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# Incorporating Meaningful Occupations of Students with Moderate to Severe Intellectual Disabilities into Structured Learning Experiences with Transition Planning at a Public School System

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INCORPORATING MEANINGFUL OCCUPATIONS OF STUDENTS WITH MODERATE  
TO SEVERE INTELLECTUAL DISABILITIES INTO STRUCTURED LEARNING  
EXPERIENCES WITH TRANSITION PLANNING AT A PUBLIC SCHOOL SYSTEM

Presented in Partial Fulfillment of the  
Requirements for the Degree of  
Doctor of Occupational Therapy

Eastern Kentucky University  
College of Health Sciences  
Department of Occupational Science and Occupational Therapy

Catherine Gardner

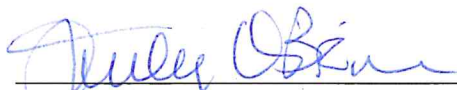
2019

**EASTERN KENTUCKY UNIVERSITY  
COLLEGE OF HEALTH SCIENCES  
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL  
THERAPY**


Certification

We hereby certify that this Capstone project, submitted by Catherine Gardner, Conforms to acceptable standards and is fully adequate in scope and quality to Fulfill the project requirement for the Doctor of Occupational Therapy degree.

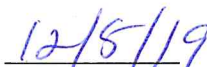
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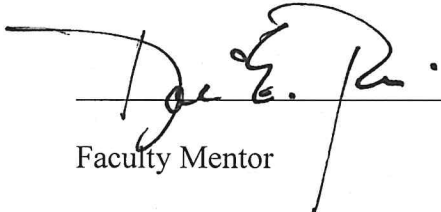
  
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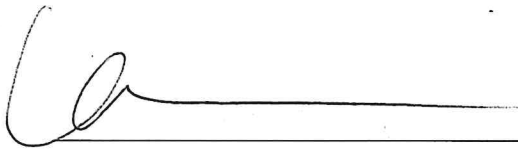
This project, written by Catherine Gardner under direction of Doris Pierce,  
Faculty Mentor, and approved by members of the project committee, has been  
presented and accepted in partial fulfillment of requirements for the degree of

**DOCTOR OF OCCUPATIONAL THERAPY**

**CAPSTONE COMMITTEE**

  
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## **Acknowledgements**

The lifelong dream of attaining my doctorate could not have been achieved without the support and understanding of many individuals. At the top of the list are my family. My husband Bob and children Andrea and Deane. You have had tremendous patience with my slow and arduous learning curve for all the new technology since I was last in school. There have been compromises on where our family vacations have been so that I could complete and submit course assignments, and for this I am most grateful. A very special thanks to Vianey Rosas for her expertise with translating all documents into Spanish for the study.

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Last, but certainly not least is my thanks and appreciation for those who participated in the project. Honest sharing of their lived perspectives was essential for being able to identify effective ways to create change in the transition planning process. These individuals shared my passion for serving the students of West New York and in knowing that by working collectively, the students can be prepared to leave the school and lead successful adult lives determined by what is meaningful to them.

## **Executive Summary**

### **Background**

The author works in a school district which did not have a transition planning process that incorporated participation of students or identification of meaningful activities for the selection of students structured learning experiences. Students in this school district were from an area which is identified as having socio-economic disparities, placing the focused population at risk for compromised quality of life as adults. Students enrolled in the creative pathway's program for students with moderate to severe intellectual disabilities were the population of interest in this project.

### **Purpose**

The purpose of this capstone project was to learn from stakeholders how to identify meaningful occupations of students with moderate to severe intellectual disabilities and how to incorporate them into their structured learning experiences in school. The project also sought to explore how to involve the students and their families in the process of identifying meaningful occupations.

### **Theoretical Framework**

The E-HOW theoretical framework by Pizzi and Richards (2017) was used for this capstone project.

### **Methods**

Active participant research in an educational environment as discussed by Stringer (2008) was used to enable a transformational experience for the participants involved. Interviews with staff and students were conducted to obtain lived experiences to inform the process. All staff involved in providing high school transition services were involved in prioritizing the action steps to be taken by the group.

### **Results**

Participation in the interviews was limited but valuable and led to further exploration of the barriers of participation by Hispanic families. A deeper understanding of Hispanic culture therefore became a secondary avenue of exploration within the project and was incorporated into the action steps created by the group. Staff members involved in the high school transition program have become empowered and the administration has increased its support of the staff to make improvements to existing services.

### **Conclusions**

Use of an active participant research method by an occupational therapist focused on identification of student's meaningful occupations. This resulted in staff becoming more attentive to how to identify what is meaningful. Staff became energized and empowered to seek more knowledge about transition planning and administration was aware of and supportive of these efforts.



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THERAPY

CERTIFICATION OF AUTHORSHIP

Submitted to Doris Pierce: \_\_\_\_\_

Catherine Gardner: Catherine Gardner

Title of Submission: Incorporating meaningful occupations of students with moderate to severe intellectual disabilities into structured learning experiences in transition planning at a Public School system.

*Certification of Authorship: I hereby certify that I am the author of this document and any assistance that I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.*

Student's Signature: Catherine Gardner

Date of Submission: 2/2/20

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## **Section One: Nature of Project and Problem Identification**

### **Background**

Students who have individualized education plans (IEP's) are entitled to receive transitional planning services from the age of sixteen through twenty-one to assist them with transition from school to adult life (Individuals with Disabilities Education Act: IDEA; Pub. L. 108-446). New Jersey mandate requires that the transition planning process begins for students with disabilities at age fourteen (New Jersey Department of Education, 2018, p. 5). The New Jersey Administrative Code for Special Education services states that transition services shall be “based on the individual child's needs, taking into account the child's strengths, preferences, and interests” (2006, p. 1). Students in the West New York (WNY) public school district currently have a program which does not incorporate what is meaningful to the students to help guide the development of their plan to achieve successful transition. In addition, the district scores on the state Local District Special Education Public Report for 2016-2017 (New Jersey Department of Education, 2018) reflect that students are not meeting the expected thresholds for the compliance indicator for transition which states that the student is present at their IEP meeting where transition services are discussed (New Jersey Department of Education, 2017a).

### **Current curriculum**

Current academic curriculum in West New York was developed in 2006 (West New York, n.d.) and included the core courses required by the Department of Education by grade level along with special education classes to prepare the student for graduation. The curriculum was based off of the work by Carter and Hughes (2006); Downing, and Peckham-Hardin (2007); and McDonnell, Mathot-Buckner, Thorson, and Fister (2001) and while the curriculum does identify what was best practice at the time it was written, and includes language for the use of a

person-centered approach, it is not being implemented and New Jersey academic standards have changed significantly since then. The curriculum was initially designed based upon a single classroom for students with multiple disabilities at the high school. There are now four classes for multiply disabled students and three classes for students with significant learning difficulties who are on the autism spectrum, for a total of seven classrooms. Included in this total are two classes for the eighteen to twenty-one aged population. The collective group of classrooms is referred to as the creative pathways program. The curriculum was scheduled for revision in early spring of 2019, which aligned well with the timing for this capstone project. The start of the curriculum revision was delayed with the retirement of the Director of Special Services, a change in the Principal of the high school and the resignation of the Assistant Director of Special Services.

## **Purpose**

The problem that this capstone project was designed to address was to mitigate the discrepancy that exists between what is set by the New Jersey Department of Education expectations for incorporation of an individualized, person-centered approach to transition planning and the current programming being provided by the West New York Public School District in West New York, New Jersey. This capstone project was designed to address the need for the alignment of student interests with the selection of structured learning experience opportunities.

The purpose of this capstone project was to explore with the school district methods that could be incorporated into the curriculum, as well as to identify how student interests could be determined and embedded into the design of structured learning experiences in the transition

planning process being provided to students in classes for moderate to severe intellectual disabilities. It was anticipated that implementation of the methods identified by this study would enable the teaching staff to provide experiences that support the students in their transition into adult life, which could be expected to include attaining gainful employment, engaging in meaningful occupation, being involved in the community, and independent living skills (Eismann, Weisshaar, Capretta, Cleary, Kirby, & Persch, 2017; Foley, Eyke, Girdler, Bourke, & Leonard, 2012; Michaels, & Orentlicher, 2004; Reynolds, M. 2019).

As mentioned above, the staff were scheduled to revise the teaching curriculum for the students in the multiply disabled and the applied behavioral analysis classrooms of the high school inclusive of the eighteen to twenty-one year old classes. While the timing for that had been altered, it was felt that the findings from this capstone project would be available for the incoming administration to consider for inclusion in the curriculum design revision.

### **Person-Centered**

The research questions put forth for this capstone project were “how can student interests be identified”, “how can the identified interests be used to create individualized and meaningful structured learning experiences”, and “what is an effective method for incorporating the identification of students’ interests. At the core was identifying ways to answer these questions so that all students in the creative pathways program could have the opportunity to have transition planning customized to their areas of interests. Literature that supports the value of meaningful occupation is rich (Argentzell, Hakansson, & Eklund, 2012; Christiansen, C.1996; Ikiugu, Hoyme, Mueller, & Reinke, 2015; Ikiugu, 2005; Pierce, 2001; Reynolds, 2019). In a search through the ECU library for the term person-centered approach, four hundred seventy-

four articles were found. The articles were from a variety of fields such as business, education, information technology, math, pastoral care, police training, and psychotherapy.

In the area of education, Timmons, Podmostko, Bremer, Lavin, and Wills (2004) created *A guide for professionals serving youth with educational and career development challenges*. This work was done by the National Collaboration on Workforce and Disability to address best practice for assessments for preparing students for careers. The guide was developed using a person-centered approach for both the assessment portion as well as the planning process supporting the use of a person-centered approach within education curriculum.

### **Needs Assessment**

In the summer of 2018, a needs assessment was conducted by the Principal Investigator (PI) to identify what the existing programming entailed and what perceived gaps and barriers existed from the viewpoint of the teaching staff. Data collection used a concerns survey sent over the summer of 2018 to eight staff assigned to the high school classes for students with moderate to severe intellectual disabilities (IDD) and therefore qualified for transition planning services. Gathering input from these stakeholders was done to increase the likelihood that the results of the needs assessment would be received and accepted by the stakeholders, and that the findings will be utilized (Finlayson, 2006). As discussed by Stringer (2008), when research is designed for active participation and individuals are able to actively engage, the participants can have a higher degree of personal investment in having change occur. The survey consisted of three components; a ranking of importance and satisfaction on fifteen statements pertaining to transition services; three open-ended questions; and six demographic questions. Analysis of the data was followed by a meeting with all staff. The collective voice of the teaching staff reflect



common concerns, which was then presented to the administration to consider as opportunities for change to the current program design.

The previous administration was receptive to the results of the needs assessment findings, indicating that there would be support for conducting the capstone project. The PI has a history of being a contracted provider to the school district for fifteen years and has worked with the Assistant Superintendent of Curriculum in the past when she was the Director of Special Services. This relationship had been a positive one. The prolonged engagement in the district helped to establish credibility, which is critical in creating transformational change to the current way of doing things (Stringer, 2008; Taylor, Kielhofner, & Fossey, 2017). This relationship was key to gaining the senior administrative approval necessary for application to the Institutional Review Board. The superintendent and board of education had a history of denying research in an effort to “protect the students” (S. Olivero, personal communication, November 28, 2018). Approval for submission to IRB required three months of strengthening the credibility of the PI with the senior administration.

The results of the needs assessment identified that the programming being provided was not meeting the satisfaction of the teaching staff. They believed that a life skills curriculum was more beneficial than using an academic curriculum; a finding that is congruent with research (Eismann, et al, 2017; Hughes and Eisenman, 1996; Michaels & Orentlicher, 2004).

Respondents to the initial needs assessment felt that students were poorly prepared for employment or meaningful activities when they turn twenty-one years old and that students and their families were only minimally involved in planning for adult life. There were mixed responses to the question of whether the district had a way to identify interest areas for students

to pursue in their structured learning experiences but there was not anyone who identified a “very satisfied” response.

The Boggs Center on Developmental Disabilities in New Jersey is the designated state center of excellence on developmental disabilities. In 2016 they released a report, titled *Exploring Transition in New Jersey* (Boggs Center, 2016), which found that in New Jersey fifty-three percent of recent graduates were not working and of those individual’s, fifty percent would like to work but did not feel prepared to do so. Focus group participants of the study reported that services in the high school had not been individualized or were not a good match for their interests or abilities.

### **Program Gaps**

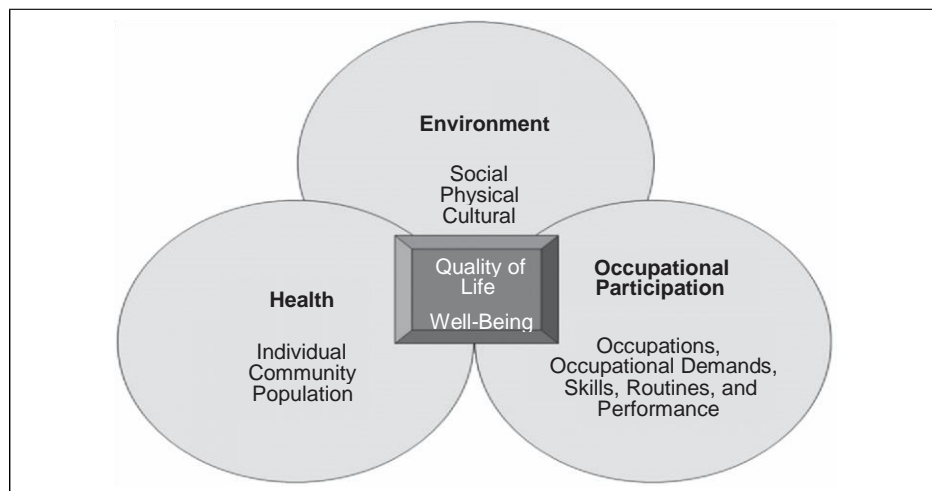
The New Jersey Department of Education’s most recent special education data for 2017 identifies students who identify with different racial backgrounds. The PI was interested in those who self-identify as being Hispanic. The Department of Education also gathers data on students classified as special education who have dropped out of school. In reviewing the top five counties for students who identify as Hispanic, all of the students who dropped out of school were from three of these five counties. The top drop out county was the one in which this research was conducted (New Jersey Department of Education, 2019). These findings further support the need to incorporate meaningful occupations as the curriculum for the creative pathways program is being revised.

Respondents to the needs assessment were also asked what features of programming were helping the students prepare for adult life following high school. The practices they described aligned with research recommendations to include independent living skills training, social skills training, and leisure activities (Foley, et. al., 2012; Hughes and Eisemann, 1996; & Michaels &

Orentlicher, 2004). When asked what could be done to improve existing programming, many of the suggestions mirrored what researchers have found. Coordination of service delivery is vital to successful transition services, working with community-based partners is important in finding locations for successful training for individuals, and job coaching is valuable in helping to prepare students for adult life and employment opportunities (Kaehne, & Beyer, 2010; Michaels, & Orentlicher, 2004; Pallisera, Vila, & Fullana, 2014; Rashid, Hodgetts, & Nicholas, 2017; Test, Fowler, White, Richter, & Walker, 2009). Barriers that were identified included the need for funding and more support from the Board of Education, training for the staff on how to do transitioning, better communication, and working as a team.

### **E-HOW Model**

Figure 1. Pizzi and Richards, 2017



The findings of the needs assessment, as well as the research noted above, identified how effective transitional services need to consider the dynamic interactions between the

environment, occupational participation, and the individual along with their community. The theoretical model guiding this project is the E-HOW Model by Pizzi and Richards (2017).

The ultimate goal of transition services is to prepare the students to have a high quality of life and well-being upon leaving the school system. This objective aligns with the outcome of the E-HOW Model. The three spheres of the E-HOW Model (environment, health, and occupational participation) converge to create quality of life and well-being as seen above in **Figure 1**.

It was envisioned that improvements to student experiences could be obtained by working with the school district to make changes to the creative pathway's program. Specifically, it was believed that the students would be able to obtain a higher quality of life and well-being upon leaving the school system.

The expected impact of this project was projected to be beneficial in a number of ways. Of primary concern was to make a difference in the lives of the students of the West New York school district so that they could transition to adult life and become contributors to their community through meaningful occupations in their lives. By incorporating meaningful occupations into the transition planning process as part of the foundation of the curriculum, the teaching staff would have a positive impact on future students. As described by Stringer, staff would likely experience more satisfaction with the services they are providing (2008). This would also enable those students leaving the school system to have a better quality of life, including a more healthy life. Healthy People 2020 identifies access to education and social interactions as social determinants to health (U.S. Department of Health and Human Services, 2019). During the needs assessment process, the PI began to question the impact which cultural

beliefs and customs were having on the transition process for both the direct care staff, who have a high percentage of Hispanic individuals, as well as on the expectations of the families.

### **Cultural Influence**

Occupational therapists are concerned with the impact of environments which, when using the E-HOW Model, incorporates the social, physical and culture influences. The PI became intrigued with exploring the impact which the Hispanic culture had with defining what quality of life meant to the participants. Gupta (2016) points to the connection between the social determinants of health and the occupations in which individuals engage. In order to deepen an understanding of the Hispanic cultural influence, the PI designed her applied leadership experience during the summer of 2019 to gain a greater awareness of Hispanic culture and the disparities of service delivery with adults with intellectual and developmental disabilities in New Jersey. Work with the Boggs Center resulted in products created that included a *Data Analysis of New Jersey Young Adults with Intellectual/Developmental Disabilities who are Hispanic* (Gardner, 2019a), and a *Draft Format for a Support System for Individuals and Families from Hispanic Cultures* (Gardner, 2019b). In addition, readings were done regarding histories of the cultures of multiple Central and South American countries. The knowledge gained through these efforts helped the PI to be more effective in understanding and appreciating the unique cultural differences with the Hispanic cultures so that this can be integrated into provision of more effective care (Wells, 2016).

The results of this project will be shared both locally and nationally, to advance the involvement of occupational therapists in transitional services as recommended by Michaels and Orentlicher, (2004) and Spencer, Emery, and Schneck (2003). This will be done both within the field of occupational therapy as well as in the interdisciplinary arena of the field of

developmental disabilities through professional forums. A short course was presented by the PI at the New Jersey Occupational Therapy Association's 45<sup>th</sup> Annual Conference on October 6, 2019. The title was *Transition Planning to Adult Life: The Role of School-Based Occupational Therapists*.

### **Summary of Project Development**

Through the federal law of IDEA, students with disabilities are entitled to have transition planning services begun by the age of sixteen years to prepare them for adult life. In New Jersey, the process begins at age fourteen for students with disabilities and by the New Jersey Administrative Code must include the student's participation and interests. In the targeted district for this capstone project, these services were not being provided, a condition also present elsewhere in the state, as identified by a report by the Boggs Center on Developmental Disabilities (2016). This capstone project focused on working with a targeted public school district to identify answers to the following questions. How can student interests be identified? What is an effective method for incorporating the identification of students' interests into the curriculum design? And lastly, how can the identified interests be used to create individualized and meaningful structured learning experiences? The findings of this project identified ways to incorporate meaningful occupations, as defined by students and the staff members, into the curriculum design for the targeted school district. As a result, a positive impact can be carried forward to future students who attend the creative pathway's program so that they will be able to attain quality of life and well-being in adult life.

## **Section Two: Detailed Literature Review**

### **Background**

This capstone project was completed in the urban town of West New York, NJ. The demographics of the one square mile town indicated that it is comprised of a predominantly Hispanic community with seventy-eight percent of the fifty thousand people self-identifying as such (DATAUSA, n.d.). The population has been growing during the past few years because of re-development of factories into multifamily housing. The school district is responsible for over nine thousand students with eleven percent of the students in the school district classified as special education. The number of special education classes is expanding on an annual basis. It should be noted that, while New Jersey is the most densely populated state in the United States with all twenty-one counties being considered urban by the Census Bureau (World Population Review, 2019), it also has the distinction of having the highest percentage of students classified as special education in the nation (Harriott, 2016; New Jersey Department of Education, 2013). In the winter of 2018, West New York (WNY) opened an eighteen to twenty-one year old classroom for students on the autism spectrum. That brought the number of classes at the High School for students with IDD who have moderate to severe intellectual disabilities to seven. There are fifteen total classes in the district for students placed in self-contained classes.

In 2006, the district opened its first high school class for students with multiple disabilities. The curriculum currently in use was written for that first class (West New York, n.d.). This curriculum was scheduled to be reviewed and revised in the spring of 2018, which aligned well with the timeframe for this capstone project. Any revision of the curriculum would need to consider that eight percent of the special education students have a classification of autism, and four percent have a classification of multiply disabled (New Jersey Department of

Education, 2016a). These students need transition plans which are customized for them to move successfully from student to young adult life. The Boggs Center for Developmental Disabilities is the Center of Excellence in New Jersey for research and training of evidence based best practice (2017). They provide extensive training at no cost to school districts on using a person-centered approach when designing transition planning from high school to adult life and have created communities of practice where school districts can share their knowledge and experiences. Up until the work done through this capstone project, work between the West New York School District and the Boggs Center had been minimal.

Individualized transition plans are essential for students to be successful in their movement from the role of being a student within the IDD population, to a young adult. They are at risk for reduced quality of life as defined by Healthy People 2020's leading health indicators (U. S. Department of Health and Human Services, 2019). The population of interest to this project falls into five of the twelve topics for the leading health indicators; social determinants, access to health services, nutrition, physical activity and obesity, and mental health (U. S. Department of Health and Human Services, 2019). The majority of the participants targeted for the study were from a lower socio-economic background, as well as many being new, undocumented immigrants whose families spoke a language other than English in the home. Some of the social determinants of health that are listed by the U. S. Department of Health and Human Services (2019) include socioeconomic conditions, culture, and social supports.

### **New Jersey Demographics**

Approximately eight percent of the students in the district were identified as being of limited English proficiency (Education Law Center, 2018). Eighty-four percent of the students



in the district qualify for free or reduced lunch, which is up from 68% in the 1998-1999 school year (Education Law Center, 2018), indicating that the gap is widening for students in this school district. If students who were the targeted population for this project could reduce their dependence upon their families and become employed and contributing young adults in their community, they would be able to help their families and give back to their community. The key to this desirable outcome was whether these outcomes are valued culturally by the individuals and their families. In 2012, New Jersey became an Employment First state where it is expected that employment will be the desired outcome for all adults, including those with intellectual/developmental disabilities and allocation of subsidized money is tied to this outcome (New Jersey Department of Human Services, 2019). If the students and their families have been experiencing occupational injustice as a result of being within a population identified as having social disparities, then they will not have access to, or be able to participate in, the variety of meaningful occupations available to others (Wilcock & Townsend, 2014). Attention to addressing this disparity was found throughout the occupational therapy literature (Hammell, 2004; Kielhofner, de las Heras, & Suarez-Balcazar, 2011; Nayar, & Stanley, 2015; Paul-Ward, 2009; Whiteford, & Townsend, 2011).

### **Occupational Therapy's Role**

Occupational therapists have a responsibility to address health and social disparities. According to the American Occupational Therapy Association's (AOTA) *Societal Statement on Health Disparities* (AOTA, 2013) and the *Vision 2025*, "Occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living" (AOTA, 2017, p. 7103420010p1).

This capstone project was designed to use an occupational therapy approach to contribute to the knowledge of how to identify what is a meaningful occupation while recognizing the population's cultural influence on structured learning experiences within the transition program for students with moderate to severe intellectual disabilities in an urban public school district. Fehringer, Marshall, Summers, and Pierce (2014) expressed that transition services for students with disabilities would result in greater success if they were based on occupational science and incorporate meaningful occupations.

## **Definitions**

**Meaningful occupation.** Ikiugu, Hoyme, Mueller, and Reinke (2015), point to the difficulty of being able to identify a consensus within the profession of occupational therapy on the definition of meaningful occupation in the literature. Instead they discuss various proposed perspectives, such as individuals feeling that they are able to make a choice, that what they are doing is right for them and worthwhile, or that they are autonomous. Another perspective offered was that when an individual has a feeling of purpose in life that results in satisfaction and happiness. The lack of clarity of a definition was also the focus of a study by Reed, Hocking, and Smythe (2011) in which they looked at the use of phenomenology as a method to determine what occupation means. For the purposes of this study, what is meaningful occupation was defined by the student participant and staff in this qualitative participatory action research study.

**Moderate to severe intellectual disabilities.** The levels of intellectual disability are determined by the IQ, or intellectual quotient, of a student. An individual with an IQ between 36 and 51 is determined to have a moderate intellectual disability. Individuals with an IQ of 20 to 35 are determined to have a severe intellectual disability (Merck Manual, 2018). Students who have been classified for special education in the West New York school district and are assigned

to the creative pathways program have met the criteria of having moderate to severe intellectual disabilities.

**Participatory action research.** Stringer defines action researchers as engaging in “careful, diligent inquiry... acquire information having practical application to the solution of specific problems related to their work” (Stringer, 2008, p. 3). Taylor defines participatory action research as “an approach to research used to confront pressing social problems. Although participatory action research can be combined with quantitative designs, it most often employs qualitative research strategies.” (2017, p. 522). Yerxa identified that action research is “directed toward the practical application of scientific knowledge” (Yerxa, 1990, p. 175). She explains that action research is “designed to solve particular problems and bring about desirable changes, usually in a specific environment” (Yerxa, 1990, p. 175).

**Person-Centered approach.** “Person Centered Thinking is a term used to describe the day to day practical application of the same skills and tools used in formal person-centered planning”. “Person-centered planning involves various facilitated approaches to listen deeply to people” (Boggs Center, 2017). Croke and Thompson (2011) define person-centered planning as “a facilitated process in which an individual with a disability and his or her circle of support are engaged in planning for the future.” In the Netherlands, Vlaskamp and van der Putten’s (2009) work referred to a person-centered planning approach as “a valuable asset in helping clients to identify issues and bring about outcomes that are meaningful to them” (p. 873). Timmons, et al. described person-centered as a process that has the purpose of “identify(ing) desired outcomes that have meaning to the youth and develop customized support plans to achieve them” (2004, p. 1-3).

**Structured learning experiences.** Structured learning experience (SLE) refers to “experiential, supervised, in-depth learning experiences aligned to the New Jersey Student Learning Standards that are designed to offer students the opportunity to more fully explore career interests within one or more of the Career Clusters” (New Jersey Department of Education, 2016b, p. 10). SLEs are designed as rigorous activities that are integrated into the curriculum and that provide students with opportunities to demonstrate and apply a high level of academic, and/or technical skills, and develop personal, academic and career goals.

**Transition planning.** The New Jersey Department of Education has defined transition planning as follows. “Transition is a formal process of long-range cooperative planning that will assist students with disabilities to successfully move from school into the adult world” (New Jersey Department of Education, 2017b). The New Jersey Administrative Code (New Jersey Department of Education, 2016c, Appendix B) defines transition services for students under sixteen years of age as transition services, which means a coordinated set of activities for a child with a disability. There are three required components. The services must be “designed within a results-oriented process” (p. 1); “based upon the individual child’s needs, taking into account the child’s strengths, preferences, and interests;” (p. 1), and includes a variety of methods such as instruction, community experiences, development of employment and independent living skills, and related services. The Boggs Center described transition planning as follows:

The period of time that marks the movement from adolescence to adulthood includes transitions in many areas of life. Success after leaving school is often measured by entrance into higher education, employment, increased independence, financial stability, and social relationships. For students with disabilities, preparation for transition should begin by age 14 and focus on academic instruction, community

experiences, employment and daily living skills to facilitate success in adult life (The Boggs Center, 2016).

## **Literature Summary**

**Meaningful occupations.** The literature is rich in varying views on the importance of engaging in doing tasks that hold value to an individual. This discussion encompasses tasks that are employment focused, as well as leisure and instrumental activities of daily living for all people. The fields of occupational therapy, psychology, vocational rehabilitation, education, social work, organizational psychology, and occupational science each have their perspective on why and how engaging in tasks holds positive meaning to individuals. A commonly cited outcome of such engagement is more active participation (Ball, & Fazil, 2012; Boggs Center, 2016; Bolman, & Deal, 2017; Clark, Jackson, & Pyatak, 2014; Fehring, Marshall, Summers, & Pierce, 2014; Hammell, 2004; Ikiugu, Hoyme, Mueller, & Reinke, 2015; Krishnasamy, Li, & Chen, 2016).

Students who have moderate to severe intellectual disabilities need to develop multiple skills in order to successfully transition from the role of student to young adult. This capstone project was designed to gather input from participants on what was meaningful, how to identify what was meaningful, and how to incorporate what is learned into the curriculum being revised. This was done in tandem with the PI gaining a deeper level of cultural awareness so that she could guide recommendations for curriculum modifications regarding the design of structured learning experiences for the students. In addition, the PI was also conducting literature searches for best practice models on methods being used to incorporate a person-centered approach. The PI used an occupational science lens to glean information through interviews.

**Hispanic culture and transition services.** The study was designed to also have questionnaires for the parents to provide input to help triangulate the data from the various stakeholders, however there were no responses from the parents. Input from teaching staff and the PI's personal experience in the district support that there is a historical trend for minimal attendance and participation of families for individualized education planning (IEP) meetings and conferences or attendance at meetings. In light of the current political climate, this has expanded to a number of parents refusing to sign their name to documents due to fear regarding their immigration status even when it means that their children will not receive free lunches (B. Wolanski, personal communication, October 3, 2019). As mentioned above, many of the families in the WNY school district are first generation undocumented immigrants to the United States. They have left a familiar culture and system and are in a country using a different language. As found in other studies, involvement by parents of school-aged children is cited as being low, which impacts the support that students are receiving during this difficult time (Kraft, 2017; Martinez, Conroy, & Cerreto, 2012). In another study, Flores, Morgan, Rivera and Clark (2019) looked specifically at the engagement of Latinx families. They found that when the definition of family was expanded to more than the parents, there was increased involvement and engagement by the expanded family and student educational outcomes improved.

A study by Sanchez-Birkhead et al. (2011), found that Hispanic women were reluctant to receive health related services when they did not feel there was a social support system in their community, had experienced prior negative interactions, or anticipated that there would be discrimination. It can be argued that gaining comfort in the formality of the educational system in America is a similar challenge.

**Occupation and context.** In discussing the connection between neuroscience and occupation, Dunn informs us that “an enriched context can enhance a person’s performance range” (1997, p. 6), thereby expanding the variety of activities that a person is willing to engage in and feel success from. Finding ways to enrich the context for each student by incorporating meaningful occupations into the curriculum design was expected to result in more meaningful experiences for the students participating in the transition process, thereby impacting the students’ adult quality of life (Christiansen, 1999; Krishnasamy, Li, & Chen, 2016; Pizzi, & Richards, 2017). Pierce (2001) stated that in order to truly engage individuals in intervention, the experience needs to be pleasurable (2001). She expressed how therapeutic power is created through occupational therapy’s unique understanding and use of the relationships between “appeal, intactness, and accuracy” (p. 252). In a similar manner, Reynolds (2019) focused on the importance of engaging the individual and their family at a young age so that they can embark on their life course journey, and along the way build their view of, as well as expand their advocacy skills to work toward, a quality life. Providing an occupational science view in the discussion on the revision of the existing academic curriculum demonstrates the interconnectedness of occupational participation, the environment, and the health of the students.

Pizzi and Richards’ E-HOW Model (2017) is being used in this project to center the study on the interplay between occupational participation, environment, and health. The premise of the Model is that when the three factors drive the services provided, the result will be well-being and increased quality of life. With an awareness that these three factors influence one another, occupational therapy can bring unique skills to the problem of how to incorporate occupations into the design of the curriculum being revised by the school district. Using the E-HOW Model to identify how to create structured learning experiences which are meaningful to

the students in a person-centered manner will provide experiences which are expected to result in positive long-term results and a greater quality of life and well-being for the student. The use of the E-HOW Model also supports an awareness of the importance of the Hispanic cultural values of family and a supportive community. When designing the SLE's incorporation of these contexts will be essential for long-term success.

**Occupational therapy involvement in transition planning process.** Previous research on student involvement with occupational therapy during transition planning points to inconsistent involvement. When it is provided, a positive impact is found (Eismann, Weisshaar, Capretta, Cleary, Kirby, & Persch, 2017; Gary, Sima, Inge, & Wehman, 2017; Gooch, Miller, Spence, Toland, & Pierce, 2015; Kardos & White, 2006; Mankey, 2011; Michaels & Orentlicher, 2004; Pierce, Spence, Sakemiller, LoBianco 2019 online release; Spencer, Emery, & Schneck, 2003).

Each of the researchers point to the need for additional work to be done in the area of occupational therapy's involvement with transition planning from high school to adult life. In research outside of the field of occupational therapy, it is frequently found that the barriers to success with students who are transitioning include students not having the cognitive skills, lacking real life experiences prior to leaving the supportive environment of school, having limited social skills, a lack of coordination between the services being provided, and an appropriate match between the skills of the job and the skills of the students (Bouck, 2012; Crabtree, & Demchick, 2017; Foley, Dyke, Girdler, Bourke, & Leonard, 2012; Hughes & Eisenman, 1996; Ohl, Sheff, Little, Nguyen, Paskor, & Zanjirian, 2017; Pallisera, Vila, & Fullana, 2014). Occupational therapists can provide their knowledge of contextual influence using a person-centered approach to address many of the barrier's students with moderate to severe IDD are faced with during transition planning for adult life. This study hoped to gain



input from those most intimately involved in the transition planning process for students in the West New York School District. Identification of what their barriers were and what if any cultural influence there was, was sought to discover what next steps could be taken by the school district to improve the services being provided.

**Person-centered approach.** In any effort to change an existing system, it is essential to engage the stakeholders (Bolman, & Deal, 2017; Doll, 2010). This study used participatory action research (Stringer, 2008) to reach out to the students, parents and staff who work in the classrooms of students in the creative pathway's program. Stringer's (2008) look, think, act research cycle was chosen to engage the participants to "observe ... and then reflect on their observations to clarify the nature of the research question" (p. 37) to create a collaborative and empowering environment. Stringer's active participant research approach can also be viewed as being person-centered because of its emphasis on active involvement of all of the participants and gaining their unique perspectives. Using a person-centered approach is used in many fields. The work by Flores et al. (2019) demonstrated that in education, when parent involvement was addressed using a person-centered approach, improvement in their level of engagement was improved. Research points to the benefits of using a person-centered approach, which can result in more sustained outcomes for students involved in transition services (Hagner, May, Kurtz, & Cloutier, 2014; Kaehne, & Beyer, 2013; Purvis, Zagenczyk, & Mccray, 2014; van Aar, Leijten, Orobio de Castro, Weeland, Matthys, Chhangur, & Overbeek, (2019); Wehman, Schall, McDonough, Molinelli, Riehle, Ham, & Thiss, 2012).

The literature is rich in its support of exploring ways to improve the transition process for students with disabilities as they prepare for adult life. The focus of this study has been to

specifically address the transition needs of Hispanic students, who are from a population identified as experiencing social, economic, and health disparities.

## **Section Three: Methods**

### **Initial Needs Assessment**

The results of a needs assessment conducted in the targeted public school district during the summer and fall of 2018 supported the impression of the PI that district transition services were not meeting the needs of students with moderate to severe intellectual disabilities. The needs assessment contained statements that respondents ranked for two variables. They first ranked the order of importance of each statement and, secondly, ranked their satisfaction with the programming being provided by the school district. Four statements that pertained to meaningful occupations of the students were worded in terms with which the staff were familiar. Ninety-one percent of the respondents felt that it was very important for students to be prepared for employment or meaningful activities when they turn twenty-one years old and that students and families should be involved in the planning for adult life beyond twenty-one years of age.

Satisfaction with the district's process for student and family involvement was neutral for 45% of the responses with 36% ranking this item as not satisfied. The response rate for the statement that "West New York currently has a way to identify interest areas for students to pursue in their structured learning experiences" had a low response rate compared to other questions (n=9). This may have been an indication that knowledge of how to do this was low or that the concept of meaningful occupation was foreign to the participants. Responses for satisfaction with performance on this statement were also the most scattered with a cluster of four responses for neutral, and one response for each of the other four ranking options.

Results of the needs assessment were presented to the staff in fall of 2018. At that meeting it was learned by the PI that it was the first time that the group had ever been brought together for any reason specific to the objectives of their unit. A discussion of transition

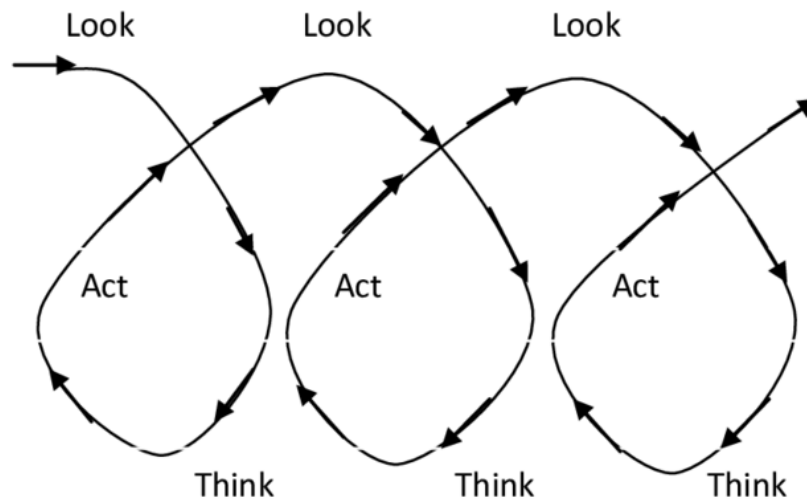
planning for their students had not been done before. Energy was expressed by the group in that they were interested in participating in making changes to the current program so that students were better prepared for adult life. As discussed by Stringer (2008), using active participatory research (PAR) is “very empowering, especially for people who have a poor self-image” (p. 35). During the meeting with the group, it was evident by their responses and enthusiasm that they viewed themselves as having little value to the school district prior to being brought together for a common purpose.

### **Project Design**

Successful incorporation of meaningful occupations into the transition planning curriculum in a school district needs to involve the stakeholders in order to create change that will be lasting. Doll (2010) expressed that outcomes that are identified by the stakeholders can lead to a sense of ownership and empowerment of the participants that will positively influence implementation of ideas they have contributed to. In addition, Bradshaw and Hultquist (2017) point out the empowerment that taking an active part in one’s learning can have on students leading to an increase in self-responsibility. Stringer (2008) speaks to the unique features of a school environment when creating an “inquiring approach to their own practices...to create a wider community of inquiry involving whole organizations” (p. 10). This capstone study was designed to include input from stakeholder groups comprised of the students, their parents, and the teachers and paraprofessional staff involved in the creative pathways program. It explored ways to identify what students in the creative pathways program found to be meaningful occupations, and how to include them into the design of the structured learning experiences. The West New York School District in New Jersey was selected for this capstone project because the PI was familiar with the existing program through working in the school district as a contracted

service provider for 15 years. A qualitative, PAR design, as described by Stringer (2008), was used to gather input from the three distinct stakeholder groups. Working within a school environment required that the selected research design be flexible enough to obtain direct outcomes without withholding services. Incorporation of the action research helix design by Stringer, (2008) allowed the PI to gather information (look, act) and analyze the data (think) without disruption of the school day. See **Figure 2** below. Staff and student participants were interviewed during their break times, rather than during the flow of their work/academic time.

Figure 2. Action Research Helix

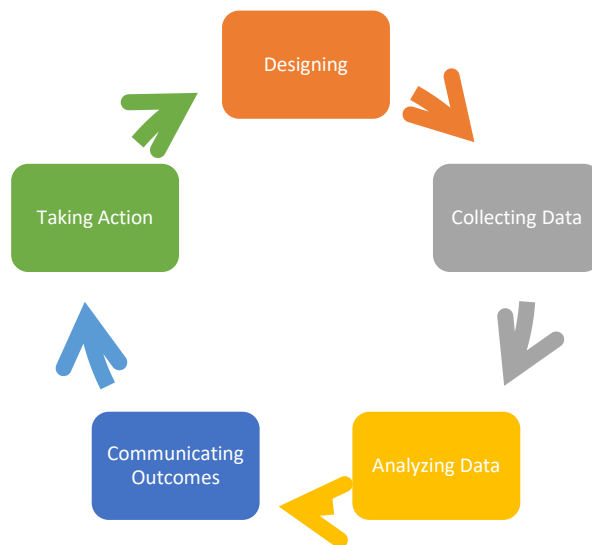


**Stringer, 2008. Adapted from *Action Research in Education*, 2<sup>nd</sup> ed., p. 4. Copyright 2008 by Merrill Prentice Hall.**

An expanded version of the look, act, think cycle began with the design of a systematic inquiry, as discussed by Stringer (2008). A democratic manner was used with the participants that empowered those involved. Developing an inquiring approach by the participants, was needed to ensure long-term involvement and commitment if there was to be transformational changes in the way things were currently being done. Recognizing that there had been a recent

expansion of the number of students in the school who participated in the special education programming for students with moderate to severe intellectual disabilities was important as this could be considered a program in its early stages. Stringer also cites the benefit of action research as fostering “effective and productive relationships” (2008, p. 27) between the participants, which was particularly important for this newly forming team of teaching staff. As mentioned above, this group was not familiar with each other and had not worked together before the needs assessment was conducted.

Figure 3. Action Research Cycle



**Stringer, 2008, Adapted from *Action Research in Education* 2<sup>nd</sup> ed., p.5. Copyright 2008 by Merrill Prentice Hall.**

The results of the initial needs assessment described above confirmed that the current curriculum was not meeting the needs of the students. As a result, the district was also not meeting the state mandates for levels of performance in including student interests in the transition planning and in attaining the expected outcomes for young adults post high school graduation (New Jersey Department of Education, 2018).

This capstone project followed the action research cycle as seen in Figure 2 of the Action Research Cycle described by Stringer (2008) to produce the study design. The information from the completed needs assessment and an initial review of the literature were used to identify an effective process of research that would have a positive impact on the studied practices. Information from the initial literature review, the results of the needs assessment, and the PI's Institutional Review Board (IRB) proposal was brought to the Superintendent of the WNY school district through meetings with the Assistant Superintendent of Curriculum. The PI had worked with this individual for many years, developing mutual respect through collaborative efforts. The importance of strong collaborative partnerships in designing meaningful programs is discussed by Doll (2010). Approval for submission of the proposal for IRB review required multiple revisions by the PI, since the school district placed a number of restrictions on what could be done and when. Audio or video taping of any of the participants was not permitted. All interviews needed to be done outside of academic time for the students or work time for the staff and completed by the end of the 2018-2019 school year. All materials needed to be translated into Spanish. In addition, interviews could not be conducted on a day when the PI was providing contracted services within the district. Breaks for the staff are fifteen minutes long and occur during pre-set times. Student's break time in the high school occurs after they have finished their lunch.

Tickle-Degnen (2014) speaks about the importance of being able to effectively communicate with those in a position of decision-making in order to present the need for research in a manner which meets the needs of the person(s) in the position of power. The feedback from staff in the needs assessment regarding the connection between the state mandates and the proposed research pointed to the district's mission statement, which is "maximizing all

students' potential in an ever changing world" (West New York, 2019). This tie to the mission statement of the district was used to gain approval from the senior administration for this capstone project. The design with amendments by senior administration was submitted for IRB approval in January 2019, and was approved in the same month. The materials were all translated into Spanish by an individual fluent in written and spoken English and Spanish, in preparation for the data collection phase of the action research cycle.

Use of the Action Research Cycle (Stringer, 2008) compliments the occupational therapy E-HOW Model (Pizzi & Richards 2017) that grounds this research. The proposed outcome of this action research study was to improve the quality of the transition planning process for students with moderate to severe IDD by incorporating meaningful occupations within their structured learning experiences. Improving quality of life and well-being is also the desired outcome of the E-HOW Model as seen in Figure 3. The action research cycle incorporates the occupational participation described in the E-HOW Model, for all three groups of participants. The students' desires, what their parent's hopes and dreams might be, along with the experiences and ideas of the staff were explored in this study. The contextual influences of the Hispanic culture of the participants, the logistical semantics of the school and the community where the structured learning experiences might take place, and the social connections between the participants address the environment portion of the model. Health as depicted in the E-HOW Model was applied to this research endeavor as the current level of quality of life being created through the existing transition planning process provided by the school district from the perspectives of each of the participants.



## **Setting**

The study took place in Memorial High School in West New York, New Jersey. Using the school building during the school day offered easy access to gather input from both the students and the teaching staff. Involvement by parents was planned via their participation in a survey in the form of a questionnaire. It would have been inconvenient for parents to make time during the work day to participate in face-to face interviews, and the logistics of having a place to meet with the parents and the school policies for visitors in the school made in-person participation by this group unrealistic. A stronger participation of parents seemed more likely through use of questionnaires sent to the home. However as discussed below, this did not prove successful.

The PI contacted the Principal of the High School for approval to perform this capstone project on the school premises. He was informed that senior administration was supportive. Permission was granted and a room was reserved on a different floor from the creative pathway's program classrooms for days when the interviews were to occur so that privacy was ensured.

## **Recruitment Procedures**

Recruitment flyers in Spanish were sent home to parents of the students who met the criteria as potential participants. These can be found in Appendices C and D. Students attend the school daily through 21 years of age, and were available for their involvement in the study during the school day. The flyers met the IRB requirements and stated the purpose of the study, and the facts that no more than minimal risk was involved, participation was voluntary, no incentives were offered, and there were no negative consequences for those who did not participate in the study. All students in the program communicate in English even if their households are bilingual or monolingual Spanish. Many of the families are first generation

immigrants and speak only Spanish at home. West New York is an urban town of just over 50,000 people within one square mile. Seventy-eight percent of the town's people self-identify as having a Hispanic background, 12% self-identify as White, non-Hispanic and 6% as of Asian background (DATAUSA, n.d). Forms for the parents included the permission form for their child and consent forms for parent participation. Forms were provided in the primary language of the potential participant. They can be viewed in Appendices E and F. The forms were all worded at a fourth grade (Cutilli, 2006).

The pool of potential participants for the staff was expanded from the teaching staff who were initially involved in the needs assessment survey. Participation was opened to each of the support staff involved in the classrooms within the creative pathway's program. The participant pool included teachers as well as paraprofessionals. There was a total of seven classrooms with approximately twenty total staff members when the proposal went to the IRB committee for approval. Potential staff participants were informed of the research through flyers in both English and Spanish in the rooms of the school that they frequent as well as through emails sent to them by the PI. Flyers explained the purpose of the study and the inclusion/exclusion criteria for participants. These forms are found in Appendices C and D.

The staff and the students were considered a vulnerable population because the study took place at the employment and academic location for the potential participants. Information provided to the staff contained the purpose of the research as well as the statements that there would be no identifying information collected about the participants, that they could discontinue participation at any time, and that participation was voluntary with no impact on the person's job if anyone chose not to participate. No incentives were offered for participation in the study.

## **Inclusion and Exclusion Criteria**

Students who met the criteria of the study were those who attend the creative pathway's program. By virtue of their special education classification to participate in the creative pathway's program, students met the moderate to severe intellectual disabilities criteria for this study.

Inclusion criteria for students was:

- Parents have provided permission for student participation
- Provide assent
- Attend the creative pathway's program
- At least 14 years old
- Able to communicate with responses which reflect original thoughts. Use of an augmentative communication device would be acceptable if the student was able to create original thoughts.

Inclusion criteria for parent/guardians were:

- Able to read in Spanish or English at a fourth-grade level;
- Have a student currently attending the creative pathway's program who is 14 years or older
- Provide consent.

Inclusion criteria for staff were:

- Provide consent;
- Be able to participate in an interview in English;

- Currently involved in working in one of the classes in the creative pathway's program.

## **Implementation**

Following Stringer's (2008) approach, once all of the materials were translated into Spanish, the PI moved on to collecting data by posting the recruitment flyers for staff and sending additional flyers home to the parents of students in the creative pathway's program who met the criteria of the study. It was determined that two of the students were not able to create original thoughts and were therefore excluded. The potential student pool dropped from thirty-two to thirty. The research study had planned to target three groups of stakeholders; students, staff, and parents.

No responses were received from the families. The PI was able to approach some of the parents in person during an evening fundraiser for the creative pathway's program. Forms were provided in Spanish to two parents who expressed interest in participating, however, subsequent follow-up with the parents did not result in consent forms being returned for either those parents or their students.

Consent to participate from three staff occurred with follow-up by the PI asking whether staff had received the invitation, asking whether individuals had any questions, and whether they were interested in participating. During the spring of 2019, the potential pool of twenty-one staff members was reduced to a potential pool of fifteen as one of the classrooms was disbanded and staff were reassigned elsewhere in the district. Another teacher resigned and one additional staff member did not understand English well enough to be interviewed. The three staff participants resulted in a response rate of twenty percent of the potential pool of participants.

During discussions with staff, it was learned that there was a student who had just turned 21 years old and was his own guardian. As he did not require parental permission, he was approached, and the purpose of the study was explained to him in terms which he could understand. At his request, he was read the consent form by the PI and he signed the consent to participate. The four participants interviewed were scheduled to be seen twice and each one selected an alias so that there could be collection of information from the two interviews, assignment of follow-up input with the initial interview, and the coding of data.

### **Analysis of Collected Data**

Analysis was completed with the data that was gathered from the participants. Data gathering was done through direct interviews by the PI with the participants on two occasions. Interviews with the student and staff participants was conducted using probe questions for each group. The probe question samples can be found in Appendix G for staff and Appendix H for students. Member checking was done at the start of the second interview. Data was reviewed multiple times to identify common threads and thematic coding as described by Creswell, (2014) and Stringer, (2008). More detailed analysis is discussed in the Results section of this paper.

### **Staff Collaboration**

Upon completion of the data analysis, the next stage in Stringer's action research cycle was to communicate outcomes to the group of staff for discussion. In the summer of 2019, the principal of the high school changed. The PI met with the incoming principal and reviewed the research project that had previously been approved by the senior administration. The PI requested a meeting with the staff of the creative pathway's program was requested to discuss with them the results of the data gathered so that member checking could be done. This meeting also provided an opportunity for additional input from the group which included new members

bringing in a fresh perspective. Exploration of the data was facilitated by the PI in order to identify further reflections from the group and the subsequent action to be taken by the group. The meeting took place in September 2019 after school was in session and occurred during a designated professional learning session afternoon.

Taking action, completed the initial full cycle of Stringer's action research cycle when the staff discussed the results of the data that was gathered and coded, and reflected on the results. Identifying the next steps and priorities with the staff also occurred during the discussion. The result of the meeting are discussed in detail under Results in this report and minutes of the meeting are found in Appendix I. The meeting was a collective group of the staff who are involved in the creative pathway's program regardless of whether or not they had participated in the interviews. Data results were shared, and discussion with the participants focused on obtaining member checking and identification of what the group felt the next steps needed to be. The group then prioritized the steps and identified items they felt they could complete immediately and without additional authorization. The group demonstrated that there was a new sense of empowerment as they were able to list what they felt were attainable steps without needing approval from administration.

The meeting with the staff marked the formal ending of this capstone project. The start of the second loop of Stringer's action research helix has begun, with the designing of how to implement the steps selected by the group. The Assistant Superintendent of Curriculum has formed a committee to start working on revising the existing curriculum. The PI has been assigned to participate in the curriculum committee as well as working with the Supervisor of Special Education to design a parent advocacy group for the school district. These will be discussed in more detail in the section on future projects. As in Stringer's model, the cycle will

continue to drive changes in the delivery of transition services for the students through the knowledge gained by this preliminary research.

In the qualitative design of this capstone project, as discussed by Creswell (2006), the PI was in the role of interpreting the information gathered from the participants and engaged in an ongoing literature review in an effort to answer the following research questions.

- How can student interests be identified?
- How can the identified interests be used to create individualized and meaningful structured learning experiences?
- What is an effective method for incorporating the identification of students' interests into the curriculum design?

### **Methods of Data Interpretation**

There were two different methods used to gather information from the stakeholder groups during the first round of data collection. Face to face interviews were conducted individually with the student and the staff members by the PI. The duration of the interviews were approximately 20 minutes long and there were follow-up interviews. As discussed by Stringer (2008) when conducting action research, multiple interviews should be used in order to maximize the participant's opportunity for providing their perspective for the topic of the study. In order to gather information on how to identify what activities were meaningful for the student, and how to incorporate them into the structured learning experiences, the student and the staff were given time to reflect on their input from the first interview. They then had another opportunity to provide added thoughts through a second interview at least one week later. Inquiries were in the form of probe questions, as discussed by Creswell (2014) and Stringer (2008), in order to create an open and unstructured opportunity for the sharing of personal ideas.

The probe questions as well as the survey questions that were to be sent to the parents were designed at a reading/comprehension level of below 4<sup>th</sup> grade, as recommended by Cutilli (2006). Sample probe questions for both staff and students can be found in Appendix B and C.

As discussed earlier, the study took place in an urban setting comprised predominantly of first generation minorities to the United States. Doak, Doak, and Root (1996) “as cited in Cutilli, 2006) found that with inner-city minorities, “two out of five read below a 5th grade level” (p. 372). The student participant in the creative pathway’s program had an elementary school level of reading and comprehension. While many of the paraprofessional staff and parents have a high school level of education, a number of them graduated in non-English speaking countries where the curriculum was not the equivalent of that found in the United States (Cray, 2007; Cray, 2009; Yomtov, 2019).

Interviews were not audio or videotaped as requested by the school district’s administration. In lieu of audio-recording, the PI captured responses in writing to the degree possible without losing the continuity of an interview. Information was categorized and coded for the discovery of themes. Participant’s self-selected alias, so that field notes of interviews could be tracked between the two interview sessions. In addition, the PI maintained a journal during the interviewing process to add additional reflection on the perspectives of the participants as well as the reflections of the PI who is also the treating occupational therapist at the high school. The results of the study were reported in an aggregate format to the participants. The expanded group of stakeholders, which includes the Assistant Superintendent of Special Services and the Assistant Superintendent of Curriculum will receive the full report by the end of the calendar year 2019. Analysis of the data gathered has been strengthened through the use of a number of strategies as recommended by Cresswell (2014) and Stringer (2008). Information



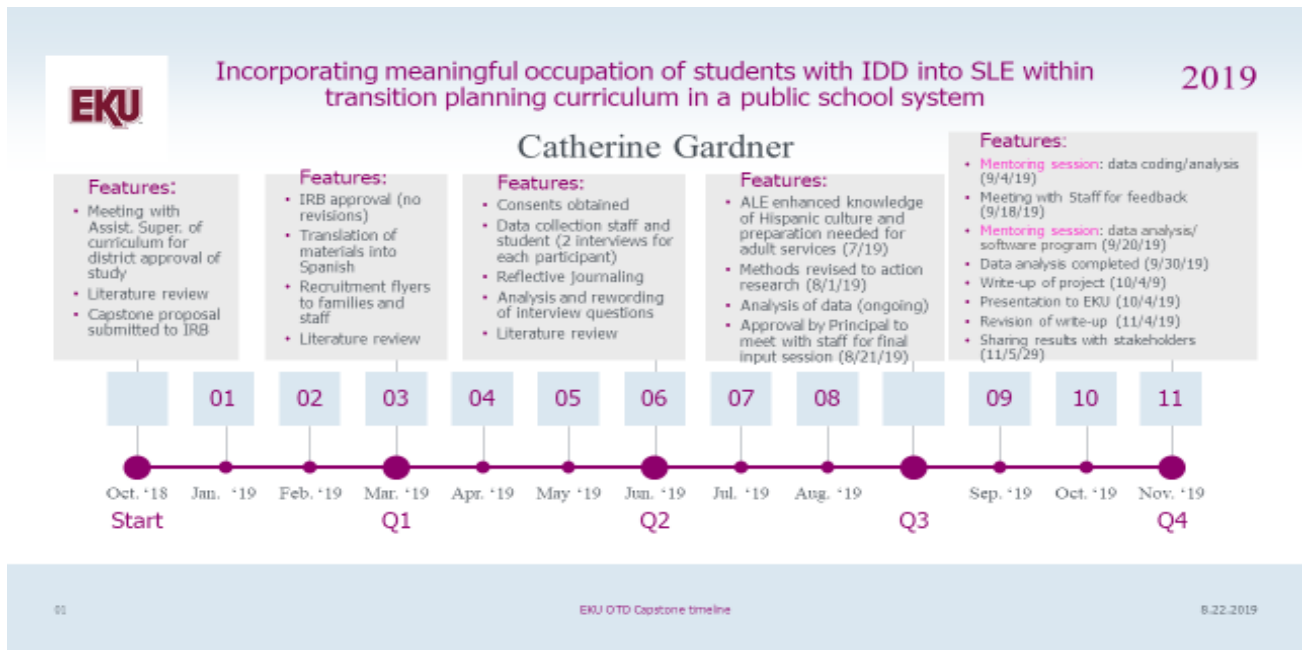
from the two groups of stakeholders was triangulated to gather both of their perspectives and to identify whether there were common themes within the data. Member checking was done following the first and second interviews with the student and staff participants, to ensure that there had been accurate capturing of their information. It was done again with the larger group of staff members during the September 2019 meeting of all staff in the creative pathway's program. Information acquired through an ongoing literature review by the PI complimented the repeated review of the raw data along with peer review with the committee from Eastern Kentucky University (EKU).

The PI has spent over ten years with many of the stakeholders as a result of involvement with the school district as a contracted provider, which adds to the strength of the research relationships with the students and the staff. This relationship also carries with it a potential for bias by the PI since this study is grounded in her desire to support improvements in the district's transition planning services for the students in the creative pathway's program. To address this bias, the data was reviewed by the PI as well as two ECU faculty advisors who provided peer debriefing and feedback from impartial advisors with strong backgrounds in research.

### **Project Time Line**

This capstone project followed the timeline depicted in Figure 4 below. It includes the various points covered as well as the dates of completion. The capstone project began in October 2018 immediately following the completion of the needs assessment done in the summer of 2018.

Figure 4. Gardner Capstone Project Timeline



As seen in **Figure 4** above, approval by the Eastern Kentucky IRB and the Board of Education for the West New York School District, was obtained in the winter of 2019. Materials were translated into Spanish by an individual who is fluent in both English and Spanish languages; both written and spoken. Interviews were set up with the staff and the student by mid-April and were completed by the middle of June 2019. Data from the interviews of the participants was analyzed repeatedly over the summer of 2019.

As a result of the probable influence of a cultural component to the low response by potential participants, especially those of the parents, this became an area of focus for the PI. In studies by Sanchez-Birkhead et al (2011), and Shedlin, et al. (2009) it was found that factors such as the lack of a social support system, stigmas, discrimination, fear of “the system” and the current political environment prevented many from the Hispanic community from participating even when it is for their own health and benefit. The E-HOW Model incorporates the importance of culture as part of the environment sphere (Figure 1), therefore the PI pursued the

recommendation of Wells (2014) in acquiring a deeper level of cultural knowledge through her applied leadership experience during the summer of 2019.

The analysis of the data gathered was completed in the early fall of 2019. A literature review continued during the summer, and into the fall of 2019 as part of the ongoing extending of understanding of the topic being studied by the PI. Searches were opened to include immigrant participation, Hispanic immigrants, and education of Hispanic students.

This added appreciation for the culture could not be used to benefit the interviewing process due to the requirement to end it by the end of the school year, however the knowledge gained was valuable in helping the PI when reviewing the data gathered and facilitating the discussion to identify next steps and priorities during the meeting with staff in the fall of 2019.

The second cycle of data gathering done in the fall of 2019 was expanded, and included all staff involved in the creative pathways program including new staff. Analysis of first round data collection was shared with the group in aggregate format for their feedback as well as to facilitate discussion of what the next steps should be with regard to the knowledge learned.

The final report completion date of mid-fall 2019 was set so that the results could be communicated to the administrative stakeholders in the school district by the end of calendar year 2019. During the winter and spring of 2020, options for sharing of the study findings through publication and/or presentation within professional arenas will be identified and pursued. The data will be transferred to the ECU advisor by May 2020. Upon the ending of the IRB approval timeframe which is May 2020, the raw data from the study will be disposed of in a secure manner.

## **Outcomes Measures**

The overarching outcome to be achieved by this capstone project was to incorporate meaningful occupations into the revision of academic curriculum for the creative pathway's program in the West New York school district. Improving the quality of life for students transitioning to adult life by creating structured learning experiences based upon student's areas of interest is the desired outcome. The achievement of the three objectives of this capstone project reflects progress made towards this outcome. A secondary outcome that may be seen in the future is increased satisfaction by the staff regarding the programming that they are providing within the creative pathway's program. Personal satisfaction in a job well done along with a sense of empowerment in seeking to make changes based upon new knowledge is now a possibility. Improved student and parent satisfaction with their participation and knowledge about the transition planning process is within sight. The selection of structured learning experiences based upon individualized meaningful occupations of the students and changes in the districts scores on the Local District Special Education Public Report within the next two years are also examples of potential long-term outcomes that may result from this study.

An active participant research approach was selected in order to gather information which would enable practical application to a specific problem (Stringer, 2008). In the process of this journey using the E-HOW Model, it became evident that the importance of cultural influence needed to be incorporated into the project. As a result of this reflection, the objectives of this capstone project were expanded:

1. How can student interests be identified?

*Outcome measure*

- Input from the stakeholders of the creative pathway's program (staff, and students who are in the program) identified ways to capture student interests.
  - Review of best practices identified models that can be used to capture input from all stakeholders and is person-centered.
2. How can the identified interests be used to create individualized and meaningful structured learning experiences?

*Outcome measure*

- Literature review and review of best practices has identified models that would create individualized and meaningful SLE's.
- Participants have expressed ways in which they feel that personal interests of students can be used to create structured learning experiences for students.

3. What is an effective method for incorporating the identification of students' interests into the curriculum design?

*Outcome measure*

- Identification of specific ways in which identifying and gathering of student interests can be incorporated into the curriculum being revised concurrent with this study.
- Adoption of using a person-centered approach by the school district will embed what is meaningful into the design of individualized plans for students.

Added objective:

4. How can parent involvement in the transition planning process be increased?

### *Outcome measure*

- Strategies from the participants are built into the transition planning process to engage parents in the process.
- Literature review and review of best practices has identified models that would incorporate parental involvement into the transition planning process.

### **Ethical Considerations**

The primary area for ethical consideration in this study was identified as being able to maintain confidentiality of the participants in the study. This included conducting the interviews in a private location so that participants felt safe and were willing to share their perspectives. In addition, keeping confidential the input that was shared by the participants when speaking with those not involved in the study was paramount to ensure that the data could not be traced back to any particular participant. This became particularly challenging with a small number of participants. Each of the participants self-selected an alias to use during the first and second interview, which allowed for their input to be linked but did not expose them to a risk for breach of confidentiality.

Other strategies to safeguard the integrity of this study included keeping the data in a secure off-site location at the PI's private office. Information shared with the ECU advisory faculty was done using Drop Box which offers multiple levels of security of the data being shared through their system (Drop Box, 2018).

## **Section Four: Results and Discussion**

### **Description of Results**

The data generated through this active participant qualitative capstone project was gathered through interviews with students and staff in the spring of 2019 and through a meeting with the entire staff involved in the creative pathway's program for students with intellectual and developmental disabilities in the high school. The meeting took place at the start of the school year, September 2019 and was the final portion of this capstone project. The study design anticipated that input would also be gathered through parental responses to surveys, however despite multiple attempts to gain consent from parents there was no one who agreed to participate.

Consent to participate was given by three staff members and one student who had reached the age of consent and was his own legal guardian. Individual interviews were conducted with each of the participants. Interviews were conducted in the high school in a private room assigned for the purpose of the study. Participants were interviewed during their break time which is fifteen minutes long. Each participant was offered two interview times to allow for time to reflect between them to allow for member checking to strengthen the validity of the input. The time between interviews ranged from four days to twenty days. At the start of the second interview, one of the participants declined to add anything stating, "I think I pretty much told you everything the last time; I can't think of anything else to say". A total of seven interviews were conducted.

### **Interpretation of Interview Results**

The data was reviewed multiple times by the PI and subsequently coded to identify repeating themes in the responses of the participants. The coding was also reviewed by the PI's

capstone committee members for input providing peer review. Six themes emerged that were relevant to the focus of the study to identify what meaningful occupations were to the students and how they could be incorporated into the selection of the structured learning experiences (SLE) and the school's curriculum. Each of these themes will be explored in detail: parent involvement, the level of support for students, the value of the SLE, role that life skills activities play in preparing for the SLE, level of knowledge of the requirements of transition planning process, and the level of involvement of the paraprofessionals.

**Parent involvement.** Parent involvement was described by the participants as being an area of great importance and concern. The probe interview questions were semi-structured to encourage participants to expand and provide additional information on what they felt was relevant. The staff interview had four questions which specifically asked about parent input or involvement while the student interview had one question specifically asking about parent involvement. Staff and student participants made comments about parents a total of twenty-three times. Both groups felt that parents needed to be more involved in the transition process in general, as well as during discussion of the selection of SLE's that would be meaningful to the student. Comments expressed also included concern that the parents are unaware of what needs to happen during the transition planning years, and the possibility that parents have limited expectations for their children that restricts choices for opportunities through SLE's thus limiting a vision for the future by students and their families. Both student and staff participants discussed a belief that parents view education and opportunities for working through a culturally influenced lens.

*I would like to see more [parent involvement]. . . If we had an open classroom*

*2-3 times a year it would be good. . . The parents could see the progression of*



*changes. . . Having the parents in the classrooms to view the progress [would help them see what the students can do]. . . We need communication and interaction with the parents. . . Times that are perfect times for them. . . There is not as much parent involvement as we would like. . . I think parents at the IEP meetings discussed the SLE and goals (Mary, June 6, 2019).*

One of the participants self-identifying as Barbara Streisand felt that the parents had valuable information that was not being shared with the school regarding SLE's.

*Absolutely!. . . Finding what is around their homes, notes home to parents – volunteering [opportunities for the students]. . . Parents may have ideas of where they want the SLE to be. . . Honestly, . . they may tell us information about the student from their behaviors to tasks the student can or can not do. . . It could be very helpful (June 3, 2019).*

Code Blue offered ideas on how to better include parent input by stating “*Add parent input into the IEP meetings; [get them] involved in the selection of sites and offer suggestions for considering what may be too much, and to table until they are ready*” (May 20, 2019).

The participant Barbara Streisand also expressed the need for education with the family on the transition process sharing;

*Family input- We should talk more than at the IEP meetings. . . There should*

*be more things for parents, to explain transition better; maybe a family day on the weekend of resources for a small window of time- say 2 hours”*

(June 3, 2019).

A student participant expressed his view of parent participation as having both positive and negative influence.

*Yes, but sometimes no. . . Some parents want students in their [family] business but students don't want to do that. . . If the child wants their parents to pick; sometimes parents don't want the child to do things. . . We could do video's of students doing things to show the parents, some parents think the child is a little kid and don't trust/believe the kids when they say they do things. . . Parents don't know different state rules, or the different country rules. It might make it hard for parents to help kids. . . Parents are overprotective.*

(Jay, May 7, 2019).

**Level of student supports.** The second theme regarded the level of support which students were getting in preparing for, selecting SLE's, and being supported while doing them. Staff and student responses indicated that efforts were being made but that without a formal curriculum in place the benefit to students was questioned by both groups. Between the interview questions for staff and students, there were twelve probe questions pertaining to ways in which the students are prepared for their SLE's, whether the students are involved in the process of selecting them, and how they are supported while they are there. Comments by the

participants indicated that communication of who and how selection of SLE's were made was not clear. Thirty-five responses were coded that pertained to support of the student for their SLE.

A staff participant, with the alias name of Mary, identified that there was some communication regarding selecting SLE's when particular students are in mind.

*We do what we hear from guidance [counselors] at the end of the school year.*

*They give them options for classes the following year. . . From what I've seen, information from the adults, observations and what students tell the adults; they communicate with each other. . . Teachers need more differentiated instruction for the students. . . Students are at many levels. . . There are voids while waiting for the teacher, if they had work prepared for the paras they could keep working.*

(June 6, 2019).

Code Blue felt that the students were being provided with some support however, there was limited structure with how it was being carried out.

*The teacher puts students where she thinks they will do best. . . students do have some selection. . . Ahh, it's tough to gauge if the student does or doesn't know some things till you try and then you run through practices. . . I find that through the CBI's and. . . the classroom stuff prepares the students for their SLE's. . . During the SLE's they try something, job sampling, conversations with students and gauge their interests in the work they are doing. . . Input from the student is needed, and good communication, to*

*be really successful. . . Really, input for the SLE, this is a positive thing for the students (May 20, 2019).*

Participant Jay felt that support for students was present for the formal SLE experience but was insufficient in other areas such as life skills:

*Actually, not really. . . The teachers tell us what to do and we do it. . . Yes, we had 3 choices last year. . . Yes, I would like to pick out my own SLE. . . Actually it Does. . . If I have a choice, yes. . . I want to help my family and I want to help myself too. . . I know it sounds selfish, but I want to travel the world. . . Yes, the teachers help to know how to get a good job. . . If students don't want the choices, they should be able to pick others. . . I want to move out and make my own family. . . I want to be a family man with a wife, and kids. . . I know it sounds crazy, right?. . . I am the only family person who wants a wife and Kids. . . I want to be a father and raise a daughter or son. . . If college doesn't work out, I am planning on working a regular job or going to a training School. . . I want to be a plumber but there is a lot of math (May 7, 2019).*

In response to the question on whether more help from staff would help students prepare for adult life, Jay commented that:

*For me, teachers should ask you; like do you have skills that you are good at?. . . Teachers should support you. . . Teachers need to pay attention to the students, so that it*

*is better for the students. . . I want to learn how to pay bills and to do construction (make tables) and home repairs. . . I want to fix my toilet if it breaks or change the lightbulb. It costs a lot to do this, so I want to do this myself. . . In today's world you pay bills on the internet & I want to figure out how to do the math to pay rent. . . Let students make their choice and work 1:1 with students to do it. . . I want to be more helpful with building things, laundry, cooking, banking, personal finance, taxes, stuff like that. (May 7 and May 20, 2019).*

Staff participant Barbara Streisand reflected on how student's interests' are included in the process of the selection of the SLE's.

*I'll ask the person who's in charge what needs to happen [potential sites]. . . We go over the skills prior and then they go. . . Yes. . . Besides picture things by the CST [child study team], and then your thing [PI uses R-FVII-2] and mine is verbally. . . I have tried trying things in the library and a couple of teachers responded with ideas for jobs in school (June 3, 2019).*

Barbara spoke to what the students view as being their future and the connection to skills that need to be covered in school. She commented on discussions held with students about future living arrangements for them.

*You ask the students, and they say they will live with their parents their whole life. . . It's a cultural thing. . . Students need the real life situations and in-school jobs. . . Also bring in speakers from the community and have them built into the*

*curriculum design. . . We have a big school; there are more staff that we could draw from. . . Ninth and 10<sup>th</sup> grade should be in-house for the CBI/SLE to start small.*

(June 3, 2019).

This participant identified that preparation of the students needed to begin in middle school to provide them with adequate time for the learning of some skills.

*It might be nice to have ideas of what is needed from the middle school to the high school. . . I feel like we've wasted a lot of years without a curriculum in place. . . We need to know what is expected at the different levels for the students. . . Having a curriculum which gives a plan for what is expected from the middle school grades through the high school grades would be very helpful (Barbara Streisand, June 10, 2019).*

**Value of the SLEs.** The third theme that was identified through the coding was the value which participants found through the SLE's. The use of SLE's at the school had only been in place for the last few years so they are still quite new for the staff and students. Despite the concerns over there being a lack of a curriculum to guide them and funding to support the curriculum, all the participants found the SLE's to be positive experiences for both staff and students. Nine interview probe questions involved performance of and the belief of value in the SLE's. Twenty-one comments were made discussing the value that the participants found in student's participation in SLE's.

*Some parents are not interested; maybe now since they are in school. . . Without a budget for CBI to prepare for the SLE's. . . We need money to take the students. . .*

*Now it comes from the teachers and the parents (Barbara Streisand, June 10, 2019).*

Participant Mary identified the personal growth and maturity of students that were involved in the SLE experience.

*Students on their SLE; I see a change in their maturity, they are more grown, they feel increased confidence and self-esteem and they have increased social skills. . . Feeling a sense of accomplishment, increased explaining what they are doing. . . There is a different focus, mindset, and they concentrate for more periods of time (June 6, 2019)*

A feeling of increased self-esteem and confidence was expressed by participant Jay as he discussed the SLE experience.

*I am really good with people and help them feel better so I chose [nearby senior center]. . . I worked there for two years. . . Well, I like the people, the workers are great. . . I like playing games with the older people. . . I like to help them with the cell phones, how to help open them, the passwords for their phones, something like that. . . Doing it [SLE] every day helps me (May 7, 2019).*

Participant Code Blue found that the SLE experiences were rewarding for both the students and the staff who are assigned with the students. Comments reflective of staff feeling valued through their role of assisting the students was expressed along with the observation of accomplishment which is seen in the student's growth at the sites.

*This is my second year doing it. . . There are very positive things coming from the*

*SLE's. . . To be able to interact, and be with the student to see what they are capable of and to see skills transfer over is good. . . I have yet to experience something negative with any part of the SLE. . . Yes, a lot seem interested; certain activities not as much as others. . . Students go in, greet the manager and go into "work mode". You don't need to force them to do this. . . I've seen conversations that are positive with the students, and their demeanor, and work performance improves. . . The SLE's are great for gathering positive experiences and are a positive reinforcement with big impact on the students. . . Yeah, a difference with SLE is they are ready to take more responsibilities, more mature (May 20, 2019).*

This participant also spoke about the impact that the SLE has on students who have not yet started them. He identified that knowing that the SLE comes after academic classroom work was highly motivating to the younger students who were seeing older students going out to work.

*It is day and night with those who are not on an SLE. . . It motivates those not on an SLE to behave differently to get excited for it. . . My job is to help prepare them for the SLE and to encourage them. . . They are nervous at the beginning but then they start seeing positive examples of what they can do. . . The older students act as mentors; they say what they like or don't like about work to help the younger ones. . . There was a student who was mentoring another student on the work site and was very positive in helping the younger*



*student to be comfortable. . . It helps them with their speaking skills too*

(Code Blue, May 20, 2019).

**Life skills.** The importance of incorporating life skills activities and training within the curriculum was identified as the fourth theme with the participant responses. In studies by Bouck (2012), Campbell (2017), and Hughes and Eisenman (1996), life skills/training was needed for students with IDD to be able to make the connections between academic skills and application of them into real life experiences. In this capstone project, there were nine interview questions that provided opportunities for participants to discuss life skills experiences for the students. Seventeen responses were coded as referencing the connection of life skills training to student preparation for adult life. Participants identified the need for including more real life or life skills training. Mary stated, “*We need more individualized learning for the students*” (June 6, 2019). Barbara Streisand also commented on this factor.

*Rather than two life skills, and current events, if we had community and vocational-technical training that would be good. . . Students need the real life Situations. . . In-school jobs. . . Also bring in speakers from the community and have them built into the curriculum design. . . Change the academic outcomes; change the goals and do core academics in the am and then in the pm’s [afternoon] use it for life prep work. . . Then in the pm’s for the individual students needs and not with a one size fits all. . . We could create for language arts class a “book” of speakers with job tasks. . . Connect them with pictures*

*with the person speaking so that the students can see the reality of the job.*

*Parents. . . give them homework assignments; for example to do laundry*

*on the weekend. . . Carryover at home is important. . . We need feedback from*

*the families on what they want the students to be able to do at home (June 10, 2019).*

Participant Jay expressed areas of life skills which were helpful as well as areas which he would have liked to have had.

*I want to help my family and I want to help myself too. . . I know it sounds selfish,*

*but I want to travel the world. . . I want to move out and make my own family. . .*

*want to be a family man with a wife, and kids. . . I know it sounds crazy, right?*

*I am the only family person who wants a wife and kids. I want to be a father*

*and raise a daughter or son. If college doesn't work out, I am planning on*

*working a regular job or going to a training school. I want to be a plumber. . .*

*I want to learn how to pay bills and to do construction (make tables) and home*

*repairs. . . I want to fix my toilet if it breaks, or change the lightbulb. . . It costs*

*a lot to do this so I want to do this myself. . . In today's world you pay bills on*

*the internet & I want to figure out how to do the math to pay rent. . . Pasta night*

*[I learned to be] great at being an experienced waiter. . . I want to be more*

*helpful with building things, laundry, cooking, banking. . . Personal finance,*

*taxes. . . Following the law and be comfortable to vote. (May 7, 2019).*

One of the participants made connections between student preparation for SLE's and their opportunities for participation in life skills in the classroom.

*During the SLE's they try something, job sampling, conversations with students and gauge their interests in the work they are doing. . . The lessons and everything taught through the life skills class are very geared for life out of the classroom and life in general and that translates to jobs for the students. . . Play out scenarios to tell better what to do and to help them improve (Code Blue, May 20, 2019).*

**Transition planning knowledge.** The fifth theme that was identified involved the level of knowledge that staff had about the transition planning process. Understanding what the process entailed, who was responsible for doing what, and at what age level was brought up by the majority of the interviewees. Responses conveyed an element of concern that students were not being properly prepared by the rather dated curriculum. There were no probe questions included to discuss this topic, however in their responses to questions regarding how the SLE's are designed and whether students are being prepared for adult life, staff responded with concerns with needing an actual curriculum and knowledge of what should be happening and along what timelines.

Eighteen responses involved questions about the transition planning process in general, curriculum design, and knowledge of either staff or family's in understanding the transition planning process. Input from the interviewees revealed that staff are not familiar with the timelines and the requirements of the transition process and they are looking for more

communication between middle school and high school staff on the planning needed. Staff and student input indicated that parents do not have an understanding of what to expect, have low expectations of students, or are not interested in opportunities available. Parents were perceived to be making decisions for students who wanted to make them for themselves, which is counter to transition planning as supporting students to become more independent as young adults.

Child Study Team (CST) members were viewed as not seeming to know what the process was or what the timelines are. Inconsistent approaches involved in the process were identified as well, further adding to confusion of the teaching staff. One of the participants, Barbara Streisand, commented that “*CST [involvement] is inconsistent now*” (June 6, 2019). The student viewed transition as what they do on their way out the door in his last year of school; not a multi-year process in which he had a say.

Participants were asked how the transition planning process is implemented with the students. Barbara Streisand’s responses indicated that the transition planning process is not handled in an organized manner or that the parents and student are an active part of the process.

*Besides picture things by the CST, and then your thing [assessments used by the occupational therapist]; mine is verbal. . . I have tried trying things in the library and a couple of teachers responded with ideas for jobs in school. . .*

*Sending home information by the ages of what needs to happen when would Help. . . we should talk more [with families] than at the IEP meetings. . .*

*There should be more things for parents, to explain transition better; maybe a family day on the weekend of resources for a small window of time- say two hours (Barbara Streisand, June 3, 2019).*

This participant also identified that there was a strong connection between knowing what, and how, to do good transition planning and having a curriculum to follow.

*I feel like as many years as I've been here there's been no curriculum. . . It might be nice to have ideas what is needed from the middle school to the high school. . . I feel like we've wasted a lot of years without a curriculum in place. . . We need to know what is expected at the different levels for the students. . . There used to be a budget, not now; this is part of the curriculum, we shouldn't need to be paying for this ourselves. . . having a curriculum which gives a plan for what is expected from the middle school grades through the high school grades would be very helpful (Barbara Streisand, June 10, 2019).*

In a similar manner, Barbara identified that parents would benefit from more information on what to expect for their child as they go through the transition planning process. “*Sending home information by the ages of what needs to happen when would be helpful*” (June 3, 2019).

One of the other participants stated that “*we need more individualized learning for the students. . . Teachers need more differentiated instruction for the students. Students are at many levels*” (Mary, June 6, 2019). A third participant expressed the need for parents to be more involved in the transition planning process because they would have valuable information about the student.

*Honestly, it may be helpful if parents are involved and given information on how the students are performing, they may tell us information about the student from their behaviors to tasks the student can or can not do (Code Blue, May 20, 2019).*

Responses from this participant also indicated that what happens at the IEP is not shared with the team. He stated that it would be important to *“add parent input into the IEP meetings”* (Code Blue, May 20, 2019).

The fourth participant shared that he had not felt that he was a part of the transition planning process and that it was something that happened only at the end of his time in school.

*For me, teachers should ask you; like do you have skills that you are good at?*

*Teachers should support you. . . Depends on the student; some are lazy and want to play video games all day in class. . . Some of the students sit and play video games all day long. . . Well, for me to read and write and to learn new words and what they mean. . . There wasn't enough in school* (Jay, May 7, 2019).

This participant also felt that parents needed more support to understand what to expect with the transition planning process, as well as how to help their children fit in when the parents had recently arrived to the United States. *“Parents don't know different state rules, or the different country rules. It might make it hard for parents to help kids”* (Jay, May 20, 2019).

**Level of paraprofessional involvement.** The final theme that was found through participant responses was the reference to paraprofessional involvement and their knowledge of the students. The comments spoke to the intensity of time that the paraprofessionals have with the students in both the classroom and the SLE's yet they are not involved in selection of the SLE's or in the IEP meetings where decisions are being made. Like the fifth theme, while there were no interview questions geared towards the involvement of the paraprofessionals, there were eight responses which addressed the level of involvement of the paraprofessionals.

Input from the participants spoke to the important role that the paraprofessionals play in students having a successful SLE. *“My job is to help prepare them for the SLE and to*

*encourage them. . . The SLE's are great for gathering positive experiences and are a positive reinforcement with big impact on the students" (Code Blue, May 20, 2019).*

Responses indicated that the paraprofessionals need to have specific skills unique to the SLE, yet all staff did not have formal training in this area.

*To be able to interact and be with the student to see what they are capable of and to see skills transfer over is good. . . If the student does or doesn't know some things till you try and then you run through practices. . . Play out scenarios to tell better what to do and to help them improve (Code Blue, May 20, 2019).*

Input from one of the participants discussed the importance of the paraprofessionals being involved in communication with team members as well as being able to communicate with students in a meaningful way. One example given was the value of teachers being prepared with materials to minimize down time for the paraprofessionals.

*From what I've seen, information from the adults, observations and what students tell the adults; they communicate with each other. . . For many of the para's [paraprofessionals], English is their second language and they have less accuracy of English. . . Especially with the curriculum, so the students need to rely on the teacher but the para's are the models for the students. . . There are voids while waiting for the teacher, if they had work prepared for the para's they could keep working (Mary, June 6, 2019).*

## **Summation**

The interview questions were geared to gather perspectives from the participants regarding identifying ways to select meaningful SLE's for students and how to incorporate it into the curriculum of the school. The responses from the student and staff participants went beyond the intended topic and raised many relevant factors which underlie being able to provide meaningful SLE's for the students. In particular, the fact that the classrooms are not working with a curriculum was identified by the staff as strongly influencing the creation of SLE's for the students and allowing for consistency among staff on how to incorporate parental input. Another factor was that the staff do not know what the requirements and expectations for effective transition planning are, and therefore are working with a trial and error method. Without there being an understanding of what the expectations and regulations are for the transition planning process and no formal curriculum, the paraprofessional staff in the classrooms who accompany the students on their SLE's do not have any formal training on what student expectations are or how to assess student performance. They are doing their best and work by trial and error. The dedication of the staff and their positive view of the existing SLE experiences were seen as positive attributes within the existing program.

## **Staff Review of Results**

In the fall of 2019, the PI had a meeting with all of the staff in the creative pathway's program to discuss the themes identified by the interviews done in the spring. While there were only seven interviews done, there were seventeen staff members in attendance at the meeting that the Principal had determined was mandatory as the staff's professional learning session for the month. Following a brief review of the initial needs assessment which the principal investigator had conducted in the summer of 2018, and the six themes from the interviews, the group



discussed what they felt the next steps should be to make changes in the transition planning programming being provided. The minutes from this meeting, which includes the discussion by the staff on each of the six themes can be found in Appendix D. The group then ranked eight action steps in order of perceived priority for making positive changes to the existing program. The meeting with the staff aligned with the action portion of Stringer's process of active participant research (2008). During this reflective meeting, this group of active participants demonstrated a cohesiveness of thought in looking for what would help to support the need for change. The group arrived at the following eight steps to further develop the transition planning within the school district. The listing is in their order of importance.

- Increase in the understanding by administration, child study team, the teaching staff and parents of what the federal and state requirements for transition planning are.
- The creation of a current curriculum for staff to align their work based upon the requirements and best practice was felt to be essential for framing the transition process.
- Appointment of a Coordinator for the Structured Learning Experiences (SLE's).
- Allocation of funding for the implementation of community-based instruction (CBI) and for support of SLE's.
- Improvement in communication in all levels of staffing and with parents.
- Increase in parent involvement beginning with education of what students are capable of.
- Appointment of a Transition Coordinator following improvements to the SLE process.
- Appointment of a Parent Liaison to further improve parental involvement in the transition planning process.

The group identified that in order to create needed changes, increased knowledge of the transition planning process was needed. They felt that this should begin at the administrative level with the senior administration of the district and therefore identified that to be the first step.

Initially, staff were working as individuals in their classrooms and had never been brought together as a group with a common purpose. There have been a few changes in staff, however, the core has remained the same and most of the changes have been the addition of staff due to a growing population of students needing the creative pathway's program. Over the last year, the PI, who also provides the occupational therapy services at the high school, has worked closely with the individuals involved in the creative pathway's program, discussing transition planning as an ongoing process and sharing the importance of creating experiences which are meaningful to the students. The introduction of assessments to create baseline information of the students in their SLE's was started in the fall of 2018, after the needs assessment was reviewed with the staff. The Vocational Assessment Rating Inventory (Malgady, Barcher, Davis, & Towner, 1980) is used for all students before they begin their SLE and then at the end of the school year to get a pre and post assessment of their skills. The Reading-Free Vocational Interest Inventory 2nd edition (Becker, 2001) is used with the sophomore or junior years to help students learn about some job skills to provide some choice by students with an assessment to support their area of interest. Gathering of this data was initiated to provide the school district with some data to be able to report on the state mandated indicators.

### **Limitations**

Limitations of the study portion of this capstone project include a variety of things. The questions selected for the semi-structured interviewing for both the staff and students elicited responses which indicated that there were underlying areas of concern about more basic needs of the program such as there being a lack of curriculum for staff to be following, limited knowledge of what the transition process requirements are, and minimal training of those carrying out the SLE's. Because of this, specific ideas or examples of how to identify meaningful occupations of

students was quite challenging for those being interviewed. While staff believed that they were thinking of the students as the most important part of the transition planning process, responses did not reflect a person-centered approach to thinking of the student. Rather the responses provided, involved how to do things that would be best for the student, not with or in support of the student as done with a person-centered approach.

An additional limitation was the restrictions placed on how data could be gathered for the interview process by the host school district. These included no audio or video taping which limited the PI's ability to accurately gather the raw data without any distortions. The low number of participant responses means that generalization of the responses cannot be applied beyond those participants. In particular, the absence of input from parents is a significant limitation of the study because it does not provide insight into the perspectives and experiences of this important group of stakeholders.

The low response rate may be partially attributed to the complexity of the formality of the research process in that specific wording and formats were needed to gain approval from the IRB. Acknowledging that the targeted population was made up of individuals from Hispanic cultures which are identified as experiencing disparities in many areas including literacy levels further added to a limitation in gathering input from valued potential participant. The required wording and formats may have been a deterrent to participation by many in the group if they did not have the sufficient literacy level to complete the work even though all of the required forms were translated into Spanish by an individual who is fluently bi-lingual. In addition, the school district had been experiencing a significant reduction in parents willing to complete any forms at all because many of them did not have legal status in the United States and do not want to put their names on a form even if it is to provide their children with free and reduced meals in the

school [personal conversation with Beth Wolanski, October 3, 2019]. A final limitation of the study was that the principal investigator is not bilingual in Spanish. If the PI had been bilingual, it is possible that a stronger connection could have been made with some of the potential participants.

## **Future Projects and Research**

This capstone project helps bring to light the importance of identifying the forces involved in the environment, and the many contextual challenges involved in identifying what meaningful occupations are for students with intellectual/developmental disabilities transitioning to adult life. Pizzi and Richards (2017) E-HOW Model was used to guide the discovery process for identifying what student and staff's lived experiences were regarding the structured learning experiences. These valuable experiences allowed the PI to pursue the influence of a variety of topics expressed by the participants. By doing so, a more holistic view of necessary future steps for this school district was attained. Occupational therapists need to continue to expand their involvement in this important area of school-based practice in order to support students who are transitioning to adult life by bringing an occupational therapy person-centered approach to the educational team. Further studies on the impact of occupational therapists involved in this area are needed.

Stringer (2008) discusses that the purpose of using an action research approach is to enable those involved at the various levels to become empowered to “solve ...significant problems that are part of the complex life of a school” (p. 1). The following examples of next steps already beginning are evidence of the impact that using an active participant approach is having in this school district.

The limitations of this project, as listed above, are also opportunities for additional work to be done within this urban school district. An immediate result of the lack of participation by parents in the spring of 2019 led the principal investigator to work with the Boggs Center on Developmental Disabilities in New Jersey in the summer of 2019 as her applied leadership experience. Work over the summer of 2019 at the Boggs Center involved the principal investigator analyzing the level of active involvement by Hispanic families in the transition planning process and adult service provision of individuals with intellectual and developmental disabilities. A product of this work was a framework for the Boggs Center to use to support work to increase efforts at creating social support networks with families from Hispanic backgrounds within counties and school districts that were identified as having larger populations who self-identify as being from Hispanic cultures.

The process of gaining approval for the study and the many relationships that were forged during the interviewing portion using an active participant approach has resulted in more awareness of and attention to the creative pathway's program and the transition planning process. At the conclusion of the formal capstone project this fall, the PI was assigned by the Assistant Superintendent of Curriculum to work with the teaching staff of the creative pathway's program to revise the curriculum for the district. In particular, the PI was asked to provide input on ensuring that the process addressed transition planning as a process which begins in elementary school and takes on a person-centered approach.

The PI was also asked to work with the Supervisor of Special Education within the school district to relaunch the district's parent advocacy group. Parent advisory groups run by parents of students receiving special education is a state requirement (New Jersey Department of Human Services, n.d.). Past efforts by the district had not resulted in creating a successful group.

The views expressed by the participants of this capstone project aligned with the findings of a study by the Boggs Center, which is that students and families are not actively engaged in the transition process (2016).

Participants in this capstone project felt that parent education and involvement is important to successful transition planning as well as in the identification of structured learning experiences that would lead to long term participation of students beyond their attaining twenty-one years of age. Involving parents younger than the high school level was also felt to be necessary for parents to have dreams for their children with special needs (Grossi, & Cole, 2013; Reynolds, 2019). Additional work is needed to explore ways to involve parents beginning when children start school so that parents can develop a social support network with other parents while the children go through the school system. New Jersey has mandated that each school district have a parent's advocacy group (New Jersey Department of Human Services, n.d.). Having a social support network was found to be particularly important for Hispanic families who are learning to live in a new country (Shedlin, Decenaa, Mangadu, & Martinez, 2009). Benefits of this would be the opportunity for families to develop higher expectations for their children and added supports to help the family and student acquire life skills to prepare them for adult life. During the summer of 2019, the occupational therapists in the district began to provide information and discussion sessions in Spanish and English with parents of the preschool disabled classes to begin to strengthen their relationship with the parents and to provide parents with a peer group that can be nurtured into a social support network as their children grow within the school district.

The lived perspectives of the interview participants expressed the desire to include both the student and their families input in the selection of the structured learning experiences and

identified the value of real life experiences in helping students prepare for adult life. Since the formal ending of this capstone project, collaboration has begun among the teachers in the different levels of the high school creative pathway's classes, and more discussion regarding how to better support and prepare our students for adult life is starting to be seen. The teachers have initiated bringing the students of different ages and skill levels together along with general education students to create more enriched experiences while in school, that focus on real life experiences. They have also created a master listing of the existing SLE contacts for all to see and get a sense of what skills younger students may need. The listing also provides the younger students what the options are for them to start thinking about and to discuss in case they have other ideas.

Following the presentation of the raw data results of the interviews done in the spring of 2019, the Assistant Superintendent of Special Services approved two case managers to attend training on person-centered planning training through the Boggs Center. They are also now considering applying to the Department of Education for the district to be part of the state cohort on training and support to implement a person-centered approach. Staff are exploring the resources available through the Boggs Center website for classroom lessons and materials pertaining to a person-centered approach and have applied to attend continuing education opportunities as well.

## **Conclusion**

The outcomes of this capstone research project demonstrate that the use of Stringer's Participatory Action Research method can have a significant impact in creating transformational change in a school district. A specific problem of was identified by the participants through a needs assessment which energized the group of staff to want to have a better transition planning

process for their students in high school with moderate to severe IDD. Using a qualitative design to gather the lived experiences of the stakeholders resulted in further active participation by the staff and student who participated in interviews. They were empowered by using the steps of the action research cycle of Stringer and are now engaged in moving into the second evolution of the action research helix. The PI is no longer a facilitator, but rather a participant with the group who are moving forward with changes in the school district.

The influence of an occupational therapy perspective on the transformational change in the school district was evident on many levels. As an occupational therapist, the PI was able to introduce the district to thinking about the transition planning process as being a continuum throughout the life of the students. This perspective was also shared with the Boggs Center during the PI's applied leadership experience. The shift from thinking about what needed to be done "for" and "to" the students to one of thinking of working "with" the students and to learn what is important and meaningful to them introduced the staff to person-centered approach to planning. The interest in this has led to the district to seek ways to work with the state's center of excellence on developmental disabilities and to approve staff attending formal training on the subject. Using the E-HOW model by Pizzi and Richards (2017) provided the PI with the framework to incorporate the importance of culture and context into the design of the interview questions which facilitated participants to expand on their responses resulting in valuable information on their lived experiences. Occupational therapy's embracing of culture into the environment was valuable in emphasizing importance of finding ways to get the perspectives of the family.

Use of the participatory action research approach by Stringer (2008) with Pizzi and Richards' (2017) E-HOW model allowed the participants of this capstone project to view the



transition planning process through a new lens. This has resulted in changes within the school district which will facilitate more active participation by students and families that will result in structured learning experiences becoming more meaningful for the students as they prepare for adult life.

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## Appendix A: CITI Training



Completion Date 04-Nov-2018  
Expiration Date 03-Nov-2021  
Record ID 29155525

This is to certify that:

**Catherine Gardner**

Has completed the following CITI Program course:

**Social & Behavioral Research - Basic/Refresher**(Curriculum Group)  
**Social & Behavioral Research - Basic/Refresher**(Course Learner Group)  
**1 - Basic Course** (Stage)

Under requirements set by:

**Eastern Kentucky University**

**CITI**  
Collaborative Institutional Training Initiative

Verify at [www.citiprogram.org/verify/?wafaf8d59-b69c-4209-af7f-b065fd240c12-29155525](http://www.citiprogram.org/verify/?wafaf8d59-b69c-4209-af7f-b065fd240c12-29155525)



## Appendix B: School District Approval Letter

### WEST NEW YORK School District

6028 Broadway, West New York, NJ 07093  
www.wnyschools.net

Maximizing all students' potential  
for success in an ever changing world.

**Clara Brito Herrera**  
Superintendent of Schools

cherrera@wnyschools.net  
Phone (201) 553-4000 x30013  
Fax (201) 351-5506

January 7, 2019

Eastern Kentucky University  
Institutional Review Board

As an authorized representative of the West New York Public School District, I grant approval for Catherine Gardner to conduct research involving students within our organization. I understand that the purpose of this research is to gather perspectives of students, parents, and staff on ways to identify what is meaningful and interesting to students so that the curriculum can reflect this and the structured learning experiences can be created which incorporate student's areas of interests and strengths.

I also allow for this project to involve staff in the Creative Pathways Program, students involved in this program, and parents of students who are a part of the Creative Pathways Program. I understand that parents will be asked to complete a questionnaire, pre-approved by this District, in their native language and that students and staff will participate in a series of 2-3 individual interviews, pending parental written permission during the winter and spring of 2019. Interviews for students and staff will occur during non-instructional time (Common Planning Time for staff or lunch for students, if approved by their parents). Ms. Gardner will conduct these interviews on the two days a week that she is not working for the District. No videotaping or audio taping will be allowed.

The West New York School District is proud to assist Ms. Gardner and the Eastern Kentucky University in its endeavors.

Sincerely,



Clara Brito Herrera  
Superintendent of Schools

THE DISTRICT IS AFFIRMATIVE ACTION/EQUAL OPPORTUNITY COMPLIANT

## Appendix C: Recruitment Flyer English

### Research Study needs people to participate

A research study is being done in West New York's Memorial High School by Eastern Kentucky University to identify how to include what is meaningful to students into the curriculum for structured learning experiences of students in the Creative Pathways Program. Approval for this study has been given by the Superintendent of Schools, Ms. Clara Brito Herrera.

The name of the research study is:

Incorporating meaningful occupation of students with moderate to severe intellectual disabilities into the structured learning experiences within the transition planning curriculum in a Public School system

Input is needed from **staff** who work with the Creative Pathways Program as well as from **parents and students** to have input from those who are most involved in the program. There is no incentive or reward for participating in the research study. It is believed that there is no more than minimal risk involved in participation in this research meaning that there is no greater risk than what happens in a typical day.

If you choose not to participate, you will not lose any rights or benefits you would normally have. If you agree to participate now and decide later that you want to stop, all you have to do is tell me, and I will let you stop. You will still keep the rights and benefits you had before volunteering.

No personal information will be taken during the interviews or on the surveys and the information will be reported by grouping of people (staff, students, parents) so there will be no way to know what a particular person has provided.

I am looking for the following groups of people to participate in the study:

**Staff** (about 8) working in the Creative Pathways Program to participate in 2-3 personal interviews to gain input on how to include student's interests into the Structured Learning Experiences. Interviews will take about 20 minutes and will be done during a staff member's break time on a Monday or Tuesday.

**Parents** (about 8) of students aged 14 and older in the Creative Pathways Program to fill out a written survey to gain an understanding of what they feel would help their child to be highly interested in participating in Structured Learning Experiences. Parents who agree to participate will have surveys sent to their home to complete with a stamped return envelope.

**Students** (about 8) in the Creative Pathways Program who are aged 14 and over who are able to think of and explain an original answer. Parental permission will be obtained first before students are able to agree to participate. Students will have 2-3 personal interviews to understand ways to learn what is important and motivating for students which can be included into the curriculum for the Structured Learning Experiences. The interviews will be done during the school day, will take about 20 minutes and will be done during the student's lunch time on a Monday or Tuesday after they have eaten their lunch.

If you want to participate in this study, contact Cathy Gardner MPA, OT, FAOTA at [cgardner@wnyschools.net](mailto:cgardner@wnyschools.net) or at 973-632-9168.

## Appendix D: Recruitment Flyer Spanish

### Se Solicita su Participación

Se realizará un estudio en West New York's Memorial High School por medio de Eastern Kentucky University. Este estudio en particular son para los estudiantes en Creative Pathways Program. El estudio va ayudar entender cómo incluir los gustos de los estudiantes en el currículo para tener mejor experiencias en aprendizaje. Aprobación de este estudio se ha dado por la supervisora de la escuelas Sra, Clara Brito Herrea.

El nombre de este estudio es:

Incorporando una significativa ocupación de estudiantes con discapacidades intelectuales de moderadas a severas en las experiencias de aprendizaje dentro del currículo de transición en las escuelas publicas

Se necesita colaboración de los **empleados** de Creative Pathways Program y también de los **parientes** y **estudiantes** quienes están involucrados más en el programa. No va ver un premio/recompensa por participar. No habra riesgo mayor en lo que sucede en un día típico. Si usted eliges en no participar, usted no va perder derechos o beneficios. Si usted ahora quiere participar, y luego decide que quiere parar, por favor avisarme y puede parar. Usted continuará tener derechos y beneficios.

Durante las entrevistas, información personal no será tomada y información va ser reportado por grupo (empleados, parientes, y estudiantes). Asi no habra manera de saber que ha dicho una persona en particular.

Estoy buscando los siguientes grupos (estimando 8 personas en cada grupo) para participar en el estudio:

**Empleados** que están trabajando en Creative Pathways Program. Necesito la participación de ellos para que hagan 2-3 entrevistas personales para saber como incluir los intereses de los estudiantes en las experiencias en aprendizaje. Entrevistas van a ser durante el descanso del día, a partir de un Lunes o Martes, por 20 minutos.

**Parientes** de estudiantes de 14 años y mayores van a llenar una encuesta escrita. El objetivo de esta encuesta es para comprender lo que los parientes creen que ayudaría a su hijo(a) a estar interesados en participar en mejores experiencias de aprendizaje. Parientes que desean participar van a recibir la encuesta por correo a su casa, cuando esté terminado, se colocará en un sobre sellado.

**Estudiantes** de 14 años y mayores quienes están en Creative Pathways Program que puedan expresar y explicar sus respuestas. Permiso del pariente se necesita primero antes que el estudiante pueda participar. Estudiantes van a tener 2-3 entrevistas para entender la motivacion y importancia de aprender para que esté en el currículo de mejores experiencias de aprendizaje. Los entrevistas serán después del almuerzo de la escuela que se llevara acabo un Lunes o Martes, por 20 minutos.

Si deseas participar en este estudio, puede contactar Cathy Gardner MPA, OT, FAOTA a [cgardner@wnyschools.net](mailto:cgardner@wnyschools.net) o 973-632-9168.

## Appendix E: Consent to participate in English

### **Incorporating meaningful occupation of students with moderate to severe intellectual disabilities into the structured learning experiences within the transition planning curriculum in a Public School system**



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#### Key Information

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You are being invited to participate in a research study. This document includes important information you should know about the study. Before providing your consent to participate, please read this entire document and ask any questions you have.

#### **Do I have to participate?**

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you decide to participate, you will be one of about 25 people in the study.

#### **What is the purpose of the study?**

The purpose of the study is to gain an understanding from the participants of what is meaningful to students in the Creative Pathways Program and how to incorporate this into a process within the curriculum of the program for determining Structured Learning Experiences. You are being asked to participate in this study because you are either a parent of a student who is over 14 years old in the Creative Pathways Program or a staff member who works in the program.

#### **Where is the study going to take place and how long will it last?**

The research procedures will be conducted at Memorial High School in West New York, NJ. Students and staff will need to meet at the high school two times during the study. Each of these interview sessions will take about 20 minutes. The total amount of time you will be asked to volunteer for this study is about 45 minutes over the next four months.

#### **What will I be asked to do?**

**Parents** will be asked to complete a written survey to gain an understanding of what they feel would help their child to be motivated for participation in Structured Learning Experiences. Parents who agree to participate will have surveys sent to their home for completion.

**Staff** working in the Creative Pathways Program to participate in 2-3 personal interviews to gain input on how to include student's interests into the curriculum for the Structured Learning Experiences. Interviews will take about 20 minutes and will be done during a staff members break time on a Monday or Tuesday. Interviews will be done between March and June 2019.

#### **Are there reasons why I should not take part in this study?**

This research study is for staff involved in the Creative Pathways Program at Memorial High School or parents of students aged 14 and over in the Creative Pathways Program. Participants will need to respond to an interview conducted in English or be able to respond to a written survey in either Spanish or English.

**What are the possible risks and discomforts?**

To the best of our knowledge, the things you will be doing have no more risk of harm or discomfort than you would experience in everyday life.

You may, however, experience a previously unknown risk or side effect.

**What are the benefits of taking part in this study?**

There is no guarantee that you will get any benefit from taking part in this study. However, some people have experienced greater satisfaction in the transition planning process when they are able to have input. We cannot and do not guarantee that you will receive any benefits from this study. Your participation is expected to provide benefits to others by gathering input from those most affected during the Structured Learning Experiences and providing input for a process to include what is meaningful to students and families into the transition planning curriculum.

**If I don't take part in this study, are there other choices?**

If you do not want to be in the study, there are no other choices except to not take part in the study.

Now that you have some key information about the study, please keep reading if you want to participate. Other important details about the study are provided below.

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**Other Important Details**

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**Who is doing the study?**

The person in charge of this study is Catherine Gardner MPA, OT, FAOTA from Eastern Kentucky University. She is being guided in this research by Doris Pierce, PhD, OTR/L, FAOTA. There may be other people on the research team assisting at different times during the study.

**What will it cost me to participate?**

There are no costs associated with taking part in this study.

**Will I receive any payment or rewards for taking part in the study?**

You will not receive any payment or reward for taking part in this study.

**Who will see the information I give?**

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

This study is anonymous. That means that no one, not even members of the research team, will know that the information you give came from you.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court (if applicable: or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else).

### **Can my taking part in the study end early?**

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the University or agency funding the study decides to stop the study early for a variety of reasons.

### **What happens if I get hurt or sick during the study?**

If you believe you are hurt or get sick because of something that is done during the study, you should call Catherine Gardner at 973-632-9168 or [cgardner@wnyschools.net](mailto:cgardner@wnyschools.net) immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study. These costs will be your responsibility.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

### **What else do I need to know?**

Approval has been received by the West New York School District to conduct this research study with the staff, parents and students in the Creative Pathways Program. Ms. Clara Brito Herrera has provided a letter of support for this research study.

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

We will give you a copy of this consent form to take with you.

Before you decide whether to accept this invitation to take part in the study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact the investigator, Catherine Gardner at 973-632-9168 [cgardner@wnyschools.net](mailto:cgardner@wnyschools.net). If you have any questions about your rights as a research volunteer, you can contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636.

If you would like to participate, please read the statement below, sign, and print your name.

I am at least 18 years of age, have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and voluntarily agree to participate in this research study.

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Signature of person agreeing to take part in the study

Date

---

Printed name of person taking part in the study

---

Name of person providing information to subject

## Appendix F: Consent to Participate in Spanish

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### Consentimiento para Participar en Estudio

Incorporado una significativa ocupación de estudiantes con discapacidades intelectuales de moderadas a severas en las experiencias de aprendizaje estructurado dentro del currículo de transición en las escuelas públicas

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#### Información Clave

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Usted esta invitado para participar en un estudio. Este documento incluye información importante que debe saber del estudio. Antes de dar su consentimiento por favor leer toda la información de este documento y preguntar o si tienen preguntas.

#### ¿Tengo que participar?

O si decide participar, es por que usted quiere ser lo por su voluntad. Usted puede parar en cual quiere momento durante el estudio y siguera con los mismos beneficios y derechos de antes. O si usted decide de participar, usted va ser uno de los viente personas en el estudio.

#### ¿Cuál es el propósito del estudio?

El propósito del estudio es para ayudar entender como incluir los gustos de los Creative Pathways Program estudiantes en el currículo para tener mejor experiencias en aprendizaje. Se le esta preguntado que participe en este estudio por que eres un pariente de un estudiante mayor de 14 años en el Creative Pathways Program o eres un empleado que trabaja en el programa.

#### ¿Dónde se llevará a cabo el estudio y cuánto durará?

Se realizara el estudio en Memorial High School para las entrevistas de los empleados. Una encuesta sera mandado a la casa para los parientes que deciden de participar en Marzo, y se regresara en Junio 2019. Los empleados participarán en 2-3 entrevistas que durarán aproximadamente 20 minutos durante el descanso del dia. Sera durante un Lunes o Martes entre Marzo y Junio 2019.

#### ¿Qué me pedirán hacer?

**Parientes** se les pedirá que completen una encuesta escrita para comprender lo que los parientes creen que ayudaria a su hijo(a) a estar interesados en participar en mejores experiencias de aprendizaje. Parientes que desean participar van a recibir la encuesta por correo a su casa para completar.

**Empleados** trabajando en Creative Pathways Program van a participar en 2-3 entrevistas personales para saber como incluir los intereses de los estudiantes en las experiencias en aprendizaje. Los empleados participarán en las entrevistas que durarán como 20 minutos durante el descanso del dia. Sera durante un Lunes o Martes entre Marzo y Junio 2019.

#### ¿Hay razones por las que no debería participar en este estudio?

Este estudio es para los empleados involucrados en el Creative Pathway Program en Memorial High School o para padres de estudiantes de 14 años o más en el Creative Pathway



Program. Los participantes necesitan responder a una entrevista en inglés o ser capaces de responder a una encuesta escrita en español o inglés.

### **¿Cuáles son los posibles riesgos e incomodidades?**

Según nuestro conocimiento, las cosas que hará no tienen más riesgo o incomodidad que experimenta en la vida diaria.

Sin embargo, puede pasar un riesgo o efecto secundario previamente desconocido.

### **¿Cuáles son los beneficios de participar en este estudio?**

No hay garantía de que obtendrá algún beneficio al participar en este estudio. Sin embargo, algunas personas han experimentado una mayor satisfacción en el proceso del estudio cuando pueden hacer aportes. No podemos y no garantizamos que recibirá ningún beneficio de este estudio. Se espera que su participación traiga beneficios a otros para recolectar los aportes de los más afectados durante las experiencias de aprendizaje estructurado y al aportar información para un proceso que incluye lo que es significativo para los estudiantes y las familias en el currículo de la escuela.

### **Si no participo en este estudio, ¿hay otras opciones?**

O si usted no quiere participar, no hay otras opciones, excepto de no participar.

Ahora, como tienes alguna información clave del estudio, por favor sigue leyendo, si quieres participar. Otra información importante sobre el estudio será llevada a continuación.

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## **Otros Detalles Importantes**

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### **¿Quién está haciendo el estudio?**

La persona encargada de este estudio es Catherine Gardner MPA, OT, FAOTA de Eastern Kentucky University. Ella está siendo guiada por Doris Pierce, PhD, OTR/L, FAOTA. Es posible que haya otras personas en el equipo que asisten en diferentes momentos durante el estudio.

### **¿Cuánto me costará participar?**

No va a ver costos asociados con la participación en este estudio.

### **¿Recibiré algún pago o recompensa por participar en este estudio?**

No va a recibir ningún pago o recompensa por participar.

### **¿Quién verá la información que yo dé?**

Su información se combinará con la información de otras personas que participan en el estudio. Cuando escribamos el estudio para compartirlo con otros investigadores, escribiremos sobre esta información combinada. Usted no será identificado en estos materiales de escritura.

El estudio es anónimo. Eso significa que nadie, ni siquiera los miembros del equipo del estudio, sabrá que la información vino de usted. Sin embargo, hay circunstancias en las que es posible que tengamos que mostrar su información a otras personas. Por ejemplo, la ley puede exigir que mostremos su información a un tribunal (si corresponde: informar a las autoridades si creemos que ha abusado de un niño o que está en peligro para usted o para otra persona).

### **¿Puede mi participación en el estudio terminar temprano?**

Si decide participar en el estudio, tendrá derecho a decidir en cualquier momento de no participar. No será tratado de manera diferente si decide dejar de participar en el estudio.



## Appendix G: Sample Probe Questions for Staff

Examples of Interview questions for staff include the following. It is anticipated that questions will be revised following information provided in the initial interviews:

I am looking for staff input on student's interests and how they might be included in the curriculum for the selection of the structured learning experiences. Please think about the structured learning experiences when answering the following questions.

So that I don't lose any of your input, I would like to write down everything that you say. Is that ok with you? There will be no identifying information used in the write-up of the report, so no one will know what is said by who.

1. Are you now finding out what students are interested in doing?
2. If so how is that happening?
3. How is that information being included in selecting a structured learning experience?
4. Do you think there are other ways to find out what students are interested in & if so, what are they?
5. Are the students involved in the selection of where they go for structured learning experiences?
6. How does this happen now?
7. Are the parents involved in the structured learning experiences now?
8. If so how does this happen & is it working well?
9. If not, do you think it would help if they were involved?
10. How would parent involvement improve the experience for the student?
11. Where do you feel this information could be used in the curriculum to help with Structured Learning Experiences?
12. When the students are doing their SLE's, do they seem interested in their SLE's?
13. Do you see any difference between the students who participate in selecting their SLE's and those who don't participate in selecting their SLE's? Can you give me examples?
14. Do you have any other thoughts on the structured learning experiences and how they can be interesting and appealing to the students?

## Appendix H: Sample Probe Questions for Students

Examples of initial questions for student interviews are below. It is expected that revisions in questions will occur following input from the students:

I am looking for your ideas on whether you feel the Structured Learning Experiences in our school are interesting to students. If it is ok with you, I am going to write down everything that you say so that I don't forget anything. Is it ok if I write things down?

Do you know what a SLE (Structured Learning Experience) is?

Have you had an SLE yet, or are you getting ready for one?

1. Has anyone asked you what kinds of things you want to learn about and try doing to help you get ready to be an adult? If yes, do you remember what they asked you?
2. Did you help pick out where to do any of your SLE's? Would you like to help pick out the SLE?
3. Do you think helping to pick out your SLE helps students be interested in doing them?
4. If you have had an SLE, what do/did you like about doing it?
5. Did/do you look forward to going to it each time?
6. If you don't know what you want to do after high school, do you think that trying things out in the SLE can help you?
7. If you don't know what you want to do after high school, do you want help from the teachers to figure it out?
8. Do you have any ideas on how we can figure out what you might like to do?

Prompt selection:

Watch movies of jobs/things people do

Look in books/internet about jobs/things people do

Go and see what people do

Answer questions about jobs/things to do

Pick from pictures jobs/things to do

Other \_\_\_\_\_

9. Do you think it would be good to have your parents help you and the teachers pick places that you might like to try working at in the SLE's?

10. Is there anything else you want to tell me about the SLE's we do through the school?

## Appendix I: Minutes from full staff meeting on September 18, 2019

1:15 pm – 2:45 pm

Comparison and contrasting of the data from the two times.

Interview data: (gathered spring 2019)	Staff meeting data: (September 18,2019)
<b>Themes:</b>	
<p><b>Parent involvement</b></p> <ul style="list-style-type: none"> <li>• Parents have limited involvement</li> <li>• Parents culture influences their comfort/interest in participation</li> <li>• Parents are viewed as being overprotective by staff &amp; student</li> <li>• Parents need to see &amp; understand what the student are actually capable of</li> <li>• Staff and student felt that parents make decisions for students and students want to make them for themselves</li> </ul>	<ul style="list-style-type: none"> <li>• Parent input is needed, but their participation is low</li> <li>• Culture is believed to be influencing participation</li> <li>• Staff would like to see a parent liaison</li> <li>• Staff agreed that parents can be unaware of students potential and overprotective</li> </ul>
<p><b>Level of support for staff &amp; students</b></p> <ul style="list-style-type: none"> <li>• Teaching staff don't have a curriculum to guide them</li> <li>• Teachers and parents are paying for what is part of the curriculum rather than being paid for by the district</li> <li>• Student felt that some teachers don't give them personal attention</li> <li>• Student felt that their interests were not included in selection of SLE or life skills taught</li> </ul>	<ul style="list-style-type: none"> <li>• The curriculum has been outdated for many years and doesn't apply to the current level of students</li> <li>• Staff and parents have been paying for public transportation themselves along with other expenses for CBI's.</li> <li>• Staff need to attend trainings to learn what is required, expected, &amp; is best practice; they need to know where trainings are available and be approved to attend.</li> <li>• Staff have only met as a group during last year's meeting and now this year's.</li> <li>• CPT time is too short and the paraprofessionals are not available. More blocks of time are needed such as the PLS days to get work accomplished</li> </ul>

<p><b>Value of the SLE</b></p> <ul style="list-style-type: none"> <li>• SLE's are viewed positively by both staff and student</li> <li>• Staff are selecting SLE's for students on a trial and error basis</li> <li>• There is limited structure to follow for the SLE's</li> <li>• SLE's are believed to be motivating by both staff and student</li> <li>• Staff and student reported increased maturity and communication skills by students</li> </ul>	<ul style="list-style-type: none"> <li>• SLE's take a lot of work by each of the teacher's doing them.</li> <li>• One point person would allow better organization of the structure, systems needed and building the relationships within the community.</li> <li>• Point person could do the on-sites that are needed.</li> <li>• The SLE's could be even more valuable if they were designed and carried out more efficiently</li> </ul>
<ul style="list-style-type: none"> <li>• Staff see that students take pride in their work</li> <li>• Staff report that older students develop mentoring skills with younger students</li> </ul>	
<p><b>Role of Life skills activities</b></p> <ul style="list-style-type: none"> <li>• Staff find students are more motivated to work on life skills activities than academic work</li> <li>• Student felt that student input is not occurring enough for life skills taught</li> <li>• Lack of curriculum does not help to guide what life skills should be caught</li> </ul>	<p>A curriculum is needed along with a way</p> <ul style="list-style-type: none"> <li>□ to collect data on student progress</li> </ul>