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The Quiet Discrimination of Lowered Expectations: A Study on the Independent Living Needs of Severely Disabled Individuals in Kansas

Joe Dalgarn

University of Arkansas, Fayetteville

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The Quiet Discrimination of Lowered Expectations: A Study on the Independent Living Needs
of Severely Disabled Individuals in Kansas

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Education in Educational Leadership

by

Joe Dalgarn
Pittsburg State University
Bachelor of Education in English Education, 2003
Pittsburg State University
Master of Science in Psychology, 2005
Pittsburg State University
Educational Specialist in School Psychology, 2008

May 2017
University of Arkansas

This dissertation is approved for recommendation to the Graduate Council.

Dr. Carleton Holt
Dissertation Director

Dr. Ed Bengston
Committee Member

Dr. James C. Christman
Committee Member

Abstract

Increasing the independence of individuals with severe disabilities is of increasing concern to schools and federal agencies. Improving quality of life for high needs individuals with disabilities is an objective of transition programs, which allow consumers to adapt from one aspect of life to the next. The purpose of this study is to examine the relationships between variables (a) vocational assessment and exploration; (b) workplace readiness training; (c) independent living skills; and (d) self-advocacy and self-care and the independence level of individuals with severe disabilities residing and receiving their education within an institutionalized setting. Finally, this study will examine the efficacy of the Functional Independent Skills Handbook curriculum and assessment in addressing the independent living skills needs of individuals with severe disabilities in-residence in a state institution. Participants include adolescents with severe disabilities receiving services from the Special Purpose School at the Parsons State Hospital.

The results obtained by this study may be of extreme use to educators, service providers, and policy makers in Kansas, as well as other states utilizing a similar institutionalization model for severely disabled individuals. The study yielded statistically significant results that a focused, leveled curriculum emphasizing (a) vocational assessment and exploration; (b) workplace readiness training; (c) independent living skills; and (d) self-advocacy and self-care can increase the independence level of individuals with severe disabilities.

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Chapter 1

Introduction

The transition to adult life represents a time of high expectations and hope for young people leaving secondary education (Levine, 2005). It is regrettable that despite decades of federal attention to their unique challenges, the outcomes of transition-aged youth with disabilities have not improved considerably, prompting the questions: Why do students with disabilities continue to fail to find vocations, engage in postsecondary education, become socially involved, or live independently after participating in a high school program designed for their specific needs? And, which students are most likely to fail to successfully transition?

Numerous studies of transition-aged youth published over the past three decades have reported disproportionately high dropout rates, significantly higher rates of unemployment or underemployment, and decidedly lower rates of enrollment in postsecondary education for individuals with disabilities completing their schooling (Benz, Doren, & Yovnoff, 1998; Harnisch, Wermuth, & Zheng, 1992; Mithaug, Horichi, & Fanning, 1985; Sitlington, Frank, & Carson, 1993; Zigmond & Thornton, 1995).

In more recent investigations, Wagner, Newman, Cameto, and Levine (2005) compared conclusions brought forth from their previous 1987 national study on students with disabilities who had been out of high school for at least 2 years. The researchers had found poor outcomes for special education students exiting their secondary educational programs in 2003. The survey concluded that more than 50% of special education students who had behavioral concerns, were found to have been fired from their jobs or had been arrested, compared to only about a third of the 1987 sample. Although there was no change between 1987 and 2003 in the 50% of youth

with disabilities who held a job at the time of their interview, 18% fewer youth with disabilities worked full-time in 2003 than in 1987. In addition, 44% of youth with multiple disabilities or moderate to severe cognitive disabilities had failed to meet the vocational or transitional living goals set for them by their Individual Education Plan (IEP) and their Individual Plan of Employment (IPE).

Historically, the perception has been that high schools are suited to develop the necessary linkages between the planning and preparation that students need while enrolled in high school and the typical roles they will assume as adults. A state's vocational rehabilitation system then becoming involved in case management if the level of need of a particular student might indicate the need for residential placement and non-competitive employment. However, despite transition-focused legislation, implementation of the Individuals with Disabilities in Education Act-Revised's (IDEA-R) transition mandates appears to be uneven in regards to the highest needs individuals. Moreover, most states have failed to achieve even minimal compliance for high needs, severely disabled students with legislated transition requirements, including meeting the needs of youth who may require non-academic, life-skills focused education (Hasazi, Furney, & DeStefano, 1999).

According to the National Council on Disability (2011), 44 states failed to ensure compliance with transition requirements for all categories of special education. The U.S. Department of Education annual performance reports of the special education program of each state showed that only nine states met IDEA-mandated transition requirements for students (2011). Such widespread lack of compliance with basic transition practices represents a major disconnect between policy and practice is abundantly clear (Williams & O'Leary, 2011), and

while states have fallen short of systematically achieving legislated expectations for youth as they enter post-secondary life, the highest needs individuals are often ignored through the quiet discrimination of lowered expectations (Dalgarn et al., 2015).

Up to this point, the post-secondary transitions of disabled individuals have been a very small field of research, and what research does exist is almost exclusively focused on higher functioning individuals with disabilities; those who have a significant amount of life skills and free agency, who would be able to participate in competitive employment, and who may be able to live independently and seek post-secondary training or education. The higher needs, severely disabled individuals become a footnote or ignored altogether. For the higher functioning individuals with disabilities, researchers have advocated for constructing methods to that complement existing federal mandates and point the field toward expectations intended to engage families, educators, and students in discussions about how best to meet exiting students' goals for roles they wish to assume after departing high school (2010). These methods include holding school personnel accountable for (a) teaching students to direct their own education in light of their desired post-high school outcomes, (b) placing students in their self-identified post-high school destinations, and (c) arranging for and coordinating post-placement supports to increase the likelihood that these students adjust successfully to their post-high school experiences (e.g., continuing their education or finding and keeping a job). While these transitional methods are a well-intentioned outline for those providing transition services, they may not be applicable to the higher needs population.

Transition-aged students with high needs, severe disabilities may take advantage of some of the same opportunities available to higher functioning individuals with disabilities; however,

they face barriers unique to their situation, barriers that prevent them from achieving a higher quality of life. While some of these barriers may stem from the individual's disabilities, social and systemic issues may also create additional barriers. Over a 10-year timeframe from 2004-2014, Kansas Vocational Rehabilitation successfully closed 218 individual cases of individuals with severe disabilities (Dalgarn et al., 2015). The 218 high needs individuals mark a 96.7% success rate (2015); however, the definition of success outlined for these individuals by the Kansas Vocational Rehabilitation Counselor's Handbook is a one size fits all answer: end the individual's educational services, designate the individual as a ward of the state (if they are not already), and place the individual in an assisted living facility (if they are not already). A high needs individual will begin this process, not when they have completed transition or educational goals, but when an opening in an adult assisted living facility becomes open (2010).

Vocational Rehabilitation is an agency within the Kansas Department of Aging and Disability Services (KDADS). Qualified VR counselors employed by the agency work together with individuals with disabilities to develop an individualized plan of services leading to an employment outcome that is consistent with the individual's abilities, interests, and informed choice. The services provided by VR can include but are not limited to the following: counseling and guidance, assessment, vocational training, post- secondary education, mental or physical restoration, assistive technology devices and services, and job placement. The Agency also provides services to high needs individuals—those with the most significant disabilities—who may require extensive supports for their daily living needs, as well as sheltered support to maintain special employment through the supplemental Supported Employment Services program (often referred to as non-competitive employment).

Since the induction of Kansas Vocational Rehabilitation Services(VR), augmenting the employment of individuals with disabilities has been the major objective and function of rehabilitation counselors (Mannock, Levesque, & Prochaska, 2002; Salomone, 1996). The VR service delivery process centers on maximizing the probability of successful rehabilitation outcomes for individuals with disabilities (Bolton, Bellini, & Brookings, 2000). The essential postulate is that becoming gainfully employed increases personal independence as well as increases empowerment among people with disabilities (Bolton et al., 2000). “Rehabilitation” is not limited solely to employment needs, but to anything that an individual with a qualifying disability may need to successfully participate in society.

Although efforts have been made to address the unemployment problem for persons with disabilities (Hasazi, Gordon, & Roe, 1985; Heal & Rusch, 1995) their employment rates remain low, and the employment participation rate for severely disabled outside of sheltered employment is essentially zero (Mannock et al., 2002; Millington & Reed, 1997; Dalgarn et al. 2015). Therefore, the past ability of rehabilitation services to achieve vocational rehabilitation for most individuals can be questioned.

School to adult life transition

The out-of-school transition to adult life is a complex process for adolescents with disabilities and only becomes more complex as the level of individual need increases (Mulkey & Brechin, 1988; Syzmanski & Danek, 1985). Addressing the needs and disparities that individuals with disabilities endure during their post-secondary transition requires consistent and resolute partnerships that are responsive to each individual (Benz, Lindstrom, & Latta, 1999).

The partnerships are between schools, agencies, youth, and the community. According to

national datum, employment outcomes of youth with disabilities remain poor. State vocational rehabilitation programs and rehabilitation counselors have jointly pursued and provided services through vocational training programs and case management in conjunction with special education programs since the 1940's (DiMichael, 1950; Hanley-Maxwell, et al., 1998). Transition policy and service delivery have changed throughout the years, but the current model includes involvement from two different federal entities: Vocational Rehabilitation and Special Education (Hanley-Maxwell et al., 1998). Vocational Rehabilitation agencies have provided services to youth with disabilities since the passage of the Barden-LaFollette Amendments of 1943. Emphasis on school-to-work transition has been influenced by factors such as altering demographics among students within the workforce, the desire for a more fruitful and competitive labor force, as well as dire concern regarding the economic prosperity of youth with disabilities (Smith & Rojewski, 1993). The need for state and local education and vocational rehabilitation agencies to work cooperatively to correct the problematic situation facing transition aged youth was recognized, thereby warranting the mandates included within both the Individuals with Disabilities Education Act - Revised of 1990 and 2004 and the Rehabilitation Act Amendments of 1992 (Benz et al., 1999).

However, two important considerations exist: 1. With the exception of the Smith and Rojewski study (2001) in which severely disabled individuals were specifically excluded, previous studies examining historical trends tend to not separate individuals by level of need or severity of disability (some small empirical studies do separate individuals by disability, however). While specific information concerning an individual's disability is medically protected information that may not have been available to the authors of previous research, it is

the postulate of this study that high needs, severely disabled individuals are at higher risk of being excluded from full participation in adult life. 2. The Kansas Vocational Rehabilitation Handbook outlines a singular approach to high needs individuals. This singular approach is largely arbitrary; not tied to goals, milestones, or accomplishments; contains no legitimate goals of its own, and signifies a case closure (2010). By closing an individual's case in this manner, Vocational Rehabilitation moves the individual into an assisted living facility, and transfers their file to the Office of Social Security Disability and no longer actively participates in case management (2010). The individual is essentially written off as one who cannot contribute to society at large, nor fully participate in it.

Vocational placement and case management

Vocational placement and case management are significant services (Fraser & Shrey, 1996) that require rehabilitation counselors to provide for living arrangements and locate competitive employment for consumers, or if the degree of individual disability warrants; organize sheltered non-competitive employment (Murphy, 1988; Roessler & Rubin, 1998). Millington and McCarthy (1998) noted that “case management should be the primary focus of all rehabilitation counselors” (p. 381) and remains the focus of the vocational rehabilitation process. Recent trends have attempted to lead rehabilitation counselors to provide services to youth with severe disabilities towards a different transitional path by forming a stronger partnership and overlapping services with Special Education (Roessler & Rubin, 2008).

Out-of-school transition includes a distinct set of challenges for individuals with disabilities along with the teachers that offer instruction and the service workers and agencies tasked with case management (Householder & Jansen, 2009). In regards to individuals with

severe disabilities, placement services begin with programs within schools that place emphasis on functional academics, life skills, and virtual work experiences (Roessler & Rubin, 2008). For these individuals, being able to find and maintain any level of employment runs parallel to a similar level of independent living.

In special education, desired outcomes are continuously identified by teachers and staff; however, this oversight and responsibilities change hands at the onset of adulthood. Students with severe disabilities may require intervention strategies in addition to their support system in order to achieve and maintain higher levels of independence (Mulkey & Brechin, 1988). The transition needs of these individuals are compounded by the uniqueness of the higher needs of individuals with severe disabilities. Rehabilitation counselors and service providers working with severely disabled individuals must be cognizant of variables associated with successful out-of-school transition, but also be aware of the fluid nature of individual independence, school, and transition (Mulkey & Brechin, 1998).

Assessing the relationship among variables and successful outcomes is important to schools and vocational rehabilitation staff. If the variables that determine successful post-secondary transition outcomes are identified and understood, then proper interventions, supports, and curriculum can be offered to increase the likelihood of positive transitional outcomes, even if the individual is of severely high needs. The purpose of this study is to examine the relationship between selected variables and the independent living outcomes on severely disabled individuals living in institutionalized settings in Kansas. Previous researchers have identified certain variables as correlates of successful outcomes for students with less severe disabilities; however, many of the variables used in previous research do not apply to severely high needs individuals.

In many cases, the Kansas Vocational Rehabilitation Comprehensive State Needs Assessment, which contained specific sections pertaining to needs of both transition-aged individuals with disabilities and the unique needs of severely disabled individuals, was used to help support variable selection and attempt to fill gaps in the research. In the following section, the author will provide research supporting the variable selection.

Research Supporting Variable Selection

Individuals with severe disabilities are confronted with exceptional challenges to increase their independence and overall quality of life (Powers, Sowers, & Stevens, 2005). Many of these individuals are plagued by disabilities that restrict their physical abilities, mobility, communication, endurance, or cognitive capabilities, these individuals often have problems performing daily activities, tending to their own self-care, and moving about their environment. For these individuals, the lack of opportunity to exercise independence diminishes their quality of life (Powers et al., 1995). “Research conducted to follow-up with [participant’s] transition into the local community indicates that society wants youths with disabilities to be employed, live as independently as possible and be satisfied with their social and interpersonal networks” (Chadsey-Rusch et al., 1991, p. 30-31). With emphasis placed on supporting those deemed more capable, high needs individuals are often disregarded, their potential to move toward a more fulfilling participation in life activities ignored.

Knowledge of variables related to positive outcomes of persons with high needs disabilities is beneficial in regard to improving post-school life and vocation outcomes for these individuals. Transition professionals and service providers agree that when an individual with a disability finds fulfilling vocational placement, that individual will become more socially

integrated, independent, and satisfied (Reiter & Palnizky, 1996).

Results from the current Comprehensive State Needs Assessment

Kansas Vocational Rehabilitation (VR) in collaboration with the State Rehabilitation Council is required to conduct a comprehensive statewide needs assessment describing the rehabilitation needs of individuals residing in the state (34 CFR 361.29). The needs assessment must be conducted every five years and include information on the rehabilitation needs of individuals with disabilities in the state examining the rehabilitation needs of three specific groups: 1) individuals with the most significant disabilities including their need for supported employment services; 2) individuals who are minorities or who have been unserved or underserved by the vocational rehabilitation program; and 3) individuals with disabilities served through other components of the statewide workforce investment system. The author of this study was a lead researcher contributing to the 2015 Comprehensive State Needs Assessment. In addition to the areas examined in the report, the 2015 Comprehensive State Needs Assessment also includes additional artifacts examining the unique needs of individuals with disabilities who are in the process of completing secondary education, considered “transition-aged youth”; as well as provisions intended to ensure that individuals with severe disabilities, especially youth with severe disabilities, are afforded full opportunity to prepare for and obtain integrated, supported, non-competitive employment (Dalgarn et al., 2015).

Before cases of youth with severe disabilities are deemed successfully closed the individual must be afforded a meaningful opportunity to access services they need to achieve employment and less-limited living arrangements. This provision, called the Workforce Innovation and Opportunity Act (WIOA), supports the priority for transitioning students towards

relatively more independence. However, this also has the potential to greatly expand the number of persons requiring VR services, as the current model of placing high needs individuals in institutional settings and then closing their cases, will no longer be sufficient.

While this old model inflated a year-in-year-out successful placement rate of 94 to 96%, the Kansas Department of Aging and Disability Services (KDADS) has expressed an explicit desire to allow high needs individuals the opportunity to attempt to achieve individualized employment outcomes and opening the possibility of a more independent and less restrictive adult living situation. This new initiative requires Vocational Rehabilitation counselors to document the completion of required activities; including pre-employment transition services, career/vocational education, information collection and referral, and other VR services deemed necessary to achieve competitive, integrated employment (Dalgarn et al., 2015).

While this change in protocol for high needs, transition-aged youth seems subtle, it is in reality very significant. Even with the new requirements of the Workforce Innovation and Opportunity Act (WIOA), the level of need of these high needs individuals will usually continue to warrant an institutional setting, but by having these requirements in place, some individuals may benefit from the quality of life enhancements gained from a less restrictive living placement and/or non-competitive, sheltered employment, and a possible increase in functional skills. The new initiatives require VR to be more proactive, partnering with schools early in a student's education, providing services and developing more thorough and inclusive Individual Plans of Employment (IPE) prior to the student leaving secondary education (Dalgarn et al., 2015).

The Comprehensive State Needs Assessment included surveys of Special Education staff, individuals and families receiving services, and Vocational Rehabilitation staff; focus groups of

families receiving services, and coded interviews with individuals selected by Vocational Rehabilitation deemed “key informants”. While not all of the information from the Comprehensive State Needs Assessment is relevant to this study, this study was lead and informed by the information collected and disseminated by the Comprehensive State Needs Assessment. A full copy of the Needs Assessment is available by request from the Kansas Department of Aging and Disability Services. Information from the Comprehensive State Needs Assessment relevant to this study is presented below.

Key informant interviews. Individual interviews were conducted with select state participants identified as being able to provide a “valuable perspective” on the employment-related needs of Kansans with severe disabilities. Nine such individuals were selected from across the state, eight agreed to participate; however, one participant could not be reached for comment. The interviews were conducted by phone in a one-on-one context, participants were presented with an informational sheet with an outline of the interview questions prior to the interview. Participants were open and forthcoming with their comments and perspective on the employment-related needs of individuals with disabilities (Dalgarn et al., 2015).

Purposive sampling was utilized, as the participants for the Key Informant Interview were selected by VR services in accordance with their knowledge and experience with the employment-related needs of individuals with disabilities. All individuals are or had been, members of steering committees, service providers, mental health professionals, state senators, or special education administrators (Dalgarn et al., 2015).

Data was collected through personal interviews with the participants. The participants in these interviews all had experience with VR services, individuals with disabilities. Interviews

conducted were semi-structured with only one interview protocol utilized. The interview protocol was designed to evaluate the participant's experience with employment-related services for individuals with disabilities and their perspective on strengths and weaknesses of VR services and related programs and initiatives. Transcripts and field notes were compiled following each interview. A triangulation of data was achieved through the inclusion of multiple perspectives from a variety of participants (Dalgarn et al., 2015).

Creating a viable transition program is an essential goal of VR services in Kansas. The majority of participants in the key informant interviews viewed VR as one geared towards oversight, communication, responsiveness, and reflection; however, some areas of concern were expressed by the participants.

The purpose of the key informant interview was to uncover issues, needs, strengths, weaknesses, and suggestions related to the implementation and maintenance of VR services. The following research areas informed this assessment:

- Perspective on the employment-related needs of individuals with disabilities
- Gaps, deficits, or unmet needs of VR services
- Perspective on a transitional development system for securing services for individuals with severe disabilities
- Perspective on most prevalent barriers to employment for Kansans with severe disabilities
- Suggestions for process and services design
- Perspective on pre-employment transition services

- Suggestions to help assure an efficient and effective strategy is put into place for the implementation of the Workforce Innovation and Opportunity Act.

Participants were also allowed to follow the interview with additional comments. All data resulting from interviews were analyzed through the use of initial coding which included in vivo and process coding. Codes were then sorted into natural categories (clusters of meaning) and reviewed to identify emerging patterns or themes. Data was organized according to theme for the purposes of analysis (Dalgarn et al., 2015).

Throughout the interview process participants revealed and discussed their experiences with, and perceptions regarding, the function and implementation of VR services. All participants provided information about the same programs, but from different perspectives and roles. While some data overlapped between the research areas, final placement was determined through a logical approach with data being placed within the area that represented the soundest fit (Dalgarn et al., 2015).

The majority of interview participants believed VR currently offer strong and comprehensive services, but bureaucracy was sometimes frustrating. Participants believed that, universally, expectations for disabled individuals and their services were low, and a concerted effort is required to improve those expectations. Respondents cited the need for additional opportunities for high needs individuals and support for individuals to take advantage of those opportunities (e.g., transportation, technology support, emphasis on strengths and interests, and life skills training) (Dalgarn et al., 2015).

Speed and cohesiveness of services were a theme among interview participants, citing services needed to be provided at a faster rate in order to take advantage of the present health and

motivation of clients, while also reducing frustration for clients and families. Interview participants possessing a background in Special Education cited the danger of severely disabled individuals losing skills due to prolonged wait-times (Dalgarn et al., 2015).

Interview participants emphasized lowering frustration and wait-times, more thorough person-centered case management, and holding higher expectations and being more innovative in what could be deemed a “successful outcome” as suggestions made to strengthen Vocational Rehabilitation Services. Participants also cited more transparency was needed through better communication between Special Education staff and Vocational Rehabilitation (Dalgarn et al., 2015).

All participants felt pre-employment services were of the utmost importance for addressing the employment-related needs of individuals with severe disabilities. Interview participants believed pre-employment services should be provided “as early as possible” and should include multiple components. Participants agreed pre-employment services should be thorough, including ability and interest inventories, generalized work-related and life skills (e.g., money practice, cleaning skills, step-by-step practice), and soft skills (e.g. cooperation, timeliness, hygiene). Interview participants viewed pre-employment services as a cooperation between service providers and schools and believed better communication with schools, strengthened, and more comprehensive school-transitions programs are pertinent to the success of pre-employment services (Dalgarn et al., 2015).

The key informant interview information reflects a desire to understand the programs, services, needs, and expectations of VR services in Kansas. Policy makers have been searching for answers to questions about how VR services in Kansas can be successful for individuals with

disabilities while avoiding meddling or negative results. Encouraging high expectations for programs and participants, more comprehensive case management, and helping establish thorough pre-employment services, were highlighted by the findings of the key informant interview as the best strategies to encourage success for VR clients. This understanding is relevant, not only to the policy-makers, but also to administrators, educators, parents, public health and education curricula designers, and clients. The findings from the key informant interviews help create a more comprehensive picture of the employment-related needs of individuals with disabilities (Dalgarn et al., 2015).

While interview participants were very complimentary of pre-employment services, participants believed more comprehensive services are needed, should be provided at an earlier juncture, and should include a stronger partnership between schools, Vocational Rehabilitation, and employers (Dalgarn et al., 2015).

Educator survey. In addition to the key informant interviews that addressed the needs of severely disabled individuals in Kansas, surveys were developed for educators across the state (the Comprehensive State Needs Assessment was also informed through additional datum collected through client and provider surveys, focus groups, and research into archival data; however, none of that collected information applies to the questions surrounding the unique needs of severely disabled individuals in Kansas). The educator survey was distributed online and was emailed by Kansas State Department of Education to 365 Special Education staff on email listserv with 47 responding, which represents a 12.9% response rate (Dalgarn et al., 2015). While the survey return-rate of 12.9% is considered to be markedly low, the researchers were unable to improve the rate of return.

The largest percentage of respondents were Transition Specialists (36.2%), followed by Special Education Teachers (17.0%), Special Education Directors (14.9%), and Coop Directors (14.9). In addition, respondents included School Administrators (8.5%), Schools Psychologists (6.4%), and a Para Educator (2.1%). The majority of respondents (70.2%) worked directly with students with disabilities. All (100%) worked with students with IEPs and 70% worked with students with 504 accommodation plans. The majority of educators (72.3%) had direct experience working with VR staff (Dalgarn et al., 2015).

Educators indicated overwhelmingly (91.5%) that their students were interested in post-secondary education or vocational training (53.2% strongly agree and 38.3% agree) and that students intend to become employed as adults (97.9% with 66.0% strongly agree and 31.9% agree) (Dalgarn et al., 2015).

Two questions asked educators to rank a number of methods for most effective learning and educating practices for severely disabled students. The first question asked about the most effective method for forming a cohesive partnership and how they can best assist students with severe disabilities during their transition period. The method ranked most effective (#1) by the majority of educators (47%) was “one-on-one contact from a VR counselor”. The method ranked most effective (#1) by 32% of educators was “VR personnel participation in IEP meetings”.

The second question specifically targeted at transition for severely disabled students asked the following question: “To assist severely disabled students to be successful in post-secondary life, which of the following pre-employment transition services are most important?” Educators were asked to rank order from 1-7 with 1 being most important and 7 being least

important. The pre-employment transition service respondents indicated was most effective (#1) by the majority of educators (37.0%) was “work-based learning experiences”. The method ranked most effective (#1) by 22.0% of educators was “workplace readiness training”. “Vocational assessment and exploration” was ranked most effective by 19.0% of respondents, while “instruction in self-advocacy and self-care” was ranked most effective by 17.0% of respondents. The three additional options: “assessment of a client’s support network and willingness to work”, “employer education and preparedness”, and “additional funding for transition services” all combined to garner the most effective ranking of 5.0% of respondents (Dalgarn et al., 2015).

In conclusion, the parts of the 2015 Kansas Comprehensive State Needs Assessment dedicated to the unique transition needs of severely disabled individuals find strong agreement between the Key Information Interviews and the Educator Survey responses. Both key informants and educators that participated in the assessment agree on the importance of addressing the needs of severely disabled individuals, and that vocational-readiness, social and living skills, along with self-advocacy and self-care should be prominently featured in any comprehensive transition program. Information from the educator survey also indicated a need for vocational consulting and assessments. The information from the Comprehensive State Needs Assessment will help to inform the variable selection for this study (Dalgarn et al., 2015).

Empirical Studies

Statement of the Problem

While past studies (Bolton et al., 2000; Heal & Rusch, 1995; Rimmerman, Levy & Botuck, 1995) have attempted to identify predictors of employment outcomes for consumers with various disabilities, but no current study has focused on extremely high needs individuals. The topics of out-of-school transitions, independent living, vocational attainment, and quality of life outcomes for extremely high needs individual—those who, due to their high level of need (low IQ, low or absent verbal communication, ambulatory issues, high-level epilepsy, with multiple disabilities) and have become wards of the state—has largely been ignored in empirical research. This study attempts to begin to fill that void. More specifically the following research questions will be addressed:

Research Questions

The following research question was developed through a review of relevant literature and results from the current Comprehensive State Needs Assessment, prepared for publication in 2015: Is there a relationship between independent living outcomes for school-aged residents of institutionalized settings with high needs disabilities and those residents receiving additional assessment and support in (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care.

Purpose of the Study

The purpose of this study was to examine the relationship between selected variables and independent living outcomes associated with a student with severe disabilities residing in an institutionalized setting in Kansas. Selected variables were developed through a review of the

research base, as well as information taken from the 2015 Comprehensive State Needs Assessment of Vocational Rehabilitation Services of Kansas. Since this study is looking specifically into severely disabled, high needs individuals, all participants in the study must be regarded by medical and mental health staff, as well as Vocational Rehabilitation and the Federal Office of Social Security Services, to have high needs disabilities. Participants must also be wards of the state, and living and receiving services in an institutional setting from a designated state hospital. Consent to participate in the study was issued from the designated human rights committee from the state hospital, and the purpose and methodology of the study was also reviewed by this committee.

Significance of the Study

This study intends to identify the individual variables associated with a level of success among program participants. Each of the four state hospitals participating in this study utilizes a uniform resident independence rating to determine the level of independence that a particular resident is allowed. Identification of the variables associated with independent living will increase the knowledge of Special Education staff and rehabilitation counselors in regard to specific content areas which warrant primary focus during the transition training for best vocational and living placement process results. More importantly, identifying the correlates may result in successful vocational and independent living placement which fulfills the objectives of transition legislation, specifically the Individuals with Disabilities Education Act-Revised (IDEA-R) and the Workforce Innovation and Opportunity Act (WIOA). The objectives of the IDEA-R are required to enable students with disabilities to achieve post-school outcomes, while WIOA attempts to ensure that even the most severely disabled individuals are able to find

their least restrictive vocational and living environments (Roessler & Rubin, 1998; Dalgarn et al., 2015). The objective of Special Education and Vocational Rehabilitation is to ensure students a transition from secondary education to high quality, needs-determined vocations and living situation (Roessler & Rubin,1998).

The remainder of this chapter provides explanations of acronyms and definitions used throughout the study.

Definitions of Acronyms

CAP- Client Assistance Program

CETA- Comprehensive Employment and Training Act of 1973

CIL- Centers for Independent Living

DOL- Department of Labor

EAHCA- Education of the Handicapped Act of 1975

HSP - Home Services Program

IDEA-R-Individuals with Disabilities Education Act-Revised

IEP- Individualized Education Program

IPE- Individualized Plan of Employment

KDADS- Kansas Department of Aging and Disability Services

OJE- On the Job Evaluation

OJT- On the Job Training

SPSS- Statistical Package for Social Services

SSDI- Social Security Disability Insurance

SSI- Supplemental Security Income

STEP- Secondary Transitional Experience Program

STWOA- School To Work Opportunities Act of 1994

TANF- Temporary Assistance for Needy Families

VCM- Virtual Case Management

VR- Vocational Rehabilitation Services

WIOA- Workforce Innovation and Opportunity Act

Definition of Terms

Primary Disability- any disability which, is determined a significant disability by a physician, psychologist, and/or rehabilitation counselor through thorough evaluation to cause a substantial physical or mental impairment.

Secondary Disability- any disability which combined with a primary disability which seriously limits at least one of any individual functional capacities.

Rehabilitation Closure - when the consumer has reached the employment outcome objective outlined within their IPE which involves maintaining employment for not less than 90 days, ensuring stability of employment following rehabilitation closure.

Non-Rehabilitation Closure - A consumer's services may be terminated at any time if the rehabilitation professional has determined that the client has refused services or failed to cooperate, cannot be located, is unable to resume services over a substantial time period, the applicant is determined ineligible, or after a period of trial work the client is incapable of achieving an employment outcome.

Severely Disabled - This term will be used in conjunction with the terms "high needs" and

"low incidence". This term refers to an individual with multiple disabilities that must include moderate to severe mental retardation and may include other disabilities acting in conjunction with the mental retardation, including autism, ambulatory disorders, schizophrenia, speech/language disorders, seizure disorders, or other low frequency medical or mental disorders. Individuals deemed "severely disabled had formerly been known under the designation of "uneducable".

Transition - A coordinated set of activities for a student designed within an outcome-oriented process that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation.

Problem Statement

Focus on Instructional and/or Systemic Issues

The purpose of this research study was to examine the effect of identified variables on the independent living outcomes of severely disabled individuals residing in an institutionalized setting in Kansas. This study attempted to determine if the variables selected through a review of the literature and the results from the 2015 Kansas Comprehensive State Needs Assessment are valuable in determining successful transition outcomes for vocational and independent living skills in hopes of helping individuals with severe disabilities improve their quality of life.

Is Directly Observable

The current baseline for severely disabled Kansans is an institutional setting: living in a highly supported and restricted living facility with no vocational tasks. The four state hospitals

operated by the Kansas Department of Aging and Disability Services utilize a consistent independence rating for individuals with severe disabilities residing on hospital grounds. This rating assesses a number, 1 through 5, for each resident based on their independent living skills. A rating of 1, the most restrictive rating, would indicate that the individual is never allowed out of supervision, off of hospital grounds, has physical and chemical restraints written into their plans of treatment, and is not allowed to participate in sheltered employment. Conversely, an individual rated at 5, the least restrictive rating, would be allowed freely travel the hospital grounds during daylight hours without staff supervision, have no restraint plan, allowed to make home visits, have some control over personal finance, allowed one-on-one trips off campus, and allowed to participate in sheltered employment. Individuals rated at either 4 or 5 are allowed by the hospital independent rating system to participate in sheltered employment. The postulate of this study asserts that if these individuals were to receive pre- and continuous assessments into their progress through a focused, leveled, and comprehensive curriculum, then the individuals participating in the curriculum may achieve a higher level of living independence, even if they remain in an institutional setting, as expressed in an increase in the hospital's resident independence rating, and the individual may be able to regularly participate in a vocation (even if that is sheltered, non-competitive employment).

Is Actionable

The Special Purpose School at the Parsons State Hospital is a school established and dedicated to serving the educational needs of severely disabled students in Kansas ages 8 through 21. Students of the Special Purpose School are wards of the state and live in an institutionalized setting within the adolescent wing of the Parsons State Hospital. Historically, when students

aged out of their educational programs, they were simply moved to one of the adult areas of the hospital. However, with legislation from the Workforce Innovation and Opportunity Act, more emphasis will be placed on the transition component of the Individualized Education Plans (IEP) of these students, and as a result, these students may have a greater chance of improving their quality of life by reaching higher levels of independence within the state hospital system.

Connects to Broader Strategy of Improvement

By focusing on the transition needs of severely disabled individuals that attend the Special Purpose School, the Special Purpose School is directly addressing the transition components of the Workforce Innovation and Opportunity Act. By instituting a comprehensive curriculum with a dedicated continuous assessment tool that thoroughly integrates the variables identified by the research-base and the results of the 2015 Kansas Comprehensive State Needs Assessment, the Special Purpose School will seek to improve the quality of life outcomes in living and vocational skills for its students.

Is High Leverage

The Special Purpose School at the Parsons State Hospital views the transition emphasis of the Workforce Innovation and Opportunity Act as an opportunity to help severely disabled individuals to make a clear and measurable quality of life improvements by instituting a leveled curriculum that supports independent living skills and vocational tasks.

Chapter 2

Review of literature

Chapter 2 provides a review of the literature related to the purpose of this study beginning with the results of empirical studies. Second, a historical overview of transition legislation including the Rehabilitation Act of 1973 (PL 93-112, 1973), Carl D. Perkins Vocational and Technical Education Act of 1984 (PL 98-524, 1984), and the Individuals with Disabilities Act; Revised 2004 (PL 101-476, 2004) is presented. Thirdly, a review of key program components of the Office of Rehabilitation Services and information on the Functional Independence Skills Handbook (FISH) being piloted by the Special Purpose School of the Parsons State Hospital, including the assessment instrument and seven domain curriculum targeted at high needs individuals with severe disabilities: (a) vocational assessment and exploration, (b) workplace readiness, (c) independent living skills, and (d) self-advocacy and self-care. Each major section in the literature review served a specific purpose in providing the reader with the necessary background for understanding the roots of the research problem.

Review of Related Literature

The purpose of this study was to examine the effect of identified variables on the independent living needs of severely disabled individuals residing in an institutionalized setting in Kansas.

This chapter provides an overview of special education, giving weight to the literature and data pertaining to special education transition services for students with severe disabilities. This literature review also delves into the historical and current context of transition services in special education. Facts about student characteristics, special education, and transition outcome

data were obtained from the Twenty-Sixth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Improvement Act (United States Department of Education, Office of Special Education Programs, 2004).

Literature Search and Review Process

This literature review began with a search of electronic journal databases in the education and social sciences subject areas, with particular emphasis on special education and the philosophical and application aspects of transition service, including the intent of transition service, models of transition service, and best practices. Searches for transition yielded a moderate number of relevant results (approximately 232). More than 60% of the results from searches on transition services were written between 1992 and 2002, placing the majority of articles and studies prior to the 2004 renewal of IDEA.

Very few of the 232 relevant articles deal with the transition from the perspective of severely disabled individuals. Due to the scope of the study, current terms "low incidence disabilities", "intellectual disability", and "developmental delay" were searched alongside the anachronistic terms "mental retardation" and "functional disabilities" were included in cross-referenced searches with transition; yielding only 17 relevant results.

In order to expand the overall search results, under the guidance of the University of Arkansas research librarian a new search of online databases was conducted using the previously searched disability-related keywords in addition to using wildcard paired combinations of the following keywords: transition, best practice, disability, outcome, employment, success, education, and postsecondary. These database searches resulted in more than 3,000 documents spanning the time-period between 1991 and 2015. Database searches were redefined, and in

some cases titles and abstracts of the documents were reviewed, and relevant journal articles, studies, reviews, and dissertations were obtained. Nonrelevant articles that were eliminated included studies that were conducted on student populations outside of the United States, studies that addressed the transition from Part C of IDEA (i.e., infants and toddlers) to Part B of IDEA (i.e., school-aged children), duplicates, and non-special education related entries.

After further sorting and discrimination, the second database search yielded 48 additional articles, studies, reviews, and dissertations were obtained and reviewed for relevance to the topic. In total, the review of the relevant literature on transition services for severely disabled individuals yielded 65 total results.

All literature sources reviewed for this study were obtained through the University of Arkansas and Pittsburg State University library collection and online journal database using the following search engines: Education Full Text, ERIC, PsychINFO, OVID, and JSTOR.

This literature review is comprised of four broad sections that examine the following areas: (a) special education, (b) transition in special education, and (c) community integration.

Examination of Special Education

This examination addresses the historical and current context of special education as it relates to services for school-age children and youth. Transition information and outcomes, conceptual models of transition service and community integration are also described in this chapter. In addition, datum on the current context of transition for transition-aged students with moderate to high needs disabilities is presented.

Historical Context of Special Education

Special education is a relatively recent field of practice within the realm of public education. In Kansas, prior to 1977, most children with disabilities were excluded from public schools entirely. These individuals with special needs often remained at their home or were institutionalized if their level of need was more than families could manage (Yell, 2005). During this time, state and federal legislation required Kansas to re-assess the education of high needs individuals. In 1977, the Special Purpose School at the Parsons State Hospital, a state-run institution, housed a record number of school-aged residents: 423 moderate to severely disabled individuals (Dalgarn et al., 2015). The subsequent decades of inclusive legislation, direct advocacy, and changes in cultural attitudes have helped in paring the enrollment of the Special Purpose School down to 27 of the highest needs individuals residing in the state of Kansas (Dalgarn et al., 2015).

While currently Kansas has no option other than institutionalization for supporting these exceptionally high needs individuals, those with severe disabilities living in institutional settings can become socially isolated and can be deprived of everyday opportunities readily available to their non-disabled peers, such as public schooling, independent living, and the pursuit of a fulfilling vocation (Yell, 2005). Due to medical, mobility, attendant care, and living supports, the cost of housing a severely disabled individual in a state-run institution in Kansas ranges from \$70,000 to \$95,000 annual with an additional \$28,000 per year to support their education (Dalgarn et al., 2015). While a moderately disabled student remaining in their home and attending their neighborhood school is estimated to cost the state of Kansas on average \$13,200 annually in disability entitlements with an additional \$10,500 to their school district to support

their education (Dalgarn et al., 2015).

Related Empirical Studies

As noted earlier, most studies on transition needs have been mainly conducted with individuals with specific learning disabilities; however, a 1986 study by Schalock, Wozen, Ross, Elliot, Werbel and Peterson (1986) stands out for their inclusion of higher needs populations. In their study, Schalock et al. (1986), examined post-secondary school students with moderate to severe disabilities from rural schools. After examining each individual's job interest, skills, and essential entry-level skills, participants were placed in supported vocations that offered training assistance and guided supervision, while also conducting continued skill maintained. Schalock et al. (1986) found that students with mild disabilities were more likely to live independently, maintain employment, and be self-sufficient as opposed to moderately and severely disabled students. Additionally, Schalock et al. (1986) found that the nature of disability, time spent in vocational programs, and IQ to be the most significant predictor variables across the factors of current living environment, primary source of income, and reported quality of life.

These studies, though few and far between, have highlighted the fact that while studies have been conducted and reported upon in the literature focusing on post-school transition outcomes, very few include severely, high needs individuals, and virtually none focus specifically upon predicting outcomes for students with severe disabilities residing in institutionalized setting.

History and Legislation of Transition

Out-of-school transition for individuals with disabilities is the procedure through secondary education and into a sustainable independent living setting. An individual's end-of-schooling is a critical period in life, especially for those in need of continued supports (Gajar, Goodman, & McAfee, 1993). Transition is a consolidation of the individual, family, community, vocation, and leisure activities which creates a personal and individual context for the person for life (Gajar et al., 1993). Wilson (1985) described transition for individuals with disabilities as an "outcome oriented process encompassing a broad array of services and experiences leading to employment" (p. 51). More poetically, Gajar et al., (1993) called transition as "the movement from the protection and dependence of childhood to the risk and independence of a fully realized adulthood" (p. 112). State and federal legislation on transition and services has been debated and amended across decades. Highlights of important and impactful legislation are outlined in the following section.

Vocational Education Act of 1963

The Vocational Education Act of 1963 and the 1968 Vocational Rehabilitation Amendments (PL 83-565, 1968) attempted to prioritize vocational education and transition of persons with disabilities. Both the Vocational Education Act of 1963 and the 1968 Vocational Rehabilitation Amendments were unfunded mandates that required vocational training for individuals with disabilities as a priority. The required programs provided limited access for targeted individuals and demonstrated a lack of significant and sustainable outcomes in personal, social and daily living skills for successful adult adaptation (Gajar et al., 1993).

The non-compliance of rehabilitation professionals in appropriately serving individuals

with disabilities and proper usage of allocated funds warranted exhaustive legislative deliberations precipitating the evolution of notable federal legislation with the intentions of improving services to persons with disabilities in the areas of education, employment, equality and vocational education.

Rehabilitation Act of 1973 (PL 93-112)

The Rehabilitation Act of 1973 (PL 93-112) passed landmark regulations for all individuals with disabilities as introduced in Section 504 of the Act, which states: No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance (p.27). The assumption of this statement implied that the law promised persons with disabilities access to any entity receiving federal funds with no exemptions, including state-funded schools and programs (Rubin & Roessler, 2001).

Education of All Handicapped Act of 1975 (PL 94-142)

The Education of All Handicapped Act of 1975 (PL 94-142, 1975) (EAHCA) earmarked federal funds as a partially-funded mandate for states to provide free and appropriate public education for children regardless of disabilities between the ages of three and twenty-one (Kibbler, 1991). The EAHCA was to ensure that all children with disabilities, regardless of the level of need, access to a free public education (Anstaett, 1990). By 1975, more than eight million children with disabilities were estimated to be living in the United States. Before the passage of EAHCA, many of these disabled individuals had not received appropriate educational opportunities or access to schools (Kibbler, 1991). EAHCA requires each state to devise a state plan meeting minimum standards, ensure grade-level to grade-level progress, and reasonable

modifications and accommodations outlined in the act (Tate, 1980). Kibbler (1991) stated “the act defines free appropriate public education as ‘special education’ and related services that:

- (a) have been provided at public expense, under public supervision and direction, and without charge
- (b) meet the standards of the state educational agency
- (c) include an appropriate preschool, elementary, or secondary school education in the state involved and
- (d) are provided in confronting with the individualized education program required under [the act]” (p. 27).

Carl D. Perkins Vocational and Technical Education Act of 1934 (PL 98-524)

The Carl D. Perkins Vocational and Technical Education Act of 1984 (PL 98-524) mandated vocational assessment, counseling, and transitional support for students with disabilities as well as preparation and cooperation with other federally funded programs (Gajar et al., 1993) to ensure the receipt of training toward recorded vocational goals and objectives in least restrictive environments which were to be reflected in a student’s IEP.

Individuals with Disabilities Act of 1990; Revised 2004 (PL 101-476)

The amendments to the Individuals with Disabilities Education Act (IDEA) (PL 101-476) (now referred to as the Individuals with Disabilities Education Act-Revised (IDEA-R)) reorganized components by installing community-based instruction and independent living as a primary focus of the transition process for individuals with significant needs. Section 626 of the IDEA-R highlights the administration of secondary education and transitional services for adolescents with disabilities (Gajar et al., 1993). IDEA legislation defines transition as a

coordinated set of activities for a student designed within an outcome-oriented process that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and community participation (Rubin & Roessler, 2001). Rubin and Roessler (2001) also noted that transition services should be based on individual's need and reflect the individual's choices and interests, and that comprehensive transition services should include instruction, community-based experiences, and the use of adult living components. The IDEA-R contains stipulations and outlines responsibilities which the state has towards students with disabilities; responsibilities that a state must perform in order to receive federal grants. The IDEA-R emphasized the significance of out-of-school transition planning and services for students with disabilities, hence the inclusion of the statement of transition services with the IPE, which outline services and responsibilities for students in achieving post-school outcomes (Rubin & Roessler, 2001).

Workforce Innovation and Opportunity Act

The WIOA provision related to severely disabled individuals are intended to ensure that individuals with high needs disabilities, especially youth with those disabilities, are afforded the full opportunity to prepare for and obtain competitive integrated employment. Before youth with severe disabilities ("youth" is defined as anyone who is age 14 through 24) can be placed in supported employment or assisted living facilities; the individual must be afforded a meaningful opportunity to access services they need to attempt to achieve less restrictive vocational and independent living outcomes. This provision is aimed at improving the quality of life of individuals with severe disabilities (2014).

Service Description

Office of Vocational Rehabilitation Services

The Kansas Department of Aging and Disability Services' (KDADS), Office of Vocational Rehabilitation Services (VR) is the leading agency in service to people with disabilities, with 51 office locations throughout the state. VR works in conjunction with individuals with disabilities and their families to provide assistance in making informed choices regarding achievement in full community participation through employment, education and independent living opportunities. KDADS/VR is comprised of nine specialized vocational rehabilitation programs for persons with disabilities between the ages of 16 through 64 who have a significant physical or mental impairment, which substantially limits their ability to work. The VR program provides Vocational Rehabilitation Services for their participants. This program is briefly described:

Vocational Rehabilitation Services (VR)

Vocational Rehabilitation Services (VR) provides assistance to people with disabilities in preparation for and seeking adequate employment that compensates through competitive wages and opportunities for advancement. The staff within the VR division is employed to converse with consumers to decipher career options that are correlated with their residual capacities. They also ensure that proper support is afforded to consumers in order to augment their career experiences (i.e. reasonable accommodations).

Functional Independent Skills Handbook (FISH)

The Functional Independent Skills Handbook (FISH) is a curriculum with a pre- and continuous assessment used for determining an individual's ability to perform certain functional

activities from daily life and vocation. FISH was developed for special education teachers and special needs service providers working with individuals with severe disabilities, the assessments, and curriculum, aimed at increasing the functional independence of severely disabled students, is designed and exclusively for students receiving a functional education. The outcome of the program, when successful, is a direct increase in personal independence in those with severe, high-needs, low-incidence disabilities (Killion, 2014).

FISH contains an assessment instrument that can assist the professional in determining a baseline of performance, and assisting in determining goals for future educational or developmental training programs for a person with severe disabilities. FISH also provides sample lesson plans with teaching technique examples for each item evaluated. The assessment directly relates to the accompanying curriculum and vice versa. If used for pretraining and follow-up skills assessment, this material may be helpful in evaluating the effectiveness of an educational or rehabilitation program in providing clear consistency and accountability for teaching efforts, since student progress is visually observable (Killion, 2014).

FISH is a criterion-referenced series of 421 tasks. The assessment instrument and lessons are organized according to seven domains: Adaptive Behavior Skills, Affective (or Emotional) Skills, Cognitive Skills, Sensorimotor Skills, Social Skills, Speech and Language Skills, and Vocational Skills. FISH has a structured curriculum targeted at high needs individuals with severe disabilities. Completion of this instrument should result in a list of skills that the person can perform independently. Within the seven concentrations of the FISH assessments and curriculum, FISH thoroughly covers the variables identified in the research questions (Killion, 2014).

FISH allows (a) Participation in transition planning for students with severe disabilities to certify that relevant planning, training, and that work experiences will be furnished to students that result in opportunities for integrated employment or supplemental training, independent living, and community participation upon completion of secondary education, (b) Strengthening of KDADS/VR enmeshment in educational/vocational/rehabilitation planning for students through involvement in multi-disciplinary staffing, school/joint agreement, personnel meetings, and involvement in the vocational and independent-living components of each student's Individualized Education Program (IEP), and (c) Assertion of continuation of services for all FISH program participants who have not achieved their vocational or independent-living goals prior to leaving school by providing supplemental transition services.

Summary

Very few studies extend themselves to the out-of-school transition of severely disabled individuals, and virtually none include individuals residing in institutionalized settings. Inge et al. (2000) stated that "health issues, soft skills, social security disincentives, and personal care needs all have been documented as impediments to employment for this group of unserved individuals" (p. 185). While the respondents to the 2015 Kansas Comprehensive State Needs Assessment indicated that a fully implemented transition program aimed at assisting severely disabled individuals gain vocational and life skills should include vocational assessments and training along with assistance in gaining social, living, self-advocacy, and self-care skills. Transition programs should focus on the needs of individuals instead of the collective needs of the system (Householder & Jansen, 1999). Transition should focus on the abilities; preferences; characteristics; and strengths; while accommodating or rectifying shortcomings and deficits.

Chapter 3

Methodology

Chapter 3 explains the methodology of the study and discusses the number of participants and their location, outside professionals' participation in data collection. The procedure section explains the use of the Functional Independent Skills Handbook curriculum and assessments. The instrumentation section explains the function and utilization of the data collection, sampling procedure used by the researcher, data collection process, and the statistical analyses used to analyze the data. Building on the foundation established by the Comprehensive State Needs Assessment (Dalgarn et al., 2015) which identified the variables in the research questions, selected the curriculum serving as the treatment, and identified the desired outcome (higher levels of independence for individuals with severe disabilities), this study was purely quantitative in nature and worked towards an outcome-oriented evaluation of the treatment curriculum.

Problem Setting/Context

The Special Purpose School at the Parsons State Hospital is a school established and dedicated to serving the educational needs of severely disabled students in Kansas ages 8 through 21. Students of the Special Purpose School are wards of the state and live in an institutionalized setting within the adolescent wing of the Parsons State Hospital. Historically, when students aged out of their educational programs, they were simply moved to one of the adult areas of the hospital. However, with legislation from the Workforce Innovation and Opportunity Act, more emphasis will be placed on the transition component of the Individualized Education Plans (IEP) of these students, and as a result, these students may have a greater chance of improving their quality of life by reaching higher levels of independence within the state hospital system.

The purpose of this research study was to examine the effect of identified variables on the independent living outcomes for severely disabled individuals residing in institutionalized settings in Kansas. This study attempted to determine if the variables selected through a review of the literature and the results from the 2015 Kansas Comprehensive State Needs Assessment are valuable in determining successful transition outcomes for vocational and independent living skills and if the curriculum selected by the Kansas Department of Aging and Disability Services was adequate in addressing those variables in hopes of helping individuals with severe disabilities improve their quality of life through higher levels of independence.

Research Sample and Data Sources

Participants for this study were 27 persons, ranging from ages 13-21 who are regarded as being severely disabled and are receiving a functional education rather than primarily academic. All participants are residents of the Parsons State Hospital and are receiving their education on hospital grounds at The Special Purpose School. Permission for the students to participate was provided from the Human Rights Committee at the Parsons State hospital following a comprehensive review of the purpose of the study. The 27 students participating in this study comprise the entire student population of The Special Purpose School. No demographic nor personally identifying data was taken from the group; however, each participant does carry a diagnosis of moderate to severe intellectual disability, and most are diagnosed with autism spectrum disorder. Some participants have additional medical and psychiatric diagnoses; however, as a special education service category, all students are served under the multiple, severe disabilities category. While ethical concerns may exist, all aspects of the study had been reviewed and approved by the Parsons State Hospital Human Rights Council. In addition, the FISH curriculum was acquired by the Kansas Department of Aging and Disability Services to

address the independent living concerns for severely disabled individuals living in-residence in the four state hospitals.

Data Collection Methods

Participants

This study involved twenty-seven severely disabled participants living in-residence at a state-run institution in Kansas. All participants in this study were between the ages of 13 and 21, all participants are regarded as having multiple disabilities. A review of relevant records indicate that all participants are moderately to severely intellectually disabled (indicated as having an IQ of 60 or below); however, the IQs of six participants are considered “unmeasurable”. Twenty-two participants are diagnosed as being on the autism spectrum, of which ten are functionally non-verbal and six are totally non-verbal. Fifteen of the participants are reported as having ambulatory, motor, or mobility impairments. Eight participants have various types of seizure disorders, and six participants require some level of assistance tending to their own self-care. No racial or gender information was collected on the individuals participating in this study. The twenty-seven individuals participating in this study represents 22.12% of individuals meeting the same criteria living in state-run institutions in Kansas.

Instrumentation

Each resident of the Parsons State Hospital is assessed a rating, 1 to 5, indicating their level of independence. The determination of the rating is done by a hospital employed psychologist and based on behavioral objectives. All residents of the State Hospital are the subject of an individualized tally sheet on which datum is collected in 30-minute segments. Datum is collected for each resident over six behavioral areas, four negative behaviors, and two positive behaviors. The 4 tallied negative behaviors: (1) temper outbursts, (2) self-injurious

behavior, (3) elopement, (4) property destruction. The two tallied positive behaviors: (5) gains attention in an appropriate manner and (6) accepts alternative activities when desired activity is unavailable. Additionally, some residents have an additional negative tallied behavior regarding inappropriate sexual behavior. Three participants in this study had the additional negative behavior regarding inappropriate sexual behavior.

At monthly intervals, behavioral data is assessed for each resident and independence ratings are updated. If a resident's datum is observed to be decreasing in the negative behaviors and increasing in the positive behaviors, the assigned psychologist makes the recommendation to move the resident to a less restrictive level of independence.

Procedure

The Functional Independent Skills Handbook (FISH) pre-assessment was used for determining each individual student's ability to perform certain functional activities from daily life and vocation. The pre-assessment information was used to determine each individual's starting place in the FISH curriculum. After determining each student's independent level, each student received the curriculum recommended 90-minute block dedicated to functional lessons rotating between direct instruction and independent work with guided prompts over all four quadrants (i.e., (a) vocational assessment and exploration, (b) workplace readiness, (c) independent living skills, and (d) self-advocacy and self-care) (Killion, 2014). The curriculum was tailored to the unique needs and levels of each individual student. At two-week intervals, each student was reassessed using the FISH continuous-assessment device to mark gains or declines, and to either progress or regress in one of more curriculum quadrants to ensure that the curriculum is responsive to the needs of the individual. The FISH curriculum recommends a

student receive a minimum of four assessments from the continuous-assessment instrument to show consistent trends in student growth and need, with two weeks in-between assessment, the term of the study was determined to be 6 weeks in length.

The FISH curriculum will be delivered by a contingent of three special education teachers, six paraeducators, and one transition/vocation specialist. All staff working with students have attended FISH facilitator training and have achieved a score of 80% or better on the FISH facilitator assessment. The facilitator training and assessment will be relied upon to maintain fidelity of treatment.

The independence rating for each participant was assessed by psychologist of the Parsons State Hospital to serve as a pre-treatment reference point. The independence ratings were combined and averaged to produce a mean for the purposes of comparison. Following the 6 weeks of treatment from the FISH curriculum, the independent rating for each student was reassessed by psychologist of the Parsons State Hospital. The post-treatment independence rating was also combined and averaged for a post-treatment mean for the purposes of comparison. The 90-minute FISH curriculum initiated on the first school day following the completion of the pre-treatment reference.

Data Analysis Methods

Statistical Analysis

The pre- and post- group mean of the independence rating were compared a pre-/post- using a paired samples *t*-test to determine if 90 minutes of FISH curriculum and continuous assessments applied with fidelity, provided 5 days a week over a 6 week period (35 instructional days) could be used to address the determined variables of (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy

and self-care were able to yield statistically significant gains in independent living as reflected in the independence rating determined by collection of behavioral data. The SPSS Statistics software package was used to perform all statistical analyses.

A review of the literature on the properties and research recommendations of the paired samples *t*-test as a function of sample size, effect size, and population distribution (e.g., Blair et al., 1980; De Winter & Dodou, 2010; Fay & Proschan, 2010; Ramsey, 1980; Sawilowsky & Blair, 1992; Sheppard, 1999; Zimmerman & Zumbo, 1993), suggests that the use of the *t*-test with very small sample sizes is not only feasible, but generally acceptable.

Fritz et al. (2012) calculated the sample size required for the *t*-test as a function of statistical power and effect size using simulations, and found that any sample size greater than 5 would suffice for a paired samples *t*-test. Fitts (2010) also investigated the criteria for simulated *t*-tests, with an emphasis on small sample sizes (3–40 subjects per group) and large effect sizes (between 0.8 and 2.0). The author found that it is possible for a paired samples *t*-test to retain appropriate statistical power, as long as very low *p* values are observed (equal to or less than .05). Campbell et al. (1995) estimated sample sizes required in two-group comparisons and concluded that a sample size as small as 5 per group may be suitable as long as one accepts very low statistical power. All of these recommendations and limitations were considered and accepted in the selection of the statistical measure used in this study. A review of the literature on the properties and research recommendations of the paired samples *t*-test as a function of sample size, effect size, and population distribution (e.g., Blair et al., 1980; De Winter & Dodou, 2010; Fay & Proschan, 2010; Ramsey, 1980; Sawilowsky & Blair, 1992; Sheppard, 1999; Zimmerman & Zumbo, 1993), suggests that the use of the *t*-test with very small sample sizes is

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Trustworthiness

The trustworthiness of the study will be pre-emptively addressed, first through training on the FISH curriculum with all participating staff; secondly, through additional training and oversight of the transition specialist. While all staff is, or will be, trained through professional development and in-service training specifically designed and delivered by national FISH trainers, the curriculum specialist will be the recipient of the training for FISH trainers.

In addition to pre-emptively addressing trustworthiness through adequate and uniformed training, the validity of the study and results will also be maintained through the regular assessments of students participating in the study. The FISH curriculum provides for regular and continuous assessments, and suggests that the assessments be performed pre-curriculum and at two week intervals. The assessments are intended to show progression, regression, or no change, with the curriculum responding to the results of the assessment by progressing the participant

further along the curriculum, re-teaching skills, or continuing to work on the same set of skills. Assessment results for each student at each interval will be included in the Results section. To insure interrater reliability and agreement, all assessments will be conducted by transition specialist and then reviewed by all three participating special education teachers.

Limitations and Delimitations

This study was limited in scope to only middle and high individuals with severe disabilities, aged 13-21, living in-residence at a state-run hospital for the severe disabled in the state of Kansas. The small group size ($n = 27$), although appropriately sized for the type of statistical analysis performed, still limits the scope of the study. The study was also limited by the lack of a control or comparison group.

Summary

This quantitative research study was designed to build on the foundation established by the Comprehensive State Needs Assessment (Dalgarn et al., 2015) which identified the vocational and independent living variables of (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care. The Kansas Department of Aging and Disability Services selected the Functional Independent Skills Handbook curriculum to address the areas identified in the Needs Assessment and identified the desired outcome (higher levels of independence for individuals with severe disabilities). This study attempts to gage the efficacy of the FISH curriculum in helping individuals with severe disabilities achieve higher levels of independence as determined by their outcomes on behavioral goal evaluations performed by the psychological staff at the Parsons State Hospital. The study was purely quantitative in nature and worked towards an outcome-oriented evaluation of the treatment curriculum.

Chapter 4

Results

Chapter 4 explains the quantitative results of the study. The research analysis for this study was two-dimensional: First, the study was interested in learning whether the Functional Independence Skills Handbook (FISH) curriculum when conducted with fidelity with individuals with severe disabilities yielded increases in the individual's independence as measured by the independence rating for residents of state institutions. Second, as a program evaluation tool, this study was also interested in evaluating if, and to what extent, the FISH curriculum is successful in achieving increases in the variables of (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care for students regarded as having the highest level of disability-related needs in Kansas and who are anticipating out-of-school transitions.

Descriptive information on the participants

This study involved twenty-seven severely disabled participants living in-residence at a state-run institution. All participants were between the ages of 13 and 21, all participants are regarded as having multiple disabilities. A review of relevant records indicate that all participants are moderately to severely intellectually disabled (indicated as having an IQ of 60 or below); however, the IQs of six participants are considered "unmeasurable" according the psychological staff. Twenty-two participants are on the autism spectrum, of which ten are functionally non-verbal and six are totally non-verbal. Fifteen of the participants are reported as having ambulatory, motor, or mobility impairments. Eight participants have various types of seizure disorders, and six participants require some level of assistance tending to their own self-

care. No racial or gender information was collected on the individuals participating in this study. The twenty-seven individuals participating in this study represents 22.12% of individuals meeting the same criteria living in state-run institutions in Kansas.

Data Analysis

Research question one: Does the Functional Independence Skills Handbook curriculum increase independent living outcomes for severely disabled, school-aged individuals living in an institutionalized setting in Kansas?

A paired samples *t*-test comparing the independence rating before and after the six weeks of FISH curriculum was conducted with the group of participants. The paired samples *t*-test showed a statistically significant increase to the participants' independence rating as measured by the psychological services staff of the Parsons State Hospital following the application of the FISH curriculum (see Table 1). This may indicate that as a group, the participants displayed fewer negative behaviors, temper outbursts, self-injurious behavior, elopement, property destruction, and inappropriate sexual behavior. The observed increase in the participant's independence rating may also indicate that participants displayed more positive behaviors by gains attention in an appropriate manner and accepts alternative activities when desired activity is unavailable.

Table 1
Results of paired samples t-test for Independence Rating

Outcome	Pretest		Posttest		n	95% CI for Mean Difference	r	t	df
	M	SD	M	SD					
Independence Rating	2.21	0.79	3.57	0.79	27	-1.83, -0.88	.85*	5.869*	27

* $p < .05$.

A paired-samples *t*-test was conducted to evaluate the impact of the Functional Independence Skills Handbook curriculum on participants' independence ratings issued by the psychological staff of the Parsons State Hospital. Results in Table 1 indicate a statistically significant increase in FISH scores from pre-assessment ($M = 2.21, SD = 0.79$) to post-assessment ($M = 3.57, SD = 0.79$), $t(27) = 5.87, p < .005$.

Research question two: Does the Functional Independence Skills Handbook curriculum increase the variables of (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care for severely disabled, school-aged individuals living in an institutionalized setting in Kansas?

A paired samples *t*-test comparing Functional Independence Skills Handbook assessment results in the areas of (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care was conducted before and after the six weeks of FISH curriculum with the group of participants. A paired samples *t*-test was run for each of the variables and results showed a statistically significant increase in all four measured variables following the application of the FISH curriculum (see Table 2). This may indicate that as a group, the participants displayed greater knowledge, abilities, and competencies in the areas of (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care.

Table 2
Descriptive Statistics and paired samples t-test Results for Q1, Q2, Q3, and Q4

Outcome	Pretest		Posttest		n	95% CI for Mean Difference	r	t	df
	M	SD	M	SD					
V(a)	12.43	6.45	17.55	7.71	27	-6.14, -4.14	.75*	10.56*	27
V(b)	15.29	10.77	20.82	12.25	27	-6.59, -4.48	.86*	10.74*	27
V(c)	22.89	11.72	36.46	14.74	27	-18.0, -9.14	.90*	6.9*	27
V(d)	12.95	4.02	14.96	4.29	27	-7.16, -5.2	.75*	12.95*	27

* $p < .05$.

A paired-samples *t*-test was conducted to evaluate the impact of the Functional Independence Skills Handbook curriculum on participants' scores on the domain of vocational assessment and exploration. Results in Table 2 indicate a statistically significant increase in FISH scores from pre-assessment ($M = 12.43$, $SD = 6.45$) to post-assessment ($M = 17.55$, $SD = 7.71$), $t(27) = 5.39$, $p < .005$.

A paired-samples *t*-test was conducted to evaluate the impact of the Functional Independence Skills Handbook curriculum on participants' scores on the domain of independent living skills. Results in Table 2 indicate a statistically significant increase in FISH scores from pre-assessment ($M = 15.29$, $SD = 10.77$) to post-assessment ($M = 20.82$, $SD = 12.25$), $t(27) = 10.74$, $p < .005$. The results indicate a statistically significant difference.

A paired-samples *t*-test was conducted to evaluate the impact of the Functional Independence Skills Handbook curriculum on participants' scores on the domain of workplace readiness training. Results in Table 2 indicate a statistically significant increase in FISH scores from pre-assessment ($M = 22.89$, $SD = 11.72$) to post-assessment ($M = 36.46$, $SD = 14.74$), $t(27) = 6.29$, $p < .005$. The results indicate a statistically significant difference.

A paired-samples *t*-test was conducted to evaluate the impact of the Functional Independence Skills Handbook curriculum on participants' scores on the domain of self-advocacy and self-care. Results in Table 2 indicate a statistically significant increase in FISH scores from pre-assessment ($M = 8.79, SD = 4.02$) to post-assessment ($M = 14.96, SD = 4.29$), $t(27) = 12.95, p < .005$. The results indicate a statistically significant difference.

Chapter 5

Discussion

The lack of research on the out-of-school transition needs of severely disabled individuals reflects an inherent misjudgment in the ability of these individuals to work to improve their vocational and independent living outcomes, and as a result improve their own quality of life. Recently, policy makers have placed more emphasis on attempting to learn the factors which contribute most strongly to successful post-school transitions, higher levels of independence, and ultimately greater quality of life improvements and enhanced independence. New legislation has also added to the need for answers to what can bring about thorough programing improvements for those regarded as the highest needs individuals in the state of Kansas.

While some instruments exist to provide educators with insight into the functional and vocational capabilities of individuals with disabilities, Kansas stakeholders identified four areas that most align the with a full ecological view of the current state of transition needs in Kansas for the most severely disabled population as identified by the Comprehensive State Needs Assessment: (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care. Policymakers at the Kansas Department of Aging and Disability Services selected the Functional Independence Skills Handbook (FISH) curriculum as a pilot program for addressing the identified variables, since the FISH curriculum best aligned with the variables and was comprehensive in nature. As a program evaluation, this study confirms the FISH curriculum's ability to show increases in all four identified variables when conducted with a severely disabled population living in a state-run, institutionalized setting in Kansas. This study also confirms the efficacy of the FISH curriculum; and by extension, the identified research variables, for increasing independent living outcomes

for the same population. While participants in the study did show faster gains in some areas over others, all four variables showed statistically significant increases, and the research suggests that each of the four variables significantly contribute to the independent living outcomes of the participants.

The goal of this research was to contribute to the field of knowledge in the vocational and independent living needs of severely disabled individuals in Kansas. The research variables of this study were as follows: (a) vocational assessment and exploration, (b) workplace readiness training, (c) independent living skills, and (d) self-advocacy and self-care. The understanding of the effect of these variables on the independent living needs of individuals with severe disabilities is relevant not only to the researcher, but also to administrators, educators, parents, disability service providers, education curricula designers, and policy-makers. The quality of the findings from this research lies in the resulting comprehensive picture of the needs and expectations of vocational and independent living training needs of severely disabled individuals living in institutional settings in Kansas. Since the transition needs of severely disabled special education students is placed at the forefront of this study, and that all participants are school-aged and currently receiving educational services, the findings may be particularly useful for administrators, educators, and researchers.

As a quantitative study, the 27 participants in the study represent 22.12% of the overall state population of severely high needs individuals; marked as those living in a state-run residential facility, viewed as being severely multi-disabled and/or medically fragile, and regarded as in need of transition and vocational services by state and federal special education regulations; the research may have a strong ability to be generalized in Kansas and other states

that use a similar institutionalized care model of service delivery. Although this study does utilize datum collected on participants in a particular context, the findings are enriching to the field of special education and disability studies concerned with transition policy, severe disabilities, and institutionalization.

The findings and conclusions generated are of potential value to stakeholders working within the context of the study, as well as individuals identified as severely disabled and living and being served in institutionalized settings. This research has provided a richer view of the quality of life needs of individuals with severe disabilities being served in institutionalized settings in Kansas, as well as identifying key variables that offer statistically significant contributions to vocational and independent living outcomes for individuals within this demographic. Administrators, educators, parents, schools, policy makers, and disability service providers and programs may use the findings from this research to further explore the quality of life and independent living needs of severely disabled individuals in Kansas.

In conclusion, all four vocational and independent living variables identified by the Comprehensive State Needs Assessment: (a) vocational assessment and exploration; (b) workplace readiness training; (c) independent living skills; and (d) self-advocacy and self-care, showed a statistically significant increase following the application of the FISH curriculum, and the increase contributed to in the independence rating and personal freedom of severely disabled individuals residing in a residential setting in a state-run facility in Kansas. This increase in independence may translate to higher quality of life for the individual and less expense for the state.

The results obtained by this study may be extremely useful to educators, service providers, and policy makers in Kansas, as well as other states utilizing a similar institutionalization model for severely disabled individuals. The study yielded statistically significant results that a focused, leveled curriculum emphasizing (a) vocational assessment and exploration; (b) workplace readiness training; (c) independent living skills; and (d) self-advocacy and self-care can increase the independence level of individuals with severe disabilities.

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Workforce Innovation and Opportunity Act of 2014, Pub.L. 113-128.



Office of Research Compliance
Institutional Review Board

December 22, 2016

MEMORANDUM

TO: Joe Dalgam
Carleton Holt

FROM: Ro Windwalker
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 16-12-351

Protocol Title: *The Quiet Discrimination of Lowered Expectations: Examining Transition and Independent Living Needs of Individuals with Severe Disabilities in Kansas*

Review Type: EXEMPT EXPEDITED FULL IRB

Approved Project Period: Start Date: 12/22/2016 Expiration Date: 12/21/2017

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<https://vpred.uark.edu/units/rscp/index.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 27 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior* to implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or irb@uark.edu.