

Health Literacy Profiles of Early Intervention Providers: Use of the Health Literacy Questionnaire

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ABSTRACT

Background: Early intervention (EI) providers work with parents of children with or who have risk factors of developmental delay or disability through Part C of the Individuals with Disabilities Education Act. Many parents in the United States have low health literacy; therefore, EI providers should be aware of and address families' health literacy needs. EI providers need to be health literate themselves to implement evidence-based recommended practices. **Objective:** This study aimed to measure health literacy levels of interdisciplinary EI providers and investigate associations between health literacy levels and demographic variables. **Methods:** A survey containing the Health Literacy Questionnaire (HLQ) was completed by EI providers working at 10 EI centers in Massachusetts. Scale scores were calculated and compared across demographic variables, including EI job role, age, years of EI experience, and highest education level. **Key Results:** Of 715 EI providers invited to participate, 376 surveys were completed (52.6% response rate). Most participants were women (92.6%, $n = 348$), reported race as White (85.4%, $n = 321$), had a mean age of 43.1 years (standard deviation [SD] 12.9) ranging from 20 to 74 years, and English as their primary language (89.6%, $n = 337$). EI providers scored the lowest on HLQ Scale 5 "Appraisal of health information" (mean [M] = 2.99 (SD 0.50) [confidence interval (CI) 2.93, 3.04]), and Scale 7 "Navigating the healthcare system" ($M = 3.83$ (SD 0.58) [CI 3.77, 3.89]). EI providers having stronger health literacy profiles were generally older, with a higher education level, were licensed providers, or had more years of EI work experience. **Conclusions:** EI providers require adequate health literacy to manage their health needs and to effectively provide services to EI families. Study results may inform future targeted professional development to support improvement of EI providers' health literacy skills, including appraisal of health information and navigation of the health care system. [*HLRP: Health Literacy Research and Practice*. 2022;6(2):e128–e136.]

Plain Language Summary: EI providers' health literacy profiles have not been previously investigated. Study results reveal EI providers struggled with health literacy skills of appraising health information and navigating the health care system, which are vital for EI practice. Health Literacy Questionnaire results can inform targeted professional development to improve EI providers' health literacy levels and their clinical practice.

The low health literacy of parents in the United States (Kutner et al., 2006; Yin et al., 2009) is associated with negative effects on child health (DeWalt & Hink, 2009; Shone et al., 2009) and health equity (Abrams et al., 2009; Logan et al., 2015), difficulty navigating the early intervention (EI) system (Conroy et al., 2018; Jimenez et al., 2013) and understanding EI information (Pizur-Barnekow et al., 2010; Pizur-Barnekow et al., 2011). The Individuals with Disabilities Education Act (IDEA) Part C EI Program serves families of infants and toddlers with developmental delay or disability

(IDEA, 2004). EI is based on a practice model of indirect services with EI providers collaborating with parents to set goals and develop strategies (Raver & Childress, 2015). Evidence-based EI practice guidelines are outlined in the Division for Early Childhood (DEC) Recommended Practices document (DEC, 2014).

EI providers are a diverse group of professional and paraprofessional providers with varying education levels and training (Hebbeler et al., 2007; Raver & Childress, 2015). Common EI services include: special instruction or child

development services; speech-language, occupational, and physical therapy; developmental monitoring; and service coordination (Hebbeler et al., 2008). Current national data on characteristics of EI providers, such as training, race and ethnicity, and salaries, are not available (IDEA Infant & Toddler Coordinators Association, 2015; U.S. Department of Health and Human Services & U.S. Department of Education, 2016).

Health care providers' understanding of health literacy can help decrease the negative influence of low health literacy to improve health outcomes and safety (Glick et al., 2019; Rothman et al., 2004; Yin et al., 2008). Unfortunately, health care providers have less than optimal understanding and use of health literacy practices (Cafiero, 2013; Coleman et al., 2017; Lambert et al., 2014; Liang & Brach, 2017; Mackert et al., 2011). Office staff and administrators are another important group requiring health literacy training and skills in health care settings (Brega et al., 2015). Research is needed on the health literacy practices of EI providers, including key members of office staff and administrators.

Current multidimensional health literacy definitions have moved beyond definitions focused on patients' reading and numeracy skills and include characteristics of patients, health care providers, and health care systems (Sørensen & Pleasant, 2017). The Calgary Charter on Health Literacy (Coleman et al., 2008) defines health literacy as:

Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills (p. 1).

Health care providers' health literacy skills, including EI providers, are clearly an integral component of the construct of health literacy.

The Health Literacy Questionnaire (HLQ) (Osborne et al., 2013) was selected to measure health literacy in this study because the HLQ: assesses skills reflective of DEC recommended best practices; reflects contemporary health literacy definitions; informs interventions to improve health literacy; and qualitative evidence lends support for HLQ use with EI providers (Leslie et al., 2020). One DEC recommended EI practice reflective of health literacy skills is the following: Practitioners provide the family with up-to-date, comprehensive and unbiased information in a way that the family can understand and use to make informed choices and decisions. Successful implementation of this recommended practice could be facilitated by strong health literacy skills of EI providers.

Research on health literacy profiles of health care professionals is lacking in the literature (Budhathoki et al., 2019; Lambert et al., 2014; Mullan et al., 2017), including EI providers (Leslie et al., 2019). To our knowledge, this is the first study to assess EI providers' health literacy. Study objectives were to (1) determine health literacy profiles of EI providers; and (2) explore associations between EI providers' health literacy levels and demographic variables.

METHODS

Study Population and Sample

This cross-sectional study collected health literacy and demographic data from employees at 10 EI centers across Massachusetts. A minimum sample size ($n = 250$) was determined using a sample size calculator (Qualtrics, 2019) with a confidence level of 95% and population size of 715. To maintain anonymity of participants, data were not collected linking participants to the EI center where the participant worked.

Data Collection

An anonymous survey containing the HLQ and demographic questions was offered on paper and online (hosted

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TABLE 1

Health Literacy Questionnaire Scales with Descriptions

<p>Part 1</p> <p>Prompt: How strongly do you disagree or agree with the following statements?</p> <p>Answer options: <i>Strongly disagree, Disagree, Agree, and Strongly agree</i></p>
<p>Scale 1. Feeling understood and supported by health care providers^a Four items that cover having at least one health care provider that a participant can trust for useful advice and help them understand information to make decisions about their health</p>
<p>Scale 2. Have sufficient information to manage health^a Four items that cover feeling confident about having all the information a participant needs to manage their health and make health care decisions</p>
<p>Scale 3. Actively manage health^a Five items that cover the ability to recognize the importance of and ability to take responsibility for a participant's own health using proactive approaches</p>
<p>Scale 4. Have social support for health^a Five items that cover the availability of a social system to provide a participant with the support they need for their health</p>
<p>Scale 5. Appraisal of health information^a Five items that cover the participant's ability to identify good information sources and to resolve conflicting information by themselves or with the help of others</p>
<p>Part 2</p> <p>Prompt: How easy or difficult are the following tasks for you to do now?</p> <p>Answer options: <i>Cannot do or always difficult, Usually difficult, Sometimes difficult, Usually easy, and Always easy</i></p>
<p>Scale 6. Ability to actively engage with health care providers^a Five items that cover the participant's ability to proactively engage with health care providers when needed for their health</p>
<p>Scale 7. Navigating the health care system^a Six items that cover the ability to find out about health services and support that the participant may need for their health</p>
<p>Scale 8. Ability to find good health information^a Five items that cover the ability to use a diverse range of resources to find information and stay up to date</p>
<p>Scale 9. Understand health information to know what to do^a Five items that cover the ability to understand written information in relation to a participant's health and complete forms as necessary</p>

^aScale characteristics from Budhathoki et al., 2019.

Measuring Health Literacy

The HLQ has demonstrated sound psychometric properties in multiple contexts (Hawkins et al., 2017; Maindal et al., 2016; Osborne et al., 2013). The 44 HLQ items in nine scales measure distinct constructs of health literacy as displayed in **Table 1**. Cumulatively, the nine HLQ scale scores provide a *health literacy profile* to highlight areas of strengths and needs. Higher scores indicate a greater level of health literacy. Sociodemographic data collected included age, sex, race and ethnicity, primary language spoken at home, EI job role, education level, and years of EI work experience.

Statistical Analyses

Data were analyzed using SPSS (v.25) and statistical significance was set at <.05. Sociodemographic data were analyzed using descriptive statistics. Data analyses reflected recommendations of the HLQ data analysis guidelines (Dodson et al., 2014). Mean scale scores, standard deviations, and 95% confidence intervals were calculated for the nine scales overall and each subgroup. One-way analyses of variance were performed to investigate differences in HLQ scores and age group, education level, and EI job role. Tukey's Honest Significant Difference post hocs were used for significant main

via REDCap) and data collection occurred October 2019 to December 2019. Eligibility criteria included currently working in EI in Massachusetts, a job role that includes communicating with families, and being age 18 years or older. EI centers received a \$50 gift card for participating. Human ethics approval was granted by the Partners Healthcare institutional review board, protocol #2019P001040.

effects. An independent *t*-test was used to determine if differences in HLQ scores existed between years of EI work experience, and race and ethnicity groups. Differences between groups by gender were not calculated for gender or primary language due to small numbers. Males made up only 1.5% of participants in the sample (*n* = 5), and only 4% of respondents (*n* = 15) identified a language other than English as their primary language. Cohen's *d* effect sizes (ES) were calculated to

assess mean differences between groups using an online social sciences calculator. Cohen's recommendations for interpretation of ES were used: "small" ES if $0.20 < d < 0.50$; "medium" ES if $0.50 < d < 0.80$; and "large" ES if $d > 0.80$ (Cohen, 1977). To explore potential interactions, associations between independent variables and multivariate analyses of variance (MANOVAs) were performed to further explore whether there were significant differences between groups for the variables of age, education, and years of EI work experience, along with job role. Roy's Largest Root multivariate outcome was used based on having independent variables with three groups and unequal group sample sizes (Field, 2013).

With 9 outcomes, and 5 categorical variables, 2 of which are binary and 3 of which are trichotomous, there were 72 hypothesis tests, resulting in 72 p-values. Robust standard errors were used. To correct for multiple comparisons, the sharpened False Discover Rate (FDR) q-value method was used (Benjamini et al., 2006). The FDR is the expected proportion of rejections that are type I errors (false rejections). Although respondents were clustered in 10 sites, cluster identifiers were not collected due to privacy considerations, and hence we were unable to account for clustering explicitly. However, before the multiple-group correction, Huber-White robust standard error, instead of regular standard error, was calculated and the correction was performed on p values calculated from these standard errors.

RESULTS

Overall, 376 completed surveys were returned with a response rate of 52.6%. Demographic data are presented in **Table 2**. Participants were predominantly women (92.6%, $n = 348$), White (85.4%, $n = 321$), had a mean age of 43.1

TABLE 2

Demographic Data for Total Sample ($N = 376$)

Characteristic	n (%)	Total Missing Data, n (%)
Sex		
Female	348 (92.6)	23 (6.1)
Male	5 (1.3)	
Age (years)		
<36	121 (32.2)	40 (10.6)
36-50	103 (27.4)	
>50	112 (29.8)	
Education level		
High school and associate's degree	19 (5.1)	21 (5.6)
Bachelor's degree	114 (30.3)	
Master's degree or Doctoral degree	222 (59)	
Years of early intervention work experience		
<1-10	198 (52.7)	28 (7.4)
>10	150 (39.9)	
Race		
White	321 (85.4)	25 (6.6)
Hispanic or Latino, Black or African American, Asian, Native American or Alaska Native, Native Hawaiian or other Pacific Islander; two or more races	30 (8)	
Primary language		
English	337 (89.6)	24 (6.4)
Chinese, Hebrew, Russian, Spanish, Tamil, and Toisanese	15 (4)	
Early intervention job role		
Developmental specialist and teaching assistant	118 (31.4)	33 (8.8)
Administrative	33 (8.8)	
Licensed providers	192 (51.1)	

years (SD 12.9) ranging from age 20 to 74 years, and reported English as their primary language (89.6%, $n = 337$).

Mean scores with standard deviations and 95% confidence intervals for the nine HLQ scales are displayed in **Table 3**. Overall, scores were broadly dispersed across response options with minimal floor or ceiling effects and scores clustering toward the high end of the scale as illustrated in **Figure 1**.

In HLQ Part 1, Scales 1-5, highest scores were on Scale 1 *Feeling understood and supported by healthcare providers*, and lowest on Scale 5 *Appraisal of health information*. For HLQ Part 2, Scales 6-9, highest scores were on Scale 9 *Understand health information to know what to do*, and lowest scores on Scale 7 *Navigating the health care system*.

Associations and ES between HLQ scores and sociodemographic characteristics are shown in **Table A**. Small ES

TABLE 3
Health Literacy Questionnaire Scores for Overall Sample

Health Literacy Questionnaire Scale ^a	M (SD)	[95% CI]
Score range (1, lowest – 4, highest)		
Part 1		
1. Feeling understood and supported by health care providers	3.27 (0.55)	[3.22, 3.33]
2. Have sufficient information to manage health	3.10 (0.49)	[3.03, 3.14]
3. Actively manage health	3.09 (0.52)	[3.03, 3.14]
4. Have social support for health	3.23 (0.49)	[3.18, 3.28]
5. Appraisal of health information	2.99 (0.50)	[2.93, 3.04]
Score range (1, lowest – 5, highest)		
Part 2		
6. Ability to actively engage with health care providers	3.93 (0.57)	[3.87, 3.99]
7. Navigating the healthcare system	3.83 (0.58)	[3.77, 3.89]
8. Ability to find good health information	4.03 (0.50)	[3.98, 4.08]
9. Understand health information to know what to do	4.19 (0.50)	[4.14, 4.24]

Note. CI = confidence interval; SD = standard deviation.

^aAll 9 scales: n = 365 [AQ1: Is 365 the total number? If so, n should be N.] (97.1%), missing data n = 11 (2.9%).

were found for age groups with participants older than age 50 years scoring higher on 7 of 9 scales versus the two younger age groups. The youngest age group of participants younger than age 36 years scored higher on Scale 4 *Have social support for health* with a small ES difference than the two older age groupings.

Differences between groups of education level had small ES (Scales 2, 4, 6, 7, 8, 9) and medium ES (Scales 6, 7, 8) with higher HLQ scores for the group with the highest education level, a masters or doctoral degree, compared to lower education level groups across all nine scales. There were no significant differences found between groups by race (*p* values ranged from 0.50 to 0.94).

Small ES between groups based on years of EI work experience were found on Scales 1, 2, 5, 6, and 9 with participants with greater than 10 years of EI work experience scoring higher than those with 10 years or fewer of EI work experience on eight of the nine scales. Similarly to the youngest group based on age, participants with 10 years or less of work experience scored higher than participants with greater than 10 years of work experience only on Scale 4 *Having social support for health*.

Lastly, small ES were found across groups of EI job roles across all nine scales, and medium ES were found on Scales 2, 5 and 8. The job role group of licensed health care providers scored highest across all nine scales com-

pared to the two groups of administrative role and developmental specialists and teaching assistants.

Statistically significant interaction effects associations were found on the combined nine HLQ scale scores (dependent variables) for EI job role, education level, age, and years of EI experience (independent variables) based on the three MANOVAs: (1) EI job role and education level, $F(9, 326) = 4.422, p < .001$; Roy's Largest Root = .122; (2) EI job role and age, $F(9, 307) = 2.534, p = .008$; Roy's Largest Root = .074; and (3) EI job role and years of EI experience, $F(9, 323) = 2.773, p = .004$; Roy's Largest Root = .077. However, when MANOVAs were computed

for the nine HLQ Scales individually, only two scales had significant associations interaction effects. An interaction association of between job role and education level was significant for Scale 2 *Having sufficient information* ($p = .001$) and Scale 5 *Critical appraisal* ($p < .001$). All other interactions associations were not significant ($p > .05$).

DISCUSSION

To our knowledge, this is the first study investigating health literacy profiles of EI providers, and the first using the HLQ with practicing health care providers rather than patients, the general public, or health professions students. Small to medium differences were found across sub-groups. Subgroups with somewhat higher health literacy scores compared to their counterparts were older in age, had a higher level of education, had more years of experience working in EI, or held a job role requiring licensure to practice in health care.

Higher levels of health literacy might be anticipated in practicing healthcare providers compared to future health care providers. However, when comparing overall HLQ scale scores (Table 3) to scale scores of Australian health care professions students, students had higher mean scores on 7 of 9 HLQ scales (Mullan et al., 2017). Although this may reflect different health literacy training for current students compared to what our participants received in college, limited evidence on health literacy curricula in higher education

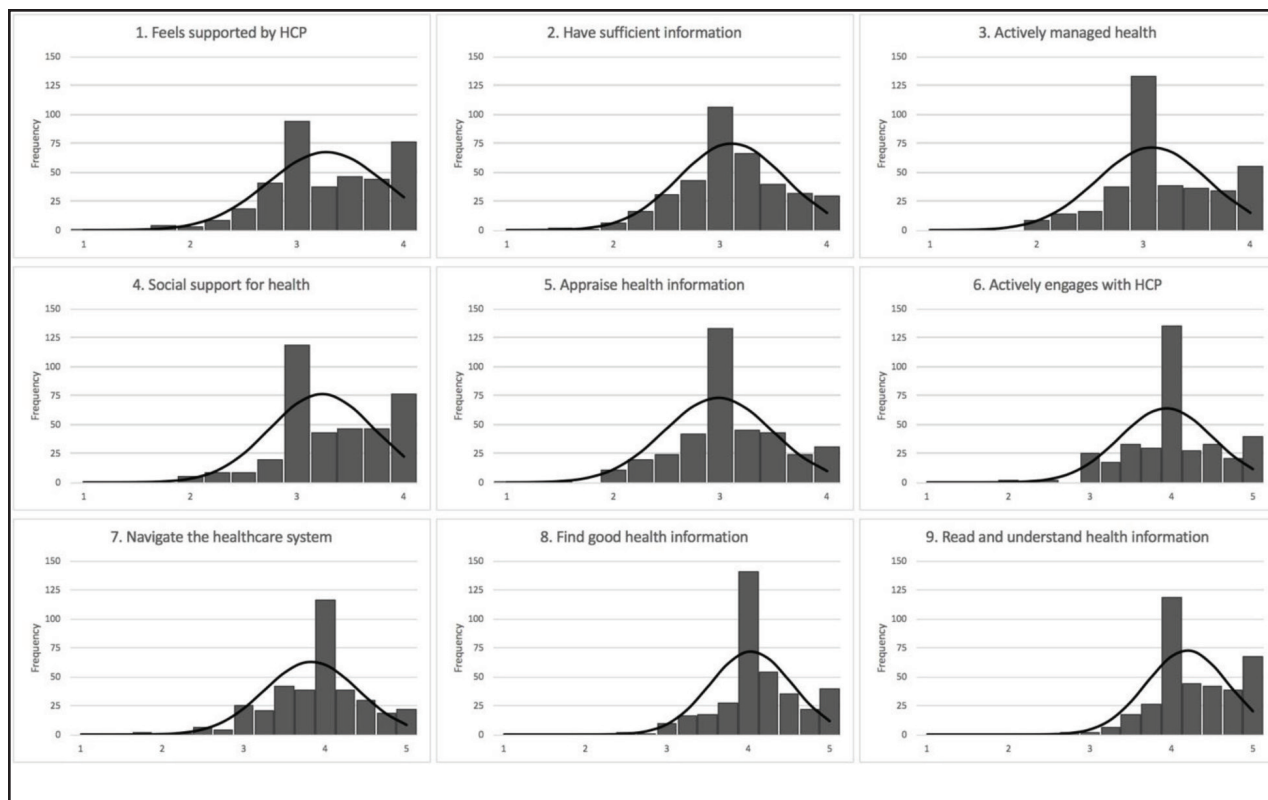


Figure 1. Health Literacy Questionnaire (HLQ) score distribution across response options for the 9 HLQ Scales.

medical programs suggests insufficient health literacy training (Coleman et al., 2016).

Highest scores were demonstrated on Scale 1 *Feeling understood and supported by health care providers* and Scale 9 *Understand health information to know what to do*. Higher scores for Scale 1 may be related to participants being health care providers working in the interdisciplinary EI setting, resulting in increased confidence in feeling understood and supported by providers. Higher scores on Scale 9, related to understanding written health information, may reflect EI providers' job responsibilities, such as reviewing health information to plan EI services (DEC, 2014).

Conversely, the sample yielded the lowest scores on Scale 5 *Appraisal of health information* and Scale 7 *Navigating the health care system*. These two scales reflect critically important skills in which one might expect early intervention providers to be proficient. Unfortunately, evidence suggests the EI workforce receives little preprofessional preparation or professional development focused on skills outlined in the DEC recommended practices (Campbell et al., 2009), which may be related to health literacy skills.

Lower scores on Scale 5 *Appraisal of health information* are consistent with published findings of health care

students' (Mullan et al., 2017) and providers' limitations related to finding and appraising health information (Ebenezer, 2015; Sadeghi-Bazargani et al., 2014). If EI providers' abilities to confidently find and evaluate health information to ensure evidence-based practice is lacking, then training in this research skill is needed. This is a key finding of the present study. Developers of the HLQ suggested Scale 5 may be one of the more difficult scales, which may contribute to our findings (Osborne et al., 2013).

Older adult participants (>50 years of age) scored higher than the two younger age groups on 7 of the 9 scales. Perhaps older EI providers in our sample reported more confidence in their health literacy skills due to increased years of experience in the health care system. Interestingly, the youngest age group (< 36 years) scored highest on Scale 4 *Have social support for health* with a small ES difference among the three age groupings. The younger group reporting more social supports related to health compared to older EI providers may be related to higher rates of social media use by younger age groups (Pew Research Center, 2018) to support connection to friends and family when dealing with health issues.

Participants in the highest education level group had higher HLQ scores across all nine scales compared to the two other groups with small and medium ES. Although this finding may seem evident and is supported in the literature (Beauchamp et al., 2015; Bo et al., 2014; Kutner et al., 2006; Paasche-Orlow et al., 2005), the literature also supports the recommendation that education level alone is not an accurate proxy for health literacy (Buchbinder et al., 2006; Evans et al., 2019). In this study, for Scale 2 *Having sufficient information* and Scale 5 *Critical appraisal*, participants in the highest education group had the highest HLQ scores regardless of their job role. Therefore, participants on these two scales with any job role had similarly high HLQ scores as long as they were in the highest education group with a masters or doctoral degree. Additionally, if participants on these two scales were in the lowest education group, job role was important and licensed providers scored higher than the other two job role groups.

Participants with greater than ten years of EI work experience scored higher on 8 of 9 scales than those with less EI work experience. This may reflect that respondents with more years of experience have gained health literacy skills over time spent working with families or through professional development. Similarly to the youngest age group, participants with 10 years or less of work experience scored higher than participants with more than 10 years of EI work experience only on Scale 4 *Having social support for health*.

Lastly, the job role group of licensed healthcare providers scored highest across all nine scales relative to all other job role groups with small and medium ES. Multivariate analyses examining the interaction association of job role with the other independent variables found that this interaction association was only significant for two scales and only when considered with education level. Licensed providers scored higher than other job role groups even when they had similarly lower education levels, and job role did not matter for only the highest level of education group. These findings may reflect the education required to be a licensed health care provider, which could provide some health literacy training compared to education received by participants working as developmental specialists or in administrative EI roles. Unfortunately, the literature related to health literacy training at the college level suggests students in health professions schools are not being adequately trained in health literacy (Brown et al., 2004; Cormier & Kotrlik, 2009).

STUDY LIMITATIONS

Participants in the current study were not diverse demographically by gender or race, which is a limitation, although

it appears to approximate the demographic makeup of EI providers reported in the literature (Hebbeler et al., 2007). As a first step in using the HLQ in the EI setting, generalizability may be limited. As with any self-report instrument, participants may have responded to the survey in a way that does not accurately represent their true health literacy profiles. To maximize anonymity of participants, data was not collected to identify which of the 10 EI centers each participant worked at, so any effect of clustering of the data collected by site was not able to be calculated. Lastly, it may be possible that participants who responded to the study invitation to complete the survey might be different from those who did not. Overall, the HLQ was an effective and easy way to measure health literacy, providing clear useful data on specific skills and areas of strength to be capitalized on, and some weaknesses that can be targeted for improvement.

CONCLUSION

To competently implement EI services in line with the DEC Recommended Practices, manage their own health, and meet the needs of parents with low health literacy who are caring for infants and toddlers with developmental delays and disabilities, a strong health literacy profile is required for EI providers. This study represents a first step in understanding the health literacy levels of EI providers, and all groups of participants in this study demonstrated some gaps in health literacy competency across the HLQ items. Based on these findings, and the literature in other healthcare settings yielding findings of low healthcare provider health literacy knowledge (Coleman et al., 2017; Coleman, 2011), professional development for EI providers to improve health literacy skills is recommended. Further research to assess the relationship among improved EI providers' health literacy profiles, caregiver satisfaction, and health outcomes of children enrolled in EI is also needed.

REFERENCES

- Abrams, M. A., Klass, P., & Dreyer, B. P. (2009). Health literacy and children: Recommendations for action. *Pediatrics*, *124*(November, Suppl 3), S327–S331. <https://doi.org/10.1542/peds.2009-1162I> PMID:19861487
- Beauchamp, A., Buchbinder, R., Dodson, S., Batterham, R. W., Elsworth, G. R., McPhee, C., Sparkes, L., Hawkins, M., & Osborne, R. H. (2015). Distribution of health literacy strengths and weaknesses across socio-demographic groups: A cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health*, *15*, 678. Advance online publication. <https://doi.org/10.1186/s12889-015-2056-z> PMID:26194350
- Benjamini, Y., Krieger, A., & Yekutieli, D. (2006). Adaptive linear step-up procedures that control the false discovery rate. *Biometrika*, *93*, 491–507. <https://doi.org/10.1093/biomet/93.3.491>
- Bo, A., Friis, K., Osborne, R. H., & Mairal, H. T. (2014). National indicators of health literacy: Ability to understand health information

- and to engage actively with healthcare providers - a population-based survey among Danish adults. *BMC Public Health*, 14, 1095. Advance online publication. <https://doi.org/10.1186/1471-2458-14-1095> PMID:25339154
- Brega, A. G., Barnard, J., Mabachi, N. M., Weiss, B. D., DeWalt, D. A., Brach, C., Cifuentes, M., Albright, K., & West, D. R. (2015). AHRQ health literacy universal precautions toolkit, second edition. https://www.ahrq.gov/sites/default/files/publications/files/healthlitoolkit2_3.pdf
- Brown, D. R., Ludwig, R., Buck, G. A., Durham, D., Shumard, T., & Graham, S. S. (2004). Health literacy: Universal precautions needed. *Journal of Allied Health*, 33(2), 150–155. <http://phstwp2.partners.org:2145/deliver/connect/asahp/00907421/v33n2/s11.pdf?expires=1517431537&tid=0000&tleid=6329&checksum=13ABAD98DC6A4DF73CFEDA3CABCA678> PMID:15239414
- Buchbinder, R., Hall, S., & Youd, J. M. (2006). Functional health literacy of patients with rheumatoid arthritis attending a community-based rheumatology practice. *The Journal of Rheumatology*, 33(5), 879–886. PMID:16511936
- Budhathoki, S. S., Pokharel, P. K., Jha, N., Moselen, E., Dixon, R., Bhattachan, M., & Osborne, R. H. (2019). Health literacy of future healthcare professionals: A cross-sectional study among health sciences students in Nepal. *International Health*, 11(1), 15–23. <https://doi.org/10.1093/inthealth/ihy090> PMID:30412262
- Cafiero, M. (2013). Nurse practitioners' knowledge, experience, and intention to use health literacy strategies in clinical practice. *Journal of Health Communication*, 18(Suppl. 1), 70–81. <https://doi.org/10.1080/10810730.2013.825665> PMID:24093347
- Campbell, P. H., Chiarello, L., Wilcox, M. J., & Milbourne, S. (2009). Preparing therapists as effective practitioners in early intervention. *Infants and Young Children*, 22(1), 21–31. <https://doi.org/10.1097/01.IYC.0000343334.26904.92>
- Cohen, J. (1977). *Statistical power analysis for behavioral sciences*. Academic Press.
- Coleman, C. A., Nguyen, N. T., Garvin, R., Sou, C., & Carney, P. A. (2016). Health literacy teaching in U.S. family medicine residency programs: A national survey. *Journal of Health Communication*, 21(Suppl. 1), 51–57. Advance online publication. <https://doi.org/10.1080/10810730.2015.1131774> PMID:27043758
- Coleman, C., Hudson, S., & Pederson, B. (2017). Prioritized health literacy and clear communication practices for health care professionals. *Health Literacy Research and Practice*, 1(3), e91–e99. <https://doi.org/10.3928/24748307-20170503-01> PMID:31294254
- Coleman, C. (2011). Teaching health care professionals about health literacy: A review of the literature. *Nursing Outlook*, 59(2), 70–78. <https://doi.org/10.1016/j.outlook.2010.12.004> PMID:21402202
- Coleman, C., Kurtz-Rossi, S., McKinney, J., Pleasant, A., Rootman, I., & Shohet, L. (2008). The Calgary charter on health literacy: Rationale and core principles for the development of health literacy curricula. http://www.centreforliteracy.qc.ca/sites/default/files/CFL_Calgary_Charter_2011.pdf
- Conroy, K., Rea, C., Kovacicova, G. I., Sprecher, E., Reisinger, E., Durant, H., Starmer, A., Cox, J., & Toomey, S. L. (2018). Ensuring timely connection to early intervention for young children with developmental delays. *Pediatrics*, 142(1), e20174017. <https://doi.org/10.1542/peds.2017-4017> PMID:29875180
- Cormier, C. M., & Kotrlik, J. W. (2009). Health literacy knowledge and experiences of senior baccalaureate nursing students. *The Journal of Nursing Education*, 48(5), 237–248. Advance online publication. <https://doi.org/10.3928/01484834-20090416-02> PMID:19476028
- DeWalt, D. A., & Hink, A. (2009). Health literacy and child health outcomes: A systematic review of the literature. *Pediatrics*, 124 Suppl, S265–74. <https://doi.org/10.1542/peds.2009-1162B>
- Division for Early Childhood. (2014). DEC recommended practices in early intervention/early childhood special education 2014. <http://www.dec-sped.org/recommendedpractices>
- Dodson, S., Good, S., & Osborne, R. H. (2014). Health literacy toolkit for low- and middle-income countries: A series of information sheets to empower communities and strengthen health systems. <https://apps.who.int/iris/bitstream/handle/10665/205244/B5148.pdf?sequence=1&isAllowed=y>
- Ebenezer, C. (2015). Nurses' and midwives' information behaviour: A review of literature from 1998 to 2014. *New Library World*, 116(3–4), 155–172. <https://doi.org/10.1108/NLW-07-2014-0085>
- Evans, A.-Y., Anthony, E., & Gabriel, G. (2019). Comprehensive health literacy among undergraduates: A Ghanaian university-based cross-sectional study. *HLRP: Health Literacy Research and Practice*, 3(4), e227–e237. <https://doi.org/10.3928/24748307-20190903-01> PMID:31637363
- Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. Sage.
- Glick, A. F., Brach, C., Yin, H. S., & Dreyer, B. P. (2019). Health literacy in the inpatient setting: Implications for patient care and patient safety. *Pediatric Clinics of North America*, 66(4), 805–826. <https://doi.org/10.1016/j.pcl.2019.03.007> PMID:31230624
- Hawkins, M., Gill, S. D., Batterham, R., Elsworth, G. R., & Osborne, R. H. (2017). The Health Literacy Questionnaire (HLQ) at the patient-clinician interface: A qualitative study of what patients and clinicians mean by their HLQ scores. *BMC Health Services Research*, 17(1), 309. <https://doi.org/10.1186/s12913-017-2254-8> PMID:28449680
- Hebbeler, K., Spiker, D., Bailey, D., Scarborough, A., Mallik, S., Simeonson, R., Singer, M., & Nelson, L. (2007). Final report of the national early intervention longitudinal study (NEILS). https://www.sri.com/wp-content/uploads/2021/12/neils_finalreport_200702.pdf
- Hebbeler, K., Spiker, D., Morrison, K., & Mallik, S. (2008). A national look at the characteristics of Part C Early Intervention Services. In C. A. Peterson, L. Fox, & P. M. Blasco (Eds.), *Young Exceptional Children Monograph Series No. 10: Early intervention for infants and toddlers and their families: Practices and Outcomes* (pp. 1–18). Division for Early Childhood of the Council for Exceptional Children., <https://www.dec-sped.org>
- IDEA Infant & Toddler Coordinators Association. (2015). 2015 ITCA annual report. <https://ideainfanttoddler.org/pdf/ITCA-Annual-Report-2015.pdf>
- Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).
- Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2013). The impact of parental health literacy on the early intervention referral process. *Journal of Health Care for the Poor and Underserved*, 24(3), 1053–1062. <https://doi.org/10.1353/hpu.2013.0141> PMID:23974380
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). The health literacy of America's adults: Results from the 2003 national assessment of adult literacy. <https://phstwp2.partners.org:3545/fulltext/ED493284.pdf>
- Lambert, M., Luke, J., Downey, B., Crengle, S., Kelaher, M., Reid, S., & Smylie, J. (2014). Health literacy: Health professionals' understandings and their perceptions of barriers that Indigenous patients encounter. *BMC Health Services Research*, 14(1), 614. <https://doi.org/10.1186/s12913-014-0614-1> PMID:25471387
- Leslie, C. J., Hawkins, M., & Smith, D. L. (2020). Using the Health Literacy Questionnaire (HLQ) with providers in the early intervention setting: A qualitative validity testing study. *International Journal of Environmental Research and Public Health*, 17(7), 1–14. <https://doi.org/doi:10.3390/ijerph17072603> <https://doi.org/10.3390/ijerph17072603> PMID:32290295
- Leslie, C., Smith, D., & Nicholas, P. (2019). Health literacy understanding of early intervention providers: A scoping review. *The Journal for Nurse Practitioners*, 15(9), 640–648. <https://doi.org/10.1016/j.nurpra.2019.06.006>

- Liang, L., & Brach, C. (2017). Health literacy universal precautions are still a distant dream: Analysis of U.S. data on health literate practices. *HLRP: Health Literacy Research and Practice*, 1(4), e216–e230. <https://doi.org/10.3928/24748307-20170929-01> PMID:29202120
- Logan, R. A., Wong, W. F., Villaire, M., Daus, G., Parnell, T. A., Willis, E., & Paasche-Orlow, M. K. (2015). *Health literacy: A necessary element for achieving health equity*. National Academy of Medicine. <https://nam.edu/wp-content/uploads/2015/07/NecessaryElement.pdf>
- Mackert, M., Ball, J., & Lopez, N. (2011). Health literacy awareness training for healthcare workers: Improving knowledge and intentions to use clear communication techniques. *Patient Education and Counseling*, 85(3), e225–e228. <https://doi.org/10.1016/j.pec.2011.02.022> PMID:21474264
- Maindal, H. T., Kayser, L., Norgaard, O., Bo, A., Elsworth, G. R., & Osborne, R. H. (2016). Cultural adaptation and validation of the Health Literacy Questionnaire (HLQ): Robust nine-dimension Danish language confirmatory factor model. *SpringerPlus*, 5(1), 1232. Advance online publication. <https://doi.org/10.1186/s40064-016-2887-9> PMID:27536516
- Mullan, J., Burns, P., Weston, K., McLennan, P., Rich, W., Crowther, S., Mansfield, K. J., Dixon, R. S., Moselen, E., & Osborne, R. (2017). Health literacy amongst health professional university students: A study using the Health Literacy Questionnaire. *Education Sciences*, 7(2), 1–11. <https://doi.org/10.3390/educsci7020054>
- Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, 13(1), 658. <https://doi.org/10.1186/1471-2458-13-658> PMID:23855504
- Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T., & Rudd, R. R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20(2), 175–184. <https://doi.org/10.1111/j.1525-1497.2005.40245.x> PMID:15836552
- Pew Research Center. (2018). Social media use in 2018. <https://www.pewresearch.org/internet/2018/03/01/social-media-use-in-2018/>
- Pizur-Barnekow, K., Doering, J., Cashin, S., Patrick, T., & Rhyner, P. (2010). Functional health literacy and mental health in urban and rural mothers of children enrolled in early intervention programs. *Infants and Young Children*, 23(1), 42–51. <https://doi.org/10.1097/YIC.0b013e3181c97633>
- Pizur-Barnekow, K., Patrick, T., Rhyner, P. M., Cashin, S., Rentmeester, A., & the Pizur-Barnekow. (2011). Readability of early intervention program literature. *Topics in Early Childhood Special Education*, 31(1), 58–64. <https://doi.org/10.1177/0271121410387676>
- Raver, S. A., & Childress, D. C. (2015). *Family-centered early intervention: Supporting infants and toddlers in natural environments*. Paul H. Brookes Publishing Co.
- Rothman, R. L., DeWalt, D. A., Malone, R., Bryant, B., Shintani, A., Crigler, B., Weinberger, M., & Pignone, M. (2004). Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program. *Journal of the American Medical Association*, 292(14), 1711–1716. <https://doi.org/10.1001/jama.292.14.1711> PMID:15479936
- Sadeghi-Bazargani, H., Tabrizi, J. S., & Azami-Aghdash, S. (2014). Barriers to evidence-based medicine: A systematic review. *Journal of Evaluation in Clinical Practice*, 20(6), 793–802. <https://doi.org/10.1111/jep.12222> PMID:25130323
- Shone, L. P., Conn, K. M., Sanders, L., & Halterman, J. S. (2009). The role of parent health literacy among urban children with persistent asthma. *Patient Education and Counseling*, 75(3), 368–375. <https://doi.org/10.1016/j.pec.2009.01.004> PMID:19233588
- Sørensen, K., & Pleasant, A. (2017). Understanding the conceptual importance of the differences among health literacy definitions. In R. A. Logan & E. R. Siegel (Eds.), *Health Literacy* (pp. 3–14). IOS Press., <https://doi.org/10.3233/978-1-61499-790-0-3>
- U.S. Department of Health and Human Services, & U.S. Department of Education. (2016). The integration of early childhood data: State profiles and a report from the U.S. Department of Health and Human Services and the U.S. Department of Education. https://www.acf.hhs.gov/sites/default/files/documents/ecd/intergration_of_early_childhood_data_final.pdf
- Yin, H. S., Dreyer, B. P., van Schaick, L., Foltin, G. L., Dinglas, C., & Mendelsohn, A. L. (2008). Randomized controlled trial of a pictogram-based intervention to reduce liquid medication dosing errors and improve adherence among caregivers of young children. *Archives of Pediatrics & Adolescent Medicine*, 162(9), 814–822. <https://doi.org/10.1001/archpedi.162.9.814> PMID:18762597
- Yin, H. S., Johnson, M., Mendelsohn, A. L., Abrams, M. A., Sanders, L. M., & Dreyer, B. P. (2009). The health literacy of parents in the United States: A nationally representative study. *Pediatrics*, 124(November, Suppl. 3), S289–S298. <https://doi.org/10.1542/peds.2009-1162E> PMID:19861483

TABLE A

Associations between HLQ Scores and Demographic Characteristics

		Scale 1: Feel supported by HCPs		Scale 2: Have sufficient information		Scale 3: Actively manage health		Scale 4: Have social support for health		Scale 5: Appraisal of health information	
		M (SD)	Effect size	M (SD)	Effect size	M (SD)	Effect size	M (SD)	Effect size	M (SD)	Effect size
Age	< 36 yrs	3.19 (0.57) n = 121	1 & 2 0.094	3.02 (0.52) n = 121	1 & 2 0.226 ^S	3.09 (0.47) n = 121	1 & 2 0.232 ²	3.35 (0.43) n = 121	1 & 2 0.360 ^{S*}	2.90 (0.50) n = 121	1 & 2 0.204 ^S
	36-50 yrs	3.24 (0.49) n = 102	1 & 3 0.414 ^{S*}	3.13 (0.45) n = 102	1 & 3 0.317 ^{S*}	2.97 (0.56) n = 102	1 & 3 0.160	3.18 (0.51) n = 102	1 & 3 0.352 ^{S*}	3.00 (0.48) n = 102	1 & 3 0.294 ^S
	>50 yrs	3.42 (0.54) n = 110	2 & 3 0.349 ^S	3.18 (0.49) n = 110	2 & 3 0.106	3.17 (0.53) n = 110	2 & 3 0.367 ^{S*}	3.18 (0.53) n = 110	2 & 3 0.00	3.05 (0.52) n = 110	2 & 3 0.100
p-value (ANOVA)		p = 0.01		p = 0.04		p = 0.03		p = 0.01		p = 0.07	
Education level	HS or AD	3.20 (0.68) n = 19	1 & 2 0.098	2.89 (0.64) n = 19	1 & 2 0.333 ^S	3.06 (0.53) n = 19	1 & 2 0.039	3.12 (0.47) n = 19	1 & 2 0.130	2.92 (0.63) n = 19	1 & 2 0.066
	BD	3.26 (0.53) n = 112	1 & 3 0.146	3.08 (0.49) n = 112	1 & 3 0.445 ^S	3.04 (0.50) n = 112	1 & 3 0.093	3.18 (0.45) n = 112	1 & 3 0.306 ^S	2.96 (0.58) n = 112	1 & 3 0.145
	MD or DD	3.29 (0.55) n = 221	2 & 3 0.056	3.14 (0.47) n = 221	2 & 3 0.125	3.11 (0.54) n = 221	2 & 3 0.135	3.27 (0.51) n = 221	2 & 3 0.187	3.00 (0.46) n = 221	2 & 3 0.076
p-value (ANOVA)		p = 0.74		p = 0.08		p = 0.54		p = 0.15		p = 0.65	
Yrs of EI Experience	<1-10	3.22 (0.56) n = 197	1 & 2 0.238 ^S	3.07 (0.50) n = 197	1 & 2 0.204 ^S	3.08 (0.53) n = 197	1 & 2 0.057	3.27 (0.47) n = 197	1 & 2 0.141	2.94 (0.50) n = 197	1 & 2 0.216 ^S
	>10	3.35 (0.53) n = 148		3.17 (0.48) n = 148		3.11 (0.52) n = 148		3.20 (0.52) n = 148		3.05 (0.52) n = 148	
p-value (independent t-test)		p = 0.03		p = 0.07		p = 0.56		p = 0.18		p = 0.06	
Race	White	3.29 (0.53) n = 318	1 & 2 0.111	3.12 (0.49) n = 318	1 & 2 0.021	3.09 (0.52) n = 318	1 & 2 0.101	3.24 (0.48) n = 318	1 & 2 0.124	2.99 (0.51) n = 318	1 & 2 0.042
	Hispanic or Latino, Black or African American, Asian, Native American or Alaska Native, Native Hawaiian or other Pacific Islander; two or more races	3.23 (0.55) n = 30		3.11 (0.45) n = 30		3.04 (0.47) n = 30		3.30 (0.49) n = 30		3.01 (0.45) n = 30	
	p-value (independent t-test)		p = 0.50		p = 0.94		p = 0.59		p = 0.52		p = 0.82
EI job role	DS & TA	3.21 (0.49) n = 118	1 & 2 0.114	3.01 (0.46) n = 118	1 & 2 0.125	2.99 (0.44) n = 118	1 & 2 0.000	3.19 (0.47) n = 118	1 & 2 0.176	2.83 (0.51) n = 118	1 & 2 0.185
	Administrative	3.27 (0.56) n = 33	1 & 3 0.230 ^S	2.95 (0.50) n = 33	1 & 3 0.421 ^{S*}	2.99 (0.58) n = 33	1 & 3 0.390 ^{S*}	3.11 (0.44) n = 33	1 & 3 0.232 ^S	2.93 (0.57) n = 33	1 & 3 0.571 ^{M**}

Licensed Providers	3.33 (0.55) n = 189	2 & 3 0.108	3.21 (0.49) n = 189	2 & 3 0.525^{M*}	3.18 (0.53) n = 189	2 & 3 0.342 ^S	3.30 (0.48) n = 189	2 & 3 0.413 ^S	3.11 (0.47) n = 189	2 & 3 0.345 ^S
p-value (ANOVA)	p = 0.18		p < 0.01		p < 0.01		p = 0.04		p < 0.01	

		Scale 6: Actively engage with HCPs		Scale 7: Navigating healthcare system		Scale 8: Ability to find good health information		Scale 9: Understand health information	
		M (SD)	Effect Size	M (SD)	Effect Size	M (SD)	Effect Size	M (SD)	Effect Size
Age	< 36 yrs	3.87 (0.62) n = 121	1 & 2 0.121	3.78 (0.64) n = 121	1 & 2 0.131	3.98 (0.55) n = 121	1 & 2 0.149	4.11 (0.57) n = 121	1 & 2 0.195
	36-50 yrs	3.94 (0.53) n = 103	1 & 3 0.239 ^S	3.86 (0.58) n = 103	1 & 3 0.173	4.06 (0.52) n = 103	1 & 3 0.141	4.21 (0.45) n = 103	1 & 3 0.287 ^S
	>50 yrs	4.01 (0.55) n = 111	2 & 3 0.130	3.88 (0.51) n = 111	2 & 3 0.037	4.05 (0.44) n = 111	2 & 3 0.021	4.26 (0.47) n = 111	2 & 3 0.109
p-value (ANOVA)		p = 0.20		p = 0.43		p = 0.40		p = 0.08	
Education level	HS or AD	3.72 (0.52) n = 19	1 & 2 0.238 ^S	3.62 (0.51) n = 19	1 & 2 0.229 ^S	3.74 (0.48) n = 19	1 & 2 0.479 ^S	4.05 (0.60) n = 19	1 & 2 0.178
	BD	3.85 (0.57) n = 114	1 & 3 0.518 ^M	3.75 (0.62) n = 114	1 & 3 0.518 ^M	3.99 (0.56) n = 114	1 & 3 0.723^{M*}	4.15 (0.52) n = 114	1 & 3 0.310 ^S
	MD or DD	4.00 (0.56) n = 221	2 & 3 0.265 ^S	3.90 (0.57) n = 221	2 & 3 0.252 ^S	4.08 (0.46) n = 221	2 & 3 0.176	4.22 (0.49) n = 221	2 & 3 0.139
p-value (ANOVA)		p = 0.02		p = 0.03		p = 0.01		p = 0.19	
Yrs of EI experience	<1-10	3.88 (0.60) n = 198	1 & 2 0.233 ^S	3.79 (0.62) n = 198	1 & 2 0.192	4.02 (0.53) n = 198	1 & 2 0.080	4.14 (0.53) n = 198	1 & 2 0.242 ^S
	>10	4.01 (0.51) n = 149		3.90 (0.52) n = 149		4.06 (0.47) n = 149		4.26 (0.46) n = 149	
p-value (independent t-test)		p = 0.04		p = 0.08		p = 0.48		p = 0.03	
Race	White, non-Hispanic	3.94 (0.57) n = 320	1 & 2 0.104	3.83 (0.59) n = 320	1 & 2 0.071	4.04 (0.49) n = 320	1 & 2 0.096	4.20 (0.49) n = 320	1 & 2 0.098
	Hispanic or Latino, Black or African American, Asian, Native American or Alaska Native, Native Hawaiian or other Pacific Islander; two or more races	3.88 (0.58) n = 30		3.87 (0.54) n = 30		3.99 (0.55) n = 30		4.15 (0.53) n = 30	
p-value (independent t-test)		p = 0.57		p = 0.73		p = 0.60		p = 0.56	
EI job role	DS & TA	3.83 (0.56) n = 118	1 & 2 0.039	3.75 (0.54) n = 118	1 & 2 0.036	3.87 (0.54) n = 118	1 & 2 0.122	4.05 (0.52) n = 118	1 & 2 0.147

Administrative	3.85 (0.45) n = 33	1 & 3 0.319 ^{S*}	3.73 (0.58) n = 33	1 & 3 0.283 ^S	3.93 (0.44) n = 33	1 & 3 0.563 ^{M**}	4.12 (0.43) n = 33	1 & 3 0.475 ^{S**}
Licensed Providers	4.01 (0.57) n = 191	2 & 3 0.312 ^S	3.91 (0.59) n = 191	2 & 3 0.308 ^S	4.15 (0.45) n = 191	2 & 3 0.494 ^S	4.29 (0.49) n = 191	2 & 3 0.369 ^S
p-value (ANOVA)	p = 0.01		p = 0.04		p < 0.01		p < 0.01	

HCP: health care provider. HS: high school degree. AD: associate degree. BD: bachelor's degree. MD: master's degree. DD: doctoral degree. DS: developmental specialist. TA: teaching assistant. * p < 0.05, ** p < 0.001. Effect size (ES) calculated using Cohen's d for standardized difference in means. Interpretation of ES: "small" ES >0.20-0.50 SD, "medium" ES approximately 0.50-0.80 SD, and "large" ES >0.80 SD. Notes: ^S Small effect size, ^M Medium effect size, ^L Large effect size