Activities, Timeline, & Budget

Transition Clinic

September 9, 2019

Activity 1: Transition Clinic

Develop a school-based clinic for high school and middle school students in the Tucson area.

Engage school, employment, independent living, and health stakeholders.

Complete start up planning activities.

Identify 1 or 2 school districts to receive referrals from for pilot.

Determine metrics and evaluation measures.

Modify the *Transition Engagement Guide* for school-based focus and rename.

Establish processes and procedures for implementation.

Pilot the clinic with 6 students and families.

Review data and stakeholder feedback and make any revisions.

Design flyer and referral informational materials.

Submit report to AZDDPC and present at Council meeting.

Timeframe: Year 1

Budget: $66,935

Itemized Costs:

Clinic Coordinator @ 50% = $32,850

Consultants (X3 who created SD clinic – Richard Parent-Johnson, Emily Meier, & Researcher/Statistician John Johnson + travel) = $28,000

Wendy Parent-Johnson (original clinic co-developer & PI) = no charge

Indirects @ 10% = $6,085

Activity 2: Expand & Replicate Transition Clinic

Identify two communities around the state to participate (e.g., Phoenix & Yuma).

Conduct start up replication activities.

Implement clinic in each community.

Conduct clinic with 6 individuals at each location totaling 12 participants.

Collect data and stakeholder/participant feedback.

Review and finalize replication process.

Finalize *Transition Engagement Guide* for school-based clinic model.

Determine protocol guidelines.

Create training and implementation materials.

Continue conducting clinic at pilot site once a month totaling 12 participants.

Finalize continuation and expansion activities.

Disseminate clinic information.

Submit report to AZDDPC and present at Council meeting.

Timeframe: Year 2

Budget: $83,065

Itemized Costs:

Clinic Coordinator @ 75% = $49,275

Project Assistant @ 20% = $10,512

Consultants (X3 who created SD clinic – Richard Parent-Johnson, Emily Meier, & Researcher/Statistician John Johnson) = $12,000

Travel = $3,000

Printing Brochures = $726

Wendy Parent-Johnson (original clinic co-developer & PI) = no charge

Indirects @ 10% = $7,552

Deliverables

School-based Transition Clinic model developed

Middle school Transition Clinic model developed

Clinic implemented in 3 communities

Clinic services provided for 30 youth and their families

School-focused Tr*ansition Engagement Guide* completed

Implementation and replication procedures established

Referral brochure and training materials created

Clinic information and outcomes disseminated

Optional (next page): *Transition Engagement Guide* for health-focused implementation produced and made available in AZ and nationally

Activity 3: Transition Engagement Guide

The *Transition Engagement Guide* was originally developed as a healthcare transition tool and measure. The instrument and guide are complete and can be disseminated following a large-scale study to establish the validity, reliability, and metrics. This would

be a product that could be shared in the state and nationally with credit to AZDDPC. The study would contribute to completion of essential metrics for school-based version.

Transition from pediatric to adult healthcare poses challenges for youth with disabilities and/or chronic health conditions and their families as they navigate across the dual systems of care. As a result, many individuals have difficulty accessing medical care and may experience gaps in healthcare contributing to the disproportionate disparities observed for this population. The lack of knowledge and tools essential for both healthcare providers and patients adds to the problems associated with preparing and planning a smooth, coordinated, and successful transition. The *Transition Engagement Guide*, developed together with a diverse group of stakeholders, is designed to facilitate the transition process offering young adults, families, and professionals the essential elements for developing an action plan that promotes assets, opportunities, and connections in preparation for the transition to adult health care. This study, using a pre-post control group design is proposed to implement the TESG with 100 young adults with disabilities and/or chronic health conditions to evaluate the extent to which the strategy improves the likelihood of a transition from pediatric to adult care. Using Goal Attainment Scaling measures, the impact on patient-centered and healthcare provider indicators of successful transition will be evaluated across participant groups following implementation of the TESG protocol.

This study is the first of a series of studies to assess the efficacy, validity, and reliability of the TEG. The purpose of this study is to validate the extent to which young adult patients, age 16-26 successfully progress with the transition from pediatric to adult health care. 65 patient indicators and 22 health care providers have been developed that are aligned with the TEG. Data will be gathered by healthcare providers at 3, 6, 9 and 12 month intervals to evaluate the status of patients with developmental disabilities and/or special health care needs ages 16 – 26 transitioning from pediatric to adult health care. Health care providers will provide data that validates the extent to which patients have completed the transition from pediatric to adult health care. In addition, data will be gathered from patients, family members and support providers to evaluate the extent that they are satisfied with the support they are receiving from health care providers to facilitate the transition from pediatric to adult health care. This data will establish the efficacy and use of the TEG.

Timeframe: 1 year (concurrent during year 1 or 2 above)

Budget: $26,417

Itemized Costs:

Coordinator @ 20% = $13,140

Data Assistant @ 20% = $10,512

Consultants (X3 who developed TEG – Richard Parent-Johnson, Emily Meier, & Researcher/Statistician John Johnson) = $14,000

Wendy Parent-Johnson (original TEG co-developer & PI) = no charge

Stipends for Participants @ $50 X 100 = $5,000

Indirects @ 10% (minus stipends) = $3,765

Subtotal = $46,417

Minus UCEDD contributions = $20,000

TransitionInAction Clinic
Sonoran UCEDD
May 19, 2019

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 and adult services. Clinic follow-up is conducted at regular intervals. Annual revisits as needed can be completed to update and address transition issues.

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.

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. The following suggestions are offered.

1. Develop the clinic in Arizona together with stakeholder and AZDDPC involvement to make any modifications and additions to best meet the needs of this community. Finalizing development and pilot-testing is anticipated to be completed in one year.

2. Complete a study to gather evidence of the efficacy, utility, and validity of the *Transition Engagement Guide* (TEG) resulting in the TEG implementation protocol and metric. The TEG would be made available for widespread use with credit to AZDDPC.

3. Expand the clinic to be available to interested persons around Arizona. Possibilities include: implementation in multiple areas in the state, a telehealth model that allows long-distance access, or development of a middle school clinic model.

4. Data collection and evaluation of impact and youth/family outcome measures will be assessed over the course of the project. Data will be analyzed and summarized in a report for AZDDPC and information conveyed to stakeholders in multiple universal formats.

5. Create training materials and learning opportunities for healthcare and other school and adult service professionals on implementing the clinic and applying the recommendations in their programming such as modules, webinars, workshops, and trainings.

For more information, contact: Wendy Parent-Johnson, PhD
Executive Director, Sonoran UCEDD
University of Arizona
wparentjohnson@email.arizona.edu
(520)626-0080 office, (785)764-2472 cell

Sonoran UCEDD Clinic Proposal Addendum

July 13, 2019

The following activities and deliverables are proposed to the AZDDPC for consideration to support the development, implementation, evaluation, and dissemination of a sustainable and innovative transition intervention designed to improve post-school outcomes related to employment, health, and independent living. It is estimated that this would be a two- to three year project as outlined below.

Adapt and pilot the TransitionInAction Clinic in Tucson and expand to two other areas in the state.

- Determine location and make logistical arrangements.
- Establish referral criteria, procedures, and materials.
- Obtain permissions and approvals.
- Contact and coordinate community and medical partners.
- Finalize workplace assessment sites.
- Develop informational and recruitment materials.
- Set up data collection and evaluation measures.
- Recruit clinic participants.
- Conduct clinics for 12 to 15 youth/families.
- Review findings and plan expansion to two additional sites.
- Implement the clinic in two new locations.
- Disseminate information through multiple written, on-line, and in-person formats.
- Explore sustainable funding through state agency referrals.

Evaluate the validity and efficacy of the *Transition Engagement Guide* (TEG) as a tool for use by physicians' offices and existing clinics independently.

- Finalize TEG protocol and training webinar.
- Establish metrics to evaluate impact on patient-centered and healthcare provider indicators of successful transition.
- Recruit participants including nurses, genetic counselors, and other health care professionals.
- Implement the TEG with 100 young adults with disabilities in Arizona.
- Utilize telehealth technologies to provide technical assistance and conduct observations.
- Collect qualitative and quantitative data at pre, three, and six month intervals.
- Analyze data and make any revisions to protocol and implementation materials.
- Summarize findings and disseminate TEG for widespread use by healthcare professionals.

Develop an innovative school-based transition clinic model.

- Modify the key components of the clinic for implementation at local schools.

- Obtain permissions and approvals.
- Determine referral criteria and procedures.
- Create a brochure, revise the TEG, and design materials.
- Identify two schools diverse in size and geography to pilot the clinic.
- Engage community partners in each location.
- Implement the clinic with six youth and their families.
- Collect and review data and feedback from participants.
- Make any revisions and plan expansion.
- Recruit two other schools and conduct clinics for high school youth with disabilities.
- Expand the clinic to serve middle school students and conduct pilot test.
- Produce resources and disseminate information through a variety of mediums.
- Explore sustainable funding through school and pre-ETS dollars.

Scale up clinic availability through training, technical assistance, and dissemination.

- Conduct regional and statewide trainings around the state on establishing a clinic in local medical and school communities.
- Develop resources for clinic start-up.
- Establish referral procedures and commitment criteria for start-up assistance.
- Provide technical assistance to four interested schools.
- Collect data and insure fidelity of implementation.
- Finalize implementation guide and procedures with resources, materials, and templates.
- Share outcomes and impact with policy and funding decision-makers.
- Explore requirements and resources for scaling up clinic implementation.

Deliverables

- Development of an Arizona healthcare transition clinic model.
- Established healthcare transition clinic in three locations around the state.
- Healthcare transition materials and resources produced and disseminated.
- A validated *Transition Engagement Strategy Guide* tool for use by healthcare professionals.
- A school-based clinic model developed and pilot-tested.
- Established school transition clinic in four diverse high schools.
- Application of clinic for middle school students and families.
- School transition materials and resources produced and disseminated.
- Increased knowledge and awareness through trainings for health and school professionals, family members, and youth/young adults with disabilities.
- Replication materials and "how to" guide produced.
- Technical assistance provided for transition clinic start-up in four schools.
- Fidelity of implementation procedures and measures established.

- Funding options for expansion and sustainability explored.
- Continuation of a UCEDD-implemented clinic.
- Outcomes and impact summarized and shared through webinars, infographics, newsletter articles, stories, and presentations.
- An estimated 150 to 200 youth and their families would receive direct transition services and action planning.
- Quarterly progress reports and end of year reports provided to AZDDPC.
- Updates provided at monthly Council meetings and presentations made to AZDDPC as requested.

Budget Justification

Personnel

Wendy Parent-Johnson, Principle Investigator & Project Director (10%) FTE will be responsible for administrative and fiscal oversight of the proposed project. She will lead hiring of new staff and provide supervision of all project staff. Dr. Parent-Johnson will function as the liaison with AZDDPC staff, medical personnel, school administrators, and community partners. She will oversee development of the healthcare and school-based clinic models and implementation procedures. Dr. Parent-Johnson will assist with site visits, design and implementation of replication clinic approaches, data collection and analyses, and development of products and resources. She will insure project activities are completed as proposed and submit progress and annual reports as requested. Dr. Parent-Johnson's responsibilities will be completed at no cost to the project. Total requested = $0.

TBH, Clinic Coordinator (100% FTE): This position is responsible for managing and overseeing implementation of the healthcare and school-based clinics, engaging local community partners, conducting recruitment activities and identifying participants, completing pre and post family interviews, and participating as train-the-trainer learning from consultants. He or she will be responsible for coordinating development and replication clinics, communicating with on-site clinic partners, and responding to questions and requests for information. The person will assist with product development and dissemination of clinic results and resources. Total requested = $50,000.

TBH, Project Assistant (50% FTE): This position will be responsible for assisting clinic operations and overall project activities. He or she will be responsible for making clinic logistical arrangements, scheduling clinic days, insuring clinics flow smoothly, collecting pre-and post-clinic information, and compiling report sections from partners. The person will monitor and complete follow-up contacts and information gathering. He or she will be the point of contact for questions, requests for information, and sharing resources with interested persons around the state. Total requested = $20,000.

TBH, Research Associate (20% FTE): This position will be responsible for designing and managing data collection efforts focused on determining clinic outcomes and impact. He or she will be responsible for conducting the validation study of the TEG and evaluating the efficacy of implementation. The person will complete all IRB and site approvals, obtain any informed consents, and insure security of data storage. He or she will complete data analyses, provide on-going data reports to project staff to inform development and make data-based decisions, and gather reliability data to assess fidelity of implementation. Total requested = $9,000.

Fringe Benefits

Salaries are based on the University of Arizona salary structure, with fringe benefits that are based on the current DHHS rate agreement (31.4% for Full-Benefit Employees; 20% for Ancillary Staff; 11% for Graduate Assistants; and 2% for Student Employees). Total requested:

$24,806.

Consultants

Richard Parent-Johnson, PhD, Clinic Director (20% FTE) will be responsible for developing the healthcare transition clinic, completing all procedural arrangements, designing protocols, training clinic staff, modeling clinic implementation, developing clinic reports and action plans, and gaining feedback to use an iterative approach to designing an AZ clinic. He will be responsible for establishing process and criteria for replication, completing start up at additional sites, and providing technical assistance. He will develop implementation materials, produce products and resources, and conduct qualitative data analyses. Dr. Parent-Johnson led development and implementation of the SD TransitionInAction Clinic and will oversee establishing both a healthcare and school-based clinic model in Arizona. Total requested = $16,000.

Emily Meier, MA, Training Specialist (20% FTE) will be responsible for assisting with developing the clinic content areas, training staff and community partners, utilizing a train-the-trainer approach to model clinic implementation, supporting peer advocates as mentors, and providing training on implementation of the TEG. She will assist with development of clinic materials, training webinars and materials, and student learning opportunities. Ms. Meier will assist in development of a school-based clinic model and provide technical assistance to replication sites. Ms. Meier led a major component of the SD TransitionInAction Clinic; oversaw resident, genetic counselor, and nurse involvement and training; and disseminated information through multiple mediums. Total requested = $10,000.

Travel

Funds are requested to support travel of project staff to meet with community partners, attend meetings with AZDDPC and agency personnel, visit participating healthcare and school clinic sites, provide training and technical assistance, and supporting replication clinics. Costs are estimated at 4,000 miles at $ .445 per mile = $1,780 and per diem for full day travel @ $20 X 25 days = $500 and travel for consultant from SD estimated at three trips $907 each (airfare = $400, hotel = $300, per diem = $160, and ground transportation = $47). Total requested = $5,000.

Printing

Funds are requested to support copying clinic materials and resources for families ($300), producing and disseminating products and informational materials ($500), and printing clinic brochures and DocTalk cards ($700). Total requested = $1,500.

Subtotal = $136,306

Indirects @ 10% = $13,631

Total Project Funds Requested Year 1 = $149,937, Year 2 = $149,937.