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LEND-Genetics Fellows: Long-Term Assessment of Interdisciplinary Skills, Service and Leadership

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Abstract

Interdisciplinary skills are a competency for all genetic counselors, however, there are no Accreditation Council for Genetic Counseling (ACGC) standards dictating the implementation of interprofessional education (IPE) within genetic counseling programs. Formal IPE is available to select institutions associated with Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. This is the first research relating to IPE for genetic counseling students. We assessed IP skills and attitudes of former LEND-Genetics fellows (n=8) at the Rose F. Kennedy Center using the Team Skills Scale (TSS) and Attitude Toward Health Care Teams (ATHCT) scale. The mean TSS score was 79.8. The mean ATHCT score was 83.2, while the mean team efficiency and team value subscale scores were 78.3 and 84.5. To assess the outcomes of the LEND-Genetics program nationally, we performed a retrospective analysis of 210 archived follow-up surveys given to fellows after program completion. These data revealed that the majority of fellows are working with maternal child health, underserved and vulnerable populations. They're more likely to work for government agencies and less likely to work in the private sector than other genetic counselors. The majority (85%) reported performing leadership activities. This assessment shows that the LEND-Genetics program is achieving its aims. We hope the success of the LEND-Genetics program will inform and encourage the creation of future ACGC IPE standards.

Key word

Genetic counseling, Interdisciplinary, Multidisciplinary, Interprofessional, Multiprofessional, Education, Professional development, Leadership Education in Neurodevelopmental and Related Disabilities, Maternal Child Health, Association of University Centers on Disabilities

Introduction

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program is a national organization funded by the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA) Maternal Child Health (MCH) department and supported by the Association of University Centers on Disabilities (AUCD). Forty-three LEND centers exist throughout the United States, focused on educating future leaders to work with underserved populations and people with intellectual and developmental disabilities (IDD). The goal of the LEND program is for students who participate to have a significant future impact on service delivery systems for children and families with neurodevelopmental and related disabilities (NARDs) and to serve in future leadership roles in academic settings, community agencies and public health/policy making positions (Cohen 2006).

As of 2010, thirteen LEND centers offer training for genetic counseling students and are referred to as LEND-Genetics programs. LEND-Genetics programs provide interprofessional (IP), disability, and leadership education to students enrolled in genetic counseling programs, with a focus on patient- and family-centered care. The first three LEND-Genetics programs began in 2005, one of which was run by the Rose F. Kennedy Center University Center for Excellence in Developmental Disabilities (RKF-UCEDD) at the Albert Einstein College of Medicine of Yeshiva University in Bronx NY. The Children's Evaluation and Rehabilitation Center (CERC) within RKF-UCEDD is the unit that provides the clinical training opportunities for LEND-Genetics fellows.

Genetics fellows at CERC are recruited from the Joan H. Marks Graduate Program in Human Genetics at Sarah Lawrence College. As genetics fellows, second year genetic

counseling students participate in various interprofessional education (IPE) training components alongside LEND trainees from other disciplines including developmental-behavioral pediatrics, psychology, nursing, occupational therapy, physical therapy, social work, nutrition, audiology, speech pathology, special care dentistry, neurology, and special education. The training includes an IP clinical team experience at CERC, a research project, a weekly CORE lecture series on NARDs, and a genetic counseling experience at CERC and the Children's Hospital at Montefiore. This opportunity allows the LEND-Genetics fellows to emphasize the importance of genetic diagnoses and their implications for medical management to other professionals and to understand how genetic counseling fits as part of a multidisciplinary team.

IPE is a unique and transformative education model in which seasoned and novice professionals "learn with, from and about each other to improve collaboration and the quality of care" for patients (CAIPE 1997). IPE is referred to in the literature using a variety of terms, including, but not limited to: multidisciplinary, multiprofessional, interdisciplinary, and transdisciplinary education or learning (Thistlethwaite and Moran 2010). The IPE model focuses on learning within a team of professionals from various specialties. In healthcare, patient care can be negatively affected by poor IP collaboration (Kvarnstrom 2008). IPE can help ameliorate these collaboration problems and improve healthcare outcomes for patients (Zwarenstein 2009). Multidisciplinary teams typically work together to manage patient care, however, professionals from each specialty train separately and have differing skill sets. IPE can bring health professionals together to understand and appreciate how each specialty serves patients and provide collaborative skills.

A single article regarding IPE has been published in the field of genetic counseling. Two Australian genetic counselors arranged their own IPE program. They reported their heightened understanding of other health professionals' roles within an oncology team, the patient experience for each of the procedures observed and the clinical processes often discussed in cancer genetic counseling sessions (Mann 2014). Additionally, the authors surveyed Australian genetic counselors. The vast majority (74%) said their knowledge of cancer-related procedures came from anecdotal accounts from patients (Mann 2014). They found a strong direct correlation between a genetic counselor's level of knowledge regarding a procedure and having obtained that knowledge directly. Almost all respondents indicated interest in participating in an IPE program. Although this singular publication intersecting genetic counseling and interdisciplinary education focuses on the continued education of seasoned genetic counselors deepening their understanding of cancer healthcare and oncology professionals, it makes a point that rings true for all areas of genetic counseling: "There is a divide between direct exposure and theoretical knowledge when it comes to discussion of the clinical procedures" (Mann 2014). IPE would provide genetic counseling students with direct exposure to professionals who perform these procedures thus narrowing this theoretical gap in knowledge.

While the RFK-UCEDD's LEND has recruited second year genetic counseling students from Sarah Lawrence College as LEND-Genetics fellows for ten years now, a long-term outcome study of this IPE program has not been performed. Now is an appropriate time to conduct this outcomes assessment, as the director, Robert Marion, MD, will be stepping down from this position in 2015. Dr. Marion took over leadership of the LEND-Genetics program from Dr. Herbert Cohen in 2006 and has expanded the program during his nine

years as director. As the torch passes to a new leader, Dr. Theodore Kastner, it is important to carefully assess and reflect on the achievements of the LEND-Genetics program at RFK-UCEDD specific to the enhanced education and training of genetic counseling students. Additionally, the broader impact of all the LEND-Genetics programs should be examined, by assessing how this IPE model has led fellows to better serve children with NARDs, to be leaders in healthcare and work in underserved communities.

Materials and Methods

Initiated in 2005, twenty-three genetic counseling students from Sarah Lawrence College (SLC) completed fellowships with the LEND-Genetics program. Additionally, two SLC students are currently receiving training in 2014-2015.

Part 1

All LEND fellows are sent follow-up surveys one, five and ten years after completing the program. The survey entails thirteen questions, covering work-related experiences and environment as well as the population of patients served. The questions measure the fellows' participation in leadership roles and service of patient populations, which include children with NARDs.

Participants

All individuals registered under the "Genetics/Genetic Counseling" discipline in the AUCD web-based National Information and Reporting System (NIRS) database were included in this study. Only those who completed one or more AUCD surveys since completion of participation in a LEND anywhere in the United States qualified for inclusion. Surveys (n=201) completed by LEND-Genetics fellows between January of 2006 and December of 2014 were collected from NIRS by an AUCD staff member. All identifying

information (including name, demographic information, location and program affiliation) was removed from the survey data before it was made available for analysis. Of the 201 surveys, 149 were one-year follow-up surveys and 52 were five-year follow-up surveys. We were unable to determine whether 201 individual fellows completed these surveys, or if as few as 149 individual fellows completed the 201 surveys.

Instrumentation

A single survey was used for 1-, 5-, and 10-year follow up by all AUCD-funded LEND and UCEDD programs., This survey consists of seven items related to both the communities served by the participant and experience in leadership roles. The survey asks questions regarding the participants current work environment and the populations they serve. The survey asks the participant to indicate which, if any, of ten listed leadership activities they have participated in since completing their fellowship and in what settings these activities take place.

Procedures

The AUCD survey is sent to fellows 1, 5 and 10 years after completion of their fellowship. The survey is sent out electronically and as a paper copy from an administrator at the site of participation.

To obtain survey data only from LEND-Genetics fellows, an AUCD staff member searched the NIRS database, filtering out all participants other than those within the “Genetics/Genetic Counseling” discipline who completed their training between 2006 and 2014. The surveys available for each of these participants were then de-identified and made available for this research study.

Data Analysis

The surveys were analyzed as two separate sets: 1-year follow up and 5-year follow-up, as they could not be linked to specific fellows. For each group, the percentage of respondents who indicated positive responses to working with specific populations, in specific settings, and participating in specific leadership activities were calculated from the total number of responses in each data set. Each outcomes' data, as a percentage was compared across groups using two-tailed Fisher's exact test. The data from the subset of the respondents who indicated participation in leadership activities was used to assess the locations in which these activities were taking place.

The workplace setting data obtained in Part 1 was also compared to information found in the Professional Status Survey (PSS) produced by the National Society of Genetic Counselors (NSGC). In order to compare the AUCD data to the NSGC data, the NSGC data was re-categorized to best match the categories in the AUCD survey.

Part 2

To measure the IP skills and attitudes toward healthcare teams of LEND-Genetics fellows, we conducted an additional survey of RFK-UCEDD LEND-Genetics fellows. The RFK-UCEDD LEND-Genetics fellows' IP attitudes and skills data is compared with the same data available about other healthcare professionals.

Participants

All former LEND-Genetics Fellows from the RFK program (n=23) were invited to participate in the interdisciplinary attitude and skills section of this study using the e-mail contact information available in the NIRS database. All fellows were graduates from the genetic counseling program at SLC. Three of the e-mails failed to be delivered, with their

servers rejecting the addresses as invalid, meaning invitations to participate in this study only reached 20 individuals. The fellows were given three weeks to return this survey, and two reminder e-mails were sent over the three week period. As this study was conducted by LEND staff members, Institutional Review Board approval for research was already in place.

Instrumentation

The Team Skills Scale (TSS) and Attitude Toward Health Care Teams (ATHCT) scales were both used for this IPE study. The TSS, developed by Hepburn (1996), is a self-assessment of the participant's interdisciplinary team skills. It is a 17-item scale, with each item rated on a five-point Likert scale from poor (1) to excellent (5). A high score on the TSS indicates a positive perception of one's own interdisciplinary skills. The scale is frequently paired with the ATHCT, described below. It has been used with students and work professionals from a variety of disciplines within health care, including doctors, nurses, occupational therapists, pharmacists, public health specialists, social workers, physician assistants and physical therapists, to assess IP skills (Grymonpre 2010; Miller 2001; Robben 2012).

An adapted version of the ATHCT, originally developed by Heinemann et al (1999), was used in this study. The original scale included a shared leadership subscale focusing on the role of the physician within a healthcare team; this fourteen-item adapted scale does not include the shared leadership subscale. In this survey, each item is rated on a six-point Likert scale from strongly disagree (1) to strongly agree (5). Three of the fourteen items required reverse coding (items 2, 6, 9), so that high scores reflect positive attitudes toward teamwork. The adapted ATHCT can be divided into two subscales. First is an eleven-item team value subscale. Second is a three-item team efficiency subscale. Though originally created for

primary care physicians in a clinical setting, using minor adaptations to wording, this scale has been modified to study the interdisciplinary attitudes of other healthcare professionals, including nurses, doctors, social workers, physiotherapists, occupational therapists, psychologists, dentists, pastoral counselors, lawyers, and speech language pathologists (Braithwaite 2012; Curran 2010; Curran 2008; Fulmer 2005; Hyer 2000; Kim 2014; Leipzig 2002; Robben 2012). In this current study, the ATHCT was used to evaluate the perception of genetic counselors toward health care teams and their own roles within the team.

Procedures

The ATHCT and TSS surveys were sent electronically to the former RFK LEND-Genetics fellows. Accompanying these surveys was an invitation to participate in this research project, noting the voluntary nature of participation. The electronic format of both surveys was a fillable PDF that could be saved and returned electronically. Included in the invitation to participate was a checkbox located at the end of the survey which inquired if the participant would be available for a brief follow-up phone interview. The participants were not contacted further if they did not indicate availability for further contact.

Data Analysis

The ATHCT data was scored using the summation of the ratings for all fourteen items. Since items were rated on a 5-point Likert scale, the maximum possible summed score for the ATHCT was 70, while the maximum possible summed score for the Attitude toward Team Value and Attitude toward Team Efficiency subscales were 55 and 15 respectively. To ease interpretation, the summations were converted to a percentage of the maximum possible score.

The TSS data was scored using the summation of the Likert rating for all seventeen items. Since items were rated on a 5-point Likert scale, the maximum possible summed score for the TSS for 105. To ease interpretation, the summations were converted to a percentage of the maximum score possible.

Results

Part 1

At the one year follow up, 149 LEND-Genetics fellows completed the AUCD survey between 2006 and 2014. At the five-year follow up, 52 fellows completed the AUCD survey between 2010 and 2014. National data were not available on the total number of LEND genetic fellows who were trained between 2005 and 2014, therefore a response rate could not be calculated. Some respondents did not complete every question, so the number of respondents who answered a given section of the survey is reported in each table and chart.

Populations served

The populations LEND-genetics fellows serve at one and five years following their training is shown in Table I. The majority of fellows reported their work relates to MCH populations (78.3% and 74%) and that they are working with underserved or vulnerable populations (78.1% and 67.3%). Additionally, the majority of fellows report working with other professionals who serve MCH populations (75.4% and 74.5%). A lower percentage of respondents reported to be currently working in a public health organization or agency (22.5% and 28%). Across all outcomes, there were no significant differences between the percent of fellows working in these areas one year versus five years after completion of the LEND-Genetics program.

Current Occupational Setting

The occupational setting of LEND-genetics fellows at one and five years following their training is shown in Charts I and II. While 11.4% of fellows reported they were still students and had not yet entered the workforce at the one-year follow-up, none of the fellows reported being students at the five-year follow-up ($p = 0.0129$). The majority of fellows identified hospitals as their primary occupational setting (69% and 74%). At one-year follow-up, 69.3% of fellows were working in hospitals. At the five-year follow-up, 79.5% of fellows were working in hospitals. The percentage of fellows working in all other occupational settings were each less than 10%, with private sector jobs (7% and 6%) and government agencies (3% and 6%) employing more fellows than the public health section (1% and 2%) and non-profits (2% and 2%). There were no significant differences between the occupational settings of fellows at the one- and five-year follow-up except for those who identified as being students.

Re-categorized work settings data from the 2014 NSGC PSS showed a smaller percentage of LEND genetics fellows working within the private sector compared to the all GCs surveyed by the NSGC at both the one-year and five-year follow-up points (7% vs. 17% and 6% vs. 17%). Both were statistically significant, but this difference was more significant at the five-year follow-up ($p = 0.05$) compared to the one-year follow-up ($p < 0.01$) (Chart III). There was no statistical difference between genetic counselors surveyed by NSGC and LEND genetics fellows in terms of working in a government agency, non-profit organization, or public health agency. The AUCD categories of student, grade school, UCEDD/LEND/LEAH/PCC/DBP and for-profit could not be analyzed since comparable PSS categories did not exist.

Participation in Leadership Activities

The various leadership activities LEND genetics fellows report participating in since their training are listed in Table II. Five years after completion of their fellowship, participants were significantly more likely than after their first year post-fellowship to be a group leader, have been a reviewer, and procured grant funding ($p < 0.05$; $p < 0.05$; $p < 0.01$) (Chart IV).

There were no significant differences between the two survey groups in terms of the settings in which leadership activities took place. Both groups took on leadership roles primarily in the clinical setting, followed somewhat closely by academic settings. Some fellows engaged in leadership roles through public health settings, and a few respondents did so through advocacy or an unspecified setting (Chart V).

Part 2

Response Rate

Of the 23 individuals from the RFK-UCEDD LEND Genetics Program who were invited to participate in the IP surveys, eight individuals responded, three e-mails were returned as invalid, 12 individuals did not respond. The overall response rate was 35%, but was adjusted to 40% to account for the incorrect contact information. All eight respondents completed the survey in full, and all noted they do currently work as genetic counselors in their responses. None of the respondents indicated they were willing to be contacted for a follow-up interview.

Attitude Toward Health Care Teams

All LEND-Genetics fellows had high overall ATHCT scores. The mean score, as a percentage of the maximum, was 83.2%, with a standard error of 2.5%. The range of scores was 18.6%, while the sample variance was 0.5%.

Attitude toward Team Value Subscale

All LEND-Genetics fellows had high scores for the ATHCT Team Value subscale. The mean score, as a percentage of the maximum, was 84.5%, with a standard error of 3.4%. The range of scores was 25.4%, while the sample variance was 0.1%.

Attitude toward Team Efficiency Subscale

All LEND-Genetics fellows had high scores for the ATHCT Team Efficiency subscale. The mean score, as a percentage of the maximum, was 78.3%, with a standard error of 3.3%. The range of scores was 33.3%, while the sample variance was 0.1%.

Team Skills Scale

All LEND-Genetics fellows had high than 60% TSS scores, showing a positive correlation with time. The mean score, as a percentage of the maximum, was 79.8%, with a standard error of 3.9%. Fellows who completed the program seven years ago had an average TSS score of 91.2%, while those who completed the program one year ago averaged a score of 71.2%. The eight respondents' individual scores are presented in Chart VI.

Discussion

The long-term outcomes assessment of the survey data collected by the AUCD over the past nine years reveal that many of the overarching goals of the LEND program are being met within the LEND-Genetics program at the one- and five-year, follow up points. It is not surprising that the majority of fellows reported their work relates to MCH populations, as this includes women, infants and children, adolescents, and their families (i.e., fathers and

children) and youth with special health care needs, which is a patient population typically served by GCs practicing prenatal or pediatric genetic counseling. It is impressive that a similar majority of fellows reported their work relates to underserved or vulnerable populations. The target was to increase the number of IPE-trained health professionals serving immigrant, migrant and tribal populations, uninsured individuals, as well as those who have experience family violence, homelessness, foster care, HIV/AIDS, or health disparities. The majority of GCs do not necessarily serve these populations, however the proportion working with underserved and vulnerable populations has not been previously reported. With regard to aiming to train health professionals to serve MCH and underserved populations, the LEND-Genetics program is achieving this goal one and five years after fellows complete their training.

The findings for the primary occupational settings of LEND-Genetics fellows are not particularly surprising. The majority of fellows are working in hospitals, which is also true of GCs in general according to the PSS. When comparing fellows to those surveyed in the NSGC PSS, it made more sense to use the data from the five-year follow-up survey, as more than 11% of the fellows reported to be students at the one-year follow-up. It is possible that these fellows participated in the LEND-Genetics program during the first year of their graduate training rather than in their second year. When comparing the five-year follow-up data to GCs in general, it is remarkable that a significantly smaller percentage of fellows work primarily in the private sector. This finding could speak to the inherent nature of the GCs who applied for the LEND-Genetics fellowships. Being familiar with the aims of the LEND program and subsequently pursuing participation in LEND-Genetics, the fellows may have inspirations, which are drawn more strongly to serving vulnerable populations at public

institutions. It seems more likely LEND-Genetics fellows own values would align, rather than contradict, the aims of the LEND program, and thus, they may be more likely to pursue these types of employment.

The participation in leadership activities by fellows increased over time after completion of the LEND-Genetics program, with almost one-third engaging in leadership after only one year in the field. The engagement in teaching and mentoring within genetic counseling is not surprising as 60% of GCs reporting additional income in the PSS attribute this income to lecturing or teaching. However, it is impressive that such a large portion of fellows are becoming group leaders, influencing other healthcare professionals and conducting research. By teaching fellows the leadership skills they need, the LEND-Genetics program is helping to train GCs who have the confidence and ability to become leaders, and therefore enabling them to disseminate LEND program values throughout the greater healthcare system.

The ATHCT survey results point to a general positive attitude toward both team value and team skills by LEND-Genetics fellows. Although this study did not survey other GCs with the ATHCT as a comparison to the fellows, we can use the ATHCT data from this study to compare IPE-trained GCs to students in other health professions and other health professionals currently working in their fields (Table II). Across the board, the LEND-Genetics fellows had higher team efficiency subscale scores than any other discipline, suggesting GCs who received LEND-Genetics IPE training greatly value the time spent collaborating with other professionals. Comparing the team value subscale to other studies is less straight forward. In two studies that did not incorporate IPE, nursing students scored slightly higher on the team value subscale than the LEND-Genetics fellows, however,

nursing staff in a separate study who had received some IPE scored lower than the fellows in our study. In two studies, Masters-level social work students who did not receive any IPE scored higher than the LEND-Genetics fellows for the team value subscale. Medical students, residents and staff, however, generally valued healthcare teams less than the LEND-Genetics fellows whether or not they received IPE. Overall, the ATHCT scores for the fellows in this study are high, though a few professions (nursing, social work, pharmacy and dentistry) scored higher on the ATHCT in other studies.

The TSS survey results revealed a high average self-assessment of IP skills by LEND-Genetics fellows, and these skills generally increase as fellows continue to develop skills during their career. Compared with other health professionals, the LEND-Genetics fellows had higher self-assessed TSS scores than studies in which nurses, pharmacists, physical therapists, occupational therapists, medical residents, general practitioners, social and paramedical professionals were given IPE training. These two other studies compared TSS scores before and after an IPE program intervention. The scores were reported with all disciplines averaged together, so it is difficult to compare, but the average TSS score reported post-IPE was lower in both of these studies than the average TSS score of the LEND-Genetics fellows. One of these studies did note the TSS scores went up over time, not just for the group of health professionals that received IPE, but also for the control group that did not receive training (Grymonpre, 2010). This finding is consistent with our study, suggesting team skills increase with time and experience, independent of IPE training.

Study Limitations

There are some limitations to this study. A general limitation is the lack of a control group of genetic counselors to compare with the IPE-outcomes for the LEND-Genetics

fellows. The NSGC PSS did provide us with some national comparison data, however, a re-categorization of some of the PSS categories was necessary to accomplish this. The de-identified nature of this data set created did not allow us to determine if there were confounding factors in this data set. Additionally, there are differences in the general structure of each individual LEND-Genetics program. Correlating LEND-Genetics program with each fellow's survey may have provided some insight into the strengths and weakness of individual programs. Lastly, since the data was de-identified, the one- and five-year survey data could not be linked for a given respondent. It would have been useful to assess the changes in responses, not just on a group level, but across individuals as well. A pre-IPE survey could have provided a baseline comparison. Lastly, sample size was a limitation. Although the response rate was high, no participants consented to be contacted for a follow-up interview. This study was initially designed with a small sample size in mind, and the addition of qualitative interviews would have enhanced the depth of our assessment.

Practice Implications

The findings in this study can inform the future development of new LEND-Genetics programs and the maintenance of LEND-Genetics programs already training fellows around the country. One of the goals of the LEND-Genetics program appears to be lacking – only a small number of fellows are working in public health organizations. It would be pertinent to reexamine this goal and assess its importance within the field of genetic counseling. If this goal remains important in the eyes of the AUCD's Genetic Task Force, then steps should be taken to encourage fellows to pursue employment within public health organizations, or to better understand why this has not occurred. Additionally, very few LEND-Genetics fellows reported to be working within UCEDD, LEND, LEAH, PPC and DBP programs. Creating

jobs for fellows within these Administration on Intellectual and Developmental Disabilities (AIDD)-funded and AUCD-supported programs would allow IPE-trained fellows to pass on their skills and knowledge to future trainees and enhance service to people with NARDs.

With regard to creating future leaders within healthcare, fewer than expected fellows participate in research, program planning and public policy than other leadership activities. LEND-Genetics programs could spend more time on these skill sets and encourage these activities. In these types of leadership positions, fellows have more of an indirect influence on the health care experience for people with NARDs by breaking down barriers to their care and envisioning solutions to problems they face throughout the medical system. GCs can be leaders outside of a genetics team, they can use their IPE training to benefit children with NARDs on a greater scale.

Research Recommendations

This study points to a number of feasible research directions that could help fill the gap in the genetic counseling literature with regard to IPE education. The ATHCT and TSS surveys could be used to survey all LEND-Genetics fellows as well as practicing genetic counselors to provide a control group and to increase the sample size, and thus the statistical power, of the study. Also, a longitudinal study could be done by surveying students at the beginning of genetic counseling and IPE programs as well as multiple time points after the IPE training and program has ended. Having this baseline measurement would be an effective way to measure the efficacy of an IPE intervention.

As the methodology genetic counseling programs use to teach IP skills isn't standardized and no literature exist in this area, this presents another important research opportunity. Since IP skills is a core competency, how programs teach this core competency

needs to be examined. Programs could be surveyed to see if and how they are providing this education.

Lastly, the NSGC PSS survey could be modified to inquire more specifically about how GCs' are participating in various leadership roles. The current survey asks about additional roles GCs take on for further compensation, however there could be leadership activities in which GCs engage in which may not be part of their job description or for which they do not receive additional compensation. A description of genetic counselors as leaders cannot be found in the literature, so examining this topic on a research basis would be feasible as well.

Conclusion

The WHO has encourage IPE for all healthcare professionals since the 1980's and a wealth of literature exists to demonstrate the efficacy of IPE programs on professional knowledge and patient care. Many healthcare fields have embraced IPE for decades, but the field of genetic counseling is late in the game to adopt this model into the accredited program curriculum requirements. Only recently has IP skills been added to the core competencies of entry level genetic counselors, however no specific guidelines or requirements exist dictating how genetic counseling programs should be providing IPE to students. Approximately one-third of the genetic counseling programs in the United States have access to LEND-Genetics programs. Only one to three students are accepted each year as fellows at each LEND-Genetics program, meaning that most genetic counseling students do not have access to this specialized IPE training.

GCs have been shown to have a greater understanding of various health procedures and experiences through first-hand knowledge. As GCs strive to make connections with and

understand their patients as deeply as possible, gaining direct knowledge of patient experiences is an important step in that process. Structured IPE teaches genetic counseling students how patients navigate the healthcare system as a whole and how other health professionals approach patient care. Students learn about when to refer to other specialties and how to discuss genetic information amongst professionals with a wide range of backgrounds. By observing how patients interact with other health professionals before and after they would see a geneticist, genetic counseling students can develop a deeper understand of patient experiences.

This study assesses the long-term outcomes of the LEND-Genetics programs. LEND-Genetics programs aim to train genetic counseling students to have a significant future impact on service delivery systems for children and families with NARDs and to prepare them for future leadership roles in academic settings, community agencies and public health/policy making positions. This study shows that the LEND-Genetics program is accomplishing the vast majority of its goals. It is a retrospective, longitudinal assessment of the current achievements of the LEND-Genetics Fellows in terms of leadership engagement, providing service to underserved and vulnerable populations, and working with MCH populations. In terms of IPE-specific outcomes, this study shows that fellows from the RFK-UCEDD LEND-Genetics program greatly value IP collaboration, believe it is an efficient means of providing patient-centered care and have appreciable team skills.

The Accreditation Council for Genetic Counseling (ACGC) has described a set of Practice-Based Competencies all entry-level providers must have to become successful genetic counselors, including being able to “establish and maintain professional [IP] relationships in both team and one-on-one settings, and recognize one’s role in the larger

healthcare system” (ACGC 2013). Genetic counseling program directors use the practice-based competencies to develop, maintain and evaluate their program curriculum. The ACGC Standards of Accreditation for Graduate Programs in Genetic Counseling describe the accreditation requirements for all master’s level graduate programs in genetic counseling. It specifically details the general content programs must include to help students develop the practice-based competencies (ACGC 2013). The list of required content areas and other curricular guidelines included in these standards do not mention IPE, even though IP skills are a practice-based competency. Due to the absence of this specific requirement in the ‘Standards’, it is possible program directors assume students will acquire these skills through clinical rotations. However, not all clinics are interdisciplinary and may not provide the structured opportunity to learn IP skills even within a multidisciplinary clinic. IPE programs have specific learning objectives and structured educational activities to ensure purposeful IPE learning occurs. IPE programs do not leave it up to chance that skills and knowledge will be gained by having students from different disciplines in the same clinical training setting. To ensure students obtain the IP competency required, IPE should be a requirement for genetic counseling programs.

Further pursuit of the incorporation of IPE into more genetic counseling programs and standardization of its implementation will enable all genetic counseling students to develop IP skills as a core competency. If the majority of entry level GCs attain this core competency, it will result in heightened understanding of patients’ experiences, better communication between GCs and other health professionals, increased likelihood of appropriate referrals, and generally, better service for patients.

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Human Studies: All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). For this type of study formal consent is not required.

Animal Studies: No animal studies were carried out by the authors for this article.

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CHART I

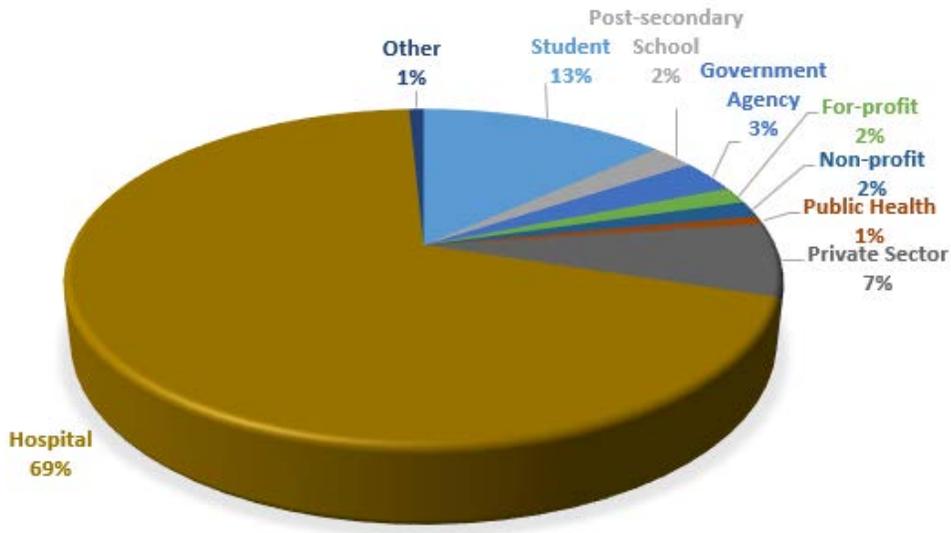


Chart I: The distribution of employment settings for LEND-Genetics Fellows one year after completion of their training. N=149.

CHART II

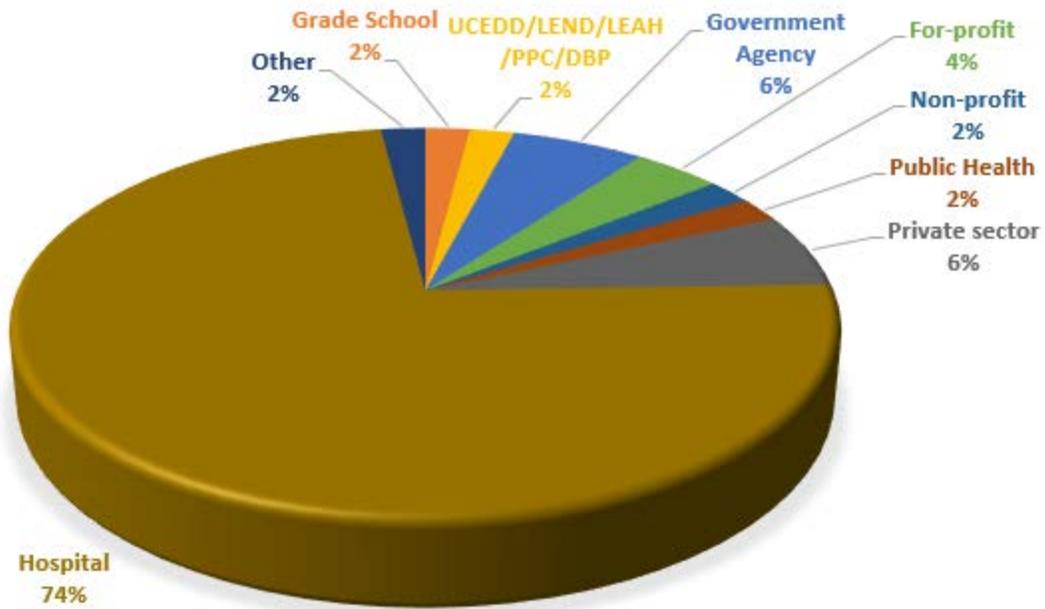


Chart II: The distribution of employment settings for LEND-Genetics Fellows five years after completion of their training. N=52.

CHART III

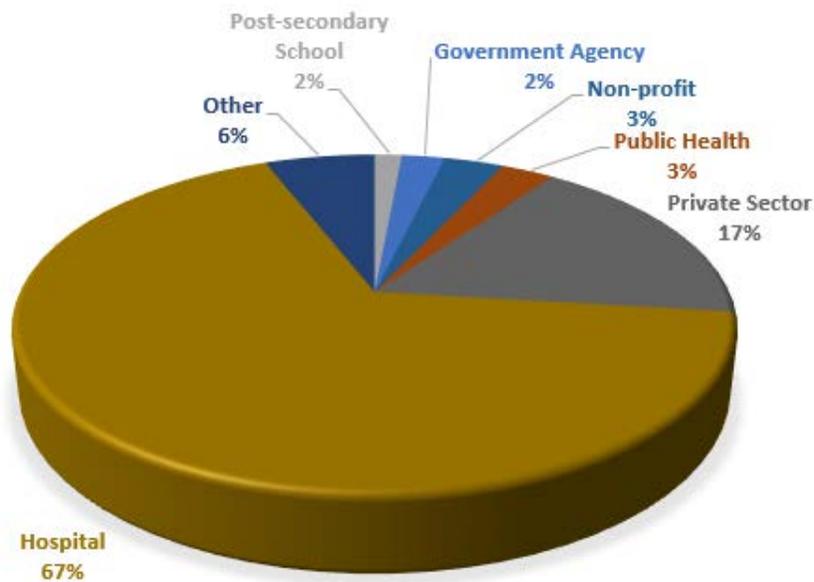


Chart III: The distribution of employment settings for genetic counselors surveyed by the NSGC and reported in the 2014 Professional Status Survey (PSS). The workplace setting categories used in the NSGC PSS were recategorized to fit the categories used by the AUCD survey so the results could be compared. Diagnostic laboratory – commercial, internet/website company, marketing/advertising company, pharmaceutical company and research development/biotechnology company were all recategorized as the Private Sector setting. Federal/state/county office and government organization or agency were recategorized as Government Agency setting. Health advocacy organization and health maintenance organization were recategorized as Public Health setting. Not-for-profit organization was recategorized as Non-Profit setting. Physician’s Private Practice, private practice – self-employed, private hospital/medical facility and public hospital/medical facility were recategorized as Hospital setting. Diagnostic laboratory – academic, bioinformatics, outreach/satellite/field clinic, and professional organization were recategorized as Other setting. No responses from the PSS were recategorized as Student, Grade School, Post-secondary School, For Profit, or UCEDD/LEND/LEAH/PPC/DBP setting. N=1502.

CHART IV

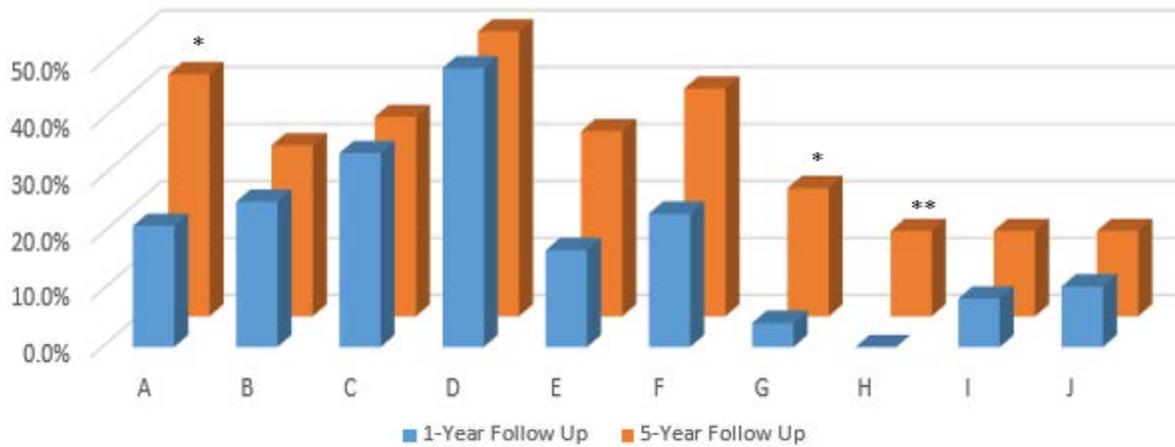


Chart IV: Leadership participation by LEND-Genetics fellows in activities A-J at one-year (blue) and five-year (orange) follow-up. A significance difference between these follow-up points is indicated by (*) for p values < 0.05 and (**) for p values < 0.01. N=47 for one-year follow-up. N=40 for five-year follow-up.

CHART V

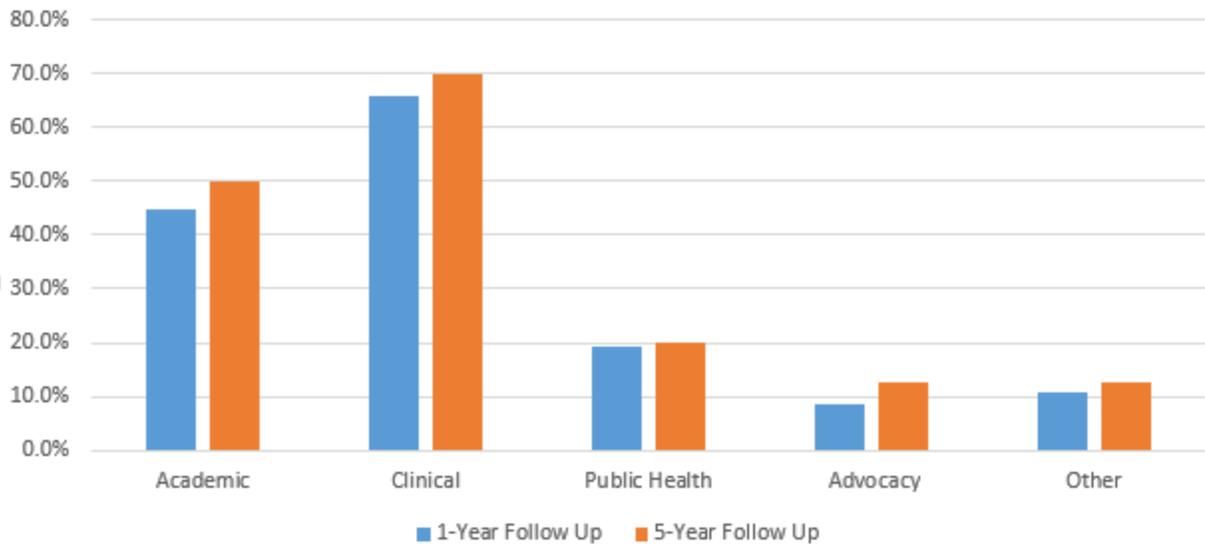


Chart V: Work settings in which LEND-Genetics fellows participated in leadership activities one-year (blue) and five-years (orange) after completion of their training.

CHART VI

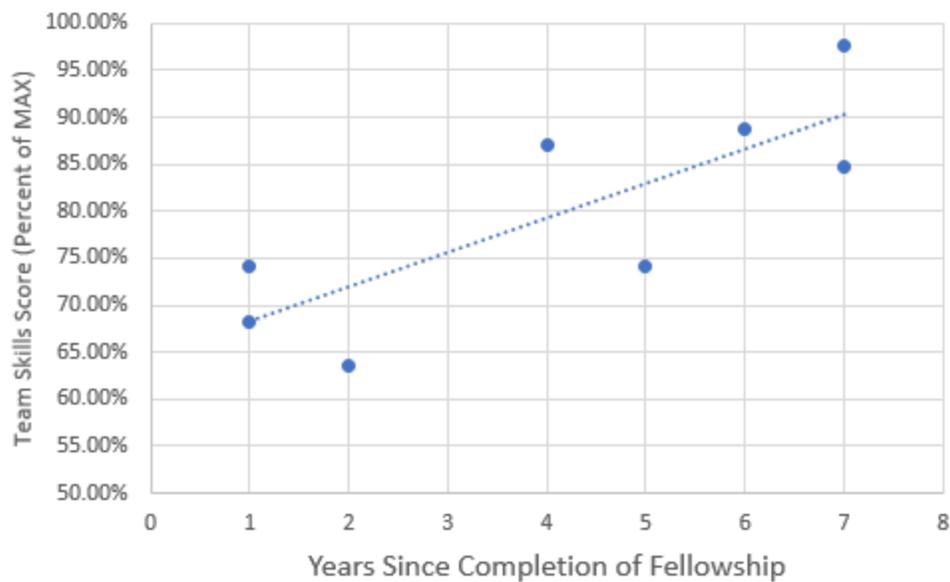


Chart VI: Self-rated Team Skills Scores for each RFK-UCEDD LEND-Genetics fellow surveyed (n=8). Scores are displayed as a percentage of the maximum possible score and plotted against the number of years that had passed since completing their training. A regression line shows the general positive relationship between the team skills score and experience in the genetic counseling field.

TABLE I

	One Year Follow Up		Five Year Follow Up	
	Percent	N	Percent	N
MCH Populations	78.3%	138	74.0%	55%
Underserved or Vulnerable Populations	78.1%	73	67.3%	49
Public Health Organizations	22.5%	71	28.6%	49
Other Disciplines working with MCH populations	75.4%	122	74.5%	47

This table shows the proportion of LEND-Genetics fellows who work with Maternal Child Health (MCH) Populations and Underserved or Vulnerable Populations, for Public Health Organizations, and with other disciplines which work with MCH populations at one- and five-years after completion of their LEND training. The number of respondents for each question is indicated.

Table II

Leadership Activity		One-Year Follow-Up (N=47)	Five-Year Follow-Up (N=40)
A	Acted as a group leader, initiator, key contributor or in a position of influence/authority within committees of state, national or local organizations; task forces; community boards; advocacy groups; research societies; professional societies; etc.	21.3% *	42.5% *
B	Served in a clinical position of influence (e.g. director, team leader)	25.5%	30.0%
C	Provided consultation or technical assistance in MCH areas	34.0%	35.0%
D	Taught/mentored within her discipline or a MCH-related field	48.9%	67.5%
E	Conducted research or quality improvement on MCH issues	17.0%	32.5%
F	Disseminated information on MCH Issues (e.g. peer reviewed publications, key presentations, training manuals, best practices documents)	23.4%	40.0%
G	Served as a reviewer (e.g., for a journal, conference abstracts, grant)	4.3% *	22.5% *
H	Procured grant and other funding in MCH areas	0.0% **	15.0% **
I	Conducted strategic planning or program evaluation	8.5%	15.0%
J	Participated in public policy development activities (e.g., Participated in community engagement or coalition building efforts, written policy or guidelines, influenced MCH related legislation)	10.6%	15.0%
K	None	10.6%	15.0%

The percentage of LEND-Genetics fellows who report participation in leadership activities A-K one year and five years after completion of training. Respondents selected as many activities that applied, or option K, none. A significance difference between the results for these two time points is indicated by (*) for p values < 0.05 and (**) for p values < 0.01.

TABLE III

Study	Participants	N	Mean ATHCT Score	Mean ATHCT Team Value Subscale Score	Mean ATHCT Team Efficiency Subscale Score	Mean TSS Score
Koptiuch 2015*	LEND-Genetics Fellows	8	83.2	84.5	78.3	79.8
Leipzig 2002	Second Year Medical Residents	349	-	80.1	69.7	-
	Advanced Practice Nursing Students	127	-	85.3	71.5	-
	Masters-level Social Work Students	84	-	85.4	77.3	-
Grymonpre 2010*	Nurses, Pharmacists, Physical Therapists, Occupational Therapists, Medical Residents	21	79.0	-	-	69.4
Braithwaite 2012*	Medical Staff	38	-	76.2	-	-
	Nursing Staff	198	-	76.2	-	-
	Allied Health Staff	152	-	81.0	-	-
	Administrative Staff	30	-	78.5	-	-
Kim 2014	Law students	25	76.7	78.0	72.0	-
	Nursing students	47	87.0	90.0	76.0	-
	Medical students	48	55.6	82.0	70.0	-
	Pharmacy students	50	83.7	88.0	68.0	-
	Social work students	61	85.4	88.0	76.0	-
	Dentistry students	18	83.2	88.0	66.0	-
Robben 2012*	General Practitioners, Pharmacists, Nursing disciplines, Paramedical disciplines, Social disciplines	78	65.8	70.7	64.4	56.6

A comparison of outcomes from studies which used either the Attitudes Toward Health Care Teams (ATHCT) or the Team Skills Scale (TSS) as a measure. All outcomes are presented as a percentage of the maximum possible score. Some of these studies measured ATHCT and/or TSS outcomes before and after an IPE intervention; in these studies, the post-IPE score is provided and indicated by a (*). Color coding was used to represent scores that were either greater than (blue) or less than (red) those of LEND-Genetics fellows.