-based model serving middle school students.

October, November, December, 2020 - Sustainability

- Share information and outreach activities to inform of clinic opportunity.
- Expand recruitment to include any middle and high school students and their families.
- Conduct the Transition Clinic twice a month for 6 youth and families.
- Review and analyze data and stakeholder feedback.
- Finalize protocol guidelines and identify critical components for replication.
- Create resources and Clinic implementation materials.
- Engage in discussions with schools and adult services to establish a fee-for-service Clinic option.
- Explore incorporation of the Transition Clinic as a pre-Employment Transition Service and/or Transition School to Work Program option within existing systems.
- Explore third party billing with health and managed care companies.
- Finalize arrangements for maintaining the Transition Clinic in Tucson as a permanent service modality through the Sonoran UCEDD.
- Submit report to ADDPC and present at Council meeting.

Who is Being Targeted

The Clinic will serve transition aged youth between 14 and 21 and their families. Criteria will include a disability and/or chronic health condition. Referrals will initially come from two school districts during pilot test activities and then will be opened up to include anyone who meets the criteria.

How will they be Targeted and How Many

Two interested school districts will participate in the pilot. The clinic team and participating schools will finalize recruitment procedures and materials including informed consent. A total of 18 youth and their families will participate in the clinic during the project year and receive comprehensive, coordinated transition services action planning.

Where will Activities Take Place

The Transition Clinic will be developed in Tucson.

When will Activities Begin and End

Year one will occur during the calendar year from January to December, 2020.

What do You Plan to Achieve by Year One

- Development of an Arizona Transition Clinic model for middle and high school youth with disabilities and their families.
- Established permanent Transition Clinic in Tucson.
- Design of Transition Clinic materials and resources.
- Funding options for expansion and sustainability explored.
- Outcomes and impact summarized and shared through multiple modalities (e.g. webinars, infographics, newsletter articles, stories, and presentations).
- Preliminary outline of replication protocols and procedures for potential expansion.
- Quarterly progress reports and end of year reports provided to ADDPC.
- Updates provided at monthly Council meetings and presentations made to ADDPC as requested.

How will the TransitionInAction Clinic be Evaluated

Pre and post qualitative and quantitative data will be collected for participants:

Youth: Self-determination measures and goal attainment scaling

Families: Personal interviews and satisfaction surveys

Professionals and Stakeholders: Focus group feedback, satisfaction and impact surveys

Budget

Clinic Coordinator @ 45% FTE Salary & Fringe: $29,565

Travel: $2,000

Printing & Copying: $750

Consultants X 3: $12,500 (Research & Evaluator, Development Specialist, and Training Specialist @ $500 per day X 25 days)

Subtotal: $44,815

Indirects @ 10%: $4,482

Total Requested: $49,297

In-kind: Principle Investigator/Clinic Director and additional time for Clinic Coordinator, $48,947 at no cost to the project

25% Required Cost Share: $12,325 (The cost share is being met through forgone indirects, difference between sponsored-mandated 10% indirect rate and 53.5% university rate)

For more information, contact:

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