

Transcript for Video from Research and Training Center on Community Living Summit, held Sept. 20, 2016 in Alexandria, VA.



Development and Testing of an Informal PA Training Program. Presenters – Researcher: Jessica Dashner, OTD, OTR/L. Participant in the research project: Katie Rodriguez Banister. Scientific and Consumer Advisory Panel Member: Stan Holbrook.

Jessica Dashner: So, I'm going to talk to you about our project. We are developing and testing an informal personal assistant training program. As Martha mentioned, I'm at Washington University in the program in occupational therapy. I'm an OT and an instructor there.

So, the objectives of this project, kind of generally speaking, are to design the content for an informal training program. By informal, we just mean unpaid personal attendants. And then we're going to do an iterative process to try to develop this training program. So we're part way through. We still have our final stage to go, so there's still time and room if you guys have suggestions, I would love to make edits and changes to the program.

I'll do the same then and kind of have it available on the computer in the back over lunch and during some of the breaks if you'd like to check out some of the content.

And then our final step in this project is going to be to pilot test this intervention. So we're going to try to do some pre/post outcomes and try to begin that step of gathering some data to see if this intervention is effective. So, this is kind of an unfair audience for me because I think you guys all understand the need, and agree that there is a need for training informal personal assistants – so unpaid help.

So we know that the number of adults needing PAS is expected to grow due to aging population, people with disabilities, some funding cuts maybe in some of the paid provisions, where there's just still a need that exists for people. There's still that unmet need, sometimes, like I said, sometimes that's due to lack of hours; maybe inadequate training, so there's not a good pool of people to pull from to be able to provide personal assistance.

This unmet or inadequate personal assistance can also be associated with different kinds of adverse outcomes, so, it can increase healthcare costs. People have chronic secondary conditions and they're needing to reenter that kind of medical system and receive care. Also, risk for institutionalization can be present when there's inadequate personal assistance services.

So there's an estimated 34 million unpaid caregivers providing assistance to someone in the U.S. And this is kind of the language shift, so this is even, some of the articles talk more about 'caregiver.' We really try to still use the term 'informal personal assistant.' I'll probably have to, at some point, give it up. But just depending on the agency, and kind of where these studies are published, has a lot to do with the language that's used.

Sometimes it's informal care, sometimes it's caregiver. So, those terms are pretty interchangeable. And I realize at some point when people are searching for this type of training program, inevitably they'll probably start to look for things like a caregiver training program.

Informal personal assistants oftentimes review their success based on the outcomes of that person. So how well is that individual that they are providing care for re-engaged in their community, are they employed, what kind of things are they doing? A lot of times the providers really feel like that's influential in the care and assistance that they provide.

So, most of the studies that are current are, talk a lot about this concept of 'caregiver burden,' which, again, kind of frustrates us a little bit, 'cause we really think that has such a negative connotation; it really makes it seem like it's a burden, it's a negative thing to provide this assistance. What you find when you talk to people is quite the opposite. People who provide informal personal assistance are really excited about what they do, that they're empowering another individual to be able to kind of get out and get on with their daily activities.

There's also a lot of research that's more relevant to individuals with Alzheimer's or dementia, and kind of some older adult training programs, but ours has taken kind of a different focus.

So this is kind of an overview. Phase 1 of the project, we've assembled a draft of this training program, so under that, the grant that Glen talked about -- the MICL grant -- we developed a similar program for paid personal attendants. Now we're trying to do this for informal personal attendants.

So we started with what we had, we tweaked it a little bit so we had a draft. We had this draft reviewed by some consumers and providers of informal personal assistance. So the idea is to bring in our experienced consumers and providers and get their feedback.

We want to make sure the content is relevant, the right level of detail, and it covers all the topics that they deem important. So that was reviewed by four consumers and four providers. So we bring them in in pairs, so they're kind of a dyad or a matched group.

Phase 2, which is where we are right now, we've modified the content of the training based on that feedback we received. We received our IRB approval, which is our internal institutional review board.

We're recruiting 10 dyads for the trial and the program. So, again, this is experienced consumers and providers that we're bringing in to go through the whole process with us, this is an in-person training so they come into our center, take some pre-surveys, go through the training and do some follow-up surveys.

Once we get finished with phase 2, we will make edits again to the training programs, we're using this iterative process to try to make sure that we're testing it, testing it again and testing it a final time.

Then we're going to pilot test the training program with 40 dyads. So these are going to be individuals that are new to receiving personal assistance or possibly at risk for institutionalization so that they can come in and have their family members trained.

So phase 1, these are just some of the highlights. When we presented the draft of the training program, we had suggestions of including things like driving adaptations and transportation options -- that was an important concept to have included in the training.

Travel accommodations, and then some safety and emergency planning. So we developed modules and included them in the training as well. Other highlights were that we needed to really consider computer literacy, so what we do with the program, is, again we're going to deliver it face-to-face, but we put everything in a Moodle, which is an online training format for courses so that people could access it at home when they are done with the training program.

So they really gave us some feedback on how to structure that and make it most useful. Then we also have the suggestion of possibly having a messaging center or blog kind of thing so that people can receive more peer support in the process as well.

During phase 1, one of the things we did is we had the consumers and the providers rank order our topics, to tell us which topics they felt were most important to include in the training. The results are on the screen. The kind of yellow side is what people with disabilities thought were most important, and the blue side with what the informal personal attendants thought were most important.

Both groups thought that having information on personal care was kind of the top; that was the most important item to have. For people with disabilities, they also felt body mechanics and transfers, effective communication, physical disabilities and conditions, health and wellness, secondary conditions, and then they selected psychological and emotional, assistive technology, and recognizing abuse and neglect. That's the order they put the topics.

Informal personal assistants, like I said, also agreed that personal care was important to have. So this is really kind of dressing techniques, just some different things you can do when you're providing assistance.

If you are working with consumer that has paralysis on one side or the other, dressing the affected side first – those kind of tips they may learn in rehab but once they're out in the community, nobody's out there teaching those skills to people.

The PAs also thought effective communication was important. Health and wellness, physical disability and conditions, body mechanics and transfers, secondary conditions, assistive technology. The psychological and emotional and then recognizing abuse and neglect.

We feel that, not that recognizing abuse and neglect isn't important, but think it's because of the pairs that we had come in were well adjusted, that wasn't a concern for them. So we included the modules that I just described and then like I said, we added one on safety and emergency planning and transportation and travel options for people.

So phase 2, this is where we are now. We're piloting the training program with experienced recipients and providers. So they come in, they take a pre-survey, then they go through the training program.

We do some pre- and post skills and knowledge test, so it's just a 10-question survey of kind of their pre-training and post-training knowledge. They'll do a longer term follow-up survey to try to gather some outcomes.

Then in this group we're going to have them provide us with some feedback. And then we're going to go over the resource that we have available with the online training program.

These are just some sample items to give you an idea of the kinds of things we asked. This is the knowledge test for the recipients. So just some sample questions are, 'How can you train a new attendant to complete tasks the way you want?' is the question.

Then the response items are 'demonstrate the task with an old attendant, assume previous experience is enough, give the attendant a test, or criticize the attendant's performance.'

That's where we would encourage them to have another attendant provide some on-the-job training. What information should you know, should your attendant know if they need to call 911, how do you resolve issues or conflict, what kind of assistive technology can be used as a toilet and a shower chair, so we have some options there at the bottom.

For the providers, we have similar questions with just a little different focus. We ask questions about, like how many stages of pressure sores are there? Do they only occur on the person's back and bottom? Are there other places that you can receive a pressure sore? If the consumer has weakness on the left side, what part of clothing should they put on first? When you are transferring your consumer, most of their weight should be supported by – and it's your back, legs, shoulder or wrists.

More questions about kind of performing range of motion. Providing consumers with choice and making sure that -they give consumers the option to pick the clothing they are going to wear.

True/false about providing range of motion exercises and kind of technique.

The outcomes we're collecting in our pre- and post- survey include what we call our CORE survey, which really talks about demographics -- age, race, gender, those kind of things, education status. Find out about the individual's health status, so any kind of secondary conditions, number of visits to emergency rooms, unscheduled visits to the doctor. Kind of some PA quality surveys, so a little bit about how their attendants provide their assistance, what kind of things they are good at, their satisfaction, if they have any injuries.

Our PARTS survey, which asks about participation, so it talks about time included in activities, if the consumer has control over the technique, how satisfied they are and how safe they feel. Then our SPARC survey, which asks about similar items but out in the community, so if they receive that informal personal assistance out in the community, how beneficial is that to them.

We like to survey, so anybody who has history with us knows we have lots of items and measures. Some of you in the room may have taken our surveys before.

So, in the other things we ask about social connectivity and relationships. So part of it's kind of community outreach and participation included in the training. We have items from the Hope scale, so just kind of a general, how much control you feel you have over events in your life. We have a general self-efficacy scale so we're trying to see if going through the training improves self-efficacy. Then a perceived stress scale.

The providers also receive the CORE survey with slightly different items. We find out about their demographics and education, employment status and things like that. Also their knowledge of secondary conditions, so we try to find out in advance what their knowledge level is and then can we improve that by them attending the training program.

We have items from the Exemplary Care Scale, ask questions about relationships and the communication between the pair. We have similar items with the Hope scale, the general self-efficacy scale and the perceived stress scale. And then we have an additional survey that is the caregiver self-assessment questionnaire. I have copies of those surveys if any of you would like to look more specifically at the items.

So once we get phase 2 completed, get their feedback on the training session, we'll make our kind of final round of improvements and then we're going to test this in phase 3.

So this is where we're going to have 40 dyads, and again those dyads are the consumers and providers working together. We're going to do a wait list control group,

which is kind of like it sounds. We're going to have individuals that are kind of in limbo waiting for the training program complete our measures and figure out if there's a difference between the groups.

So the group that received the intervention, do they have different kind of outcomes than the control group? For our recipients, we're looking for individuals who are over 18 who live in a community setting or have a desire to live in community setting, with a newly acquired or progressing mobility or sensory disability, or individuals that are at risk for institutionalization. So our training is not disability-specific, it's just in general for the tasks that people may need help with. Then our providers are pretty loose on our criteria, so we're looking for people over age 18 who are willing to provide unpaid personal assistance to a consumer.

So the phase 3 folks will attend this face-to-face training. During one of the training sessions, we're going to also train the informal providers on the use of our CHEC assessment, which is the Community Health Environment Checklist, the survey that we developed that looks at usability of buildings in the community.

The thought behind this is that the family members and friends, a lot of the times if somebody's newly injured, want to know what they can do. We feel this is something they can do. They can take our checklist out into the community; they can look at the sites where the individual used to go -- where they like to go out to eat and those kinds of things, and determine the usability of buildings in the community. That'll just kind of help with that process of community re-integration; so the individuals know up front what kind of buildings they can get into and where they can participate.

They are going to complete the pre-survey, do the skills and knowledge test at the training center, and then we're going to do a three-month follow-up survey – the post-survey – to determine those outcomes. We're also going to get some feedback on what it was like to be a consumer or participant in this project.

We're trying to hypothesize that the people who attend the training program, that the consumers are going to have improved health status, increase their exercise participation – we have that section on health and wellness where we introduce them to some different adaptive equipment. Our research office is located inside Paraquad Independent Living Center, so we have access to the health and wellness center at Paraquad, so we take people over on a tour and show them some adaptive exercise equipment. They get to see people with disabilities working out.

Hopefully they'll have increased social contact, with the attendant understanding the importance of community participation and getting out socializing, they'll have more opportunities for that.

We're also hoping to improve the relationship between the consumers and the providers. Hopefully, there'll be more satisfaction and reduction in injury and all those kinds of things. For the providers, we're hoping that it will kind of improve their approach

preparing the consumer for going out in the community, report less difficulty with completing tasks, have fewer injuries and have higher levels of self-efficacy so they have a little bit more confidence in what they are doing once they feel like they've learned some techniques and some skills that they can apply to providing personal assistance.

So, some future implications and directions. This is a tool that we hope can be used by rehab facilities or independent living centers to assist with informal personal assistant training programs. In rehab, again, this is an audience where you guys know this, but decreasing the length of stay can sometimes put a little bit of a squeeze on how much education family members are receiving.

So we're hopeful that this is another tool that once people get out of rehab, they would be able to have this as a resource and a tool. Also all of their family members might not be, you know, there at the rehab center. So this is something, once the consumer has a good handle on it, they can train additional providers when they get home.

Our community practice at Washington University provides various kinds of OT services. They are interested in determining if there's a way that this could be a billable service – so is there a policy change that needs to be in place for that to happen, or is this a fundable, billable service that OTs can charge for kind of family education?

And then we want to try to look at this in service context. So it's one thing to bring people into the research center, again, we've got smooth tile floors and adjustable height exam tables to teach transfers, but we realize that is not the reality when people get home. So, moving forward we'd like to do some different kinds of work where we test this intervention in-home versus in kind of a lab setting, if you will, to determine if it makes a difference.

We can also do the same thing with just the online version of it. So, the people who just do the computer training have the same outcomes as the people that come in for their face-to-face. Again, we want to try and reach people in a rural area or who don't have transportation to come in for this kind of training.

So some of the challenges -- Washington University is a pretty rigorous university. We have our institutional review board that has its hands in our project a lot, which is a good thing. But, when you are doing this kind of iterative process where you are constantly changing things and you have to re-submit, so every change that we make to the training program, we have to re submit to our IRB which can cause some significant delays.

So, if I want to change a little bit of wording, I have to re-submit and get approval. Just something to know as we go along.

And then, obviously the loss of Dr. Gray was a huge one. This project was really important to him. I swore I wouldn't cry. And so, it's been a big effort to try to continue.

This is the online training, if you guys are interested. You can log on, those are some IDs and passwords. Or you get on there, kind of scroll around and go through some of the modules.

I have some OT students that have been helping put the project together, so it's a huge undertaking, so I just wanted to acknowledge them as well. My contact information, if anybody would like, I can send a link out to the training, I have cards and you guys can feel free to contact me at any time. We have our, one of our star research participants on the phone. Right, Katie?

Katie Rodriguez Banister: Good morning.

Jessica: Hi Katie.

Katie: Hi everybody.

Jessica: This is Katie Rodriguez Banister. She was a participant in phase 1 of the study who gave us some feedback on the training program. Katie and her husband, Steve founded Access-4-All and their mission is to educate and empower others through motivational speaking and disability education.

So, Katie's a motivational speaker, educator and author. She's authored several books, including Aunt Katie's visit, which is designed for children, a personal attendant care training guide, so she published a training guide for personal assistants, a pocket of poems and how to write your own, and then Karmic Validation.

So we're blessed to have Katie on the phone. She's a great friend of our research lab and has done a lot of good stuff. So, thank you for joining us, Katie.

Katie: Great! It's been wonderful being a part of this project. As an original participant I've gotten to see this thing bloom, this whole project bloom. And I liked it because it's interesting working with other people.

I have a spinal cord injury, C-5, C-6. And I worked with a variety of other people with disabilities. And it was cool making this tool and a process, and a ranking regarding the informal training of unpaid personal care attendants.

And I used these folks – folks who are unpaid – at home, in my community, where I work, recreation and travel, and I use them every day. These people include family, friends, neighbors, co-workers and former classmates.

The neat thing about this project is it starts the conversation about personal care attendants, especially for the newly injured. It's a tool, it's kind of a blueprint for living with a disability, and it's a healthy way to problem solve. Because it's tough. It's a working relationship in many ways. It really helps to teach respect, and for both sides to take nothing for granted.

Stanley Holbrook: I'd like to give some of my thoughts. First of all, I think community participation is a pinnacle of independent living. Being able to participate fully in a community, you know, is something that, a right that everybody should have.

And I thought this tool that provides the proper training for informal caregivers. I know as a center for independent living director at one time, we had a personal care program. Those programs are limited to formal care, to hours when people can do things. And I think the best network that people have are their families or people close to them. And what even makes that a little better is those folks are going to work with you anyway because they have passion and they want to help.

I think having this tool, the online tool, the videos that come with it, is essential, you know. And I think we should look at this informal training in such a way where everyone around that wants to be able to do things, do things right and at the bequest of the consumer.

I do like the dyads. I think it is very important that the consumer is part of the training as the trainer. 'This is the best way to lift me, this is the best way to work with me.' I do have a question. I couldn't see the slides, there were a million surveys and so I said, how do you take all that data and how does it base the formation of, or foundation of the training, that's a question that I have, because it's a lot of data. So how does that translate into which direction we're going? But I mean, other than that question, I also think, this is health promotion project, you know.

I think it's something that is desperately needed. I think that as we move to the next level -- we're talking about change. You know, centers especially, need to look at health promotion and this is a big part of health promotion. By having someone there to assist you correctly and open up education, you know, the things that are covered here. You know, some people on the street don't know it. Now you are educating a whole different set, family that need that education. So, I laud this project, I'm looking forward to phase 3 and seeing how this works. But if you can help me with that, the survey data.

Jessica: Sure. Like I said our research is well-known for the outcomes that we provide. And so, I think it's looking at a variety of things that try to kind of determine which things change. So, participation being kind of the underlying thing. We want to make sure what we do and the information we provide means something. So it's not just about making the job or the task easier, but what does that do for the person? Kind of what's the bigger picture, if you will. How does it change? Are people able, that they now have a provider that helps them get dressed, so they are not as fatigued so they're able to get out and do more.

Are they able to go out in the community? Go to restaurants, go to grocery stores. These are all the kinds of questions that we ask. We try to look at it from a couple of different levels, so the first is kind of that that basic level. Do you know more about X, Y and Z than you did before, and then how does it translate into the individual's life and what they are able to do out in the community?

Katie: I sure wish I would've had this tool when I was injured 26 years ago. It probably would've made the transition from my parents' a lot easier, and we could smooth over any of the challenges it would take for me as a person needing the care and my parents as the persons, people providing it.

Question from participant on phone, relayed by Val Renault (off-camera): We have some questions from Peg Nosek, who's joining us from Houston. She has three questions. I'll read them all. Since the providers are not paid, what incentives do you use to maintain their interest and enthusiasm for participating in the study? Second question, are there alternative forms of compensation? And then do you include any counter measures for provider burn out and consumer feelings of being a burden, excessive gratitude, etc.

Jessica: For the participation of the study, we do pay individuals, so they are paid for their time. That's just kind of a bonus to being in the study. So, we pay participants to come in to take our surveys pre- and post- and to attend the training program.

Just, again, I think this is an inherently important thing and people, family members are going to be providing this assistance, so they want to receive this training. So they want to do things the right way. They want to make sure that it is safe for them, safe for the consumer. So, again these are not, you know this is family. This is love. This is what you do for people. So I feel like, we haven't had a lot of struggle with that. People are very willing to receive this information and, like I said, really want to learn the skills and the techniques to do the job and to make it, you know as easy and safe as possible.

Val: Are there alternative forms of compensation?

Jessica: I don't - financially not so much. But again, I think it's just the fact that you are reducing injuries, you know the proper techniques to perform transfers, making the tasks and the job a little bit easier.

Val: Do you tell include counter measures for provider burn out and consumer feelings being a burden, excessive gratitude, etc.?

Jessica: That's all included in the survey, so we get at it in a couple of different ways just to see if there's an effect. So through things like the HOPE scale, which is about problem solving, figuring out ways to get out of a jam, some of those kind of questions. The perceived stress scale is another way that were able to measure those effects. And that caregiver self-assessment questionnaire that goes to the providers talks about their ability to still participate in their own activities and make sure they are not feeling burned out or overwhelmed.

Val: Will you be involving adolescents in transition? We are working with a spina bifida, transition clinic where this issue has come up and we are looking for training resources. In this context the young adults want to move away from family and out on their own, but usually lack the money to hire attendants. Do you include tips on how to locate and

engage informal personal assistance, especially with alternative forms of compensation room and board, English assistance, etc.?

Jessica: Yeah, so our study is 18 and over, is kind of the focus. So definitely, I think that's a piece that we could enhance. We do have information on resources and things that are out there in the community, but I think we could definitely get more specific on that. That's a good suggestion of a module that we could include if people need it to transition.

Phil Rumrill (off camera): I'm Phil Rumrill, I'm with the Center for Disability Studies at Kent State University. I was wondering if your selection criteria imply any threshold of cognitive functioning or psychological functioning. It seems that the process of informal care works best when it's customized to the care recipient's needs and wishes and I was just wondering what might happen if the person's ability to understand his or her needs were compromised due to disability.

Jessica: The content is really more for that kind of self-directed, so for individuals who are able to communicate kind of their needs and self-direct the assistance that they need. That's really our focus for this project, but I think it could be still adapted, and that's why coming in as a dyad is so important if both individuals are receiving that information together and can process it and work through it together to modify it or tweak it as it works best for them.

Jean Ann Summers: Jean Ann Summers. I wanted to follow up on Peg Nosek's question about compensation for personal caregivers who are family members. In some states, there are incorporated into their HCBS waivers opportunities to provide family caregivers with compensation. If they do, it seems to me that having some kind of training that you could certify a person as having those competencies to provide that personal care would strengthen advocates who want family caregivers to be compensated. That means a lot of these folks can't go to work if they have to provide that care and so this is a just kind of compensation.

Jessica: That was definitely, the first project under the MICL grant, that's the exact population that we focused on, was that consumer-directed personal assistance services program. A lot of our participants came from Paraguard and that was in its, friends and family can be paid attendants for that program. The modules were similar, obviously, and the skills that you are providing are the same. But we add a little bit of additional kinds of things as far as managing that relationship because now the consumer is kind of your boss and the recipient of the care. So a little bit about how to manage that, and how complicated that can make a relationship then, if you are not satisfied with the assistance that you are being provided in that consumer-directed model.

Martha Hodgesmith (off camera): Jessica, can you speak to the value, we know it in working with you, but the value of having this research done in partnership with a department of occupational therapy and occupational therapy students.

Jessica: It's been great. Our kind of perspective of understanding what occurs in rehab and what time allotments are in rehab, and how that information can translate into the community is -- has been a benefit of this program. So working closely with the rehab institutes -- we're situated right next door to the Rehabilitation Institute of St. Louis -- and they've really been able to help and promote the study, and give us some ideas and suggestions of things they just don't have time for due to decreased length of stay, and what kind of things they hear from their consumers are issues once they get home. So we're hoping to be able to eliminate some of those kind of concerns that they have as well. It's been a great partnership.

Martha: And I think this speaks to a point that John had made about the interface in NIDRR's research portfolio over the years and with the transition to the Administration on Community Living, and I think our work and certainly David Gray's work over his time at Washington University really helped the occupational therapy profession get a better insight into the concepts that you have talked about. Do you have a thought on that, Stan, in terms of it being in an OT setting?

Stan: I think that it enhances the value a hundred percent just having it in an OT setting. I know we at Three Rivers in Pittsburgh look for OT students to assist us in that arena and look for funds to even pay the interns that assist us. I think it's a value added when you do that connecting with the OT department and the students.

Martha: And Katie, can I ask you on the phone if you have thoughts about how important that is to the success of something like this?

Katie: Why it's important to have something, a tool like this?

Martha: Yes.

Katie: It's invaluable. When my accident happened, I was in an SUV that rolled over when I was 25 and we were lost. My family was lost. We had some great social workers, but even the social workers didn't give us a lot of resources on living with a disability and the dynamics of a family helping somebody who's been injured. So the value of this -- it's been wonderful being a part of it because I got to have my say and what I've learned in the past 26 years as living as a woman on wheels, is that it really needs to continue. The project needs to continue.

David Keer (back to camera): Are you tracking the amount of hours that OTs put into the training program per se? The reason I ask that question is that a bit of a complementary research project would look at the potential savings of providing solid training to informal PAS providers versus the risk of development of pressure sores and other complications that lead to hospitalization, that run up medical costs for CMS, which might in turn lead CMS to see this as an area of service that it should fund because of the potential cost savings down the road.

Jessica: We probably don't have enough of that in our measures. So we definitely find out what outcomes -- so the experience of secondary conditions, receiving

hospitalization and that kind of stuff, but I think that's a great point to include a little bit more about the time it takes to offer the training and what that could cost per hour versus the financial costs associated with secondary conditions and complications. Absolutely. That could be enhanced for sure.

END