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Growing older with intellectual and developmental disabilities: implementing and evaluating a project ECHO for dementia education

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ABSTRACT

The needs of the rapidly expanding population of adults growing older with intellectual and developmental disabilities (IDD) and their families span both the IDD and the aging service systems. The use of Project ECHO (Extension for Community Healthcare Outcomes) for professional education can bridge gaps and span boundaries between them at the macro, meso, and micro levels. A series of 10 ECHO sessions over 12 months was developed, incorporating key content on IDD and AD/ADRD for 145 providers in over 20 agencies. Impacts were assessed by a follow-up survey sent to participants after each program. The evaluation included quantitative assessment of ECHO features and a retrospective pre- and posttest of knowledge acquisition; a separate item assessed intention to apply information. Qualitative data were collected from open-ended items. The case presentation and discussion were the most effective ECHO components. Knowledge acquisition was significant for all sessions; most important uses included providing better care to clients/patients, training staff, and educating family and/or caregivers. Participants were aligned with two distinct groups, one with a predominant knowledge focus, the other with an emphasis on networking. Project ECHO can bridge gaps and span boundaries between the IDD and aging care systems at multiple levels, improving interprofessional collaboration and care by addressing both knowledge and networking needs of providers.

Introduction

Health and social care in the US are characterized by extensive fragmentation, weak coordination, and communication challenges between and among clinical providers and community-based organizations. There is a growing recognition by providers of the need to foster collaboration, develop partnerships, and create networks that improve care and facilitate more efficient and effective programs (D'Amour et al., 2008). In addition, different professions increasingly need to reach across disciplinary and organizational boundaries to improve care to persons with complex health and psychosocial conditions that fall into multiple care and service categories and systems (Clark, 2020). This is especially the case for

persons with lifelong intellectual and developmental disabilities (IDD) as they grow older with increasing risk for Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD). The population of older adults (60+) with IDD in the community is projected to increase dramatically from 850,600 in 2010 to 1.4 million by 2030 (Heller, 2017). Persons with Down Syndrome are particularly at risk for developing AD/ADRD (National Down Syndrome Society, 2022).

Project ECHO (Extension for Community Healthcare Outcomes) was developed in 2003 at the University of New Mexico School of Medicine to improve access by underserved communities to specialized care for persons with hepatitis C (Arora et al., 2017). Since that time, its use and training content focus have grown dramatically in many healthcare specialties and settings, currently with over 600 ECHO training centers and 3,000 programs created to reach rural, underserved, and marginalized populations around the world (https://hsc.unm.edu/echo). Recently, its use has been fueled in part by the COVID-19 pandemic in such settings as nursing homes (e.g., Baughman et al., 2021). Particularly in the field of geriatrics, examples include teaching medical residents as future primary care providers (Bennett et al., 2018) and primary care clinicians to improve both general geriatric care (Jafari et al., 2020) and geriatric mental health care (Fisher et al., 2017). More recently, its use has also been extended to dementia education (e.g., Lindauer et al., 2020; Rhoads et al., 2021).

Using a Zoom videoconferencing platform, Project ECHO creates a virtual community of practice by connecting Spoke sites of health and social care provider organizations with an interprofessional Hub team of specialists. Described as both "tele-mentoring" and "tele-networking," Project ECHO facilitates the sharing of information through a typically brief (e.g., 15–20 minutes) didactic presentation originating at the Hub, and the presentation of a complex case by a Spoke site for the remainder of each session, often one hour in total. The sharing of information through this "all teach, all learn" model to democratize the exchange of knowledge leads to a second impact in the development of networking between the Hub and Spokes, as well as among the Spoke sites themselves. The networking feature strengthens the virtual community of practice by building respect and trust among participants.

These educational elements have implications for developing ECHO programs linking the IDD field with that of gerontology and geriatrics, particularly related to AD/ADRD. Project ECHO methods can be used to bridge gaps and span boundaries between organizations, programs, and professions. Gaps refer to the effective communication of knowledge between both professions and organizations; boundaries describe the nature of challenges in networking between healthcare and human service organizations that make communication and cooperation challenging.

The focus of this paper is on the question of whether Project ECHO can be effective in achieving these bridging and spanning objectives. First, the unique characteristics of the rapidly growing older adult population with IDD and how they pose challenges to health and social care providers are described. Secondly, a framework for conceptualizing the different tiers of policies, organizations, and teams that embody gaps and boundaries – including macro, meso, and micro levels – is developed. Applications to both knowledge acquisition and networking development are described. Thirdly, the basic Project ECHO model and the specific program developed to address gaps and boundaries between the IDD and aging service systems are presented. This is followed by a description of the novel evaluation methodology used to assess the program and analyze its impacts. A discussion of

the implications of the outcomes is followed by recommendations for the continued use of ECHO methods for professional education.

Older adults with IDD

Though the prevalence rate of dementia in the population with IDD overall is similar to that in the general population (6.1%) (Strydom et al., 2009), it is estimated that Alzheimer's disease affects about 30% of people with Down syndrome in their 50s, and 50% by their 60s (National Down Syndrome Society, 2022). In addition, adults growing older with IDD have higher risks of developing chronic health conditions at younger ages than the overall population. In particular, they may experience different signs of dementia than other adults, and evidence "trigger" symptoms of memory loss, changes in personality and behavior, withdrawal from activities, and general deterioration in function (Strydom et al., 2009). Service providers are challenged to recognize and interpret changes in behavior and function and to differentiate those changes that may be associated with aging in the population with IDD from those characteristic of dementia. Failure to differentiate the probable causes of changes can lead to inappropriate treatment plans, unneeded medications, lack of accessing available healthcare and community resources, and even taking no action at all. Many healthcare providers, including physicians, are not trained in the care of older adults with IDD; and they are consequently unprepared and ill-equipped to provide assessment, diagnostic, and treatment options and recommendations.

The demand for specialized programs to address the needs of this population has long been recognized. Over thirty years ago, Ansello and Rose (1989, p. 10) noted, "For the population of older persons with developmental disabilities, current programs, services, and funding sources are incremental, fragmented, categorical, and confusing. There is a need to stimulate high quality, coordinated, collaborative, and integrative program development." Heller (2017, p. 2) has noted that "Traditionally, the aging and developmental disabilities service systems have run on parallel tracks . . . [I]t is critical for the two systems to work together . . . ," reaffirming still-pertinent observations by Ansello and Coogle (2000). With regard to training, there is an urgent need for staff education in dementia care that combines knowledge from both the IDD and the aging/AD/ADRD fields.

Framework for analysis: levels, gaps, and boundaries

An understanding of the challenges in creating greater coordination, collaboration, and integration of services for the population aging with IDD can be developed by examining the contexts and systems created for delivering care and the resultant gaps and boundaries that are established within them. An analysis of these factors creates a framework for understanding the unique potential of Project ECHO to address these gaps and boundaries, as well as to assess its impacts on them. The development and implementation of services can be visualized at three levels: (1) the macro, the level of policies and funding streams that establish systems of care; (2) the meso, the level of different organizations providing health and social care; and (3) the micro, the level of actual individual professionals providing direct care. Each of these levels creates a unique set of gaps to be bridged or boundaries to be spanned, as illustrated in Figure 1.
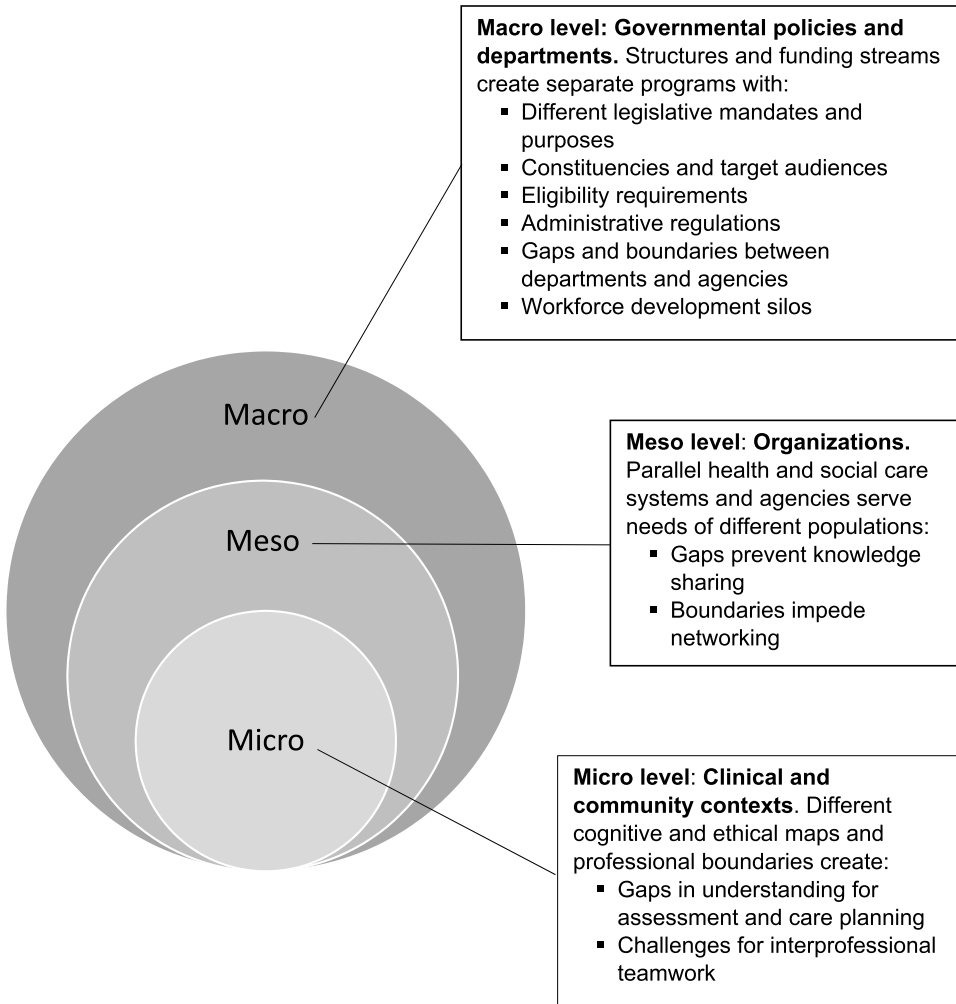
Macro level: Governmental policies and departments. Structures and funding streams create separate programs with:
- Different legislative mandates and purposes
- Constituencies and target audiences
- Eligibility requirements
- Administrative regulations
- Gaps and boundaries between departments and agencies
- Workforce development silos

Meso level: **Organizations.** Parallel health and social care systems and agencies serve needs of different populations:
- Gaps prevent knowledge sharing
- Boundaries impede networking

Micro level: **Clinical and community contexts**. Different cognitive and ethical maps and professional boundaries create:
- Gaps in understanding for assessment and care planning
- Challenges for interprofessional teamwork

Figure 1. Model of analytical framework.

Macro level

At the macro level, governmental policies, departments, and funding streams create separate programs with different legislative mandates and purposes, constituencies and target audiences, and eligibility requirements and administrative regulations. Differing political realities, ideological loyalties, and ethical assumptions lead to differing approaches to addressing social and health-related problems and priorities (Clark, 2007). These factors can complicate subsequent service coordination (Bull et al., 2008).

Policies establish structures and systems that create information and knowledge gaps between departments and agencies, with boundaries drawn between them. In addition, healthcare workforce policies and funding streams for different professions can reinforce the disciplinary silos that mediate against collaboration in delivering care. Traditionally, the IDD and aging networks have been separated and housed in two federal agencies. Even

though they are now combined into one Administration on Community Living (ACL), they still have a history of unique identities and different populations served.

Meso level

Similarly, at the meso or organizational level, clinical and community-based programs embody the gap between health and social care providers, one representing the traditional focus on clinical care itself, the other the broader psychosocial dimensions of human services. In particular, there are separate agencies and programs serving the population with IDD and the older adult population. Due to federal and state legislative and administrative requirements, there is a disconnect between one service system and the other.

For example, the sharing of knowledge can be inhibited by the boundaries between organizations from the healthcare and human service fields. Such provider organizations are essentially "knowledge systems" in which certain types of information are collected, processed, and used in planning and providing care. Their unique histories, cultures, and populations served all create a "knowledge ecosystem" that focuses on specific types of information and how it is utilized to meet the client's needs, making networking between agencies from the IDD and aging service systems challenging.

In addition, boundaries between organizations can be a barrier to effective networking to improve care coordination. Networking between organizations is increasingly recognized as an important competency for health and social care professionals (Dow et al., 2017), and one component of a continuum of teamwork, collaboration, and coordination (Reeves et al., 2018). The organizational context is a critical component for how interprofessional teams operate (Bull et al., 2008; Widmark et al., 2016), but the skill set for achieving this competency is seldom included in the training of professionals for collaborative practice (Ryan et al., 2013).

Micro level

Finally, at the micro or clinical level, individuals within different professions are trained in their own methods of assessment and care plan development that impede the design of integrated approaches to defining and solving problems. They have different "cognitive maps" representing unique methods of using information to define problems and seek solutions. They also represent differing "values maps" embodying different assumptions about quality of life and values in care (Clark, 2006). Taken together, these divergent cognitive and moral maps create different ways of thinking and working with persons aging with IDD.

One type of knowledge sharing is by bringing together providers from different professions, such as medicine, nursing, pharmacy, social work, rehabilitation, and social care/human services. The formation of interprofessional teams requires members to understand how their own perspective on the patient is different from that of others, and how each approach can complement the other. Different professions in both the IDD and aging fields are trained to see the client or patient differently, including methods of assessment, problem definitions, and care plan development. Differences among the professions are magnified when they come from two differing "worlds," namely IDD and aging.

Due to these multiple levels of challenges to collaboration, efforts are needed to bridge gaps and span boundaries in health and social care between the IDD and aging fields. The premise of this paper is that Project ECHO can serve as an effective method of connecting these two care systems.

Project ECHO: application to IDD and aging

The adaptation of Project ECHO for IDD and aging required the creation of a unique interprofessional and interorganizational partnership, including the following elements: (1) sponsoring organizations and participating professions on the Hub team, (2) recruitment of Spoke sites, and (3) curriculum for the series and sessions. The specific focus of this Project ECHO was on "Growing Older with Lifelong Intellectual Disabilities: When Dementia Is Suspected or Diagnosed."

The Hub team represented a partnership among academic institutions, community organizations, and service agencies. The academic institutions included Geriatric Education Centers (GECs) at the University of Rhode Island (URI) and Virginia Commonwealth University (VCU). Joining these university-based centers was a national advocacy and training organization, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). Finally, a service agency focusing on the needs of persons with developmental and intellectual disabilities, YAI, joined the partnership.

The basic design of Project ECHO in geriatrics education has been well described in the literature with regard to structural elements of the model, curriculum content development, and the actual implementation process (Bennett et al., 2018; Fisher et al., 2017; Jafari et al., 2020). Our unique model development was informed by a recognition of the need to bridge knowledge gaps and span organizational boundaries as described in our multi-level analytical framework. Professionals on the Hub team were drawn from the sponsoring organizations, and included medicine (neurology), nursing, social work, nutrition, and gerontology. This interprofessional team had the dual responsibility for both developing the curriculum content and being present as an interprofessional resource at each session. The Hub team met in advance of each actual ECHO series for planning to create themes, develop learning objectives for each session, and identify outside experts to present the didactic mini-lectures. The program consisted of five biweekly sessions with two series over a year. Didactic presentation topics included nurturing brain health across the life course; types of dementia, assessment, and diagnosis; impacts of physical and social environments; behavior and communication; family dynamics; communication and future/end-of-life planning; medications for both IDD and AD/ADRD; nutritional considerations; and working with peers.

As mentioned earlier, appropriate care depends upon differentiating changes in behavior due to aging with IDD from those attributable to dementia. Diagnostic foreshadowing, for instance, refers to the practice of attributing subsequent changes to an earlier diagnosis; what happens if that diagnosis was incorrect? Some aspects of aging with IDD can mimic or be confused with dementia, so it is essential to explore these conditions. Through didactic and case study discussions, this Project ECHO exposed Spoke site learners to content relevant to these factors. This included: a focus on medication review of the particular mix of prescriptions that individuals with IDD are likely to be taking; Down Syndrome regression, which may be misdiagnosed as dementia; federal legislation related to IDD and

related resources that healthcare providers should know; the NTG-EDSD (National Task Group on Intellectual Disabilities and Dementia Practices – Early Detection and Screen for Dementia) for individuals with IDD; long-COVID and its impacts on cognitive function in adults with IDD; and intersystem collaboration between the aging and IDD networks;

Participating Spoke sites included 145 individuals affiliated with over 20 organizations and agencies, including day and residential care, home care, community support, primary care, and academic institutions. Professions represented included the general categories of facility administration, nursing, social work, allied health, behavioral health, and direct service providers. An average of 35 individuals participated in each session. Spoke sites also took responsibility for developing and presenting a case study at each session, particularly one focusing on a multi-faceted, complex situation with a client/family for which they were seeking suggestions and recommendations on improving care management and outcomes.

Program evaluation: challenges with assessing ECHO impacts

Program evaluation has become increasingly important in assessing impacts on participants' knowledge acquisition and application, as well as in responding to funders' requirements to demonstrate program effectiveness in changing provider practices. A challenge that often occurs in evaluating ongoing voluntary educational programs is that attendance is inconsistent. This problem is particularly complex when trying to analyze data. The novel methodology developed to gauge the impacts of our Project ECHO and the results are presented below, with analytic considerations included to understand and mathematically account for people who attended only occasionally.

Methodology

Assessing the reception and impact of our Project ECHO series required the collection of both quantitative and qualitative data. The former included two different types of assessment: (1) program satisfaction, and (2) knowledge acquisition and application. The latter involved collecting responses to open-ended questions. We analyzed quantitative data first, and then examined qualitative data for explanatory statements to provide illustrations of, and insights into, the quantitative findings. This project was considered exempt from human subjects review by the University of Rhode Island's Institutional Review Board (IRB) based on its educational program evaluation nature.

Quantitative and qualitative data collection

Upon registration for the ECHO series, information about participants' work title or role, profession, and agency affiliation was collected. Additional items included what sites hoped to gain from the program prior to participation in the series. Data on discipline were too broad and nonspecific and could not be individually linked to the evaluations, making their inclusion in the analyses impossible.

The impacts of each session were assessed by a follow-up survey generated and sent to participants immediately after each program was completed (see online Appendix for a copy). Quantitative questions measuring program satisfaction as reported by participants at Spoke sites were related to the effectiveness of the presenter, relevance to stated objectives, and the effectiveness of the various ECHO components (e.g., didactic and case study

presentations, and Hub and Spoke responses to cases). Additional quantitative items included the use of a retrospective pre- and posttest of knowledge acquisition, based on the specific learning objectives for each session (Colosi & Dunifon, 2006). A separate item assessed how participants intended to apply the information they had gained. This included uses for providing better care for clients/patients, training staff, educating clients, educating family and/or caregivers, and educating providers. Qualitative data were collected from open-ended items (e.g., What was the most significant thing you learned as a result of participating in this ECHO session?) that required participants to enter their written responses into text boxes in the survey for each session.

Data analytic techniques

Quantitative analysis of data was by Bayesian principal components analysis with means nested by ECHO session and missing data accounted for using pattern mixture modeling (Bishop, 1998; Gibson, 1959; Little, 1993; Spurk et al., 2020; Tanzer, 2021). For each multi-item questionnaire (rating satisfaction, relevance of material, and knowledge), the average scores by question and training session were estimated, while accounting for common variation attributable to individual uniqueness. This approach allowed for the comparison of which specific items received the highest scores individually, as well as which sessions received the highest scores across items. Additionally, principal components weights could be interpreted to identify which items tended to co-occur (Gibson, 1959; Spurk et al., 2020; Tanzer, 2021). This methodology provided insights into whether there were particular subsets of responses that were identified as most valuable.

Lastly, because the modeling included estimating variations attributable to individual uniqueness, this approach directly addressed the challenge of respondents not attending all sessions. For each participant that did not complete an evaluation survey, the analytically implied individual uniqueness score was included with the scores of participants who attended (Little, 1993). This weighted the final estimated item and session averages toward the more likely values, had every participant attended every session. In addition to correcting for nonattendance bias, this method provided an understanding of how individual ratings of evaluations related to attendance patterns. The analytically implied individual uniqueness scores were reflective of where there were empirical clusters in the data (Gibson, 1959; Spurk et al., 2020). Examining how this trait correlated with nonattendance provided a more detailed understanding of what kinds of participants were more or less likely to attend.

As mentioned earlier, qualitative data were not formally analyzed, but comments were utilized to provide illustrative examples to support the understanding of our quantitative results.

Results

Results are reported in Tables 1 and 2 and Figures 2 and 3 below, with an elaboration following each of them.

As indicated in Table 1, the case presentation, and both the Hub and Spoke responses to it, were the most highly effective and relevant components for participants. The least consistently meaningful aspect of the case presentation was the topic's relevance to work, which may be a

Table 1. ECHO model component feedback (N = 106*).

Item	Weight	SD	LL	UL	Inference
Didactic	0.68	0.09	0.49	0.86	Significant
Case Presentation	**0.82**	0.10	0.62	1.01	Significant
Spoke Response	**0.79**	0.10	0.59	0.97	Significant
Hub Response	**0.76**	0.09	0.58	0.93	Significant
Topic relevance to work	0.35	0.09	0.19	0.53	Significant
Case relevance to work	0.51	0.09	0.34	0.69	Significant

*Number of completed evaluations across all sessions.

Note. Weight represents how frequently the item corresponded with other items, which subset of items were valued the most. Standard deviation (SD) represents the precision of the estimate, with smaller numbers indicating more precision. Lower limit (LL) and upper limit (UL) represent the 95% credible interval range of likely values. A range excluding a value of zero indicates that respondents valued that item with the rest at a level that is likely different from chance. Ranges excluding zero are identified by the inference column. Bolded items indicate those responses that were most popular with respondents.

Table 2. Areas of intention to apply knowledge (N = 106*).

Application	%	SD	LL	UL	Inference
	Percentages				
Providing better care to clients/patients	**73.61**	21.57	60.45	83.16	Significant
Training staff	**65.26**	27.49	53.57	76.37	NS
Educating clients	35.72	17.82	23.47	49.67	Significant
Educating family and/or caregivers	**72.72**	20.36	60.86	81.55	Significant
Educating providers	36.71	19.82	24.93	50.12	Significant

*Number of completed evaluations across all sessions.

Reported are the estimated percentage of participants endorsing the listed application. Standard deviation (SD) represents the precision of the estimate, with smaller numbers indicating more precision. Lower limit (LL) and upper limit (UL) represent the 95% credible interval range of likely values. A range excluding a value of zero indicates that respondents valued this application at a level that is likely different from 50%. Ranges excluding zero are identified by the inference column. Bolded applications indicate those that were the most popular.

reflection of the wide range of disciplines from varied work settings that participate in IDD/ADD/ADRD education. Examples of the responses from open-ended items include:

> Feedback from the Hub and Spoke groups brought some new perspectives.

> It is so valuable to hear the suggestions and input from others.

> The information provided around the case study gave me ideas about how better to support the individual in the program I manage.

These comments reinforce the importance of incorporating different perspectives on how to address complex care issues, particularly those from other professions that can lead to better care outcomes.

As shown in Figure 2, session satisfaction scores were generally above 4 ("somewhat effective") out of a possible 5 ("very effective"). While analytically accounting for incomplete participation, this result indicates that participants were generally satisfied with all aspects of the ECHO. Though a global measure, overall satisfaction can be an important indicator of ongoing participation in the ECHO program and its creation of a virtual community of practice.
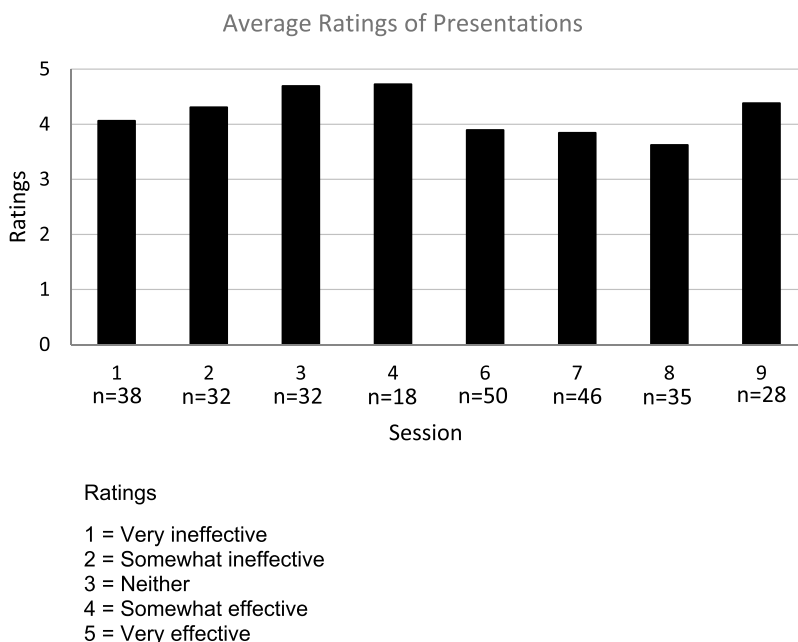
Average Ratings of Presentations

Ratings

1 = Very ineffective
2 = Somewhat ineffective
3 = Neither
4 = Somewhat effective
5 = Very effective

Figure 2. Session satisfaction.

The three most important uses for acquired knowledge included "providing better care to clients/patients," "training staff," and "educating family and/or caregivers," as reported in Table 2. "Educating clients" and "educating providers" were rated as less important. These results reveal the major focus of participants on quality of care and on the importance of both staff training and family and caregiver education as a means for achieving it. This finding is consistent with the results reported above for the ECHO elements of greatest importance to participants, including those contributing to improved care outcomes.

Finally, as indicated in Figure 3, knowledge acquisition showed significant improvement for all sessions. This suggests that participants felt that the training was helpful across the entire program, even while nonresponse bias was analytically adjusted for. Indeed, knowledge acquisition is a major motivator for participants in ECHO programs, as discussed below.

In a review of the analytically implied individual uniqueness scores, results suggest that participants were aligned with two distinct groups, one with a predominant knowledge focus (Group K), the other with an emphasis on networking (Group N). These groups were identified empirically based on the mathematical densities of where item response scores were located within the data. There were identifiable patterns across session attendance, as indicated by the associations between trait scores and attendance and qualitative data that showed consistency in validating the conceptual coherence of these groups.

Group K focused particularly on knowledge acquisition and was larger than Group N. Individuals in this group tended to: (1) complete fewer evaluations, perhaps due in part to the fact that they chose only specific sessions because of their interest in certain topics; (2) rate knowledge (both before and after each session) as higher, on average, than Group N; and (3) choose fewer options from the list of possible uses of their acquired knowledge,
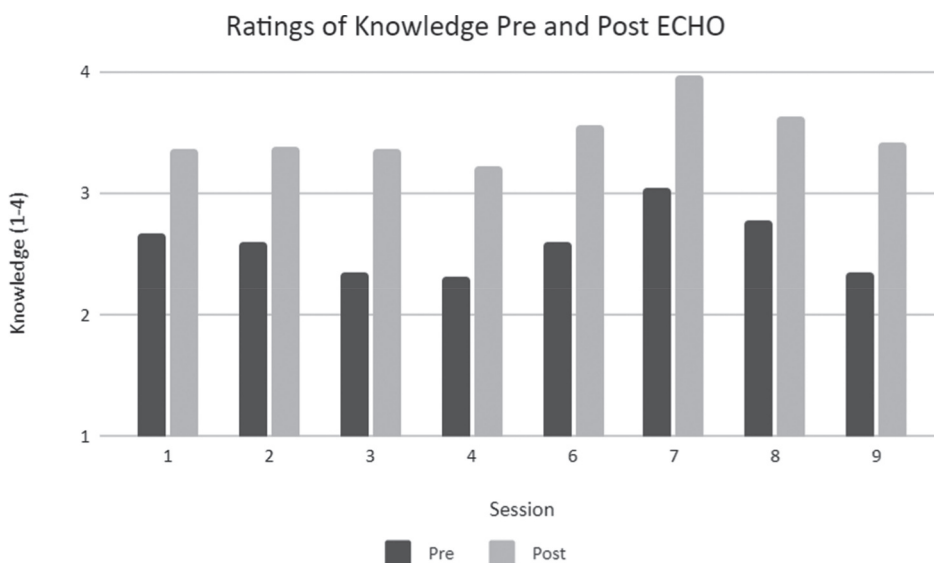
* Number of completed evaluations across all sessions

Knowledge

1 = No knowledge
2 = Minimal knowledge
3 = Moderate knowledge
4 = High knowledge

Figure 3. Retrospective pre- and post-knowledge acquisition ($N = 106^*$). Note. Post-session ratings of knowledge increased significantly (beta = 0.69, 95% CI [0.23, 1.15]).

including "provide better care for clients/patents," and "educating families and/or care-givers." On the open-ended question, "What are you hoping you and others at your site will gain from participation in this Project ECHO?," examples of comments related to the acquisition of knowledge were:

> Learning more about the topic and understanding how to serve our aging clients better.

> Gain knowledge for people with intellectual and developmental disabilities affected by dementia.

In contrast, Group N had a smaller number of participants, but they participated in more sessions and completed more evaluations than Group K. In addition, they reported lower levels of knowledge (both before and after each session) than Group K, and they tended to choose all the response options on the evaluation item related to the intended use of their acquired knowledge. Their focus seemed clearly to be more aligned with the community-building and networking goal of the Project ECHO, as they participated more frequently and were more engaged than Group K. On the open-ended question, "What are you hoping you and others at your site will gain from participation in this Project ECHO?," examples of comments related to community, collaboration, and networking were:

To gain insight into the process of collaboration for supporting individuals to have the best possible lives until the end of their lives. I hope that participation in this project will lead to future collaborations in our area.

We hope to learn more about specialized care to this population and work with others in developing enhanced services and supports. Leverage our resources through participating in this project by learning from, and collaborating with, those in the IDD community.

Discussion: what does it all mean?

What are the implications of our results when set into the context of the analytical framework developed earlier in this paper? In other words, what is the answer to the question posed at the beginning of this paper: does Project ECHO offer an innovative educational method to span the knowledge gaps and bridge the organizational boundaries between the IDD and aging service systems? As discussed, Project ECHO incorporates two methods for achieving these goals: (1) knowledge sharing, and (2) networking.

Knowledge sharing

Previously published reports on the use of Project ECHO in geriatrics education have consistently emphasized its positive impacts on the acquisition and application of knowledge (Baughman et al., 2021; Bennett et al., 2018; Fisher et al., 2017). Our results are consistent with this outcome, as knowledge acquisition showed a significant increase across all sessions, as well as a clear pattern of its application to improving the quality of care through staff training and family/caregiver education. Project ECHO series and sessions on topics related to IDD/AD/ADRD address gaps in knowledge in two ways. The first is at the micro or clinical level by bringing together providers from different professions – such as medicine, nursing, pharmacy, social work, rehabilitation, and social care/human services – to serve as the Hub team. The formation of interprofessional teams requires members to understand how their own perspective on the patient is different from that of others, and how each perspective can complement the other. This "cognitive map" (Clark, 2006) includes the conceptual framework of each profession on the team and how it affects assessment and care plan development. As one of our participants noted, "We see what we know."

Typically, as mentioned earlier, ECHO sessions start with a short didactic presentation on a topic relevant to the series; in addition, a case study discussion following the mini-lecture leads to the sharing of information relevant to the case from the perspectives of different professions. The power of the case discussion – as evidenced in our findings that the case presentation and the Hub and Spoke responses to it were considered by participants to be among the most effective elements – is that it brings to bear multiple lenses through which to view the problems described in the case, resulting in a richer array of potential solutions to them. Our Group K participants placed particular importance on the knowledge acquisition function of our Project ECHO with their emphasis on specific topics. They could be characterized as the "Need-to-Know Selectives."

The second knowledge-based sharing was by bridging gaps at the meso or organizational level. As Widmark et al. (2016) have noted, "knowledge systems," i.e., service agencies, need

to take into account the perspectives of other organizations. For example, organizations serving primarily persons with IDD understand and use knowledge differently from those serving predominantly older adults or those with dementia. Understanding normal aging processes and the changes that can affect persons as they grow older is a different type of knowledge from that needed to provide services to persons with IDD. Many of these agencies grew out of services that started with caring for younger adults and, in some cases, even children.

Importantly, the project Hub team was largely comprised of individuals from different health professions who had experience in both the IDD and aging/AD/ADRD systems. They were able to share critical information and recommendations based on this background with the Spoke participants, who came predominantly from the IDD system. Members of the Hub team were, in this sense, bridge-builders with dual identities and were conversant in the cultures of both the IDD and aging/AD/ADRD worlds. They were therefore able to serve as intermediaries between them (Long et al., 2013).

Networking

The networking feature of ECHO programs can facilitate the kind of interagency boundary-spanning that is crucial for successful interorganizational collaboration, in which effective communication, trust, respect, and shared goals are essential (Karam et al., 2017). Though conceptualized at the organizational level, this kind of networking relies on the formation of personal and professional relationships (Dunlop & Holosko, 2004) and the shared understanding of the motivations of participants from different professions, programs, and organizations (Clark, 2020). Our results characterizing the formation of a group of participants emphasizing the community, collaboration, and networking features of the program are consistent with this outcome. Previous applications of Project ECHO in geriatrics education have consistently emphasized the development of a professional support community based on mutual respect and trust as one of the major outcomes (Baughman et al., 2021; Fisher et al., 2017).

In our IDD/AD/ADRD ECHO program, the development of trust, respect, and relationships among the spoke participants was a critical component of the experience, facilitated by an informal and nonhierarchical atmosphere encouraging participation by all attendees at each session. Through the sharing of case studies presenting particularly problematic client behaviors and challenges, respect and trust were built between the Hub and the Spoke sites, as well as among the Spoke sites themselves. The "all teach, all learn" feature of Project ECHO is based on the establishment of a virtual community of practice that facilitates the establishment of interpersonal, interprofessional, and interorganizational relationships among participants. A key aspect of this networking was the shared goal or mission of the Spoke teams to improve the care of their clients (Bull, Markle-Reid, & Browne, 2008). Group N participants seemed more engaged in the community of practice feature of our Project ECHO, with a networking focus on the boundary-spanning function of the program. In this sense, they could be philosophically characterized as ECHO "True-Believers."

Recommendations and conclusions

The increased use of Project ECHO methods in geriatrics suggests that its potential is great for impacting clinical practice and patient outcomes. One of the strengths of the current study is its dual focus on knowledge dissemination and network-building incorporates two different, yet related, objectives. These should be recognized as such by both those developing Project ECHO programs and those participating in them. For example, the advertising of ECHO programs to recruit participants could differentially emphasize the knowledge acquisition or networking impacts for different groups of potential Spoke sites, depending on what is more important to them.

Regarding the transmission of new knowledge at various levels, ECHO addresses gaps between professions and organizations. At the clinical or micro level, the use of interprofessional teams at both the Hub and Spoke sites suggests that information conveyed through didactic presentations and case study discussions should be shared across professional boundaries, thereby adding important knowledge to the assessment of patient problems, the development of more comprehensive care plans, and better outcomes for clients. In other words, using multiple professional "lenses" improves the understanding of patients' problems and how to address them. This feature is particularly important in creating interprofessional teams of providers working with persons aging with IDD.

With respect to program evaluation specifically, one limitation of this project was related to its inability to assess and correlate professional role or workplace setting with outcomes assessed, including the acquisition of knowledge and intention to apply it in different areas of practice. In addition, it would have been helpful to know whether membership in groups K and N was related to profession to further explain the differences between them. Similarly, greater qualitative data on group preference would have provided further insights into the significance of this identification. Finally, the development of targeted recruitment efforts, focusing on the participation of different professions at spoke sites, would have benefited from greater insight into differing motivations of a range of health and social care providers.

At the next higher meso level of the organization, knowledge gaps between agencies with different funding sources, histories, target populations, and health or social care priorities can be bridged through Project ECHO programs that reach out to a variety of provider sites. Diversity in participating organizations can add an important dimension regarding acquisition of the types of information considered relevant to patient care. For example, ECHOs having a broad focus on health and social care may incorporate more diverse perspectives than those with a more limited biomedical focus.

With the increased recognition of the importance of interorganizational collaboration or networking, the boundary-spanning impacts of Project ECHO methods should be recognized and valued. Increasingly, research suggests that this type of collaboration is as, or more, important than collaboration across individual professions (Reeves et al., 2018). At the meso level, partnerships based on trust, respect, and relationships between organizations can strengthen efforts to improve patient care, particularly when these organizations come from different backgrounds and can contribute new perspectives on addressing complex patient problems.

In sum and in summary, Project ECHO presents many potentials and possibilities for sharing information and networking among organizations, agencies, and professionals at

the intersection of the fields of IDD and aging. It is important for those developing ECHO projects to be aware of the differences among these elements to maximize their effects and effectiveness in continuing professional education and building communities of practice addressing the needs of persons aging with IDD.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

Ansello, E. F., & Coogle, C. L. (2000). Building intersystem cooperation: Partners III integrated model. In M. P. Janicki, & E. F. Ansello (Eds.), *Community supports for aging adults with lifelong disabilities* (pp. 457–475). Baltimore: Brookes Publishing Co.

Ansello, E. F., & Rose, T. (1989). *Aging and lifelong disabilities: Partnership for the 21st century*. College Park, MD: University of Maryland Center on Aging.

Arora, S., Kalishman, S. G., Thornton, K. A., Komaromy, M. S., Katzman, J. G., Struminger, B. B., & Rayburn, W. F. (2017). Project ECHO: A telementoring network model for continuing professional development. *The Journal of Continuing Education in the Health Professions*, *37*(4), 239–244. doi:10.1097/CEH.0000000000000172

Baughman, A. W., Renton, M., Wehbi, N. K., Sheehan, E. J., Gregorio, T. M., Yurkofsky, M. . . . Lipsitz, L. A. (2021). Building community and resilience in Massachusetts nursing homes during the COVID-19 pandemic. *Journal of the American Geriatrics Society*, *69*(10), 2716–2721. doi:10.1111/jgs.17389

Bennett, K. A., Ong, T., Verrall, A. M., Vitiello, M. V., Marcum, Z. A., & Phelan, E. A. (2018). Project ECHO – Geriatrics: Training future primary care providers to meet the needs of older adults. *Journal of Graduate Medical Education*, *10*(3), 311–315. doi:10.4300/JGME-D-17-01022.1

Bishop, C. (1998). Bayesian PCA. *Advances in Neural Information Processing Systems*, *11*, 382–388.

Bull, G., Markle-Reid, M., & Browne, G. (2008). Interprofessional partnerships in chronic illness care: A conceptual model for measuring partnership effectiveness. *International Journal of Integrated Care*, *8*(2). doi:10.5334/ijic.235

Clark, P. G. (2006). What would a theory of interprofessional education look like? Some suggestions for developing a theoretical framework for teamwork training. *Journal of Interprofessional Care*, *20* (6), 577–589. doi:10.1080/13561820600916717

Clark, P. G. (2007). Understanding aging and disability perspectives on home care: Uncovering facts and values in public policy narratives and discourse. *Canadian Journal on Aging*, *26*(Suppl.), 47–62. doi:10.3138/cja.26.suppl_1.047

Clark, P. G. (2020). Potentials and pitfalls of networking in interdisciplinary education: Taking on the challenges in gerontology and geriatrics. *Gerontology & Geriatrics Education*, *41*(3), 264–272. doi:10.1080/02701960.2020.1725750

Colosi, L., & Dunifon, R. (2006). *What's the difference? "Post" then "pre" and "pre then post."*. Ithaca, NY: Cornell University Cooperative Extension. Retrieved from http://www.healthymarriageinfo. org/wp-content/uploads/2018/05/What-s-20the-20Difference-20Post-20then-20Pre-20and-20Pre-20then-20Post.pdf

D'Amour, D., Goulet, L., Labadie, J. -F., San Martin-Rodriguez, L., & Pineault, R. (2008). A model and typology of collaboration between professionals in healthcare organizations. *BMC Health Services Research*, *8*(1), 188–202. doi:10.1186/1472-6963-8-188

Dow, A. W., Zhu, X., Sewell, D., Banas, C. A., Mishra, V., & Tu, S. -P. (2017). Teamwork on the rocks: Rethinking interprofessional practice as networking. *Journal of Interprofessional Care*, *31*(6), 677–678. doi:10.1080/13561820.2017.1344048

Dunlop, J. M., & Holosko, M. J. (2004). The story behind the story of collaborative networks: Relationships do matter! *Journal of Health & Social Policy*, *19*(3), 1–18. doi:10.1300/j045v19n03_01

Fisher, E., Hasselberg, M., Conwell, Y., Weiss, L., Padrón, N. A., Tiernan, E. . . . Pagán, J. A. (2017). Telementoring primary care clinicians to improve geriatric mental health care. *Population Health Management*, *20*(5), 342–347. doi:10.1089/pop.2016.0087

Gibson, W. A. (1959). Three multivariate models: Factor analysis, latent structure analysis, and latent profile analysis. *Psychometrika*, *24*(3), 229–252. doi:10.1007/BF02289845

Heller, T. (2017). *Service and support needs of adults aging with intellectual/developmental disabilities*. Testimony to the US Senate Committee on Aging. Washington, DC. Retrieved from https://www. aging.senate.gov/imo/media/doc/SCA_Heller_10_25_17.pdf .

Jafari, P., Kostas, T., Levine, S., Martinchek, M., Johnson, D., Graupner, J., & Thompson, K. (2020). ECHO – Chicago Geriatrics: Using telementoring to "geriatricize" the primary care workforce. *Gerontology & Geriatrics Education*, *41*(3), 333–341. doi:10.1080/02701960.2019.1572005

Karam, M., Brault, I., Van Durme, T., & Macq, J. (2017). Comparing interprofessional and inter-organizational collaboration in healthcare: A systematic review of the qualitative research. *International Journal of Nursing Studies*, *79*, 70–83. doi:10.1016/j.ijnurstu.2017.11.002

Lindauer, A., Wild, K., Natonson, A., Mattek, N., Wolf, M., Steeves-Reece, A., & Messecar, D. (2020). Dementia 360 ECHO: Using technology to facilitate diagnosis and treatment. *Gerontology & Geriatrics Education*, *43*(2), 202–208. doi:10.1080/02701960.2020.1835658

Little, R. J. (1993). Pattern-mixture models for multivariate incomplete data. *Journal of the American Statistical Association*, *88*(421), 125–134. doi:10.1080/01621459.1993.10594302

Long, J. C., Cunningham, F. C., & Braithwaite, J. (2013). Bridges, brokers, and boundary spanners in collaborative networks: A systematic review. *BMC Health Services Research*, *13*(1), 158–170. doi:10. 1186/1472-6963-13-158

National Down Syndrome Society (2022). *Alzheimer's disease and Down Syndrome*. Retrieved from https://www.ndss.org/resources/alzheimers .

Reeves, S., Xyrichis, A., & Zwarenstein, M. (2018). Teamwork, collaboration, coordination, and networking: Why we need to distinguish between different types of interprofessional practice. *Journal of Interprofessional Care*, *32*(1), 1–3. doi:10.1080/13561820.2017.1400150

Rhoads, K., Isenberg, N., & Schrier, A. (2021). UW Project ECHO - Dementia: Implementation of a virtual clinic and telementoring program to improve dementia diagnosis and treatment in rural

and under-resourced primary care settings. *Alzheimer's & Dementia*, *17*(Suppl.8), e051217. doi:10.1002/alz.051217

Ryan, D., Barnett, R., Cott, C., Dalziel, W., Gutmanis, I., Jewell, D. . . . Puxty, J. (2013). Geriatrics, interprofessional practice, and interorganizational collaboration: A knowledge-to-practice intervention for primary care teams. *The Journal of Continuing Education in the Health Professions*, *33*(3), 180–189. doi:10.1002/chp.21183

Spurk, D., Hirschi, A., Wang, M., Valero, D., & Kauffeld, S. (2020). Latent profile analysis: A review and "how to" guide of its application within vocational behavior research. *Journal of Vocational Behavior*, *120*, 103445. doi:10.1016/j.jvb.2020.103445

Strydom, A., Lee, L. A., Jokinen, N., Shooshtari, S., Raykar, V., Torr, J. . . . Maaskant, M. A. (2009). *Report on the state of science on dementia in people with intellectual disabilities*. IASSID Special Interest Research Group on Ageing and Intellectual Disabilities. Retrieved from https://www.iassidd.org/wp-content/uploads/2019/02/state-of-the-science-dementia-2009.pdf .

Tanzer, J. R. (2021). Reliability and physiological validity: Bayesian principal components analysis and group comparison [Master's Thesis, University of Rhode Island]. ProQuest Dissertations Publishing.

Widmark, C., Sandahl, C., Piuva, K., & Bergman, D. (2016). What do we think about them and what do they think about us? Social representations of interprofessional and interorganizational collaboration in the welfare sector. *Journal of Interprofessional Care*, *30*(1), 50–55. doi:10.3109/13561820.2015.1055716