CONCEPTUALIZATION OF ADVOCACY AMONG ADOLESCENTS WITH DISABILITIES AND CHRONIC ILLNESSES

by

Elizabeth A. Winter

BS in Psychology, The Ohio State University, 2016

Submitted to the Graduate Faculty of

the Department of Behavioral and Community Health Sciences

Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2018

UNIVERSITY OF PITTSBURGH

Graduate School of Public Health

This thesis was presented

by

Elizabeth A. Winter

It was defended on

July 3, 2018

and approved by

Thesis Advisor:

Mary Hawk, DrPH, LSW
Assistant Professor
Department of Behavioral and Community Health Sciences
Graduate School of Public Health, University of Pittsburgh

Committee Members:

Thistle Elias, DrPH
Assistant Professor
Department of Behavioral and Community Health Sciences
Graduate School of Public Health, University of Pittsburgh

Elizabeth Miller, MD, PhD
Chief, Division of Adolescent and Young Adult Medicine
Children's Hospital of Pittsburgh of UPMC
Professor of Pediatrics
School of Medicine, University of Pittsburgh

Sarah Elizabeth Morrow, MA
Department of Pediatrics, School of Medicine, University of Pittsburgh
Division of Adolescent and Young Adult Medicine
Children's Hospital of Pittsburgh of UPMC

Mary Hawk, DrPH, LSW

CONCEPTUALIZATION OF ADVOCACY AMONG ADOLESCENTS WITH DISABILITIES AND CHRONIC ILLNESSES

Elizabeth A. Winter, MPH

University of Pittsburgh, 2018

ABSTRACT

Adolescence is a turbulent time for most people, and it is accompanied by many transitions. Many adolescents will transition into post-secondary education and/or employment. All adolescents must transition into adult medical care and adult life. Adolescents with disabilities go through these same transitional periods, and literature supports that knowledge of advocacy and practice with advocacy skills can ease these transition processes. However, gaps remain surrounding evidence-based interventions for advocacy building. The primary goal of this research was to investigate how adolescents with disabilities think about and understand advocacy and advocacy skills. Adolescents were recruited from Children's Hospital Advisory Network for Guidance and Empowerment (CHANGE), which is a youth-led initiative based out of Children's Hospital of Pittsburgh of UPMC that focuses on medical transition and leadership development for youth with disabilities and/or chronic illnesses. Additionally, adult mentors who are all members of a highly active community advocacy group and are all individuals living with disabilities/chronic illnesses were recruited as a comparison sample. This was a mixed-methods exploratory study that investigated the understanding of advocacy and advocacy skills among groups of adults and adolescents living with disabilities and/or chronic illnesses. Cultural domain analysis and validated surveys were the principle methods used with each sample. The public health significance of this work lies in the cultural models surrounding the concepts of advocacy

developed from these populations and the novel adaptation of cultural domain analysis methodology. Accommodations were made to the research protocol for it to be accessible to any willing participant, regardless of their level of ability. This broadened the application of this mixed methods approach and allowed for more diverse voices to be included.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

PREFACE

people. I have been happy to get to know the young people in CHANGE and I am excited to see where your futures lead. Thank you all for sharing your thoughts with me; I've learned so much from all of you.

Lastly, thank you to my family: my parents, Steven and Lynn, and my siblings, Charles and Emily. You have supported me and loved me always. My parents have always inspired me to dream big, work hard, and do good. You have raised me with a caring heart and your own dedication to helping others, in your careers and lives, has formed me into who I am and driven my passions. I love you. Thanks also to all of my friends and those in Pittsburgh who have become like family. You have gotten me through the highs and lows of the last two years. I am lucky to have all of you in my life.

1.0   INTRODUCTION

Adolescence is a turbulent time for most people. There are many transitions and changes that young people must go through at this time in their lives, and each of these transitions present challenges. All adolescents engaged in health care must go through medical transition; this is the process of shifting out of the pediatric health care system and moving into an adult-centered health care system. Older adolescents in pediatric clinics generally have three fates: transfer to adult doctors, which involves finding new providers and successfully navigating those new relationships; term retention in the pediatric clinic, if possible- many pediatric clinics have mandatory ages when youth can no longer receive services; or leaving medical supervision, either voluntarily or by neglect (Viner, 1999). Youth may also have to face the increased independence and responsibility of managing their own care. When medical transition does not occur smoothly, individuals can experience financial and emotional stress for themselves and their families, delayed or inappropriate medical care, loss of medical care through falling out of the system, and worse health outcomes compared to those who maintain consistent care (Crowley, Wolfe, Lock, & McKee, 2011; Coyne, Hallowell, & Thompson, 2017). For individuals with special or complex health care needs, the importance of consistent medical attention is heightened.

Children's Hospital Advisory Network for Guidance and Empowerment (CHANGE) is a youth-led initiative of Children's Hospital of Pittsburgh of UPMC (CHP), which focuses on

medical transition. This group is comprised of adolescents and young adults, ages 14 to 26, living with chronic illness and/or disability. CHANGE aims to increase support for youth as they go through transition by fostering leadership opportunities and advocacy skills and encouraging members to work towards goals that the youth determine themselves.

The primary research question that drove this thesis was: how do members of CHANGE, a group of adolescents with disabilities and/or chronic illnesses, think about advocacy? This question encompassed not just what makes up their understanding of advocacy and advocacy skills, but also how they cognitively construct and organize that information. Additionally, this thesis investigated if and how the concept of advocacy was shared among members of the same group, and then compared these results to how a group of adult advocates living with disabilities and/or chronic illnesses think of advocacy.

The adult participants were all members of the Consumer Health Coalition's Healthcare Committee for People with Disabilities (HCPD). This group, like CHANGE, is cross-disability; HCPD is an advocacy group comprised of adults living with disabilities and/or chronic illnesses. HCPD members are highly active in both self- and systemic advocacy work. One aspect of this research surrounded evaluating an intervention aimed at uniting members from HCPD and CHANGE. A mentorship program was designed to connect experts in advocacy, selected from members of HCPD, with youth members from CHANGE, with the goal of increasing advocacy skills and deepening the understanding of advocacy among the participating youth. However, due to challenges and delays in implementation, the evaluation of this program was limited and only a brief case study of this mentorship program is presented here.

This thesis will begin with an exploration of the relevant literature: an overview on the adolescent experience of medical transition, the intersection of advocacy skills and people with

disabilities, and the theory behind the selected methods. Gaps in the literature surrounding this population and the lack of tested interventions will also be discussed. This will be followed by a short study on the design and implementation challenges of the mentorship program between HCPD and CHANGE. Next, the methods used to investigate the primary research questions will be introduced. Following this, the results, limitations, practice implications, conclusions, and future steps will be provided. The significance of this project to the field of public health lies in the adaptability of the research methods used and what was learned from this unique population. Both of these ideas will be explored throughout this work.

2.0   BACKGROUND

In this paper, the primary research question surrounds exploring how adolescents with disabilities and/or chronic illnesses think about and understand advocacy and advocacy skills. Addressing this question requires examining several questions within the literature including: why is advocacy important to this group, how has this importance changed over time, and what are potential strategies for developing and investigating advocacy knowledge and skills with this population? The following sections address the literature on these questions as well as elucidate where these questions are left unanswered and how this work fits in to existing frameworks.

2.1   TRANSITION AND ADOLESCENCE

The human lifespan can be divided into many stages (pre-natal, neonatal, infancy, childhood, juvenile, puberty, adolescence, prime and senescence) and each are critical for development of both biological and psychological processes (Rosenfeld & Nicodemus, 2003). While these phases overlap and the distinctions can be somewhat arbitrary, each phase is accompanied by its own physiology, and internal and external factors (Bogin, 1999). The period of transition from adolescence to adulthood is complex and important; it in itself may constitute a life phase with its own physiology and characteristics unique to *Homo sapiens* as a species (Rosenfeld & Nicodemus, 2003).

The concept of transition from childhood/adolescence to adulthood is different and varied across cultural and historical contexts. Globally and over time, there is a prevalent attitude that transition to adulthood involves the gradual development of personal character qualities, such as impulse control and diligence, and culminates in marriage; in contemporary America, the dominant criteria for the transition to adulthood are individualistic qualities, such as accepting responsibility for one's self and making independent decisions, along with becoming financially independent (Jensen Arnett, 1998).

Over the last several decades, one growing area of focus and concern in the transition process is the movement of individuals from pediatrics health care to adult-oriented health care, known as medical transition, particularly for those with complex health care needs. This problem has increased in relevance and discussion in the literature, partially, due to advancement of medicine over time leading to more chronically ill children surviving into adulthood (Blum et al., 1993). While this should be entirely positive, it means that certain conditions that were previously only known in childhood now must be understood across the lifespan, and successful transition must be accomplished for many more individuals, increasing the demand on existing medical systems. Each year in the United States, nearly half a million children with complex health care needs become adults and must navigate adult systems of care (American Academy of Pediatrics, American Academy of Family Physicians, 1996). Attention on this process, in policy and practice, is important for guiding these youth through successful transition.

2.2   SELF-ADVOCACY FOR PEOPLE WITH DISABILITIES

Advocacy, and more specifically self-advocacy, has been defined in many ways over time. Self-advocacy has been defined as an educational goal, an act or skill, a civil rights movement, and more. One publication reviewed and combined these many definitions to derive a single conceptual framework that included four pillars: knowledge of self, knowledge of rights, communication, and leadership (Test, Fowler, Wood, Brewer, & Eddy, 2005). Knowledge of self and rights are important because individuals must first know and understand aspects of themselves, as well as the rights that they possess, before they can successfully communicate to others what they want or need. Then, effective communication becomes vital to self-advocacy. This includes varied modes of communication, including potentially written, verbal, nonverbal, etc., as well as an understanding of negotiation, persuasion, and compromise. Finally, leadership skills allow an individual to not just advocate for their own needs but also to advocate for others and organize groups of individuals with common concerns. Successful interventions for self-advocacy development should touch on these four essential components.

The movement for civil rights for people with disabilities drew inspiration from the civil rights movements of the 1950s and 1960s, advocacy groups for parents of individuals with disabilities, 1970s movements towards normalization and deinstitutionalization of people with disabilities, and the self-help movements of the 1980s; the movement's beginning is traced back to the founding of People First in 1974 (Longhurst, 1994; Test et al., 2005; Williams & Shoullz, 1982). This is an organization promoting the idea that people with disabilities can be responsible for their own social organization, speaking for themselves and sharing their ideas. The founding of this group was followed by chapters being formed around the country for individuals with

disabilities to advocate for their rights. Movements for independent living around this same time period also fostered self-advocacy and activism (Brooke, 1992).

Society often views people with disabilities as being incapable of making decisions about their own lives and needing the guidance and protection of professionals; people with disabilities who are strong self-advocates challenge this view (Siegel & Kantor, 1982; Wehmeyer, Bersani, & Gagne, 2002). Paternalistic views of people with disabilities can be a detriment to their autonomy and independence (Ward, 1988; Wehmeyer, 1992). Self-advocacy for people with disabilities is an ongoing movement that fosters sharing of diverse voices, building of community, and speaking up for individual and group rights.

2.2.1 Disability, Advocacy, and the ADA

People with disabilities have been a part of society throughout the history of humankind. The way that other people and cultures have responded and treated those people has changed significantly overtime. From archaeological evidence of Neolithic tribes viewing disability as possessions by evil spirits and Judeo-Christian beliefs of disability signifying "sinners", through seeing people with disabilities as "deviant" or "nonproductive", history was not always kind, and even through modern times, society has bred stigma and shame around these populations (Mackelprang & Salsgiver, 1996). As described previously, the powerful self-advocacy movements initiating in the 1960s and 1970s began to establish disability consciousness in the United States. From a legal perspective, two landmark moments in time shifted public policy surrounding disability and discrimination dramatically: the passing of Section 504 of the 1973 Rehabilitation Act and The Americans with Disabilities Act of 1990 (ADA). Section 504 banned discrimination on the basis of disability by recipients of federal funds and marked the first time

that exclusion of people with disabilities was viewed as discrimination (Mayerson, 1992). This was also the first time that people with disabilities were viewed as a class, whereas previous public policy addressed the needs of particular disabilities based on diagnosis (Mayerson, 1992). In 1990, the ADA marked the nation's and the world's first comprehensive declaration of equality for people with disabilities (Equal Employment Opportunity Commission, n.d.-a). This law addressed the needs of people with disabilities, prohibiting discrimination in employment, public services, public accommodations, and telecommunications (Equal Employment Opportunity Commission, n.d.-a). In the words of President H. W. Bush at the signing of the ADA, "It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard: independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the rich mosaic of the American mainstream. Legally, it will provide our disabled community with a powerful expansion of protections and then basic civil rights (Equal Employment Opportunity Commission, n.d.-b)."

These impressive pieces of legislation marked dramatic changes in the lives of people with disabilities. Regarding the ADA specifically, those changes have largely been researched and reported surrounding the impact of this legislation on employment for people with disabilities (e.g. DeLeire, 2000; Hotchkiss, 2004; Schall, 1998). However, studies on the impact on the quality of life as well as more intrinsic qualities (self-esteem, self-advocacy, etc.) of people with disabilities remain a large gap in the literature. The ADA and other legislation marked a change in the way people with disabilities are able to engage with the world and spelled out the rights that they are entitled to. Those who lived before the implementation of this policy, those who lived through its creation and implementation, and those who have and will live with this legislation always in place have faced related, but different battles and may

experience different narratives surrounding disability, ability, and advocacy. How implementation of the ADA and challenges in these battles may or may not have affected the people living through those changes and the people living after remains an important questions that warrants further exploration.

2.2.2   Advocacy and Transition

Young people go through many transitions during their adolescence. Many adolescents will transition into post-secondary education and/or employment. All adolescents must transition into adult medical care and adult life. Adolescents with disabilities go through these same transitional periods, however literature shows that education about self-advocacy skills and opportunities to self-advocate are often not given to students with disabilities, despite evidence from both disability and educational research that development of these skills is crucial to successful transition into adult life, including post-secondary education and employment (Arnold, 1991; Aune, 1991; Izzo & Lamb, 2002).

Advocacy skills are also critically important in the context of medical transition. In 2011, the American Academy of Pediatrics (AAP) released a statement entitled, "Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home" which summarizes the process of medical transition, its importance, and states the consensus on practice based implementation recommendations for transition for all youth, including youth with special health care needs and those without, beginning in early adolescence (American Academy of Pediatrics et al., 2011). The statement encourages primary care physicians, nurse practitioners, physician assistants, and other medical subspecialists to adopt their recommendations and describes coordination of the shared responsibilities of parents, family,

and providers to best enable youth to transition successfully. Specifically for youth with special health care needs, there is a section of the AAP statement that directly addresses the need for development of self-advocacy. It states:

> Critical topic areas for the empowerment of youth with special health care needs include self-advocacy and making plans about decision-making status, educational and/or employment opportunities, living arrangements, and community-inclusive opportunities. It is critical to encourage families to initiate training and decision-making opportunities for children with special health care needs at a young age. Families should receive assistance from experts in self-advocacy when considering the range of potential support, which may include personal informal advocates, power of attorney, and limited-to-full guardianship. Important resources include organizations, such as Family Voices; local chapters of The Arc; and lawyers who are experienced in disability issues. Because of the importance of self-advocacy for youth with special health care needs, it is essential that providers initiate conversations about decision-making and begin to plan advocacy support for these youth far in advance of the age of majority (American Academy of Pediatrics et al., 2011).

This reinforces how critical self-advocacy is for the process of medical transition and transition to adult life for those living with disabilities/chronic illnesses. It also stresses the need for starting the conversation, and potential intervention, at a young age.

Related to transition, disclosure is another important disability issue that requires strong self-advocacy skills. People with disabilities must often disclose their disability status in many settings, such as educational, employment, medical, etc., in order to access accommodations that they are entitled to by law. Many studies review issues related to disclosure in the educational setting; they highlight self-advocacy as being important and report that self-advocacy training has become a critical component in enabling a smooth transition from high school to postsecondary education (e.g. Lynch & Gussel, 1996). One systematic review of disability disclosure and accommodations for youth in postsecondary education revealed several barriers and facilitators. Barriers to disclosure and accessing accommodations included stigma, discrimination, and lack of knowledge regarding existing supports and how to access them.

Facilitating factors included self-advocacy skills, mentorship, and realizing the benefits of disclosure (Lindsay, Cagliostro, & Carafa, 2018).

For these settings and others, it is clearly demonstrated that advocacy skills are important to the youth going through these transitions. It is clear how knowledge of legal rights, knowledge of your own needs, and the ability to communicate this information effectively all make up relevant and important advocacy skill sets and why this might be relevant to people with disabilities.

2.2.3   Possible Intervention Strategies

While the importance of skill development and training in self-advocacy can clearly be established for this population, it is more difficult to find evidence-based interventions that can effect this desired change. One systematic review of life skill programs for young people with physical disabilities evaluated 5642 papers from 1985 to 2006 and identified only six programs that met their inclusion criteria (Kingsnorth, Healy, & Macarthur, 2007). Criteria were that a study be empirical research evaluating the effectiveness of promoting the development of life skills, a comparison group was included, there was at least one quantifiable outcome measure, study population consisted of young adults aged 12 to 21 with a primary diagnosis of a physical disability, and that the study was published between 1985 and 2006. While different life skills were being promoted across the different programs, all of the programs utilized a variety of approaches to encourage skill building. Most programs included (among other aspects) goal-setting, group discussions of experiences, coaching or mentorship, and experiential learning opportunities. All but one of the interventions studied demonstrated significant changes in targeted life skills.

A meta-analysis of the impact of mentoring programs supports that youth with backgrounds of risk can benefit from mentoring more strongly than the average adolescent (DuBois, Holloway, Valentine, & Cooper, 2002). Those risks were varied and included environmental risks and disadvantaged youth. This study also provided recommendations for best practices in design and implementation of mentorship programs. Another study, (Britner, Balcazar, Blechman, Blinn-Pike, & Larose, 2006) specifically focused on mentorship with "special youth populations", which consisting of abused and neglected youth, youth with disabilities, pregnant and parenting adolescents, juvenile offenders, and academically at-risk students. Specifically with youth who have disabilities, they found that two key mentor characteristics may impact program goals or outcomes. These characteristics were whether the mentor is a peer or an adult, and whether the mentor also has a disability. Having a mentor who has a disability and/or having a peer mentor appears to be more beneficial than the alternative; however, positive results were demonstrated for a variety of mentor relationships, including a mentorship program with adult mentors who had disabilities.

2.3   CULTURAL DOMAIN ANALYSIS

Literature and policy discussed thus far explored the importance of advocacy skills within populations of people with disabilities, and some studies explored potential intervention strategies. However, there is little research exploring the opinions, thoughts, and feelings of people with disabilities regarding advocacy. The question of how these individuals think about advocacy remains, and utilizing research methodologies that are inclusive and accessible to all people is necessary. In this study, cultural domain analysis methods were chosen to explore this

question with samples of adults and adolescents living with disabilities and/or chronic illnesses. Cultural domain analysis is a methodology from cultural anthropology that allows for combining quantifiable information with qualitative knowledge (Romney, Weller, & Batchelder, 1986). A cultural domain could be any topic of information that is culturally salient, meaning it is familiar to a population of interest. Cultural domain analysis begins by eliciting content around a central domain. Once the content is elicited, it can be tested to understand if there is a cultural model; this is a shared understanding of the content and structure of a domain held by members of a shared group. There are several strategies that can be used to elicit and explore cultural models; we chose to use free listing and unconstrained pile sorting (Schensul & Lecompte, 2012). Free listing elicits all members of a domain as an individual generates all ideas that they understand to be part of the concept. Pile sorting explores the structure of a domain through understanding similarities and differences among salient terms that are held through participants' shared cultural knowledge. Cultural consensus analysis is used to explore the amount of agreement that members of the group have and the potentially shared cultural model (Weller, 2007).

For example, one common illustration of cultural domain analysis is exploring the topic of animals with a group of people (D'Andrade, 1995). You could ask people from a shared group to individually list all the animals that they can think of. This would be generating all the members of the domain "animals". Then, you could ask them to individually sort these members into groups. Someone might group animals into taxonomic groups, such as mammals, birds, fish, etc.; another person might group them by physical characters, such as big or little; and still another could group them by other methods, such as domesticated or wild. If individuals who are all part of a shared cultural group all name similar animals and group them in similar ways, you can use cultural consensus analysis to test if agreement is statistically significant and a cultural

model is present. Throughout these steps, there is also the opportunity for participants to describe their choices, allowing for qualitative information of thought processes to be documented and compared. This method can be applied to many different topics to explore more complex ideas, such as culturally specific medicinal practices or diseases (Garro, 1994).

Cultural domain analysis is a valuable mixed-methodology approach that helps to explore shared understanding of ideas among members of a group. Here, we are exploring the concept of advocacy as it is understood by people living with disabilities and/or chronic illnesses. Review of the literature has not revealed use of this method with adolescents or with people with disabilities previously. The flexibility of the data collection methods for cultural domain analysis creates room for adaptation that makes this method accessible for anyone in ways that other research methods are not. This first application of this method in this setting is, thus, novel and significant.

3.0   AN ATTEMPTED INTERVENTION

As noted, despite evidence supporting the importance of advocacy skills among adolescents and particularly adolescents with disabilities, there are few existing evidence-based interventions designed to teach or develop these skills. In 2017, a mentorship program was designed with this intent. The goal was to unite two local community groups for people with disabilities and individuals within them. Several factors motivated this program: 1. there was and is a desire from the leadership of these two groups, CHANGE and HCPD, for a more formal connection and opportunities for collaboration; 2. the goals and missions of these two groups are closely aligned and the connection could benefit both parties; 3. evidence from the literature supported that mentorship could be a successful model for developing advocacy skills and understanding; and 4. as youth turn 27 and outgrow the age restrictions of CHANGE, HCPD could be a source of continued social support and a space to continue applying the skills and knowledge that they have been working on developing. The mentorship program experienced delays and challenges to implementation, but, at the time of writing this thesis, there is still support to keep this program going beyond the completion of this thesis research. There is also value in disseminating what was learned from this process. Thus, presented here is the design of the mentorship program, a discussion of the challenges to implementation that were faced and lessons learned, and the proposed evaluation plan and what adaptations were made during the process.

3.1   MENTORSHIP PROGRAM DESIGN

The design of the mentorship program was to pair adolescent and young adult mentees from CHANGE with adult mentors from HCPD. Mentorship pairs were to be matched based on qualitative similarity, guided by the leaders of CHANGE and HCPD as they knew all individuals personally. Efforts were made to match individuals based on like-disability, when possible (e.g. matching a visually impaired mentee with a visually impaired mentor), and on like-interests (e.g. a mentee with interest in government and politics was matched with mentor who is experienced with speaking to legislators and advocating in state government settings). The personalities of individuals as well as preferred methods of communication were also taken into account. This matching was based on the existing knowledge of the respective group leaders, and did not require specific disability disclosures to the research team.

The mentee-mentor pairs were to have at least two points of contact per month of the mentorship program. "Contact" could include meeting in person as well as communicating through preferred channels such as phone, texting, or emails. Contact was broadly defined intentionally so it could accommodate all individuals, regardless of preferred modes of communication or other structural limitations, such as transportation, which might otherwise be a rate-limiting factor. The mentorship program was piloted from March 2018 through July 2018, with the hope that it would continue on after this time point pending further funding and conclusions from the evaluation. Each month, the research team was to plan one social event that focused on the topic of advocacy or a relevant skill. This social event was an opportunity for the mentee-mentor pairs to interact as well as to focus specifically on advocacy, the target for this intervention. For example, the first social event featured speakers from the Pennsylvania Youth Leadership Network and the topic was communication skills. Other topics highlighted included

stress management, setting boundaries, transportation, writing op-eds and contacting legislators. Speakers were brought in for some social events (e.g. Communication Skills and Stress Management), while other social events (e.g. Writing Op-Eds) were to be led primarily by the HCPD mentors. These social events were to give the mentee-mentor pairs opportunities to work on skills together and share experiences and knowledge with each other. The mentorship program was to be evaluated in a pre-test/post-test design with corresponding process measures collected throughout implementation. A logic model for the mentorship program and evaluation metrics can be reviewed in Appendix A.

3.2   CHALLENGES TO IMPLEMENTATION

The challenges the research team faced during implementation were not issues that are uncommon to community work. While we had no problem getting individuals on board with the idea of the program and enthusiastically agreeing to support it, we experienced difficulty in getting individuals to follow through with their commitments and, simply, showing up. When asked what barriers impacted attendance, individuals expressed that some issues were organizational (wanting to know details further in advance), but many more were structural or personal. Transportation was a significant issue for many people, and, relatedly, many people were much more comfortable commuting to places for meetings/events that they were familiar with compared to spaces that were new. Additionally, people had work schedules, families, and medical and personal emergencies that interfered with their available free time. These challenges are not uncommon when working with people, especially disadvantaged populations, but an additional complication was the very small sample we were working with. We had eight mentees

agree to participate in the program and corresponding research, so we aimed to recruit a corresponding eight mentors. Starting with a small group of 16 makes it so that absences from events are noticeable. Despite some events having to be cancelled and delays in connecting the mentors to the mentees, the program did continue on and is planned to continue through at least August of 2018. The support from the mentors and community leaders and interest of the mentees has not waned. The research methods utilized gave individuals additional chances to speak directly to the research team, who were coordinating this program. One individual whose main involvement with this program by time of post-test was with the research, expressed that they really enjoyed participating in the data collection and having the opportunity to explore their own thoughts and feelings about advocacy that they had not previously explored. Promisingly, the individual participants did not lose their enthusiasm for the program, and, instead, many expressed that they were looking forward to the chance to become more involved.

3.3   IMPACT ON EVALUATION PLAN

The mentorship program was to be evaluated in a pre-test/post-test design. The same methods of cultural domain analysis and quantitative surveys, which will be discussed further in the following section, were to be completed with the mentees before the mentorship program began and then several months after they had become involved with the program. Ideally, the program would have run for at least three months in between pre-test and post-test. Separately, the same methods were to be collected with the adult mentors to be used for comparison. Additionally, process measures were to be collected throughout the entire implementation timeline, including tracking attendance and points of contact between mentor/mentee pairs.

Collecting post-test measures after three months of implementation was chosen to allow for participants to give direct feedback and evaluation results to inform how the mentorship program continued moving forward. The questions we hoped to investigate were if a shared mentee model of advocacy (to be identified through cultural domain analysis) shifted from pre-test to post-test, and if that model of advocacy more closely aligned with a model of advocacy shared amongst the mentors. Due to the challenges in implementation, this plan was amended. Collected process measures fell below our targets, and fidelity of program implementation according to our plan and timeline was low. Because of this, the full post-test procedure with the mentees was not collected. The research team decided to collect surveys with the mentees at the post-test time point and not to repeat the cultural domain analysis methods. A description of the research that took place and what was learned is included in the following sections.

4.0   METHODS

The research team designed a mentorship program for youth with disabilities and chronic illnesses. The selected research methods were chosen to both monitor and evaluate this mentorship program as well as to conduct basic research with this unique sample group. This research protocol was designed to investigate both adolescents' and adults' individual and shared understanding of advocacy. This was a mixed-methods exploratory study which investigated the understanding of advocacy and advocacy skills among adults and adolescents living with disabilities and/or chronic illnesses. Cultural domain analysis and survey methodology were utilized with each sample. Validated surveys were used to measure self-esteem and future orientation at the same time, with the same sample groups. The surveys were collected a second time with the mentees for comparison.

4.1   PARTICIPANTS

For the mentorship program and accompanying research, adolescents were recruited from CHANGE as mentees, adults were recruited from HCPD as mentors, and then individuals were to be matched as described previously. Recruitment of mentees was conducted through established CHANGE communication channels, primarily monthly meetings and sending out information to the CHANGE email listserv. Recruitment of mentors was conducted primarily

with the help and guidance of our community partner and leader of HCPD. She identified individuals from HCPD that she thought would be successful mentors based on her personal and professional knowledge of working closely with all HCPD members; she then approached them to discuss the mentorship program. If they were interested, she provided their contact information to the research team. We then contacted those individuals to organize them for the mentorship program and to potentially recruit them for research involvement. Participation in the research was not a condition of involvement with the mentorship program. Individuals were free to choose to participate in the accompanying research or not without affecting their involvement with the mentorship program.

Research participants were offered $20 compensation for participating in each research session. Mentees could earn a maximum of $40 for participant in pre-test measures and post-test surveys, while mentors could earn a maximum of $20 for a one time data collection. All other involvement with the mentorship program was on a volunteer basis. All participants completed a verbal consenting procedure before participating in any research; University of Pittsburgh Institutional Review Board (IRB) granted a waiver for requirements to obtain written consent and parental consent for minors based primarily on this study's minimal risk classification. During research procedures, participants were assigned a random study ID, which was used for data collection, to allow for the possibility of individual level comparisons while maintaining confidentiality.

Participants were identified as having chronic illnesses and/or disabilities based on their membership of CHANGE or HCPD. Participants were not asked to disclose disability status or any personal health information to research staff. Both groups are cross-disability by design. No

attempt was made to specify the health status of participants beyond what was necessary for accommodations.

4.2   CULTURAL DOMAIN ANALYSIS: FREE LISTING AND PILE SORTING

Cultural domain analysis and cultural consensus theory were used to construct and analyze shared models of advocacy and advocacy skills among research participants. This process was done once with young people from CHANGE and once with adults from HCPD. These methods were used to elicit and then analyze the distribution of cultural knowledge among a group of respondents. The first step of this process is eliciting content for a potential cultural model around a specific domain of knowledge. In this study, we used free listing and unconstrained pile sorting to complete this process.

We began by having participants individually or collectively come up with free lists of words or short phrases in response to our research questions. The research questions we used were: (Q1) "What is advocacy?" and (Q2) "What skills does an advocate need?" We asked these questions separately and had participants generate separate lists of items (though they were allowed to repeat themselves). Data were collected in individual sessions for adolescents and small-group sessions with adults, and then the separate free lists from each participant were compiled together. The result was four lists containing all terms generated by every participant for Q1 and Q2 across both groups. Then, related items were nested into a single item (i.e. items that were phrased differently but conveyed the same meaning were grouped into a single phrasing). For example, if participants said during free listing both "listening" and "listening skills", these two items were combined and both coded as "listening." This was done using a

combination of the SoundFX function in the Anthropac software (Borgatti, 1996) and sorting by hand in Microsoft Excel (2013) and on paper. There is some amount of personal bias that can affect this grouping process due to the interpretation of meanings, so a group consensus approach was used. For the adolescent compilation, the primary investigator completed the initial nesting and then a second individual reviewed the final item list and tracking document of what items were nested before moving forward. Any controversial items were discussed and resolved by reaching agreement amongst the larger three person research team. Once the compiled free lists were finalized, about 40 items from each list were selected and written on note cards. The selection process was primarily based on high saliency, determined as the items with highest frequency counts among all research participants in each group, and theoretical interest, determined by the research team. Because this data collection process for free listing is qualitative, there was an effort by research staff to also represent the majority of terms that were most important among the majority of the participants even if they were not reflected in frequency counts. Approximately 30 items were selected based on raw frequency counts, which indicates these items as being more salient among the group of respondents. The remaining 9-10 items were chosen because they were of interest to the research team and influenced by qualitative information from participants. The result was four sets of cards; adolescents and adults each produced one set of cards for both Q1 and Q2.

Then, at individual sessions, all adolescents were given the same sets of note cards, one set for each question, and were asked to group the cards into piles. The same process was used with adults, with the sets of notecards used representing the content generated by their group sessions. Each participant was told to sort the items into related categories however they see fit (i.e. "put them in piles that make sense to you"). Pile sorts were unconstrained, meaning they

could make as many or as few piles as they saw fit. The only constraint was they were asked to avoid grouping all items into one group or making groups of only one item. Photographs were taken of the resulting pile sorts for data collection, and then later the piles were transcribed for analysis. Participants were given a chance to talk through their piles, explaining why they placed certain cards together and to reflect on the sorting process. This qualitative element allowed the researchers to glean more information about the thought process of the individuals as they made their choices and organized their thoughts.

Some adaptations were made to this general process to make this procedure accessible to all participants, so that anyone who was interested in participating was able to, regardless of their disability status. Adaptations made to this process included printing the pile sorting cards in braille for visually impaired participants. Additionally, to accommodate different processing speeds and styles, for free listing, the initial prompt was given and then repeated and restructured for some participants and all participants were given as much time as they needed. For pile sorting, some participants laid out all of the cards at once and other participants went through cards one by one with assistance from the research staff. Participants were able to ask research staff for clarification if any terms were confusing to them; standardized definitions were provided to anyone who asked. These small adjustments maintained the overall methodological structure but allowed for all individuals to participate.

Pile sort data were analyzed in Anthropac. This generated a variety of analyses including a map for the cultural domain, one for each research question for each group. Compiling individually collected data during analysis allows for measurement of how much agreement exists between members of this group and how much an individual's choices matched up with any overall group model. Multidimensional scaling (MDS) visually represents an aggregate

similarity matrix (combined from all participants) across two dimensions. Items commonly grouped together are represented as spatially close to one another and differences are represented by increased distance. The exception to this rule is that an MDS plot takes many dimensions and compresses them into and displays them in two dimensions. This can create distortion. Stress, a measure from 0 to 1, is used to measure the amount of distortion of the MDS plot. Stress of 0 would mean no distortion. Results were compared against a hierarchical cluster analysis in order to verify if and where distortion occurs in the visual representation of the data. Anthropac software and SPSS version 22 (IBM Corp., 2013) were used to perform MDS analysis and visualization. Cultural consensus analysis allowed us to determine from the pile sort data and MDS analysis if a model exists among the group. From the pile sort data, an informant by informant matrix of response correlations was created. This is a matrix of the responses of each individual being correlated with the responses of every other individual who participated. This results in a measure of patterns of agreement, and the principle components are expressed as eigenvalues through a modified factor analysis. These values measure the underlying variability of the informant by informant matrix. The first factor calculated from cultural consensus should explain the majority of the variation observed between respondents and can be used to develop an "answer key" of the most culturally agreed upon model of the domain. The first factor should be compared to the second factor to test if cultural consensus, and therefore a cultural model, is present. Cultural consensus occurs if the first factor explains more variation than the second factor in a ratio of at least 3:1 (Weller, 2007).

As mentioned, the research collection was conducted similarly with adults from HCPD, but due to time constraints, the free listing was conducted in small groups rather than individually. This consisted of creating three free lists from three small groups. The nesting

process was handled slightly differently to accommodate this change. The nesting was done collectively as a three person research team, by hand. Frequencies, while not calculated specifically, were still considered as a measure of saliency as we made an effort to include all of the topics that were mentioned many times or that were very important within our group discussions. An effort was made to represent ideas from each group equally, prioritizing the ideas that were most important to the participants based on frequency and qualitative information. Following this nesting process, the method matches the mentee methodology. Pile sorting was conducted individually, exactly the same as with mentees, with the same adaptations as necessary.

4.3   QUANTITATIVE MEASURES

At the same time as the free listing, participants were asked to complete surveys. Additionally, the surveys were collected a second time with the adolescent mentees three months later at the planned post-test of the mentorship program. These surveys measured self-esteem and future orientation through validated quantitative metrics. The full survey given to participants is included in Appendix B. Self-esteem was quantified with the Rosenberg Self Esteem Scale (Rosenberg, 1965), which consists of ten statements. On a four point Likert scale from "Strongly disagree" to "Strongly agree", participants responded to the following statements: 1) On the whole, I am satisfied with myself 2) At times, I think I am no good at all 3) I feel that I have a number of good qualities 4) I am able to do things as well as most other people 5) I feel I do not have much to be proud of 6) I certainly feel useless at times 7) I feel that I'm a person of worth,

at least on an equal plane with others 8) I wish I could have more respect for myself 9) All in all, I am inclined to feel that I am a failure 10) I take a positive attitude toward myself.

Future orientation was quantified through combined validated measures (Lippman et al., 2014). This prior study identified these measures as "Hope" and "Goal Orientation". On a four point Likert scale from "Strongly disagree" to "Strongly agree" (for consistency with the other survey metric) participants responded to six statements: 1) I expect good things to happen to me 2) I am excited about my future 3) I trust my future will turn out well 4) If I set goals, I take action to reach them 5) It is important to me that I reach my goals 6) I know how to make my plans happen.

Survey statistics were analyzed using SPSS version 22. Agreement ratings for survey items were converted to a numeric score, 1-4, with the higher score indicating strongest agreement. Means for each statement were calculated and paired-sample t tests were used to identify any significant differences between pre and post-test surveys. Independent-sample t tests were used to compare adolescent surveys to adult surveys.

5.0   RESULTS

As discussed previously, the mentorship program hit some roadblocks during implementation, which greatly limited our ability to evaluate this program. However, research methods were conducted as described and our primary research question, regarding the understanding of advocacy among adolescents with disabilities/chronic illness, was still able to be investigated. The results are as follows.

5.1   PARTICIPANTS

Eight mentees were recruited from CHANGE to participate in the mentorship program and accompanying research. Attempts were then made to recruit eight individuals from HCPD to serve as mentors. Due to difficulty with engaging the mentors and constraints on time, seven adults members of HCPD were recruited to participate in this research and not all were established mentors at the time of testing. The domains explored are thus representative of those shared by members of HCPD, adult advocates living with disabilities and/or chronic illnesses.

This was a smaller sample than we were hoping for; we were aiming for 10-15 individuals in each group. However, literature on cultural domain analysis indicates that sample sizes between seven and thirty are statistically meaningful (Bernard, 2011). We met the

28

minimum sample requirement of seven in both groups, so meaningful conclusions can be drawn

from this data, despite the small number of participants.

The demographics of the eight mentees are summarized in the following table (Table 1).

Table 1. Characteristics of Adolescent Participants

Data collected at time of free listing. N = 8.	
Age, years	Mean = 19.88 (Standard Deviation = 3.72) Min = 14 Max = 25
Gender	Female: n = 5 (62.5%) Male: n = 3 (37.5%)
Race, ethnicity*	Asian: n = 2 (25.0%) Black or African American: n = 3 (37.5%) Hispanic or Latino: n = 1 (12.5%) White: n = 4 (50.0%) Other, please describe: n = 1 "Island" (12.5%)
*Does not add up to 100%; participants could select more than one choice.	

The demographics of the seven HCPD research participants are summarized in the

following table (Table 2).

Table 2. Characteristics of Adult Participants

Data collected at time of free listing. N = 7.	
Age, years	Mean = 58.43 (Standard Deviation = 5.56) Min = 50 Max = 66
Gender	Female: n = 5 (71.4%) Male: n = 2 (28.6%)
Race, ethnicity	Black or African American: n = 2 (28.6%) White: n = 5 (71.4%)

5.2   ADOLESCENTS

With the adolescent research participants, we collected surveys at two time points (February/March 2017 and June 2018) and completed cultural domain analysis methods once (February/March 2017). Research was conducted largely in individuals' familiar environments, including the regular CHANGE meeting space or in their homes, based on their individual preferences. Several post-test surveys were collected over the phone for efficiency.

5.2.1   Surveys

As displayed in Table 3, there were slight differences between certain items when comparing pre-test to post-test. However, paired t-tests indicated that none of these differences were statistically significant (p set at 0.05) and there was also no statistically significant difference between the average of all items for each survey, with reverse coding for negatively worded items. This is as expected due to the limited amount of intervention that many of the participants experienced with the program; with this in mind, to see that self-esteem and future orientation within this group is fairly stable over time is positive. One thing to note is that the surveys contained both positively worded items (e.g. "On the whole, I am satisfied with myself") and negatively worded items (e.g. "I feel I do not have much to be proud of"). In general, participants were starting off already in the "right" direction, agreeing more strongly with the positively worded items, and disagreeing more strongly with the negatively worded items. Additionally, no participants selected that they "Strongly agreed" with negative items or "Strongly disagreed" with positive items at either time point.

Table 3. Summary of Survey Responses from Adolescents

Metric	Statement	Average Response Pre-test Mean (SD) N=8	Average Response Post-test Mean (SD) N=8
Participants were asked to respond to each item on a 4-point scale of "Strongly Disagree" to "Strongly Agree", which were then converted to numeric scores 1-4 with higher scores indicating stronger agreement. To compute average of all items, negatively worded items were reverse coded.			
Self-Esteem	"On the whole, I am satisfied with myself"	3.13 (0.64)	3.63 (0.52)
	"At times, I think I am no good at all"	2.25 (0.46)	2.00 (0.53)
	"I feel that I have a number of good qualities"	3.50 (0.53)	3.50 (0.53)
	"I am able to do things as well as most other people"	3.50 (0.53)	3.13 (0.35)
	"I feel I do not have much to be proud of"	1.75 (0.46)	1.75 (0.46)
	"I certainly feel useless at times"	2.13 (0.46)	2.00 (0.76)
	"I feel that I'm a person of worth, at least on an equal plane with others"	3.13 (0.64)	3.13 (0.64)
	"I wish I could have more respect for myself"	2.88 (0.64)	2.88 (0.64)
	"All in all, I am inclined to feel that I am a failure"	1.50 (0.53)	1.63 (0.52)
	"I take a positive attitude toward myself"	3.38 (0.51)	3.13 (0.35)
	Average of all items	3.11 (0.25)	3.12 (0.21)
Future Orientation	"I expect good things to happen to me"	3.13 (0.64)	3.50 (0.53)
	"I am excited about my future"	3.13 (0.64)	3.50 (0.53)
	"I trust my future will turn out well"	3.13 (0.64)	3.50 (0.76)
	"If I set goals, I take action to reach them"	3.50 (0.53)	3.88 (0.35)
	"It is important to me that I reach my goals"	3.75 (0.46)	3.75 (0.46)
	"I know how to make my plans happen"	3.25 (0.71)	3.37 (0.74)
	Average of all items	3.31 (0.35)	3.58 (0.35)

5.2.2   Cultural Domain Analysis

When individual data from adolescents was combined, free lists contained a total of 248 items for Q1 and 204 items for Q2. After nesting, there were 164 terms for Q1 and 86 for Q2. Frequencies of items ranged from one to eight for Q1 and one to seven for Q2. The frequency distribution was graphed on a scatter plot as depicted below:
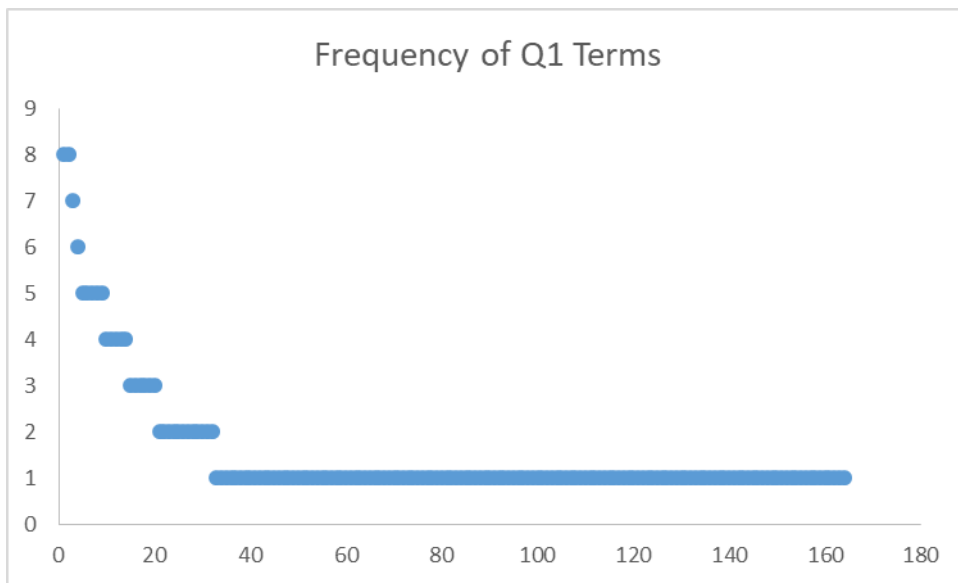
Figure 1. Frequency plot of Q1 Terms: Adolescents

This plot was used to determine the "drop off" point for selecting frequency-based terms for sorting. For Q1, for example, all terms with frequencies two or greater were included in the pile sort. This was how 32 items were selected. The remaining 7 terms (for a total of 39 cards), were selected based on theoretical interest. Each of these seven terms had frequency counts of one and were chosen either because of researcher interest or to represent ideas that the researchers felt were important to the participants but did not become high frequency items because they were not nested with other similar, but nuanced concepts. The same procedure was followed for Q2,

with all terms with frequencies greater than three being automatically selected for a total of 30 frequency-based cards. The remaining 10 cards chosen based on theoretical interest were largely (all but one) items with frequency counts of two.

The amount of terms each individual participant free listed ranged between 11 and 94 for Q1 and 11 and 37 for Q2. Most participants were able to name around 20-30 items for each question. The smallness of the sample size meant that if one individual said many things about a similar idea that all ended up being nested together, it inflated the frequency count for that item. This was another reason to justify the inclusion of some low frequency items, to balance the representation of selected terms more equally between participants.

Results from the unconstrained pile sort of Q1 terms and Q2 terms were each analyzed in Anthropac software to create individual proximity matrixes, aggregate proximity matrixes, and MDS plots. First, cultural consensus analysis indicates that a model does exist among the group for Q1. The eigenvalue ratio comparing the first factor to the second factor was 2.913:0.286, which is above the recommended ratio of 3:1 or greater. This score indicates that there is a shared model of advocacy within this group. Another calculation of cultural consensus analysis is individual knowledge scores: a score for each participant of how much they agree with the shared cultural model. This score is from zero to one and should always be positive for the first factor, which represents the "answer key." A score of zero would indicate an essentially random assignment of terms to piles, and a score of one would indicate total agreement with the model. For Q1, there was an average score of 0.585 with a standard deviation (SD) of 0.149.

For Q2, the initial consensus analyses indicated that all variation was explained by the first factor, with an eigenvalue ratio of 2.987:0, which indicates a model exists with a single factor solution. However, one participant had a negative knowledge score. This participant is

what is what the literature calls a "lumper"; they put all of the cards into two big piles. Since most other participants had several different piles, the lumper does not align with the model and throws off the calculation. Running consensus again with the lumper removed, it does not drastically affect the eigenvalue ratio (change from 2.987:0 to 2.969:0), but the average cultural competence score shifts from $0.548 \pm SD\ 0.27$ to $0.646 \pm SD\ 0.086$.

After consensus theory supported that a model exists in each case, multidimensional scaling and hierarchical cluster analysis were used to examine the structure of the domain and identify clusters. The depicted clusters are not rigid; they merely delineate similarities in participants' organization of the terms. The decision of where to draw the cluster boundaries is also informed by the qualitative data. These are presented in Figures 2 and 3 below. All of the notecards/items had corresponding number codes; the number codes are depicted on MDS plots, with a corresponding table key beneath it.

For Q1, there were some straightforward clusters that emerged, such as the grouping of "helping", "listening", and "collaborative" or the grouping of "inclusive" and "respect". The biggest and tightest cluster contained "stand up for yourself", "asking for help", "knowing yourself well", "self-confidence", "agreeing with your strengths", "believing in yourself", and "self-motivation". Qualitatively, many people expressed grouping these ideas around the concept of confidence and speaking up. Some explained that you need to know yourself, know your strengths, know what you need, and then have the confidence to stand up for yourself and ask for help. One surprising cluster was the group of "awareness of your perspective", "not depending on others", and "not following the status quo". While maybe not as obvious of a connection on face level, awareness of your perspective was mentioned as a necessary step for creating change and how you interact with others; with this in mind the connection to changing the status quo and

independence becomes clearer. The stress value for the MDS plot is 0.195. This indicates that there is some distortion to the visual depiction, but it is fairly low.
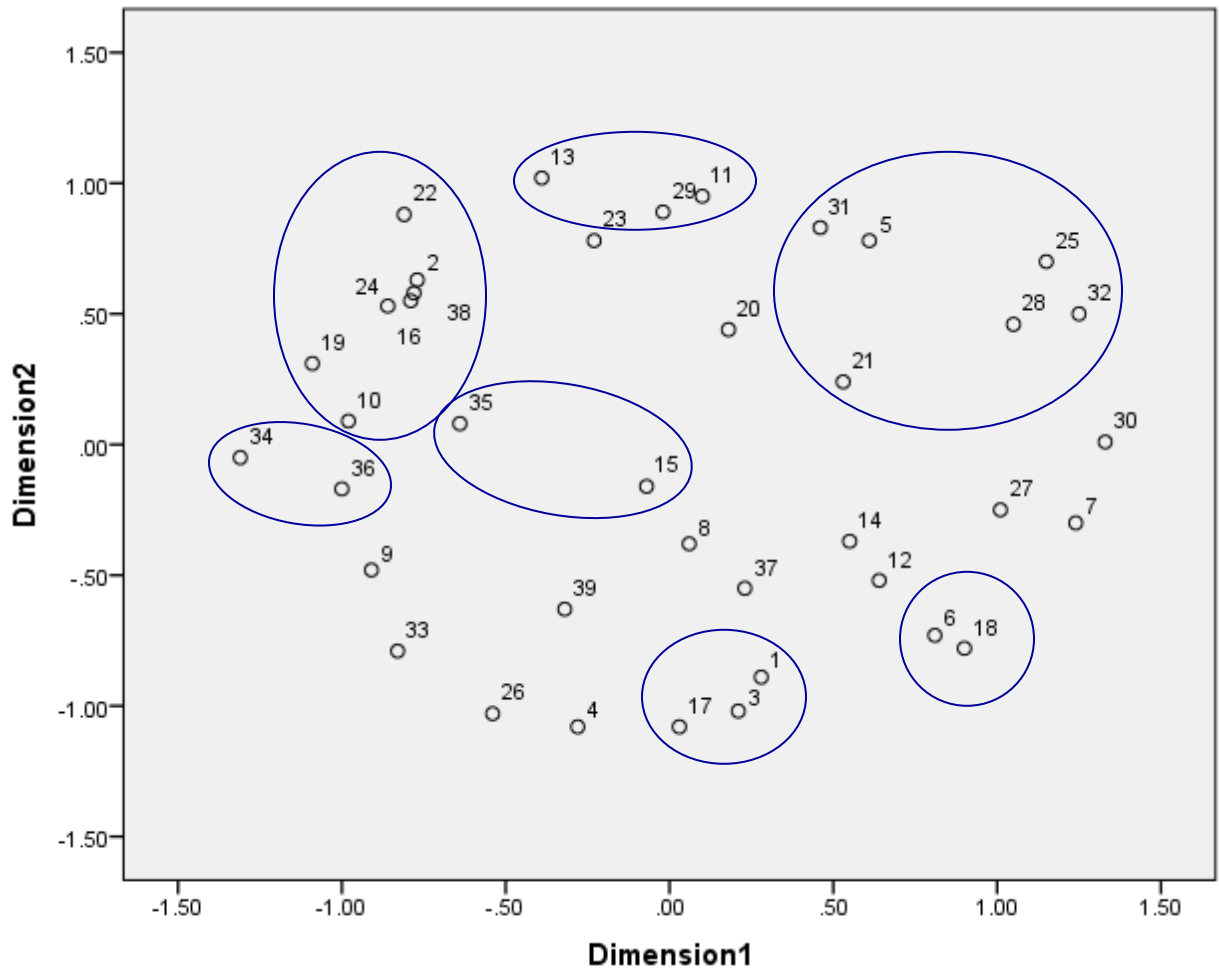

Figure 2. Q1 (What is advocacy?) MDS plot: Adolescents

Table 4. Q1 Item Numbers: Adolescents

Card Numbers	
1. Helping	21. Acceptance
2. Stand up for yourself	22. Agreeing with your strengths
3. Collaborative	23. Being proactive
4. Understanding people who think/act different than you	24. Believing in yourself
5. Access	25. Disparity in wealth
6. Inclusive	26. Doing something right
7. Politics	27. Education
8. Stand up for others	28. Equality
9. Knowing what's happening in your community	29. Not following the status quo
10. Asking for help	30. Protests
11. Awareness of your perspective	31. Raising minority voices
12. Getting others to understand	32. Women's rights
13. Not depending on others	33. Honesty
14. Teaching	34. Knowing it's hard
15. Awareness	35. Knowing what resources are available
16. Knowing yourself well	36. Knowing your rights
17. Listening	37. Leadership
18. Respect	38. Self-motivation
19. Self-confidence	39. Spreading ideas to other communities
20. Taking a stance	

For Q2, some interesting clusters that emerged were the grouping of "strength", "self-confidence" and "trusting yourself", and the grouping of "prepared for adversity", "taking a stance", and "bravery". Many of these were personal characteristics viewed as skills. One divide discussed qualitatively by participants during sorting was the separation of intrinsic qualities and skills you learn; these were terms generally seen as personal qualities that may or may not be possible to develop through practice. Conversely, a cluster also emerged surrounding "organization" and included other ideas like "managing a group", "planning a meeting", "coming up with different solutions", "setting goals", and "transportation." This group was also formed around their familiarity with CHANGE – participants described the elements that were important

to helping CHANGE run smoothly, such as managing a group during discussions and making sure everyone can get to the events. CHANGE was clearly an important part of how these adolescents viewed and understood advocacy. Another tight cluster formed around the idea of working with others and included items such as "communication", "people who can help", "talking to people", "trust in others", "involving everyone", and "using connections." Group dynamics and collaborating with others was highlighted as important both during free listing and the discussion after pile sorting. One item, 12- "patience", surprisingly stood out as being not tightly clustered with anything else. This was not a card highlighted during pile sorting as one that did not belong. This separation could reflect different individuals placing this card in very different piles, so it did not get strongly associated with any particular grouping. The stress value for this MDS plot was 0.184, which also indicates that distortion is present but low.
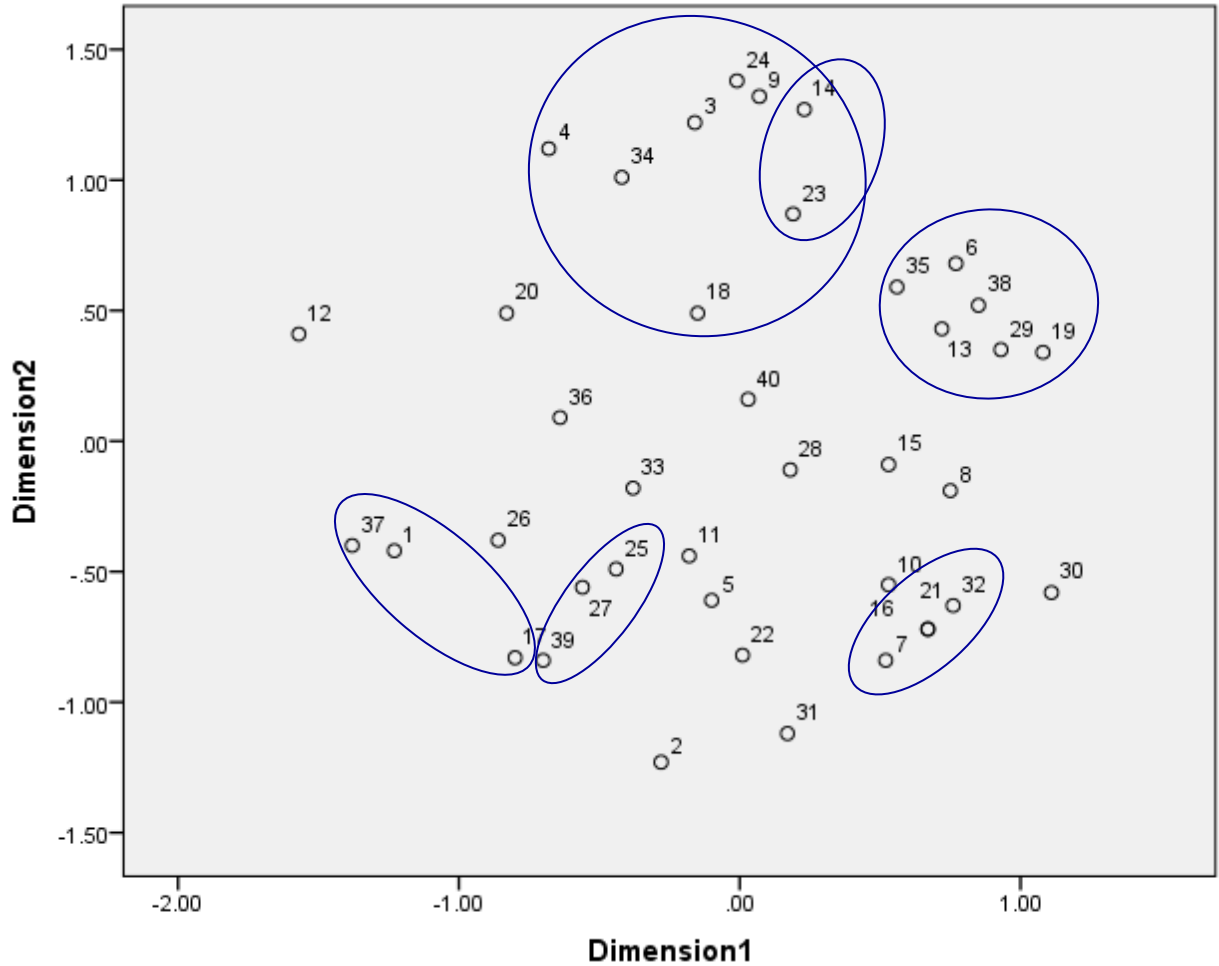
Figure 3. Q2 (What skills does an advocate need?) MDS Plot: Adolescents

Table 5. Q2 Item Numbers: Adolescents

Card Numbers	
1. Strength	14. Public Speaking Skills
2. What to do with doctor	15. Respect
3. Organization	16. Seeking Information
4. Transportation	17. Self confidence
5. Asking for things you need	18. Setting goals
6. Communication	19. Talking to people
7. Learning	20. Teaching
8. Listening	21. Understanding a subject
9. Managing a group	22. Asking questions
10. Speaking out about things that upset you	23. Effective spreading of voice
11. Equal rights	24. Planning a meeting
12. Patience	25. Prepared for adversity
13. People who can help	26. Staying true to what you believe

Table 5 Continued.	
27. Taking a stance	34. Coming up with different solutions
28. Thinking	35. Involving everyone
29. Trust in others	36. Motivation
30. Understanding how things impact people	37. Trusting yourself
31. Basing beliefs on knowledge	38. Using connections
32. Being aware of your surroundings	39. Bravery
33. Being responsible	40. Keeping promises

5.3   ADULTS

Surveys and the cultural domain analysis methods were conducted with adults from HCPD in late-May/early-June 2018. Research was again conducted in familiar environments for the participants including a public library, individuals' homes, and other public spaces like coffee shops or cafes. After the initial free listing was collected in a public library after their monthly book club, participants were able to choose when and where they would like to complete the follow up pile sorting. The research staff was able to be quite flexible and accommodate the preferences and schedules of all participants.

5.3.1   Surveys

Like the adolescents, adults were mostly answering in the "right" direction. On average, participants agreed more strongly with the positively worded items, and disagreed more strongly with the negatively worded items. There were some significant differences between the two groups that are explored further in the following comparison section.

Table 6. Summary of Survey Responses from Adults

Metric	Statement	Average Response Mean (SD) N=7
	Participants were asked to respond to each item on a 4-point scale of "Strongly Disagree" to "Strongly Agree", which were then converted to numeric scores 1-4 with higher scores indicating stronger agreement. To compute average of all items, negatively worded items were reverse coded.	
Self-Esteem	"On the whole, I am satisfied with myself"	3.57 (0.78)
	"At times, I think I am no good at all"	2.00 (1.00)
	"I feel that I have a number of good qualities"	3.57 (0.53)
	"I am able to do things as well as most other people"	2.71 (0.95)
	"I feel I do not have much to be proud of"	1.57 (0.78)
	"I certainly feel useless at times"	1.71 (0.95)
	"I feel that I'm a person of worth, at least on an equal plane with others"	3.29 (0.95)
	"I wish I could have more respect for myself"	1.86 (1.06)
	"All in all, I am inclined to feel that I am a failure"	1.57 (0.78)
	"I take a positive attitude toward myself"	3.43 (0.78)
	Average of all items	3.28 (0.69)
Future Orientation	"I expect good things to happen to me"	3.57 (0.54)
	"I am excited about my future"	3.43 (0.78)
	"I trust my future will turn out well"	3.57 (0.54)
	"If I set goals, I take action to reach them"	3.43 (0.78)
	"It is important to me that I reach my goals"	3.57 (0.54)
	"I know how to make my plans happen"	3.43 (0.78)
	Average of all items	3.50 (0.65)

5.3.2   Cultural Domain Analysis

Free listing and nesting of terms was done slightly differently with the adults compared to what we did with the adolescent data. While we asked the same questions, free listing was not done individually, but instead in small groups of 2-3. This meant we could not track individual contributions separately and also that the process of creating the free list is more collaborative; they became more similar to group discussions, and while many singular terms and phrases were stated, some participants shared personal stories and examples of advocacy/advocacy skills from which the research team had to extract representative terms/short phrases. The three lists that emerged from the three small groups had some overlap but were largely very different from each other based on the flow of conversation in each group. For Q1, we started with a total of 259 terms between the three lists, and, for Q2, we started with a total of 200 terms. From that, the research team worked collaboratively to nest by hand as many terms as possible to pare down those lists. At the same time we were selecting the approximately 40 terms that would be used for pile sorting. We could not use the raw frequency counts to determine saliency among the group, as we did with the adolescents, because we did not have individual lists so the frequency numbers would be skewed. Instead, we noted the frequently occurring items within each list and between the three lists and focused on including as many of those as possible. Ultimately, 40 items were chosen for Q1 and 39 items were chosen for Q2. The majority of these terms represented what where the most frequently occurring items and most important items, qualitatively, to our participants. There was an effort to represent the ideas of the three groups fairly equally, despite different groups listing many more terms than others. Only a select few items were chosen because they were of theoretical interest, all other terms were either mentioned by multiple participants and/or stressed as important. The similarity with the

adolescent data collection resumed at pile sorting. This collection was identical to that of the adolescent procedures, and the same steps of analyses followed:

For Q1, for adults, cultural consensus analysis indicates that there is a shared model due to an eigenvalue ratio of 1.408:0.170, which is again higher than the recommended 3:1. There is a very low average knowledge score among participants at $0.303 \pm$ SD 0.330. There was also one participant with a negative knowledge score, which was the same issue we ran into with the adolescents. This participant was also a lumper, and put most of their cards together, almost entirely in one pile, with only a few cards left separately. From the way the participant described their sorting decisions, this individual seemed to separate the cards into one pile of cards that they agreed with or identified with personally (almost all of the cards) and then the few that they did not connect with were put together in a separate pile. A challenge of this method is that an individual sorting in this manner complicates the group analysis. However, because of the individual level comparisons, it is helpful to be able to identify why an individual participant may be different from the other participants. If the lumper is removed and the consensus run again, the model is still present, however the sample size then drops below 7 which is traditionally less meaningful.

Similarly, for Q2, cultural consensus analysis indicates that there is a shared model due to an eigenvalue ratio of 1.801:0.181. The range in participant knowledge scores is quite large for this question, the average knowledge score is $0.22 \pm$ SD 0.456. The same "lumper" participant for Q1 again had a negative knowledge score for Q2, another participant had a knowledge score of zero, which implies essentially random sorting, while other participants had knowledge scores up to 0.54 and 0.86. While the eigenvalues indicate a model is present with or without the lumper, the combined factors of a small sample, low average competency, and both lumping and

42

potentially random respondents all indicate that a larger sample would be required to verify this model. These ratios do suggest that models exist for both Q1 and Q2, which is then followed by multidimensional scaling and hierarchical cluster analysis to examine the structure of the domain and identify clusters. As before, the Q1 MDS plot and Q2 MDS plot are presented in Figures 4 and 5 and corresponding Tables 7 and 8 are below them as a key for the item numbers.

Within the MDS plot for Q1, there are many tightly grouped clusters. The largest cluster contains: "collaboration", "self-care", "right to employment", "independence", "power", "courage", and "pride". With regard to this clustering, during free listing and during pile sorting, many participants talked about the importance of personhood and being more than just a disability. Many participants connected very strongly to the ideas of power, pride, and independence, while also noting the importance of working with others, taking care of yourself and your own mental health. Some used their own examples of wanting to work and facing challenges at work, as well as in education settings, to demonstrate advocacy. Another interesting grouping contains: "forms of protesting", "fighting discrimination", "working towards solutions", "giving back", and "get involved". Many participants referenced their work with HCPD as an advocate and described advocates as being problem-solvers, working towards systematic change, and utilizing protests as a method to do so. Another related grouping contained: "advocacy becomes part of life", "changing the system", "fighting for others" and "access to services". Many participants described advocacy as being a public service or bigger than the individual; community and fighting with and for others was an important component to their definition of advocacy. One polarizing item was "not everyone is ready". Some people agreed that you have to meet others where they are at, and the grouping of this term with "educating others" and "learning" makes sense in this framework. This term was interpreted both

43

as some people are not ready to be advocates and some people are not ready to hear your message. The second interpretation elicited a strongly negative response in one participant. Conversely, one term that was collectively responded to very positively and people connected with very directly was "do not give up". This was frequently read during pile sorting and followed by a "Yes!" or a "Do. Not. Give. Up. Ever." It is interesting that this was grouped with "assertive" and "communicating your needs". This connects to the ideas of persistence and determination in getting what you need/want. Finally, the stress value of this MDS plot was 0.176, which is fairly low.
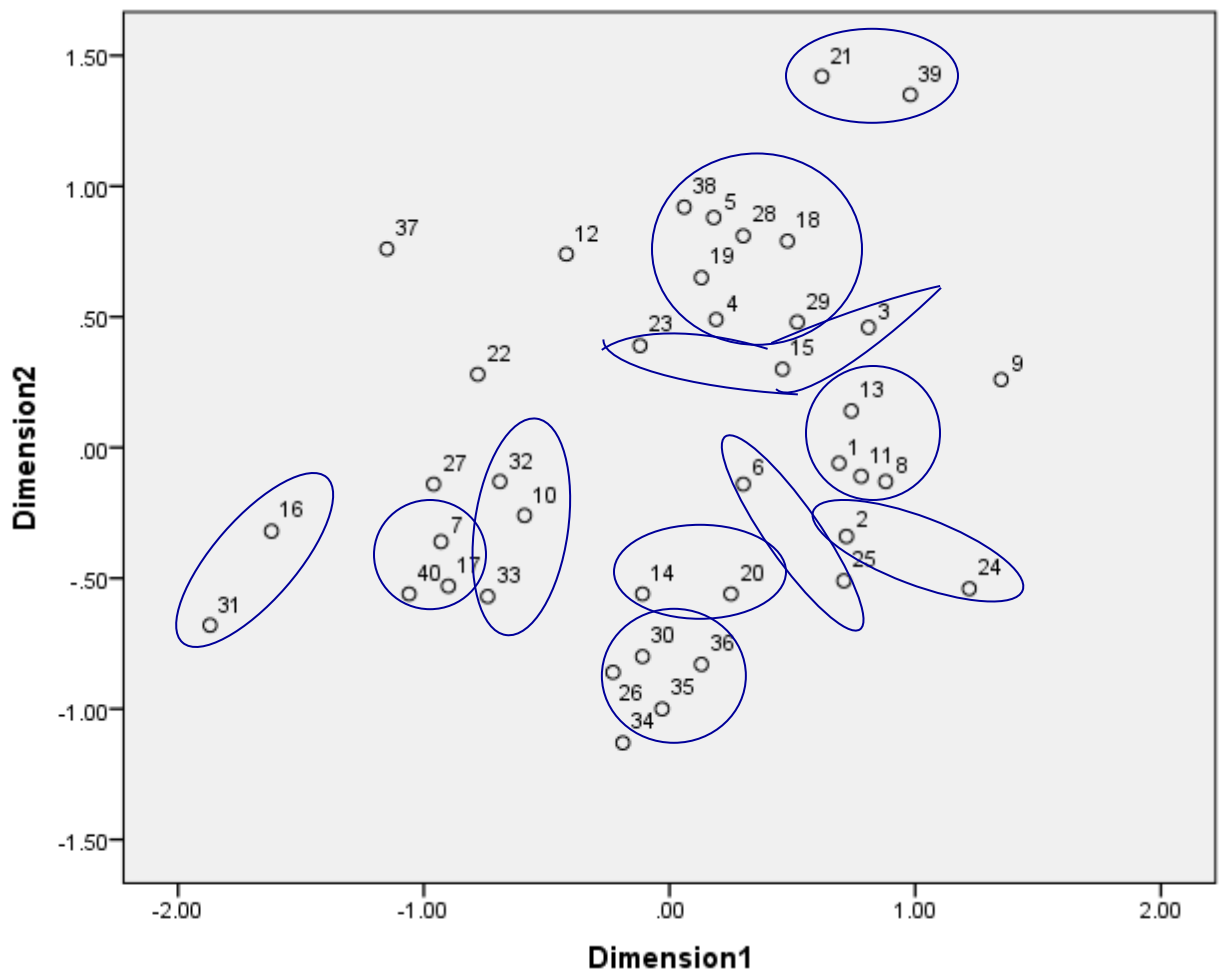

Figure 4. Q1 (What is advocacy?) MDS plot: Adults

Table 7. Q1 Item Numbers: Adults

Card Numbers	
1. Advocacy becomes part of life	21. Confidence
2. Political engagement	22. Commitment
3. Do not give up	23. Communicating your needs
4. Collaboration	24. Visibility
5. Self care	25. Avoiding loneliness
6. Erasing stigma	26. Fighting discrimination
7. Educating others	27. Empathy
8. Fighting for others	28. Power
9. Advocating for self	29. Courage
10. Sharing your view	30. Forms of protesting
11. Changing the system	31. Different styles of communication
12. Navigating different worlds	32. Asking questions
13. Access to services	33. Being persuasive
14. Strength in numbers	34. Working toward solutions
15. Assertive	35. Giving back
16. Finding common ground	36. Get involved
17. Learning	37. Movements
18. Right to employment	38. Pride
19. Independence	39. Sustainability
20. Part of something bigger than yourself	40. Not everyone is ready

For Q2, though the stress measure was 0.159, which is fairly low, it was much harder to visualize the clusters on the MDS plot that the hierarchical cluster analysis revealed (the data output of the hierarchical cluster analysis is included in Appendix C). For example, the output shows that items 2, 9, and 32 are a grouping, but 16 is grouped with 36 and 15. Items 26 and 25 are also highly related, but spatially it does not appear that a circle should go around them, and there is a similar grouping of 3, 19, and 39, which do look spatially close, but are grouped together with 4, which is quite spatially far. Despite these visual peculiarities, there were many clusters identified, and the qualitative data can help inform some of this variety.

The largest grouping contains: "writing op-eds", "helping others", "representation", and "communicating to different audiences". This connects specific communication skills (writing

45

op-eds) as well as communicating to different audiences (such as using different modes of communication and being aware of tone and audience). These ideas were connected with the idea of representation – representing both yourself and your cause, and to use communication and visibility to help others. Another interesting grouping is one mentioned above but is not outlined on the plot: 2, 9, and 32, or "showing up", "problem solving", and "learning from others". As mentioned in Q1, the view of advocates as problem solvers collaborating with others was important to this group's definition of advocacy and these qualities were also identified as necessary skills. To pair it with "showing up" is interesting, because it strengthens the ideas surrounding group action and actually doing the work.
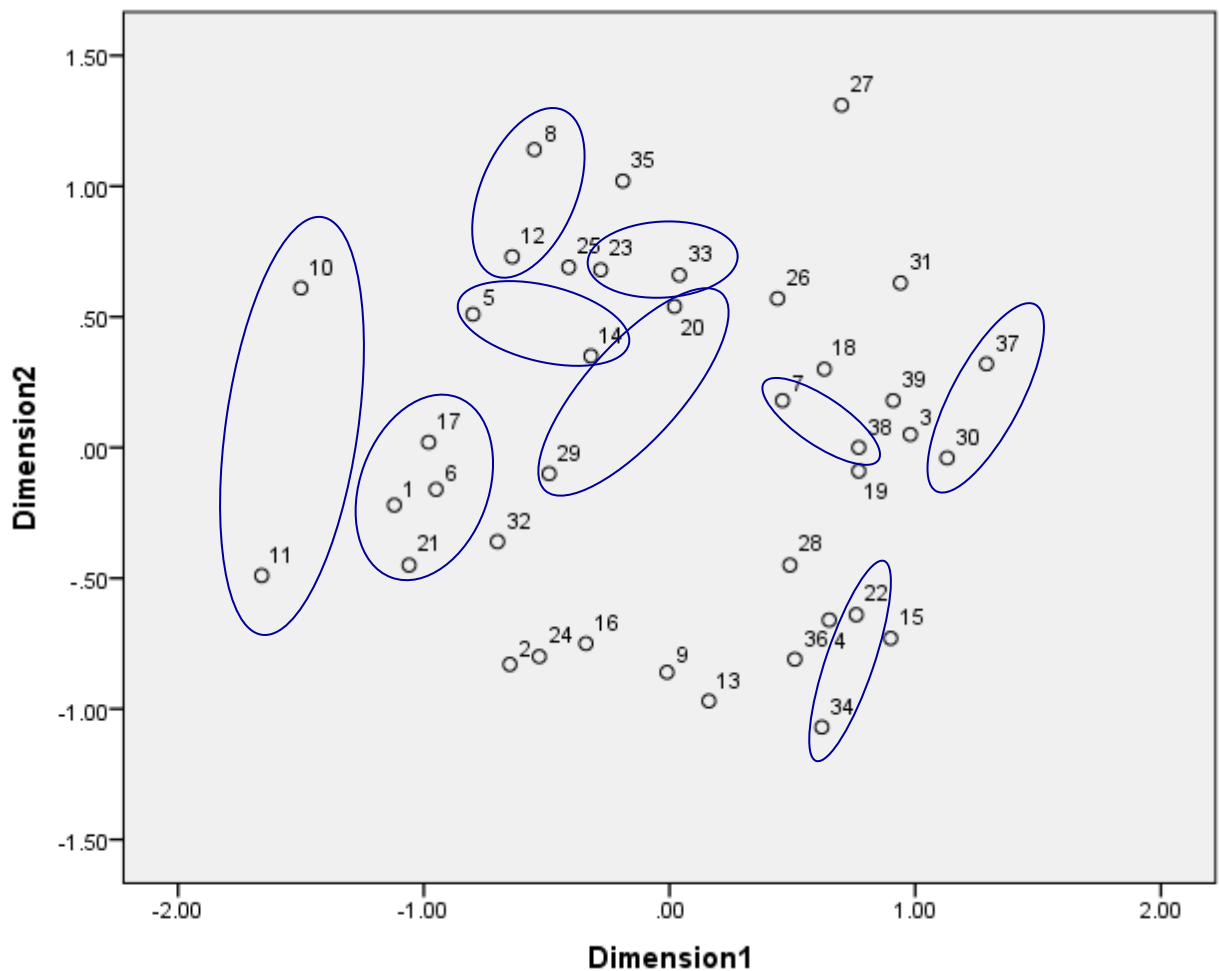

Figure 5. Q2 (What skills does an advocate need?) MDS Plot: Adults

Table 8. Q2 Item Numbers: Adults

Card Numbers	
1. Writing op-eds	21. Communicating to different audiences
2. Showing up	22. Speaking up
3. Self-confidence	23. Communication skills
4. Loving yourself	24. Building relationships
5. Teaching others	25. Collaboration
6. Helping others	26. Understanding different perspectives
7. Learning from experience	27. Knowing what is going on in the community
8. Knowledge on topics	28. Adapting
9. Problem solving	29. Giving back
10. Knowing system structures	30. Stand up for yourself
11. Awareness of political systems	31. Seeing opportunities
12. Community organizing	32. Learning from others
13. Inclusive for all	33. Empathy
14. Picking your battles	34. Leading by example
15. Determination	35. Commitment
16. Willing to lose	36. Finding passions
17. Representation	37. Asking for help
18. Choosing to get out in the-community	38. Honest
19. Knowing yourself	39. Not a victim
20. Giving credit to-others	

5.4   COMPARISONS

There were many similarities and differences between the data collected with adolescents versus adults. They are presented as follows.

5.4.1   Comparing Surveys

Because there was no significant differences between pre-test surveys and post-test surveys with adolescents, we arbitrarily chose the first survey collection to compare to the adult surveys. The average responses are summarized in the table below for reference.

Table 9. Comparing Survey Responses from Adolescents and Adults

Metric	Statement	Average Response Adolescents Mean (SD) N=8	Average Response Adults Mean (SD) N=7
Participants were asked to respond to each item on a 4-point scale of "Strongly Disagree" to "Strongly Agree", which were then converted to numeric scores 1-4 with higher scores indicating stronger agreement. To compute average of all items, negatively worded items were reverse coded.			
Self-Esteem	"On the whole, I am satisfied with myself"	3.13 (0.64)	3.57 (0.78)
	"At times, I think I am no good at all"	2.25 (0.46)	2.00 (1.00)
	"I feel that I have a number of good qualities"	3.50 (0.53)	3.57 (0.53)
	"I am able to do things as well as most other people"	3.50 (0.53)	2.71 (0.95)
	"I feel I do not have much to be proud of"	1.75 (0.46)	1.57 (0.78)
	"I certainly feel useless at times"	2.13 (0.46)	1.71 (0.95)
	"I feel that I'm a person of worth, at least on an equal plane with others"	3.13 (0.64)	3.29 (0.95)
	"I wish I could have more respect for myself"	2.88 (0.64)	1.86 (1.06)
	"All in all, I am inclined to feel that I am a failure"	1.50 (0.53)	1.57 (0.78)
	"I take a positive attitude toward myself"	3.38 (0.51)	3.43 (0.78)
	Average of all items	3.11 (0.25)	3.29 (0.69)
Future Orientation	"I expect good things to happen to me"	3.13 (0.64)	3.57 (0.54)
	"I am excited about my future"	3.13 (0.64)	3.43 (0.78)
	"I trust my future will turn out well"	3.13 (0.64)	3.57 (0.54)
	"If I set goals, I take action to reach them"	3.50 (0.53)	3.43 (0.78)
	"It is important to me that I reach my goals"	3.75 (0.46)	3.57 (0.54)
	"I know how to make my plans happen"	3.25 (0.71)	3.43 (0.78)
	Average of all items	3.31 (0.35)	3.50 (0.65)

Independent sample t-tests were calculated between each survey item across adolescents and adults as well as between the average of all items for each survey. The only statistically significant difference was item eight in self-esteem (t = -2.27, p<0.05): "I wish I could have more respect for myself." Adults more strongly disagreed with this statement, indicating that they may feel like they have more respect for themselves already compared to the adolescent respondents. Another difference that was not statistically significant (p > 0.05) but approached significance (with p = 0.066) was item four in self-esteem: "I am able to do things as well as most other people." The group of adults consisted of more participants with physical disabilities that impact mobility compared to the adolescent group; several adult respondents made comments to researchers during survey collection such as, "well, I can't walk as well as most people (while laughing)" or "I do things differently than other people." The difference in this item between the adult respondents and adolescents could reflect a slightly different interpretation of the statement, or could reflect the slightly different make-up of groups.

5.4.2   Comparing Cultural Domains

During free listing and interpretation of pile sorting, there were many ideas that spanned both groups. Many of the exact same terms or the same ideas were brought up during free listing and were included for pile sorting. For example, both groups highlighted skills like listening and communication, and both groups talked about collaborating with others and educating others. Many participants across both groups highlighted specific internal qualities such as confidence, bravery, and strength, while also mentioning similar actions and knowledge such as politics. Some differences included: adults talked more about personal examples of battles they had fought and also talked more about the perspective needed to fight, such as picking your battles,

being willing to lose, etc. Youth mentioned more specific skills to running a group, such as organizational and managerial skills, that did not come up with the adults.

During pile sorting, many more of the adults preferred to make fewer, larger groups compared to have numerous smaller groups. Additionally, a researcher must always be careful not to influence the participant as they are deciding where to place cards, but particularly when the researcher is offering more assistance for the purpose of accommodation. Particular differences were noted between pile sorting with the two visually impaired participants. One visually impaired adolescent participated in this research, and their mentor, a visually impaired adult, also participated. For both of these individuals, the cards were printed in braille so that they could read them. The terms were also printed in text on the card, so that I, as the research facilitator, also knew what the card said. Both of these research sessions were very interesting, because the individuals processed their thoughts verbally as they went through the cards compared to the more silent processing of other participants. The adolescent would read each card aloud, and as they picked up and read additional cards, they would decide if/how they should be grouped. I helped physically place the cards into piles and frequently reminded the participant what groups they had already created and what cards were already in each group. The adult participant received much less guidance from me. This participant would read each card and then place it in front of their self in piles. Because they stacked the cards on top of each other, they would compare each new card they read to only the top card of the stacks in front of them. Being unable to look at and read all of the cards on the table increases the cognitive load of the task because it requires more reliance on memory. But, because both visually impaired participants would verbally process the cards and describe their decisions as they made them, I was able to learn a lot more about the thinking process and their interpretation of each card.

In regards to the MDS plots and cultural consensus analyses, it appears that while all groups developed models around advocacy and advocacy skills, the adolescents appeared to have better agreement than the adults. Visually, the adult MDS plots appear to have items more tightly grouped, however the adolescent MDS plots have cleaner divides between the different groups.

6.0   DISCUSSION

The primary question of this research thesis was: how do adolescents with disabilities/chronic illnesses think about advocacy? We investigated this question primarily through cultural domain analysis. We aimed to determine if a shared understanding existed of advocacy and advocacy skills within this population and then to probe the shared model and compare it to a sample of adults with disabilities/chronic illnesses who are experienced advocates.

Results indicated that shared models did exist for both adolescent and adult groups surrounding both research questions. The first research question, "What is advocacy?", was intended to elicit the individual and group definition of advocacy. The second question, "What skills does an advocate need?", was intended to elicit all of the skills that are necessary for successful advocacy work.

While similar ideas came up during free listing and were discussed during pile sorting in both adult and adolescent populations, the resulting models were different. Youth had higher average knowledge scores and a smaller standard deviation compared to adults, meaning that the adolescent group more strongly agreed with each other. There are many potential reasons why this might be. Many adults described during this research that they were doing advocacy work for a long time before they had a name for it. All of the adolescent participants are members of CHANGE, which is a leadership group that has educated them about advocacy skills and given

them many opportunities to practice skills and educate others about advocacy-related concepts. While the adults all share membership of HCPD now, and many of them have been members for some time, they all had many, many years of lived experience that they brought with them. The difference in formal introduction of advocacy from a young age may have had an impact on the adolescent understanding. Additionally, narratives surrounding disability have changed over time. Cultural consciousness has risen and people with disabilities have many more legal rights today than they did 25, 30, 50 years ago. While experience with disability/chronic illness and advocacy was obviously linked within these populations, it is hard to say how much of the definition of advocacy stems from the narratives that are told to young people with or without disabilities. Finally, it is possible that the differences in agreement are a result of or an artifact of the different make-up of adult participants and adolescent participants. This is discussed more in limitations due to the inability to further explore this question, but the disabilities represented in the adult sample may have been different enough from the youth sample that this could impact their concept of advocacy.

7.0   LIMITATIONS

Some limitations surrounding this research have been discussed throughout this paper. The difficulties and challenges we faced working with community partners greatly impacted the implementation of the mentorship program, which had a significant impact on the research and evaluation plan. We had a slow start to the program, largely due to delays in engaging mentors and having some mentors agree to participate and then later back out. Because we recruited our mentee sample first, mentor recruitment was conditional on the amount of mentors we needed and also guided by the interests and qualities of the individual mentees. This delay was a challenge to implementation and essentially halted the evaluation. Process data was continually collected throughout the program, but it was not particularly meaningful. The research protocol for the planned post-test with mentees was also amended significantly.

Another thing to note is the small and unique sample we were working with. Since we recruited from CHANGE, these teens/young adults have likely already had specific exposure to ideas of advocacy and leadership due to the focus on related concepts in this group. They may be a different sub-set from a larger group of adolescents with disabilities and do not necessarily represent the average adolescent with a disability. However, despite this sample being small, data indicated that there were indeed cultural models around advocacy shared among this group. While these models are interesting and the information we learned from the participants is valuable, this data likely reflects the opinions of adolescents and adults with disabilities/chronic

illnesses *who are engaged with advocacy* and cannot necessarily represent the opinions of all adolescents or adults living with disabilities/chronic illnesses.

Finally, we made the choice not to ask for disclosures of specific disability or any health information beyond what was needed for accommodations. This was decided as the most appropriate action, because it was not necessary for the research staff to know personal health information in order to conduct the intended research. However, because we did not ask for these disclosures, I cannot confidently report the types of disabilities/chronic illnesses that are represented in these samples. Additionally, because of the lack of disclosure and the small sample size, we were unable to do subsample comparisons within the data collected. Statistically, the first factor and second factor score for each participant could be graphed on an XY plot and this could be examined to see where they fall within the models and if there are clusters by participants. For example, it may have been interesting to look at different attitudes that someone might have surrounding advocacy if they are an individual with a visible disability versus an invisible illness. An invisible illness, defined simply, is any impairment (physical, mental, neurological, etc.) that is invisible to the onlooker. As examples, this may include sensory impairments, mental health concerns, chronic pain, or other chronic illnesses. These individuals are not identifiable as "disabled" by sight, so this could change certain aspects of their life, such as the choice of disclosure, and this may have an impact on how those people think about self-advocacy or advocacy skills. Though there was a mix of visible and invisible disabilities represented among the participants in this study, there was not a large enough sample to statistically investigate if any differences were significant or what those differences might be.

8.0   CONCLUSIONS, NEXT STEPS, AND SIGNIFICANCE

The research presented here was an exploration into the concept of advocacy with samples of people with disabilities/chronic illnesses. Literature previously established advocacy knowledge and skills as highly relevant to these populations, specifically relating to issues such as disclosure, employment, education, independent living, healthcare and medical transition. In this study, mixed methodology was used to investigate this concept from multiple perspectives and to include measures of related qualities, such as self-esteem and future orientation as they relate to self-determinism and self-advocacy.

Much was learned about the groups we were working with, CHANGE and HCPD, and the populations of adolescents and adults living with disabilities and/or chronic illnesses. Results established that the participants did share an understanding of advocacy and advocacy skills amongst their respective groups and that they organized their thoughts similarly, but with some differences. One remaining goal of this work is to investigate how stable those models of advocacy are within the youth population and what intervention strategies may exist to develop advocacy knowledge and skills further. Our hypothesized strategies surrounding mentorship have largely remained untested to date. Future steps should entail further development of this program and additional measurement of any change that may occur. Despite the literature support for the importance of advocacy, a notable gap remains in the lack of evidence-based

interventions. This work could contribute to filling that gap, if support, implementation, and evaluation of the mentorship program carries on from here.

Another aspect noted during data collection was how meaningful the act of participating was to many of the individuals. Several people across both adolescent and adult groups expressed how thankful they were that they were able to participate. Many of the participants mentioned that they had never really thought about these concepts before in this way and they enjoyed and appreciated the opportunity to do so. Many of the adult participants shared their own personal stories during data collection. They described challenges they have faced in their lives, how they've overcome those challenges, and how that has affected the advocacy work that they do now. It was important to our research team that every participant felt listened to and that they understood their position as experts we were learning from. The goal with the mentorship program and related research was to understand and intervene on adolescent understanding of advocacy, however one further area of interest is how participating in research or mentorship could also benefit the adults with disabilities/chronic illnesses.

At present, the main significance of this work to the scientific community and the field of public health stems from the novel methodological approach. We were able to make minor adaptations to our methodology to allow any individual to participate, regardless of their level of ability. We were able to accommodate different processing speeds and cognitive styles, and mobility and sensory impairments within our samples. Had we recruited a larger sample, we were prepared to adjust the methodology to include people with limited verbal communication abilities and to make use of assistive technology or remote/online data collection methods as well. Additionally, the cultural domain analysis methodology has not been widely used with any adolescent populations before. Disseminating the novelty of this approach in these populations is

an important first step in allowing for more diverse voices to be represented in research. More work needs to be done to explore these adapted methods and establish their rigor, however this work introduces the feasibility of this approach with these populations. Because of the adaptability, people in populations who are already othered, labelled as different or subordinate, and marginalized by society would not have to be excluded. Adding strategies such as these to a researcher's toolbox is critical to the development of research and working towards making research and all facets of life more inclusive and accessible to all.

APPENDIX A: LOGIC MODEL PROPOSED FOR MENTORSHIP PROGRAM

LOGIC MODEL

Problem Statement: Adolescents and young adults who are disabled and/or chronically ill must go through the same transitional stages as all youth, including the medical transition process from pediatric to adult care. When this is handled poorly, individuals can end up with financial and emotional stress on themselves and their families, delayed or inappropriate medical care, loss of medical care through falling out of the system, and worse health outcomes. Literature shows that education about self-advocacy skills and opportunities to self-advocate are often not given to students with disabilities, despite evidence from both disability and educational research that development of these skills is crucial to successful transition into adult life.

INPUTS	OUTPUTS		OUTCOMES		
	Activities	**Participants**	**Short**	**Medium**	**Long**

Staff: Research team consisting of myself as PI, Sarah Morrow as Co-PI and project mentor, and Jodi Allison as a Research Assistant, who will together to implement the program and research activities
 	
Funding: internal funding from UPMC (at least $1000)
 	
Space: UPMC Facilities - conference rooms in Children's Hospital Office Building in Oakland
 	
Support: The Adolescent & Young Adult Medicine division of the Children's Hospital of Pittsburgh [Dr. Elizabeth Miller]
 	
Health Committee for People with Disabilities (HCPD) [Sally Jo Snyder and the Mentors, who are trained disability advocates]
	• Mentorship program matching adult mentors to adolescent/young adult mentees:
	  o One social event for the mentee-mentor pairs organized and hosted by the research team each month
	  o Pairs will interact at least one additional time per month outside of these events in a manner determined by the pair
	• Deliver a pre-test and post-test around the mentorship program, through Free Listing and Pile Sorting (FLPS) sessions and surveys with the mentees, to measure how they understand the concept of advocacy and related metrics (Self-esteem and Future Orientation)
	• One Free Listing and Pile Sorting session held with the mentors for comparison
		• 10-15 adolescents or young adults who are members of CHANGE (Children's Hospital Advisory Network for Guidance and Empowerment), participating as mentees
		• 10-15 adults who are members of HCPD, participating as mentors
			• Meet recruitment goals by 100% (at least 10 per group)
			• Hold at least one social event per month for first three months of mentorship program
			• At least 90% attendance at each social event
				• Overall, 90% mentor-mentee pairs had at least 2 times of contact per month
				• In the second adolescent FLPS session results, the concept of advocacy will have broadened, compared to the first FLPS session results.
				• The second adolescent FLPS session results will more closely align with the adult mentor FLPS session results, compared to the first adolescent FLPS session results.
				• Mentees will show an increase in Self-esteem and Future Orientation after participating in the mentorship program for several months, as measured by validated surveys.
					• Improved advocacy skills and understanding of advocacy in participating youth
					• Mentorship program will be fine-tuned for generalization and dissemination to other groups
					• Improved transition process created for adolescents with chronic illness and disability – see reduction in poor health outcomes for this population

Assumptions/Theoretical Constructs
Social Cognitive Theory: Mentors will model advocacy skills to youth
Interacting with mentors and practicing advocacy skills will lead to an increased understanding of what advocacy is and better advocacy skills in the youth
Increase in advocacy skills leads to improved medical transition/quality of life for participating youth as they age

External Factors
The participating mentors will certainly have an impact on the success of this program: their own familiarity with advocacy should be high, but their investment to their mentee and the time they devote to this program may vary. Low engagement from mentors will reduce overall effects seen from this program. Additionally, structural barriers, such as transportation, technology, scheduling, medical issues, etc., could impact a mentor or mentees ability to be able to participate in the mentorship program.

APPENDIX B: FULL SURVEY GIVEN TO PARTICIPANTS

Study ID: _____

Please don't put your name on this.

<u>Demographic Information:</u>

1. How old are you? _____ years

2. How do you describe yourself? (Circle all that apply)
   o American Indian or Alaska Native
   o Asian
   o Black or African American
   o Hispanic or Latino
   o Native Hawaiian or Other Pacific Islander
   o White
   o Other, please describe: _____

3. How do you identify your gender?
   o Female
   o Male
   o TransFemale
   o TransMale
   o Genderqueer/Gender non-binary
   o Other, please describe: _____
   o Prefer not to share

Questionnaire:

Part One: For the following ten statements, please circle how much you agree with them:

1) On the whole, I am satisfied with myself

Strongly Disagree   Disagree   Agree   Strongly Agree

2) At times, I think I am no good at all

Strongly Disagree   Disagree   Agree   Strongly Agree

3) I feel that I have a number of good qualities

Strongly Disagree   Disagree   Agree   Strongly Agree

4) I am able to do things as well as most other people

Strongly Disagree   Disagree   Agree   Strongly Agree

5) I feel I do not have much to be proud of

Strongly Disagree   Disagree   Agree   Strongly Agree

6) I certainly feel useless at times

Strongly Disagree   Disagree   Agree   Strongly Agree

7) I feel that I'm a person of worth, at least on an equal plane with others

Strongly Disagree   Disagree   Agree   Strongly Agree

8) I wish I could have more respect for myself

Strongly Disagree   Disagree   Agree   Strongly Agree

9) All in all, I am inclined to feel that I am a failure

Strongly Disagree   Disagree   Agree   Strongly Agree

10) I take a positive attitude toward myself

Strongly Disagree   Disagree   Agree   Strongly Agree

Part Two: For the next six statements, please circle how much you agree with them.

1) I expect good things to happen to me

Strongly Disagree   Disagree   Agree   Strongly Agree

2) I am excited about my future

Strongly Disagree   Disagree   Agree   Strongly Agree

3) I trust my future will turn out well

Strongly Disagree   Disagree   Agree   Strongly Agree

4) If I set goals, I take action to reach them

Strongly Disagree   Disagree   Agree   Strongly Agree

5) It is important to me that I reach my goals

Strongly Disagree   Disagree   Agree   Strongly Agree

6) I know how to make my plans happen

Strongly Disagree   Disagree   Agree   Strongly Agree

APPENDIX C: HIERARCHICAL CLUSTER ANALYSIS – ANTHROPAC OUTPUT

```
JOHNSON'S HIERARCHICAL CLUSTERING
ÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄÄ

Input dataset:          C:\AGPROX
Method:                 AVERAGE
Type of Data:           Similarities

HIERARCHICAL CLUSTERING

          1 1   1   2 2 2     3   1 2 2   1 2 2 2 2 3 3 3 3 3 2 3 1 3 1 1 1   3 1     3
 Level    0 1 6 7 1 1 7 4 2 9 2 8 2 6 5 5 4 0 9 8 3 3 1 5 7 0 2 4 6 6 5 3 8 7 8 9 3 4 9
 ------   - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -
 0.8571   XXX . XXX . . . . . . . . XXX XXX . . . . . . . XXX . . . XXX . . XXX XXX XXX
 0.8095   XXX XXXXX . . . . . . . . XXX XXX . . . . . . . XXX . . . XXX . . XXX XXXXXXX
 0.7143   XXX XXXXX . . . XXXXX XXX XXX XXX XXX . XXX . . XXX XXX . XXX XXX XXX XXXXXXX
 0.6786   XXX XXXXXXX . . XXXXX XXX XXX XXX XXX . XXX . . XXX XXX . XXX XXX XXX XXXXXXX
 0.6667   XXX XXXXXXX . . XXXXX XXX XXX XXXXXXX . XXX . . XXX XXX XXXXX XXX XXX XXXXXXX
 0.6190   XXX XXXXXXX . . XXXXX XXX XXX XXXXXXX XXXXX . . XXX XXX XXXXX XXXXXXX XXXXXXX
 0.6054   XXXXXXXXXXX . . XXXXX XXX XXX XXXXXXX XXXXX . . XXX XXX XXXXX XXXXXXX XXXXXXX
 0.6032   XXXXXXXXXXX . . XXXXX XXXXXXX XXXXXXX XXXXX . . XXX XXX XXXXX XXXXXXX XXXXXXX
 0.5714   XXXXXXXXXXX . . XXXXX XXXXXXX XXXXXXX XXXXX XXX XXX XXX XXXXX XXXXXXX XXXXXXX
 0.5626   XXXXXXXXXXX . . XXXXX XXXXXXX XXXXXXX XXXXX XXX XXX XXX XXXXX XXXXXXXXXXXXXXX
 0.5524   XXXXXXXXXXX . XXXXXXX XXXXXXX XXXXXXX XXXXX XXX XXX XXX XXXXX XXXXXXXXXXXXXXX
 0.5503   XXXXXXXXXXX . XXXXXXX XXXXXXX XXXXXXX XXXXX XXX XXX XXX XXXXXXXXXXXXXXXXXXXXX
 0.5317   XXXXXXXXXXX . XXXXXXX XXXXXXX XXXXXXXXXXX XXX XXX XXX XXXXXXXXXXXXXXXXXXXXX
 0.5073   XXXXXXXXXXX . XXXXXXX XXXXXXXXXXXXXXXXXXX XXX XXX XXX XXXXXXXXXXXXXXXXXXXXX
 0.4968   XXXXXXXXXXX . XXXXXXX XXXXXXXXXXXXXXXXXXX XXX XXX XXXXXXXXXXXXXXXXXXXXXXXXX
 0.4783   XXXXXXXXXXX . XXXXXXX XXXXXXXXXXXXXXXXXXX XXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXX
 0.4504   XXXXXXXXXXX . XXXXXXXXXXXXXXXXXXXXXXXXXXX XXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXX
 0.4001   XXXXXXXXXXX . XXXXXXXXXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
 0.3790   XXXXXXXXXXX . XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
 0.3508   XXXXXXXXXXX XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
 0.3073   XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
```

This is the data output from Anthropac used to help draw the cluster boundaries on an MDS plot. This example is Q2 with Adults. The drop-off lines indicate the divisions between clusters.

BIBLIOGRAPHY

American Academy of Pediatrics, American Academy of Family Physicians, A. C. of P.-A. S. of I. M. (1996). A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. *Pediatrics*, *98*(6 Pt 1), 1203–6. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8951283

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley, W. C., & Sagerman, P. J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *128*(1), 182–200. https://doi.org/10.1542/peds.2011-0969

Arnett, J. J. (1998). Learning to stand alone: The contemporary American transition to adulthood in cultural and historical context. *Human Development; Sep-Dec Psychology Database Pg*, *41*(56). Retrieved from https://search-proquest-com.pitt.idm.oclc.org/docview/224011897/fulltextPDF/B6A440F309214CE4PQ/1?accounti d=14709

Arnold, E. J. (1991, April 3). Can I Make It? A Transition Program for College Bound Learning Disabled Students and Their Parents. Retrieved from https://eric.ed.gov/?id=ED335836

Aune, E. (1991). A transitional model for postsecondary-bound students with learning disabilities. *Learning Disabilities Research & Practice*, *6*(3), 177–187. Retrieved from http://psycnet.apa.org/record/1992-29314-001

Bernard, H. R. (2011). *Research Methods in Anthropology: Qualitative and Quantitative Approaches* (Fifth Edition). Plymouth, United Kingdom: AltaMira Press.

Blum, R. W. M., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions. *Journal of Adolescent Health*, *14*, 570–576. Retrieved from http://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/Nov-93-Transition-Child-Centered-Adult-Chronic.pdf

Bogin, B. (1999). *Patterns of Human Growth. Cambridge Studies in Biological Anthropology* (Second Edition). Cambridge: Cambridge University Press. Retrieved from http://assets.cambridge.org/97805215/64380/sample/9780521564380WS.pdf

Borgatti. 1996. *ANTHROPAC 4.0*. Natick, MA: Analytic Technologies.

Britner, P. A., Balcazar, F. E., Blechman, E. A., Blinn-Pike, L., & Larose, S. (2006). Mentoring special youth populations. *Journal of Community Psychology*, *34*(6), 747–763. https://doi.org/10.1002/jcop.20127

Brooke, V., Barcus, M., Inge, K. (Eds.) (1992). Consumer Advocacy and Supported Employment: A Vision for the Future. Richmond: Virginia Commonwealth University, Rehabilitation, Research and Training Center. Retrieved from https://search-proquest-com.pitt.idm.oclc.org/docview/236326924/fulltextPDF/FC57770621894D04PQ/1?accounti d=14709

Coyne, B., Hallowell, S. C., & Thompson, M. (2017). Measurable Outcomes After Transfer From Pediatric to Adult Providers in Youth With Chronic Illness. https://doi.org/10.1016/j.jadohealth.2016.07.006

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood*, *96*(6), 548–53. https://doi.org/10.1136/adc.2010.202473

D'Andrade, R. G. (1995). *The development of cognitive anthropology*. Cambridge University Press.

DeLeire, T. (2000). The Wage and Employment Effects of the Americans with Disabilities Act. *The Journal of Human Resources*, *35*(4), 693. https://doi.org/10.2307/146368

DuBois, D. L., Holloway, B. E., Valentine, J. C., & Cooper, H. (2002). Effectiveness of Mentoring Programs for Youth: A Meta-Analytic Review. *American Journal of Community Psychology*, *30*(2), 157–197. https://doi.org/10.1023/A:1014628810714

Equal Employment Opportunity Commission. (n.d.-a). The Americans With Disabilities Act of 1990. Retrieved June 20, 2018, from https://www.eeoc.gov/eeoc/history/35th/1990s/ada.html

Equal Employment Opportunity Commission. (n.d.-b). Transcription: Remarks of President George Bush at the Signing of the Americans with Disabilities Act. Retrieved June 20, 2018, from https://www.eeoc.gov/eeoc/history/35th/videos/ada_signing_text.html

Garro, L. C. (1994). Narrative representations of chronic illness experience: cultural models of illness, mind, and body in stories concerning the Temporomandibular Joint (TMJ). *Social Science and Medicine*, *38*(6), 775–788. https://doi.org/10.1016/0277-9536(94)90150-3

Hotchkiss, J. L. (2004). A Closer Look at the Employment Impact of the Americans with Disabilities Act. *Journal of Human Resources*, *XXXIX*(4), 887–911. https://doi.org/10.3368/jhr.XXXIX.4.887

Izzo, M., & Lamb, M. P. (2002). Self-Determination and Career Development: Skills for Successful Transitions to Postsecondary Education and Employment. *A White Paper for the*

Post-School Outcomes Network of the National Center on Secondary Education and Transition (NCSET) at the University of Hawaii at Manoa. Retrieved from http://www.rrtc.hawaii.edu/documents/products/phase2/pdf/062d(1)-H01.pdf

Kingsnorth, S., Healy, H., & Macarthur, C. (2007). Preparing for Adulthood: A Systematic Review of Life Skill Programs for Youth with Physical Disabilities. *Journal of Adolescent Health*, *41*(4), 323–332. https://doi.org/10.1016/j.jadohealth.2007.06.007

Lindsay, S., Cagliostro, E., & Carafa, G. (2018). A Systematic Review of Barriers and Facilitators of Disability Disclosure and Accommodations for Youth in Post-Secondary Education. *International Journal of Disability, Development and Education*, 1–31. https://doi.org/10.1080/1034912X.2018.1430352

Lippman, L. H., Anderson Moore, K., Guzman, L., Ryberg, R., McIntosh, H., Ramos, M. F., Kuhfeld, M. (2014). *Flourishing Children*. Dordrecht: Springer Netherlands. https://doi.org/10.1007/978-94-017-8607-2

Longhurst, N. (1994). *The self-advocacy movement by people with developmental disabilities: A demographic study and directory of self-advocacy groups in the United States*. Washington, DC: American Assocaition on Mental Retardation.

Lynch, R. T., & Gussel, L. (1996). Disclosure and Self-Advocacy Regarding Disability-Related Needs: Strategies to Maximize Integration in Postsecondary Education. *Journal of Counseling & Development*, *74*(4), 352–357. https://doi.org/10.1002/j.1556-6676.1996.tb01879.x

Mackelprang, R. W., & Salsgiver, R. O. (1996). People with disabilities and social work: Historical and contemporary issues. *Social Work*, *41*(1), 7–14. Retrieved from https://search-proquest-com.pitt.idm.oclc.org/docview/215272364?pq-origsite=summon

Mayerson, A. (1992). The History of Americans with Disabilities Act: A Movement Perspective. Retrieved June 19, 2018, from https://dredf.org/about-us/publications/the-history-of-the-ada/

Romney, A. K., Weller, S. C., & Batchelder, W. H. (1986). Culture as Consensus: A Theory of Culture and Informant Accuracy. *American Anthropologist*, *88*(2), 313–338. https://doi.org/10.1525/aa.1986.88.2.02a00020

Rosenberg, M. (1965). Rosenberg self-esteem scale (RSE). *Acceptance and Commitment Therapy. Measures Package.*, 61–62. Retrieved from http://www.integrativehealthpartners.org/downloads/ACTmeasures.pdf#page=61

Rosenfeld, R. G., & Nicodemus, B. C. (2003). The transition from adolescence to adult life: physiology of the "transition" phase and its evolutionary basis. *Hormone Research*, *60*(Suppl 1), 74–7. https://doi.org/10.1159/000071230

Schall, C. M. (1998). The Americans with Disabilities Act – are we keeping our promise? An analysis of the effect of the ADA on the employment of persons with disabilities. *Journal of Vocational Rehabilitation*, *10*(3), 191–203. https://doi.org/10.3233/JVR-1998-10303

Schensul, J. J., & Lecompte, M. D. (2012). *Specialized Ethnographic Methods: A Mixed Methods Approach* (Second Edition). AltaMira Press.

Siegel, J. F., & Kantor, O. (1982). Self-Advocacy: Change within the Individual and the Professional. *Social Work*. Oxford University Press. https://doi.org/10.2307/23714013

Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A Conceptual Framework of Self-Advocacy for Students with Disabilities. Remedial and Special Education, 26(1),. *Remedial and Special Education*, *26*(1), 43–54. https://doi.org/10.1177/07419325050260010601

Viner, R. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood*, *81*(3), 271–5. https://doi.org/10.1136/ADC.81.3.271

Ward, M. J. (1988). *The many facets of self-determination: Transition summary*. Washington, DC: National information Center for Children and Youth with Handicaps.

Wehmeyer, M. (1992). Self-Determination: Critical Skills for Outcome-Oriented Transition Services. *Journal for Vocational Special Needs Educaion*, *15*(1), 3–7. Retrieved from https://eric.ed.gov/?id=EJ452506

Wehmeyer, M., Bersani, H., & Gagne, R. (2002). Riding the Third Wave. *Focus on Autism and Other Developmental Disabilities*, *15*(2), 106–115. https://doi.org/10.1177/108835760001500206

Weller, S. C. (2007). Cultural Consensus Theory: Applications and Frequently Asked Questions. *Field Methods*, *19*(4), 339–368. https://doi.org/10.1177/1525822X07303502

Williams, P., & Shoullz, B. (1982). *We can speak for ourselves: Selfadvocacy by menially handicapped people*. Bloomington: Indiana University Press.