

A National Study Evaluating the Use of Marketing and Communication Principles Employed by the University Centers for Excellence in Developmental Disabilities to Assure the Rapid Dissemination of Information

September 15, 2006

When referencing this publication please cite as:

Kreutzer, C.B., Fleming, A., Hsu, E., Schweers, L. (2006) *A National Study Evaluating the Use of Marketing and Communication Principles Employed by the University Centers for Excellence in Developmental Disabilities to Assure the Rapid Dissemination of Information*. California: USC University Center For Excellence in Developmental Disabilities, Childrens Hospital Los Angeles.

This Study was conducted under Grant# 90DN0097, a project of National Significance, Administration on Developmental Disabilities (ADD), Administration for Children and Families (ACF), United States Department of Health & Human Services (DHHS), funded to the University of Southern California, University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles.

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I. BACKGROUND

In the Summer of 2001, the Administration on Developmental Disabilities (ADD) released a request for proposals for Priority Area #1 under their Project of National Significance (PNS), asking applicants to address the *Rapid Deployment of Good Ideas, Area of Emphasis: Health-Related Activities*. ADD's interest was to fund projects that would transfer information and knowledge through the utilization of creative and innovative methods of implementation, replication and dissemination. The grantee was to assure that program activities were directed toward achieving the *Roadmap to the Future* goals. The impetus for this grant, as ADD proposed, was a result of new design models for transferring knowledge and fostering utilization that needed to be explored in order to meet the needs of Americans with disabilities and their families. ADD believed that these models should surpass our standard methods of communicating best practices and should offer practical solutions to those we serve and others who serve them. Projects were to be outcome driven, demonstrating effectiveness and behavioral changes of the targeted population. ADD viewed this Priority Area as an unprecedented opportunity to harness what has been learned through federally-funded projects and seek enterprising, inventive, and imaginative ways of promoting the use of knowledge so that all will benefit: people with developmental disabilities and other disabilities, professionals who serve them, their families, and the communities in which they live, in all segments of our American society.

The University of Southern California (USC), University Center for Excellence in Developmental Disabilities (UCEDD), responded to the RFP and was awarded funding for 3-years (October 2001 – March 2005) under a grant entitled: *Parents, Providers and Policymakers (P3): Partners in Using an Integrated Marketing Communications Approach to Deploy Preventive Health Resources*. The USC UCEDD is one of 64 Centers across the nation that operates to support the independence, productivity, and community integration of individuals with developmental disabilities. While service models and program emphasis may vary substantially among the centers, there is a shared mission to improve the quality of life for individuals with developmental disabilities and their families. Through program and research project activity, valuable educational materials are developed which have enormous potential to positively impact such individuals.

The concept for this PNS emerged from a state and national consensus regarding the lack of established guidelines and methodology for the dissemination of products/materials. This project proposed to address this need for a standardized mechanism that facilitates expanded dissemination of such valuable yet to date underutilized materials. Dissemination of these materials has largely been limited by the reluctance to use, or unfamiliarity with, the discipline of marketing in the non-profit sector. The adoption of the skills and expertise offered by marketing professionals can play a critical role in the endeavor to profoundly broaden dissemination and reach a greater number of individuals who desperately need resources generated by these organizations. Recognizing the effectiveness of professional marketing approaches that have been enhanced by emerging technologies, this project proposed to partner with private sector agencies in the marketing and communication fields to develop marketing models for the rapid deployment of information.

The goal of the project was to *develop and widely disseminate a non-profit organization marketing model to provide agencies serving persons with developmental disabilities with the necessary tools and strategies to integrate marketing throughout the organization and to ultimately enhance the rapid deployment of information to consumers (parents, providers, policymakers).*

The project, directed by Cary Kreutzer, Community Education Director, USC UCEDD, proposed building on the USC UCEDD's years of experience developing /disseminating products and Ms. Kreutzer's active participation with the Association of University Centers on Disabilities (AUCD), National Community Education Directors Council, a group of community education directors representing UCEDDs from across the country, all with similar mandates to develop and disseminate products and to provide training/technical assistance within their state/communities. Discussion over many years has addressed the national need for better strategies to assure wider access to products developed by the UCEDDs. In addition, with new avenues available for dissemination of information the time was critical for exploring, across the network, how the UCEDDs could utilize some of the new communication methods available to expand our reach to a broader community. UCEDD's through their ADD funding receive core support to conduct community education and disseminate information/ products. In addition, UCEDDs receive financial support through other grants/contracts that include the development and dissemination of information and products to the community.

II. NEEDS ASSESSMENT SURVEY

A. PURPOSE

Pursuant to the Administration on Developmental Disabilities (ADD) Grant, a Project of National Significance (PNS) entitled: *Parents, Providers and Policymakers (P3): Partners in Using an Integrated Marketing Communications Approach*, a needs assessment was conducted in the Spring of 2003. Components of the needs assessment included a web-based survey and teleconference focus groups with UCEDD directors, community education directors and dissemination directors/coordinators. The purpose of the needs assessment was to establish baseline data and to evaluate (as suggested by ADD for this specific PNS) whether the UCEDDs are able to rapidly deploy information to parents, providers and policymakers. The secondary purpose of the study was to defining unmet needs and barriers the project could address through training and technical assistance. The needs assessment was designed to answer the following questions:

- Where are UCEDDs regarding the use of integrated marketing communications (IMC) for dissemination of information/ products?
- How do UCEDDs incorporate the principles of marketing into grant RFP language when submitting grant proposals?
- Does the UCEDD have an organization-wide marketing/ dissemination plan?
- What are the barriers and unmet needs of the organization to successfully market/ disseminate products?
- What percentage of time do faculty /staff devote to marketing, communications dissemination and evaluation?
- What are the marketing distribution strategies utilized by the organization for dissemination of products (eg. post to organization Web page, contract with a PR firm to develop a marketing plan, contract with publication house or clearinghouse for distribution)?
- How does the organization evaluate a product's effectiveness and track outcomes of products disseminated and their ability to affect behavior change in the target audience?
- Do the UCEDDs employ trained/experienced staff to carry out marketing, public relations, communications, dissemination, branding, fund development or contract with consultants?
- Do the UCEDDs conduct consumer research prior to and throughout the development of products?
- Who is responsible within the organization for packaging, marketing and distribution of products, is the function centralized or de-centralized?
- How does the UCEDD continue to distribute products once the project funding has ended, who is responsible and how is the person's time funded?
- What are the training and technical assistance needs of the organization and it's faculty/staff?
- What is the perceived organization and AUCD network needs to...?
 - ◆ integrate marketing
 - ◆ improve dissemination
 - ◆ identify outcomes
 - ◆ improve utilization

B. METHODOLOGY

WEB-Based Needs Assessment Survey

The survey was conducted online during February/March 2003. Emails requesting participation were sent out via the AUCD National Community Education Directors' Council listserve (72 members) and included a link routing participants to the online survey. The survey was developed by project staff using web surveying software provided by Websurveyor, the company hosting the survey. The survey included question/answer formats including yes/no, likert scale and open-ended responses. The survey instrument is included in Appendix A and Survey Items by Domain are listed in Table 1.

Table 1. Number of Survey Items by Domain		
	Short Survey Revised Version 35 questions	Long Survey Original Version 64 questions
Domain	Number of Items	Number of Items
UCEDD General Questions	2	7
Grant Writing	3	11
Product Research and Development	6	16
Products	4	8
Marketing/Dissemination	10	19
Post Initial Dissemination - Product/Strategy Modification	5	9
Organizational & Administrative	10	19
Job Function/Demographic Information	17	19
Comments/Suggestions	1	1
Total	58	109

Seven participants experienced difficulty related to operating system/software incompatibility and were either mailed a hard copy or received a Word version via email. The response rate to the long survey following the second reminder was 18.

In February 2003, in the interest of increasing participation, George Jesien, PhD, AUCD Executive Director, suggested that a second request be made using an abbreviated survey (the survey was shortened from 64 to 35 questions, see Appendix B: Short Survey) and disseminated more broadly to include UCEDD Dissemination Coordinators and UCEDD Directors by utilizing the AUCD listserves serving these two groups. The short survey was sent out via these three AUCD listserves on February 6, 2003. Additionally, Dr. Jesien announced the survey in the February 24, 2003 edition of the *AUCD Digest*. Thirty-nine (39) individuals responded to the short survey.

Because we received 18 long surveys (58 questions), prior to editing the survey down to 35 questions, we were able to evaluate which questions were the most informative and retain only those questions in the short survey. We also relied on focus groups to address a number of the questions we removed from the long survey, which were better answered in a focus group environment.

Focus Groups

In an effort to look in greater depth at some of the more prominent issues and themes uncovered in the survey, we asked survey participants to identify if they would be interested in participating in a 1-2 hour teleconference focus group with other UCEDDs across the country. Fifteen (15) survey respondents identified their interest in participating in focus groups. Four separate focus groups were conducted May 5, 6, and 7, 2003 via tele-conference with one to three participants in each of the four focus groups. The average length of the focus group was 1 ½ hours. Eight central questions were discussed, allowing each UCEDD representative to respond to each question, focus group questions are listed in Appendix C. The central questions asked of the focus groups are listed in Table 2.

Table 2. Focus Group Central Questions
What does "effective dissemination" mean to you?
How important is "effective dissemination" to you and your UCEDD?
Does your UCEDD have a dissemination plan?
Do you formulate marketing plans for your individual products?
Who are your customers/end-users?
Who are your distributors?
How satisfied are you in terms of how effectively you and your UCEDD disseminate products and information?
How would you feel about receiving dissemination assistance from the state, regional, and/or national level?

C. RESULTS / DISCUSSION

Response Rate

A total of 57 individuals responded to the survey, with 18 completing the long version and 39 completing the revised/shortened version of the survey. Survey respondents represented 36 states and the District of Columbia. Fifty-three of the respondents identified themselves as Community Education Directors while 4 reported their position in the UCEDD as Dissemination Coordinator. The eight focus group participants included 6 Community Education Directors/Coordinators, 1 Dissemination Coordinator and 1 UCEDD Director. See Table 3 for participant demographic information.

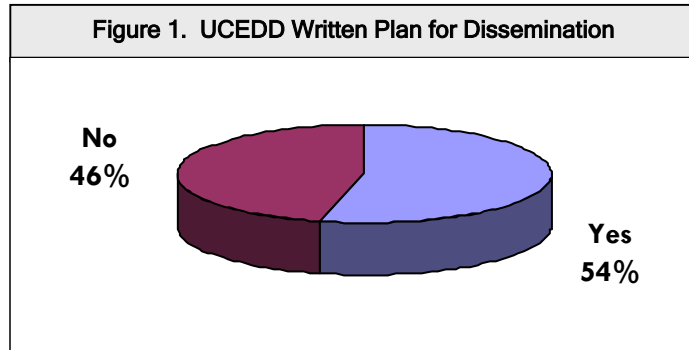
Table 3. Demographic Information		
Online Survey - Long Version: 18 participants	18 UCEDD Community Education Directors	
	18 States	
Online Survey - Short Version: 39 participants	35 UCEDD Community Education Directors 4 UCEDD Dissemination Coordinators	
	37 States & Washington, D. C.	
Focus Groups: 8 participants	6 UCEDD Community Education Directors/ Coordinators 1 UCEDD Director 1 Dissemination Coordinator	
	7 States & Washington D.C.	

Marketing and Communications: Organization-Level

1. Establishing Organization Goals and Objectives for Marketing

A slight majority of respondents (54%), indicated that their respective UCEDDs have a well-developed dissemination plan, however when asked to describe them most could not.

Focus group discussion revealed that many respondents consider their UCEDD's compliance included within the general provisions of their ADD Grant, which includes a brief paragraph on the dissemination of information, to be, in effect, their organization's dissemination plan.



Most respondents admitted to not understanding how their center dissemination plan (e.g., ADD's general provisions) applies specifically to their project-related work. The fact is that very few UCEDDs have formal, widely circulated, internal dissemination plans or processes in place. One center director said: "We don't have a dissemination plan in place. I'd be surprised if anyone does. But we can't say that – it's [dissemination] what we are supposed to be doing." While another focus group participants stated that "We probably have a dissemination plan, I don't know. I think it's part of the values statement."

Some respondents, however, are in the process of creating a more formal and sophisticated dissemination process by standardizing the identification and segmentation of end-users, determining the life cycle stages of their existing product lines, formulating process flow charts, inventorying products, creating evaluation cards to accompany products and moving to a centralized organization structure for oversight of all product dissemination in the UCEDD.

More often UCEDDs reported individual dissemination plans were in place related to a specific product that responded to the grant objectives /required deliverables, carried out by the grant PI, not an individual in the UCEDD changed with marketing and dissemination of products.

2. Level of Organization Priority Given to Marketing/Communications

Participants were asked what level of priority is given to marketing /dissemination of a product vs. completion of funded products. As Figure 2 shows, more emphasis is placed on completing products and less emphasis on marketing/dissemination. Forty-six percent (46%) of survey respondents stated that dissemination is only of moderate importance to them and their organizations, and although 62% indicate a high level of importance given to completing funded products, only 5% rate product dissemination as a high priority. Most focus group respondents reported that they do not feel they do an effective job at disseminating and acknowledge a heavy reliance on websites, clearinghouses, listserves, and brochures as the primary means of dissemination. This heavy focus on product development vs. dissemination is likely due to the

specific grant outcomes the grantee is required to address, with product development/completion of higher importance than how the product is actually disseminated. Some respondents, reported frustration with their own dissemination efforts, and suggested dissemination should be a function of the UCEDD and/or the funding agency, not the product developers.

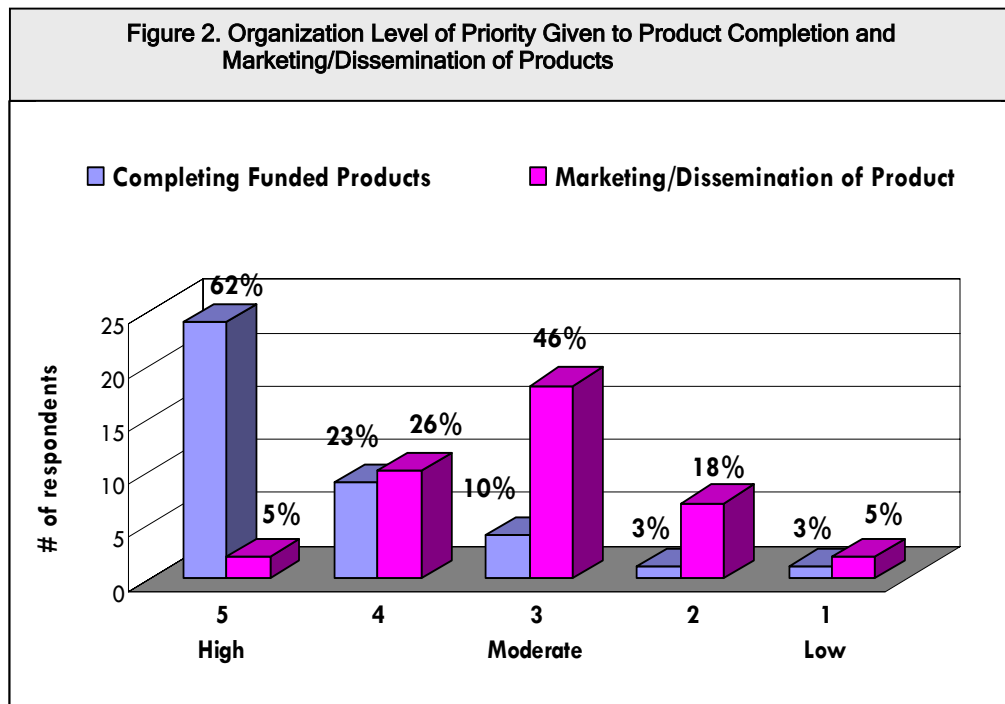
After lengthy discussion among focus group participants on what is meant by “effective dissemination,” a consensus was obtained for the following definition:

Effective

dissemination is the development and distribution of information or content to the people who need it. Focus group participants were also asked how they determine whether or not the marketing/ dissemination of a product has been successful? The following is a list of their responses.

- We don't...at most, [we use] word of mouth.
- I'm not sure we do.
- We send them out and count them. That's how we measure effectiveness.
- Look at phone call influx.
- We keep track of the numbers of copies that have been disseminated and keep a record of where they have gone.
- They'll call us and request something. And then we get it to them.
- Everything's always posted on the web and then we also bring hard copies with us wherever we go.
- We don't do a good job of this. We live up to the grant and that's where it stops. We're just now starting to ask questions about usage.

Additionally, many other barriers, in terms of the priority or focus given to marketing, were uncovered in the survey and focus groups, including a general lack of marketing interest and expertise by UCEDD personnel, fragmented organizational structures that inhibit communication within and across centers or departments, an inability to track dissemination results, and the absence of any incentives or accountability to promote dissemination effectiveness.

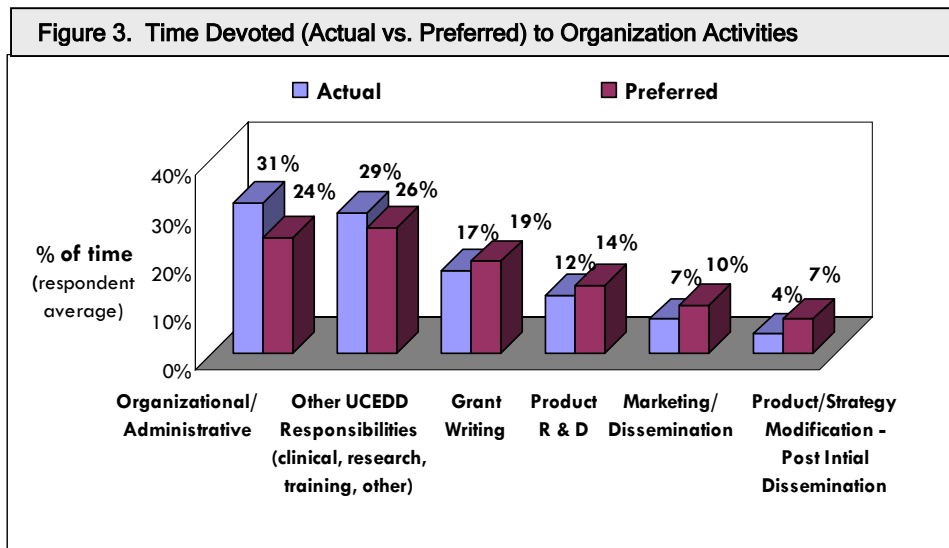


The most important barrier uncovered is the lack of attention by respondents to the ultimate desired outcome – *utilization* of the products by their intended end-users. Very few individuals formulate dissemination plans, set goals, or specify any formal objectives per project or product other than the mandates placed on them by the funding agencies, which rarely specify anything beyond dissemination planning and the identification of process outcomes. These agency objectives are output-related rather than outcome-related, and this is a critical distinction because output alone is not an indication of utilization. Data points to a passive nature of the evaluation that takes place, a weak methodology that determines effectiveness merely by counting the number of units distributed. There is a subtle movement within the network towards a more sophisticated approach, one that incorporates end-user input throughout the product-development process, the formulation of measurable and meaningful objectives, and an evaluation piece that assesses utilization.

3. Organization Staffing and Job Functions of Faculty

Less than 7% of survey respondents reported devoting (actual) time to marketing and dissemination. When asked the amount of time they would like to devote, the data only revealed an increase from 7% to 10% who said they would increase their time, if available, to market/ disseminate product. As Figure 3 shows, organizational administrative and other UCEDD responsibilities take up the majority of time of the survey respondents. And even if they had

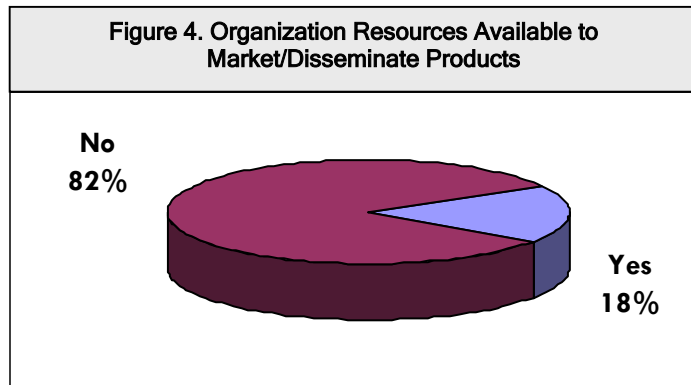
more time to devote to marketing/ dissemination few would spend additional hours in that area. Focus group participants echoed this sentiment stating that other organization/ administration tasks and responsibilities including grant writing, encompass the majority of their work time with little time remaining to focus on product development/ dissemination.



Interestingly, despite the high level of dissatisfaction expressed by respondents about their own dissemination activities, or lack thereof, many would still prefer to do it themselves rather than send it out to a hypothetical external state, regional or national disseminator. Many acknowledged control and trust issues as the reasons. Others embrace the idea of having an external disseminator entity, but would like to retain some form of control locally in their respective markets.

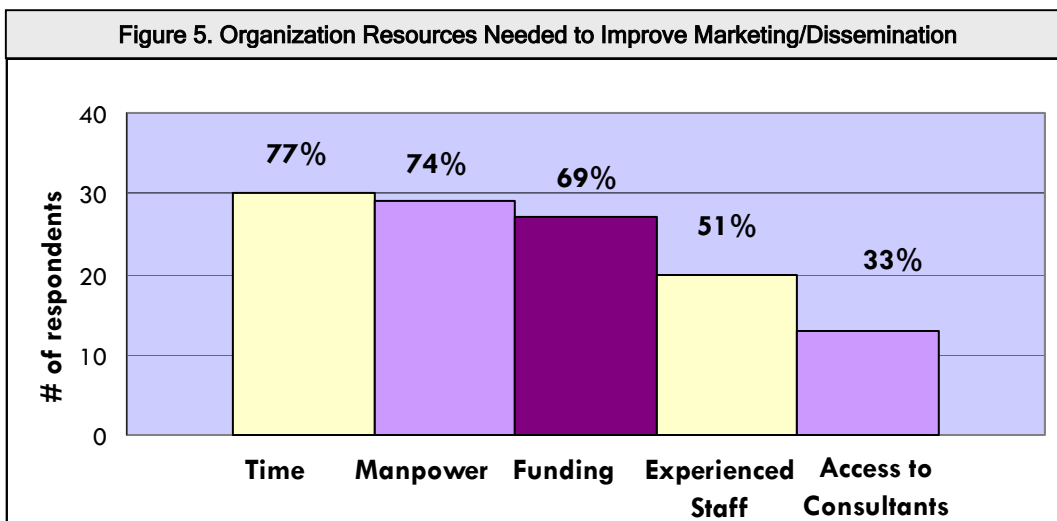
4. Existing Organization Resources for Marketing and Dissemination

Overall, most respondents (82%) feel as if they do not have the necessary resources (e.g. time, manpower, money, experienced staff, access to consultants) to satisfactorily market/disseminate products that are developed. Improving dissemination was a topic that elicited a variety of common responses that adequately characterize the needs of the different UCEDDs.



5. Organization Resources Needed to Improve Marketing and Dissemination

When asked what resources were needed to satisfactorily disseminate products 77% of survey participants (see Figure 5) reported that time was their greatest need. While over half (51%) of the survey respondents would like to have experienced in-house staff.



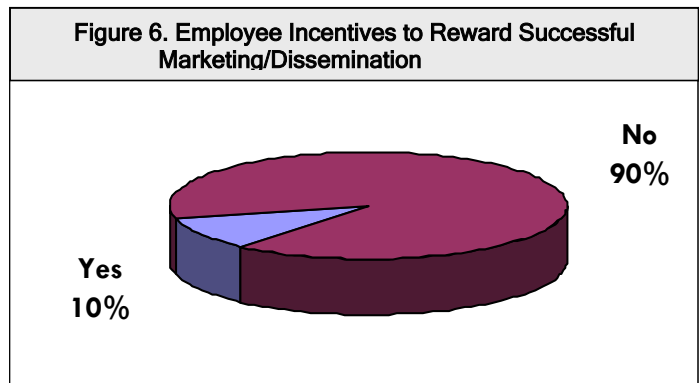
Many respondents reported feeling hampered by a lack of expertise in the marketing area. A high-level of respondent interest exists for access to technical advice within the network to assist them in formulating and implementing dissemination and marketing plans. One focus group participant stated “dissemination needs to be made a priority by ADD (and other funding agencies), only then will AUCD and UCEDDs follow.” Specific activities mentioned where assistance is needed included:

- More Funding
- End-user research and segmentation of the target audience
- Electronic system to track product dissemination and conduct follow-up evaluation to identify outcome and product utilization
- More staff time and support

- Additional personnel available to assist in dissemination
- Knowledge about software that is compatible with print and copy shops
- TA listserv for marketing / dissemination
- Marketing expertise / expert to oversee that component
- Wider dissemination (state, national)
- Methods to create a sustainable dissemination model
- Low cost marketing strategies
- Up-to-date contact information on agencies/programs for mailings
- Marketing discussion boards
- Recommended publishers, video distributors, magazines, etc.
- More formalized networking across the UCEDDs

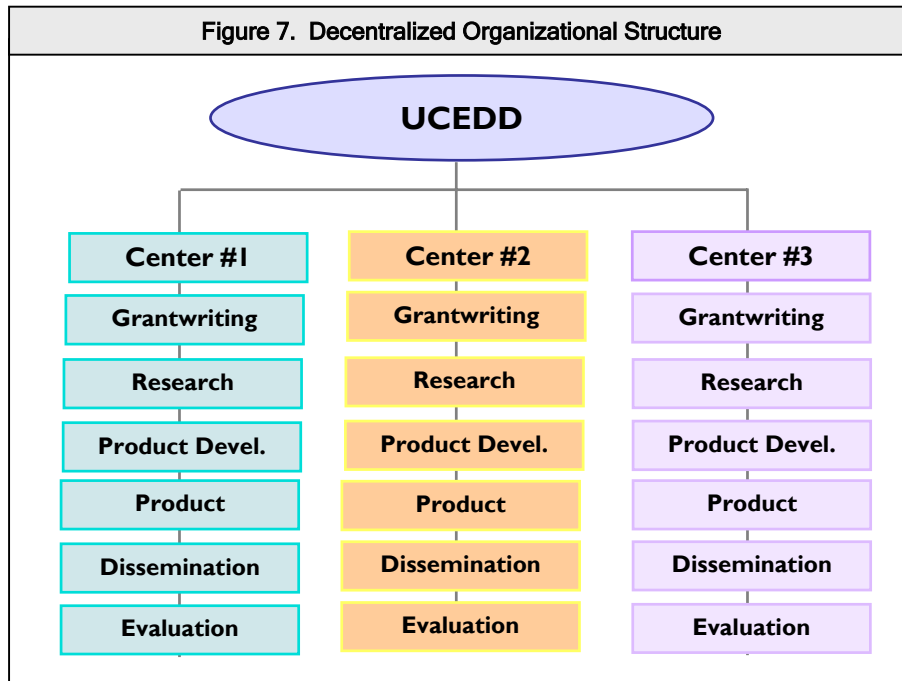
6. Organization Incentives for Successful Marketing and Dissemination

Survey participants were asked if the organization offered incentives to reward them for successful dissemination. Only 10% of the respondents reported (see Figure 6) that incentives were offered. The absence of incentives has a significant impact on the priority given to dissemination of products. The employee is thus left with the goal of the project, to disseminate a finite number of products to meet the grant objective. Incentives within UCEDDs are more often reserved for the successful award of grant proposals, completion of publications, number of individuals receiving clinical services or the number of trainee graduates.

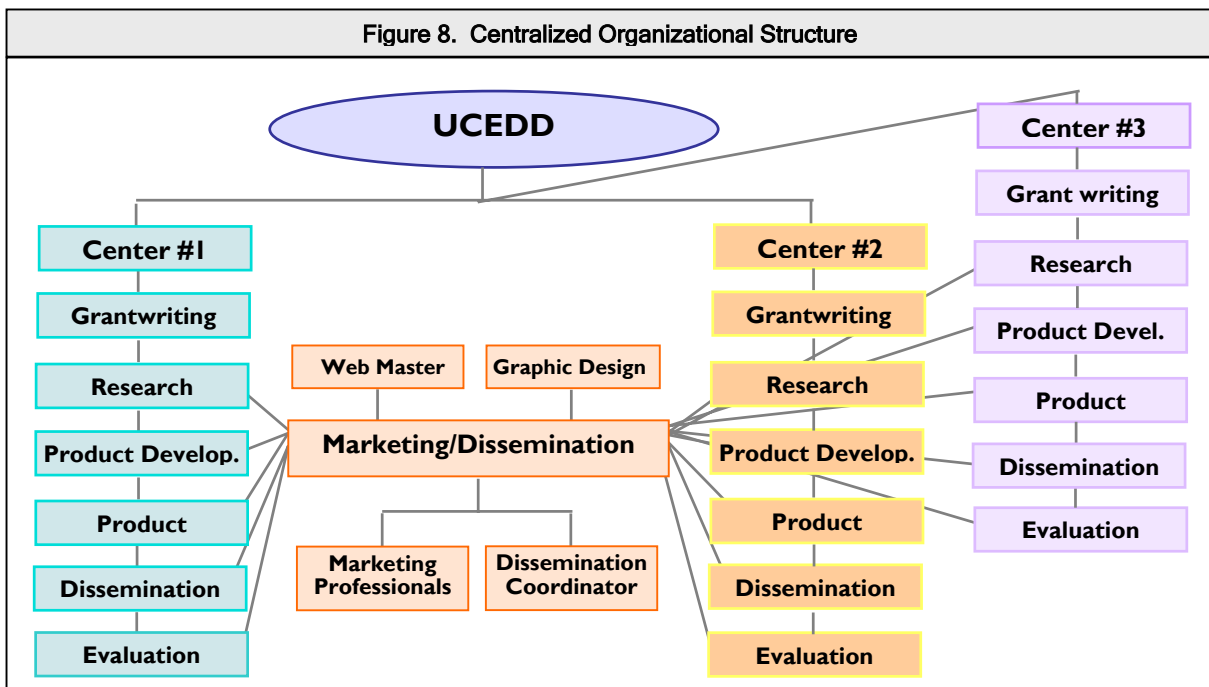


7. Organization Structural Barriers to Effective Dissemination

A variety of organizational issues came to light during the course of the needs assessment research and highlight the difficulties in overcoming internal barriers to dissemination, tracking, utilization and evaluation. Most UCEDDs reported the presence of a decentralized organization structure in reference to product development, dissemination, marketing and communications as depicted below in Figure 7. In this type of organization a variety of concurrent project-related grants are underway at any given time. For the most part principal investigators/project directors, along with their support staff, remain relatively autonomous in conducting their activities and various levels of experience/training to carry out effective marketing dissemination is in the hands of each of the P.I.s and/or their staff. Depending upon the grant and their willingness to seek outside help and TA, they will involve the services of other professionals, such as community education directors, outside experts, graphic designers, etc.

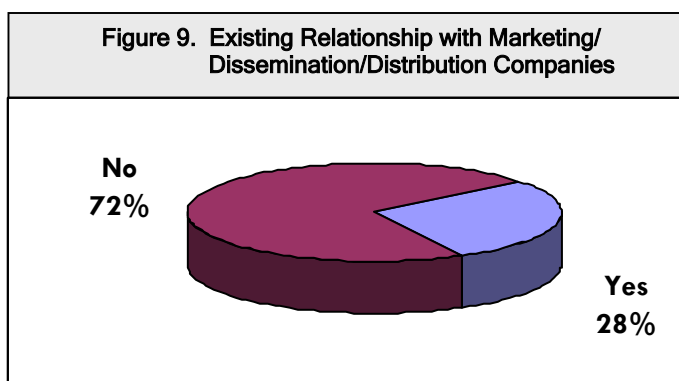


The UCEDDs that are making strides in the area of dissemination and utilization are those that are not only hiring dissemination coordinators and/or marketing professionals within their organizations, but are also placing these individuals in the center of the organizational structure (see Figure 8), so that they are able to influence all of the *products* developed and distributed within the organization. This also provides an opportunity for consistent branding of products in one central location.



8. Leveraging Marketing and Dissemination Resources

The need to seek outside consultation and technical assistance appears to be a complex issue, one that differs depending upon the UCEDD and the specific experiences of each respondent. As Figure 9 shows only 28% of respondents reported that they have relationships with existing marketing, dissemination, distribution companies. These companies are diverse and include the resources available to the UCEDD through their University or



host-organization and in some instances they are non - or for-profit publication houses, public relations firms or clearinghouses who have agreed to sell the UCEDD's network product under contract or other financial arrangement. For those who have not established relationships, knowledge of how to seek out this type of resource is not available through the UCEDD network and many survey respondents asked if AUCD could provide this level of TA to organizations, or even take final products and establish the contractual arrangements with outside sources. While other respondents report that they are not connected in the AUCD Network to be in a position to ask for TA from AUCD or other UCEDDs and suggested that a listserve on communication mechanism be established so that this information could be shared across the network. Focus group participants identified the following barriers and needs:

- Sometimes I'm able to leverage the network, at least to get started.
- I don't feel like I'm part of a network. I don't know who I'd turn to if I needed help.
- Yes, I feel it is a good network. I obtain information primarily through directors, but occasionally others.
- AUCD needs to become a REAL network.
- There's a big difference between directors and non-directors in terms of our access to the AUCD Network.

9. Organization Branding

Some respondents noted a general frustration with the awareness level and understanding of their UCEDD and its activities by the local communities within which they operate. They noted a difficulty in determining how best to depict themselves as an organization due the obvious complexities inherent in their work as well as the wide range of activities undertaken by the facility as a whole. Much of the challenge lies in the need to oversimplify what they do to everyone's satisfaction. A few facilities have taken this challenge on and are now attempting to formulate a look, name, and logo of their respective facilities or "branding". One focus group participant reported "We do a good job of getting products out the door, but we don't do well at disseminating information about who we are and what we do."

Summary: Organizational –Level

These brief comments highlight the various obstacles to successful dissemination including:

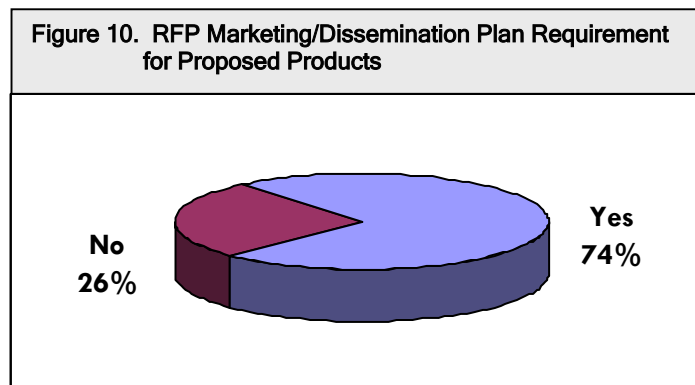
- Rapid facility or center growth
- Decentralization of dissemination within the organization
- The constantly spinning treadmill of attempting to complete grants while pursuing new ones
- A lack of resources

Data show that marketing and dissemination is not a priority in most UCEDDs for a variety of reasons. The function of marketing and product dissemination is more often entrusted to chronic multi-takers rather than specialists with training and experience. This lack of resources seems to inhibit efforts and successes and most organizational structures are not conducive to successful marketing and dissemination. Data also show that the funding agency system does not, in any meaningful way, facilitate, monitor, mandate, promote or reward effective dissemination. Furthermore, by stipulating output-related benchmarks in their grants (versus process outcomes), the system further reinforces behavior and activities that limit effectiveness. Focus group and survey data point to the lack of experience of many UCEDD staff members who are being asked to effectively disseminate products. As well as their shortage of resources and time to effectively disseminate their products. Staff members and their support teams get little encouragement to be effective nor are they held accountable for their efforts. Instead, they do exactly what the grant specifies and rarely more. The end result appears to be the development of products designed with limited end-user involvement that are distributed using mostly passive methods (e.g., posted on website, listserves, etc.). Such products typically reach only a small fraction of their potential audience before project staff must move on to the next funding opportunity, thus effectively ending the dissemination process of existing products.

MARKETING/COMMUNICATIONS: PRODUCT-LEVEL

1. Request for Proposals: Grant Requirements for Establishing Marketing Dissemination Goals and Objectives

Survey participants were asked if the requests for proposals (RFPs) they respond to generally require that a product marketing/dissemination plan be defined in the grant proposal. As Figure 10 shows, (74%) reported yes, while 26% reported no. Upon further discussion in the focus groups participants stated that the RFP requirements were most often limited to the number of products that would be developed and the number that would be distributed and to what audience. Upon further exploration it was apparent that most grant proposals did not employ a consumer-driven, marketing-based approach to the development of products in the proposals submitted. Further, most focus group participants stated that the process of developing a specific plan and methodology for dissemination did not occur in the grant period until completion of the product.



2. Developing Product Marketing and Dissemination Plans

Few respondents indicated that they formulate product-related marketing plan as depicted in Figure 11, that rely on target audience defined needs. Most respondents reported that the

“marketing plan” is simply the number quoted in the grant proposal for products distributed and a list of agencies and program where the products will be distributed. Of the few formal marketing plans that have been developed, they were done so out of a particular principal investigator’s passion for the project. Moreover, since these agency requirements are output-related rather than outcome-related, the UCEDDs have little incentive to determine whether or not they are affecting the change initially intended by the grant; instead they merely count the number of products distributed and inform the funding agency of those numbers. Focus group participants reported that:

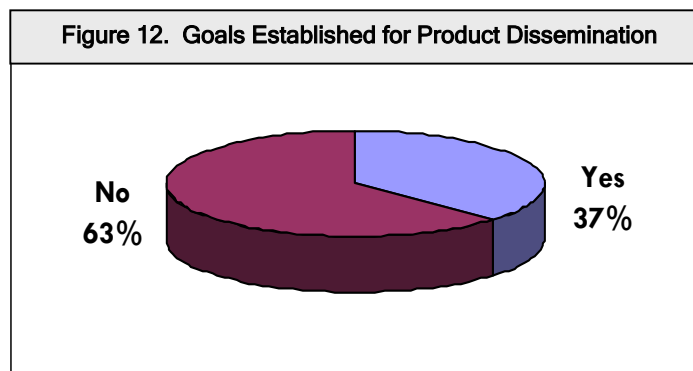


- Most products are based on specific grant outcomes and that grantees know where they intend for the products to go.
- We should develop a better marketing plan. We just don’t.
- Not many people within our network would know what a marketing plan would look like.

There are signs of progress within the network, however. One UCEDD revises its own written dissemination plan regularly as part of its core ADD grant. Every product developed comes with a written document that outlines the goals, specific objectives, and various evaluation tools that will be used to record and measure results.

3. Establishing Product Dissemination Goals

On a micro level, 63% of respondents indicated that they do not establish goal or set measurable objectives when disseminating products (Figure 12). Such a practice, of course, makes the project evaluation component impossible and therefore does not result in any lessons learned that can be carried over to other projects, personnel, or UCEDDs. Without clear objectives, how can success be measured.



Summary: Product-Level

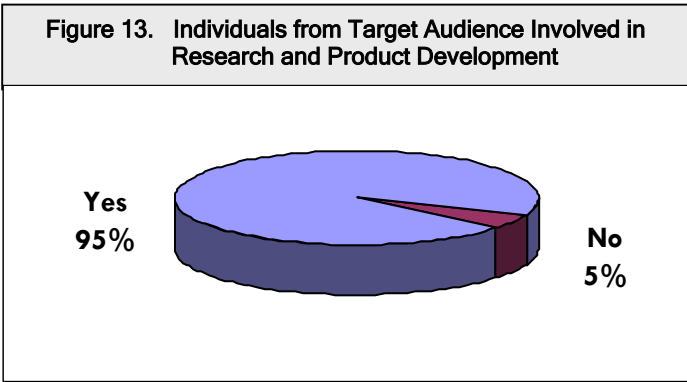
Clearly there is a need for a more sophisticated approach to marketing products, establishing clear objectives and goal setting. The fact that a great divide appears to exist between those UCEDDs that practice more sophisticated marketing practices and those that do not, points to the fact that there is a significant communication gap

within the network of UCEDDs. Limited information sharing takes place. What results is a vast duplication of efforts network-wide. Most survey and focus group participants feel as though they could do a better job with dissemination, but are limited in terms of time, expertise and other resources. The resulting frustration prompts most do only what is required of them -- that is, whatever is stipulated in the grant. For example, if the grant stipulates, at the minimum, 500 pamphlets distributed to providers, 500 pamphlets are distributed. If asked later whether providers took the time to read the pamphlet, let alone incorporate the information into their practice, the researchers will say they have no way of knowing.

MARKETING/COMMUNICATIONS: RESEARCH

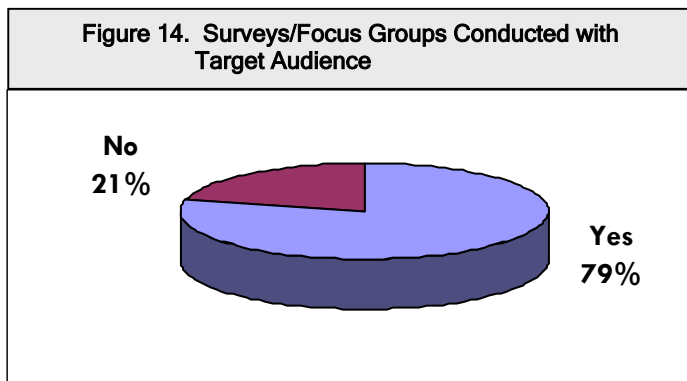
1. Seeking Input from End-Users in Research and Development Stages

Almost across the board 95% respondents indicate that they somehow involve their target end-users during the research and product-development stages (Figure 13). As Figure 14 show 79% of respondents reported that they conduct focus groups with their target end-users to develop their products.



Perhaps due to this high level of end-user involvement in the product-development process, there appears to be a pervasive underlying assumption, voiced in numerous different ways, that researchers feel as if they know exactly what their end-users want or they rely on existing networks or partnerships to inform them of their end-user wants and needs.

Through the focus groups we asked participants to further define how they reach their end-users and who they are. The majority reported that the end-users are represented on their Consumer Advisory Board or Medical Advisory Board and are very familiar with the target audience in the community or state. It is questionable if these advisory groups are truly representative of the target community group. If they are not representative the grantee will develop products that will not reach or be usable by those who truly need the information. Reliance on organization advisory groups to define specific target audience needs is often easier to accomplish and less costly than going out into the community and conducting focus groups with a narrowly defined target audience. The “universal product” that results from



asking an advisory group may not provide a viable product as it is not focused and specific to a defined target audience.

Obviously, different respondents target different end-user groups, such as professionals, individuals with developmental disabilities and their families, state human services, provider agencies, community agencies, etc. In most cases, respondents understand that it is important, and try very hard, to involve end-users in developing products, but in practice such collaborations often prove to be difficult and time consuming. Stipends for participants are becoming more common. At the minimum, many respondents indicated that end-users often review material before it is distributed. Some respondents feel they do a good job of actively involving end-users in the product-development stage and, by doing so, develop more effective products. In most cases, however, the respondents are referring to the specific content they intend to deliver, rather than its format or delivery channel.

The skill involved in developing products for particular segmented audiences is in the willingness and ability to procure intimate knowledge about the end-users' specific preferences (e.g., content, language, reading level, format, delivery channel, etc.). Much of this is derived from knowing the right questions to pose and conducting end-user research prior to determining the end product. Ignoring this research step or biasing it with long-held assumptions, can contribute greatly to the production of ineffective products.

Focus group participant comments related to end-user involvement in product development included:

- When we're in the field, we try to gather information and bring it back to the group. It works more like that rather than some formal process.
- We don't involve end-users as much as we should. There's a stronger reliance on advisory boards.
- Depending upon the project, we try very hard to have end-users – young adults with DD involved – advisory boards, family members and young adults participate on the action research committee.
- We try to target segments [policymakers, self-advocates, service providers, general public].
- We've been doing this a long time. We know what they want.
- We know what our customers want based upon what the proposal says they want.
- We know what they want because we work with them all the time.
- We probably don't do any [end-user research].
- What we write ends up being too complicated for the general public, so we miss large segments of our population. We need to target those other groups and prioritize based on what our partners tell us is important. We don't involve them [partners] as much as we should and we struggle with that.

Summary: Research

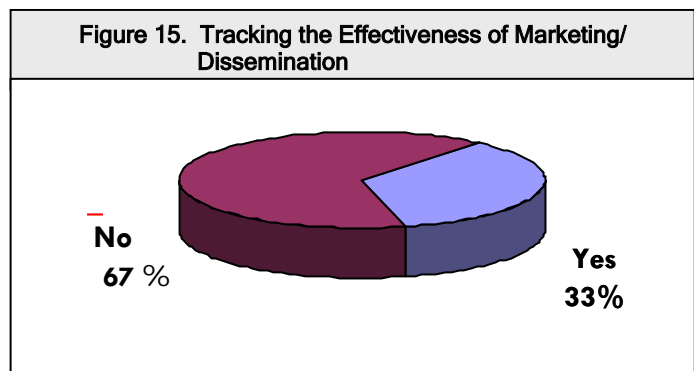
Most survey and focus group participants agreed that much more effort needs to go into defining and working with the clearly-defined targeted end-user group throughout the product development cycle. Many respondents assume they know what end-users want, despite the fact

that the respondents have not researched to any great extent end-user preferences as they relate to specific content, format, and/or delivery channel. Although seventy-nine percent of survey respondents report that products are modified to improve upon them or to expand the target audience, responses from focus group participants suggest that only rarely is a prototype product tested on end-user subjects and the feedback gleaned from them incorporated into product modifications before, during, or after the initial dissemination. In most cases, a grant product is a single version of a product that is disseminated to all end-users, without consideration of their inherent differences (e.g., reading level, preferred delivery mode, language, etc.). Some focus group participants referred to this as *universal design* (one product suited to many different audiences) and most considered this approach to work well. Granted, budgetary constraints or other limitations may preclude the development of multiple products targeting difference audiences; however, this approach relies on process measures (e.g. counting of output such as the # of items distributed as stipulated in the grant, # of brochures, # of “hits” on the website) as the benchmark of success rather than the actual realization of intended outcomes (outcome measures, e.g., increase in the utilization rate and/or intended behavior change) and targeting specific end-users. By developing materials with a “universal design” few may be reached as the information is not targeted to any one group or specific population.

MARKETING/COMMUNICATIONS: EVALUATION AND UTILIZATION

1. Tracking Dissemination of Products

Only 33% of survey respondents reported that they track the effectiveness of their marketing/ distribution of products (Figure15). The limited ability of UCEDDs to track dissemination results is a theme echoed by many throughout the network. Those UCEDDs that have their own servers are able to count *hits* on a website and/or files downloaded by users while many that rely on university servers are unable to access even this most basic information. Many universities pose bureaucratic challenges to UCEDDs, requiring content approvals and placement provisions on files posted to their websites. Most, but not all, UCEDDs keep records of the number of products distributed. Others rely more on word-of-mouth, e-mail, and evaluation cards for feedback. Some are even starting to offer incentives to end-users to complete evaluation cards so as to obtain more prompt feedback.



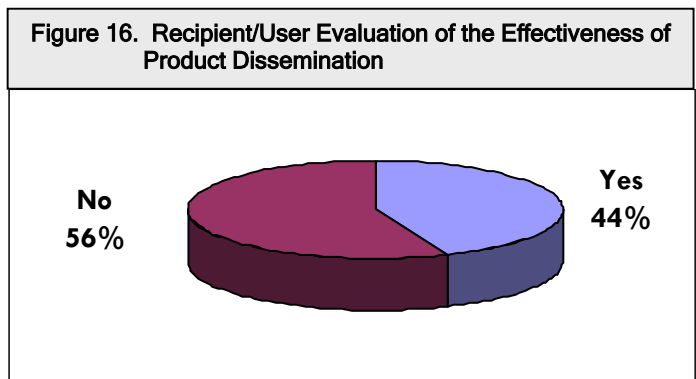
2. Evaluating the Effectiveness of the Product and Dissemination

Regardless of the methodology many respondents point to the difficulty in collecting the data and transferring them into some kind of usable form, citing the lack of systems in place, the considerable time commitment involved, as well as the ongoing need to cajole end-users to respond. In fact, very few respondents indicated that any of the feedback they glean from end-users is captured in any kind of usable form that would make it useful later-on. Interestingly, as

the below graph indicates, less than half of respondents indicated that they enlist end-users to evaluate their UCEDD's effectiveness at disseminating information.

Focus group participants were asked to describe the barriers they encounter when evaluating their effectiveness of products distributed. Their comments included:

- The tech person who used to track product dissemination left, so now no one tracks it now.
- We have no idea if users find us effective.
- There's only so much we can do. Follow up is not really a priority due to lack of time, money and resources, especially when grant funding has ended.
- Very little effectiveness tracking.
- We don't do a good job of tracking it.
- We don't track downloads because the university can't do that.
- Dissemination is an afterthought. It's not that we're not doing it, but we're not recording it. So many things going on at one time it's difficult to communicate, track, record, etc.
- We could benefit from a more systematic approach – we are not recording what we are doing.
- Anything that goes out of here has an evaluation with it sent out. It goes to whomever requested the product. This may or may not be the end-user. We don't have a system that tells us who's using the product.
- We are tied in with the state and so have a tight feedback loop. People aren't shy about saying something.
- We are trying to reach out and measure effectiveness, but we're not doing a good job of it.
- We've recently moved from measuring output to getting real outcomes.
- We do high quality work and it is appreciated. But there's so much more we could be doing.
- We need a more systematic approach – what are we doing, why are we doing it, and what outcomes are they contributing to. We need to focus the commitment with the personnel.



Survey data also pointed to the notion that respondents equate effective tracking with large office staffs, which most of them do not have. Some facilities do conduct summative on-site follow-up evaluations, however these tend to be on projects conducted regularly and over long periods of time (i.e., 10 years or more).

Summary: Evaluation and Utilization

The common purpose of developing and disseminating a product is to instill change of practice in a group or behavior in an individual. If products are developed and fail to result in practice or behavior change the product developer has likely not studied the target audience well enough to deliver information in a shape and form capable of affecting change. As stated earlier, the UCEDDs often fall prey to the development of a one-size-fits-all approach to product

Development. As a result, short timelines and budget constraints, and in hopes of reaching as many as possible, the product is too general and reaches too few. Clearly there is a need across the network to develop and implement a more sophisticated approach to marketing which will ultimately lead to improved targeting of population segments, collection of data defining product effectiveness and documentation of actual utilization. This approach would need to include:

- Clear objectives, goal setting
- More representative end-user involvement
- Measure effectiveness throughout product development and learn from it
- Allow end-users to evaluate your effectiveness
- Ask end-users to clearly define how the product was utilized and why it was effective (e.g. measurement of behavior change).

III. AUCD ANNUAL MEETING FOLLOW-UP SURVEY

A. PURPOSE

At the AUCD Annual Meeting and Conference, November, 2003, the USC UCEDD, under the ADD PNS P3 grant, coordinated the Pre-Conference Training Symposium *Developing a Marketing Mindset: Reaching Diverse Audiences and Improving Outcomes*. The training was designed to raise awareness of the benefits of utilizing the principles of marketing and its inclusion as a new discipline across the AUCD network. The impetus for this training came from a needs assessment survey, administered to the AUCD network in 2003, that uncovered an interest in assistance for incorporating stakeholders more deeply into the UCEDD process of developing and disseminating materials based on research, teaching and community service activities. Training topics included: becoming a consumer-centered organization, measuring effectiveness in terms of consumer utilization of products and services, and increasing accountability to funding sources and federal agencies.

Also conducted by the USC UCEDD at the November 2003 AUCD Annual Meeting and Conference was *Making Health Communication Programs Work*, a concurrent conference session, based on the National Cancer Institute resource of the same name, commonly known as the “Pink Book”. The Pink Book is a guide for the development of health communication program plans. Participants were given step-by-step guidance on the integration of a marketing and communications model in the development of products.

Our interest in conducting a follow-up survey with participants was to assess participant learning outcomes and organizational changes implemented as a result of their participation. We were also interested in additional training needs as well as preferred training delivery formats. Both presentations at the AUCD Annual Meeting were brief and covered a great deal of information. Our intent under the ADD PNS P3 grant was to provide more detailed information and training across the UCEDD network, addressing topics that were most important to the network.

Data on UCEDD training and information needs was the foundation for developing a seven module teleconference training series, *Tune Up your Dissemination Plan: A Marketing Toolbox for UCEDDs*, delivered in the Winter of 2004. The training curricula was then revised based on participant feedback and is available as a self-study module through the USC UCEDD WEB page at: <http://child.uscucedd.org/ProductsResources/EducationalMaterialsCurricula/tabid/573/Default.aspx>

B. METHODOLOGY

The Survey

The survey consisted of thirteen questions, some with multiple parts. Question formats included yes/no, multiple choice and open short-answer. The survey instrument is included in Appendix D.

Data Collection

The data collection for the survey consisted of two steps:

1. Completing the survey. A paper survey was sent to each participant of the Pre-Conference training and the Pink Book session. The outgoing packet contained a self-addressed return

envelope, cover letter and a survey form, the face page of which identified the evaluation as part of the P3 grant, described the motivation for the survey and promised an incentive. Participant mailing and email addresses were available via the AUCD network website. The survey was sent three times: by post, electronically and by post, in three-week intervals. Pre-conference attendees were offered a copy of *Making Health Communication Programs Work*, in print or on CD-ROM, as an incentive for survey completion. Pink Book session attendees were offered another National Cancer Institute resource, *Clear and Simple*.

2. Tallying the data. Once surveys were received, the data fields were checked for missing data and responses to each question were counted.

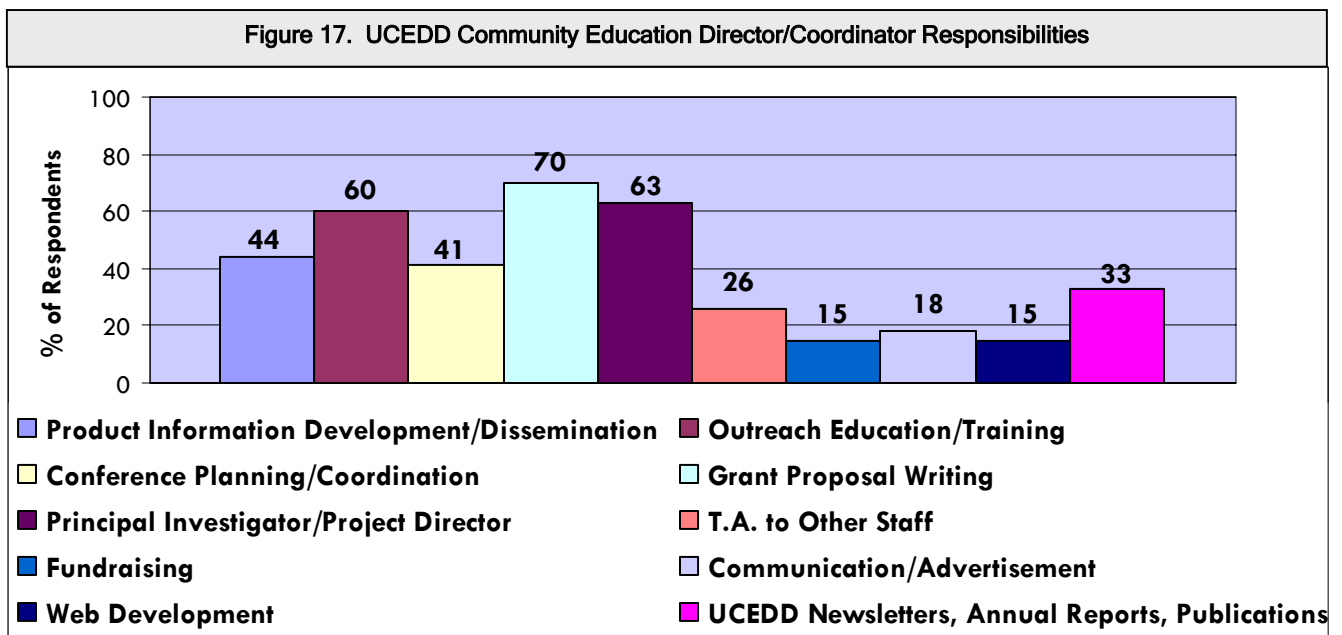
Survey Implementation/Response Rate

The population surveyed consisted of 110 Pre-Conference Training and 22 Pink Book session participants. Titles of participants varied from Director to Coordinator-level. Twenty-seven (27) individuals responded to the mailed surveys (22 who participated in the pre-conference training and 5 who participated in the concurrent session on health communications). A 21% response rate was achieved.

C. RESULTS /DISCUSSION

Participants' Responsibilities Within Their UCEDD

Survey participants were asked to define their role /responsibilities within their UCEDD in relation to community education/ marketing and dissemination. The top job roles /responsibilities included, grant/proposal writing (70%), PI/Project Director (63%), outreach education/training (60%), product information development/dissemination (44%), conference planning/coordination (41%), UCED newsletters, annual reports, publications (33%), conference planning/coordination (41%), UCED newsletters, annual reports, publications (33%). As Figure 15 shows, less than 18% reported job responsibility for communications, advertisement, fundraising or Web development.



Definition of Marketing and Changes in Survey Respondent Mindsets

Participants were asked to define the term marketing before the AUCD Pre-Conference Training and to identify information and recommendations they found most useful through their participation in the training event. Not surprisingly, most participants defined marketing in a negative tone, “selling a product”, “commercialized, glitzy, for-profit”. What participants took away from the training was a different definition or image of what marketing is and can be. Most important, participants walked away defining marketing as a behavior change, a focus on the consumer or target audience, conducting research to identify audience needs and wants before products are developed/ disseminated, a consistent look or branding across products.

The most critical marketing/communication elements identified by participants that they felt would be most useful in their own job included:

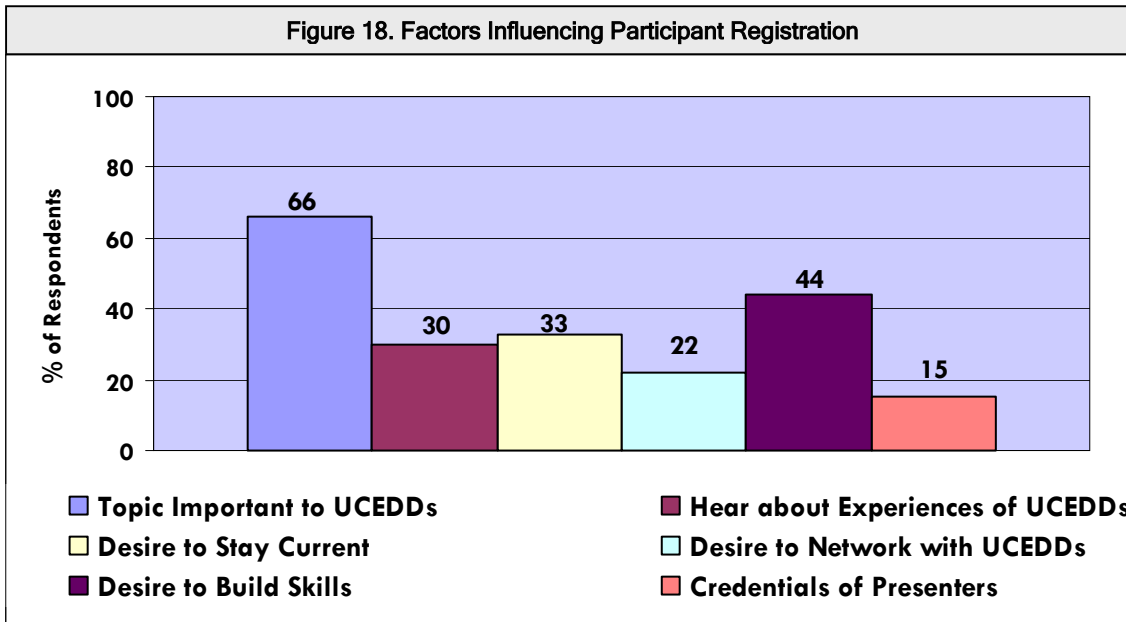
- Involving the target audience before developing a product
- Clearer identification of the target audience
- Using available media resources
- Considering what is important to consumers
- Keeping marketing messages simple
- Use of multiple communications strategies
- Asking the target audience to evaluate the product in development prior to final print, and after dissemination.

We then asked survey respondents to tell us how they have made changes in their UCEDD as a result of their participation in the training. Over half of the survey respondents had one area or more where they had implemented changes in their UCEDD. Changes included:

- Implementation of marketing concept in product development on a project
- Expanded use of marketing strategies
- Establishing links with University public relations
- Reaching out to Publication and Communication Departments
- Development of public service announcements and press releases
- Accessing increased consumer input in project planning and product development
- More focus on target audience needs vs. organization needs
- Incorporation of marketing models in grant proposal development

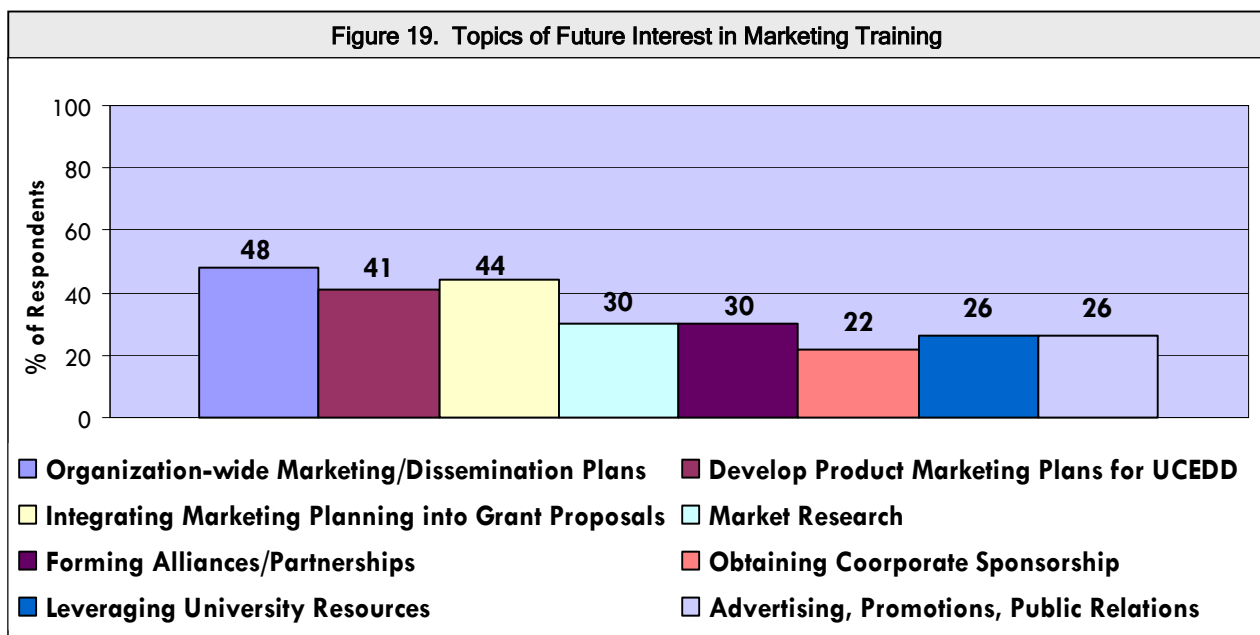
Factors Influencing Participants Decision to Attend Marketing/Communications Training

More than half of the survey respondents stated that the topic’s importance to their individual UCEDD was the primary factor that influenced their decision to register for the pre-conference training or health communication concurrent session. Forty-four percent (44%) attributed their participation to their desire to build their own skills, while 33% reported a desire to stay current and 30% reported an interest in hearing from other UCEDDs about their experience.



Marketing Topic of Interest for Future Training

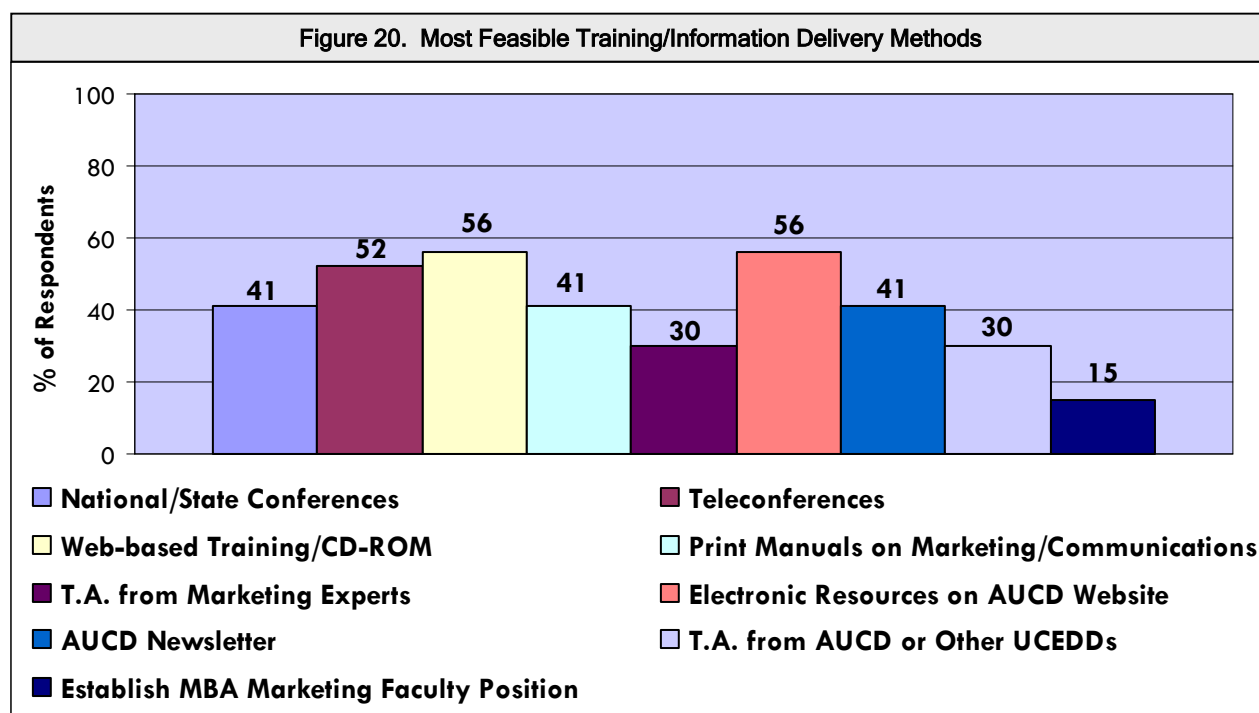
Because the intent of the project was to define best practices for marketing and dissemination for the UCEDDs, we were interested in identifying future training topics we should address based on UCEDD perceived needs for training. Survey respondents were asked to identify training topics related to marketing, communications, dissemination and evaluation/utilization that they would be interested in attending if offered in the future. Participants' interest in marketing topics for future training, as shown in Figure 19, included development of organization-wide



marketing/dissemination plans (48%), integrating marketing planning into grant proposals (44%), developing product marketing plans for the UCEDD (41%), market research (30%), forming alliances/ partnerships (30%), leveraging university resources (26%), advertising, promotions, public relations (26%). Survey participants identified the following marketing topic at less than 20%, working with an outside distributor/publisher, seeking copyrights and patents, branding (style, positioning), distribution channels, contracting with a public relations/marketing agency, pricing and forming an effective board of directors.

Preference for Receiving Training

Given the technological advances in how information/training can be delivered, and in order to deliver training across the network of 64 UCEDDs, it was important to the project that we identify how UCEDDs prefer to receive information/training. Preferred training/information delivery methods, as listed in Figure 20, in order of preference, included: Web-based training (56%), electronic resources on AUCD Website (56%), teleconference (52%), presentation at national/state conferences (41%), print manuals on marketing/communications (41%), AUCD Newsletter (41%), T.A. from marketing experts (30%), T.A. from AUCD or other UCEDDs (30%).



In addition, survey respondents were asked to identify how they currently seek information in order to improve their own professional skills and career development. The top four responses in order of preference included:

1. Seeking internet and online references
2. Reading peer-reviewed journals
3. Consulting with colleagues
4. Attending conferences

The survey asked participants to define how they stay current on information that is important to serving families and individuals with developmental disabilities and understanding their needs. Most often identified was:

- Their communication with families/individuals about their concerns
- Reading materials that are aimed at families individuals with developmental disabilities
- Their own or their agencies' affiliations with community organizations
- Observations during clinical visits

Summary

1. Training participants reported significant changes in how they would define marketing, understanding that the focus of marketing is to identify a specific target audience and develop /deliver a product capable of changing or influencing behavior. In order to change behavior the audience must clearly be identified prior to product development and their needs (research), not the needs and interests of the organization, should drive product development.
2. Products developed by the UCEDD should have a consistent look/feel or “branding” such that the community recognizes the organization and its products.
3. UCEDDs should explore how to access existing University resources available to assist them in marketing/ dissemination of products/projects, including public relations, communications, media and marketing.
4. UCEDDs need to develop an organization-wide marketing/ communication plan to centralize and have a coordinated, consistent marketing/dissemination plan, freeing up Project Directors from spending time overseeing this component of product development.
5. Grant proposals must include methodology and adequate funding (for existing staff or sub-contracts with agencies) to assure successful marketing, dissemination and evaluation of products developed.
6. The survey data were useful to the grantee (USC UCEDD) in planning and conducting a marketing /communications training via teleconference in the Winter of 2004-05 (*Tune Up Your Dissemination Plan: A Marketing Toolbox for University Centers for Excellence in Developmental Disabilities*). The teleconference training format and content delivered were a direct result of the survey data we received. Top training needs identified included:
 - Organization-wide marketing planning
 - Steps for integrating marketing into grant proposals
 - Conducting market research
7. The top 3 preferred modalities for accessing training included:
 - posting of electronic resources on the AUCD Web page
 - Web-based training/CD-ROM
 - Training via tele-conference

IV. SUMMARY AND RECOMMENDATIONS

Although many barriers have been reported by the UCEDDs in assuring utilization of products through improved marketing and communications, the needs assessment survey and follow-up survey of training participants did identify some signs of progress across the network. In the past 5 years we have witnessed through our work on the ADD Project of National Significance a number of UCEDDs who have hired marketing specialists, fund-developers, communications experts, and/or public relations managers, while others are contracting with the same. One UCEDD (Wyoming) developed /implemented a very successful branding initiative as a means of increasing the local profile and awareness of their UCEDD and its activities. The goal of these new positions (or the new discipline of Marketing/Communications) within the UCEDDs, is to enhance and improve practices such as consistent branding and more importantly, establishing a stronger presence in the community, often resulting in additional funding streams becoming available to the UCEDD. Additional signs of progress include:

- UCEDDs are developing strategies, while government/non-government grant funding sources are beginning to ask questions about, product utilization.
- UCEDDs are beginning to evaluate effectiveness, looking beyond counting number of products distributed, instead taking a closer look at outcomes.
- UCEDDs are pursuing branding to improve their image in community/state and their organization's visibility.
- More UCEDDs are beginning to implement a consumer-driven marketing approach to product development vs. an organization-driven approach. When the consumer needs are more important than the organization needs the product has a much better chance of reaching the consumer group targeted.

Even with these small signs of progress survey and focus group participants clearly identified that we have a long way to go to see improvement in how products are disseminated and how we as UCEDDs are viewed by the community, are our ability to integrate the theories and practices of marketing into the UCEDDs. Bringing marketing into the organization as a new discipline, making dissemination as well as measurement of product utilization and behavior change a high priority in the organization, equal to research, training and services, will provide the organization with data needed to compete for new grants and establish a stronger consumer-base of supporters in the community who recognize what the UCEDD is able to offer. A rough-draft position description for a Marketing/Communications Specialist is included in Appendix E.

Organization and systems change also needs to happen beyond the individual UCEDD-level to assure that consumers receive timely and targeted information and resources that results in informed choices and positive changes in behavior. Survey and focus group respondents identified gaps and barrier within their own organization and also informed the project of local, state and national barriers that can be addressed to better reach consumers. Recommendations to address defined barriers are described below under each of the following three sections:

- Organization-level (UCEDD)
- Network-level (AUCD)
- State /Federal-level (ADD, Federal Grants, Contracts)

RECOMMENDED CHANGES BY AGENCY-TYPE OR LEVEL

A. Organization-Level

◆ *Developing a dissemination plan at the organization and product-level*

It is essential that each UCEDD develop a formal, written, and detailed dissemination plan outlining its own philosophical framework for dissemination and utilization and any necessary internal policies that should be adhered to (e.g. centralized vs. decentralized, persons responsible, job qualifications). Once formulated, UCEDDs should draft more specific dissemination plans. According to the National Institute on Disability and Rehabilitation Research *Developing an Effective Dissemination Plan*, and the *Marketing Health Communications Program Work, Product Lifecycle* (see next page, Figure 21) the plan should start at the beginning of each project's research activities and should include:

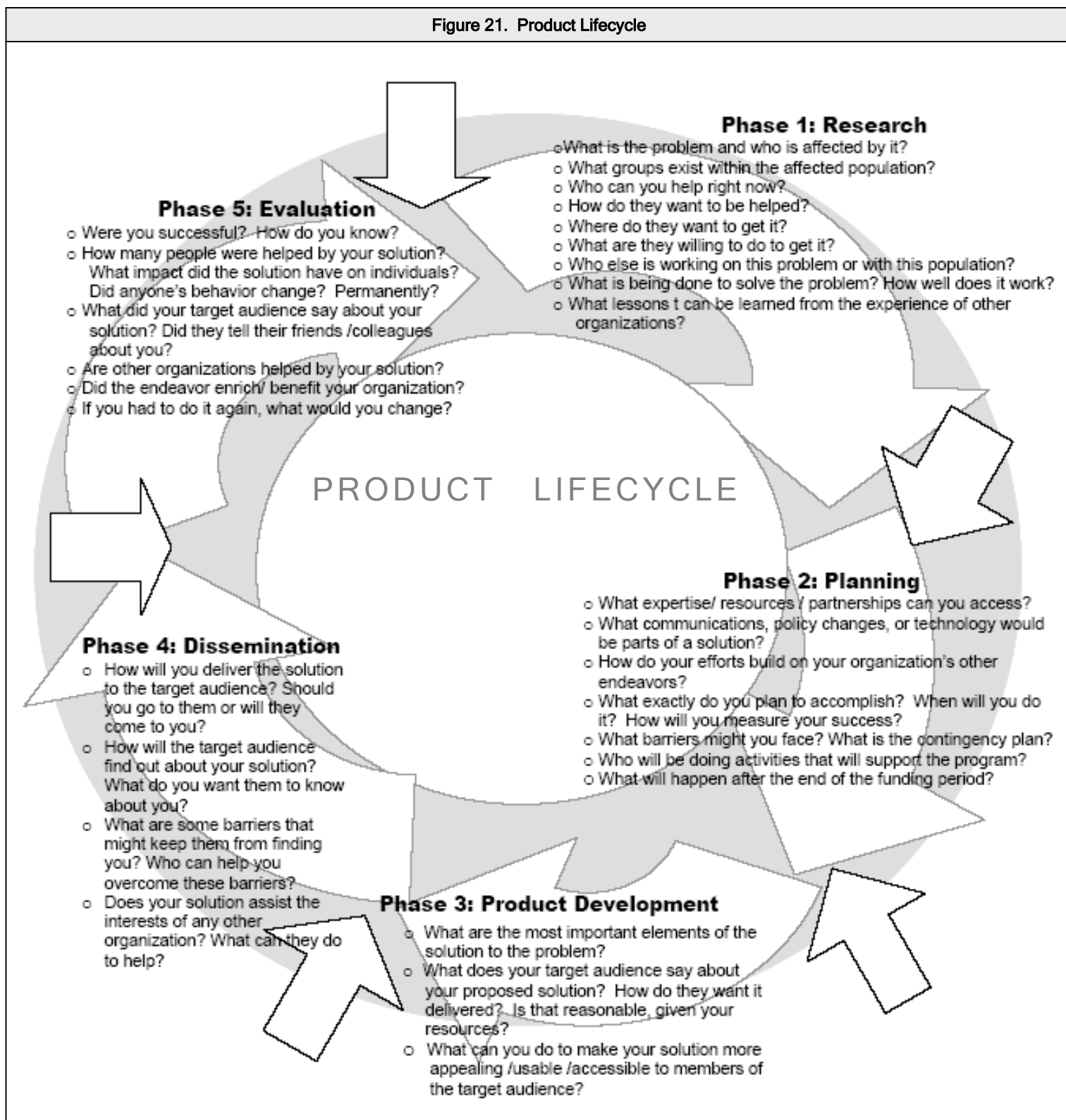
- Goals: Document goals of dissemination effort.
- Objectives: Break down goals into objectives that clarify specific activities to accomplish those goals.
- Define Primary and Secondary Potential Users Groups
- Content: Identify basic elements of projected content to be disseminated.
- Source(s): Identify and partner with primary source(s) that potential user groups perceive to be credible.
- Medium: Describe the media preferred by those user groups through which the message can be delivered.
- Success: Describe how P.I.'s will know if dissemination activities have been successful.
- Access: Describe how to promote access to information and how it will be made accessible.
- Availability: Identify strategies for promoting awareness of the availability of information.
- Barriers: Identify potential barriers that may interfere with targeted users' access or utilization of information and develop actions to reduce the barriers.

By thinking through each of the above components prior to beginning work on a grant, researchers will be in a much better position to develop more robust strategies, isolate their target end-users, focus their efforts and activities, anticipate potential pitfalls, and evaluate their effectiveness.

◆ *Staff Education*

Employing the principles of marketing as well as dissemination and utilization must become a priority across all UCEDDs. To do so requires the buy-in of all members of their respective senior management teams as well as all principle investigators, many of whom may be resistant to it or just not see it as a priority. It is not enough to attempt *capacity building* at the community education or dissemination coordinator-levels because their efforts will be mitigated if management does not support their efforts. This is clearly no easy task and it will not take place in one fell swoop; rather, it will likely begin with a few practicing evangelists who – through their publicized successes as well

Figure 21. Product Lifecycle



as their ongoing interactions with others -- will slowly win converts, achieve best practices and affect policy change.

◆ ***Organizational Structure and Personnel***

Another significant barrier to effective dissemination is a decentralized organizational structure. Implementing a centralized structure and placing the dissemination function at the center, with trained/ experienced marketing specialists will assist greatly in educating staff and increasing the level of effectiveness of any and all products developed and disseminated at each facility. Although the conventional wisdom within the network is to build capacity among existing employees, many respondents indicated a distinct lack of time, money, and interest in practicing marketing (chronic multi-tasking) within their respective UCEDDs. It is therefore recommended that UCEDDs be encouraged to hire marketing personnel to oversee dissemination rather than continuing to rely on capacity building, which stretches already limited resources. Such a re-structuring will allow the educational process to take place gradually and within the day-to-day work environment, rather than requiring staff to attend off-site classes or seminars. A sample job description defining the role of a marketing/communications specialist is included in Appendix E. The discipline of marketing should be thought of as a new and unique discipline rather than an add-on to an existing skill set. Of course, such a concept requires funding, which many UCEDDs may not be have the financial resources to commit. It is for these reasons that needs assessment participants recommended that AUCD create a technical advisory office so that facilities unable or unwilling to make such a commitment will be still be able to obtain technical assistance. Over time, as these facilities become more successful, they may be more willing to commit funding towards hiring a part or full-time marketing expert.

◆ ***Measuring Outcomes***

UCEDDs should establish uniform collection of qualitative and quantitative data to not only track dissemination but to evaluate the outcomes, measure utilization and identify products that can be replicated in other states or communities or disseminated in other languages. They should be encouraged to acquire their own servers so that they can easily post files and feedback systems on their websites without having to fall victim to university bureaucracies.

◆ ***Define Consumer Needs and Target Audiences***

Grants and projects must focus on the audience they are trying to reach, through sound research design, including surveys and focus groups, rather than rely on existing faculty, staff, advisory boards and community partnerships to identify needs. Research needs to be translated for the target audience to enable the information to be put into practice.

◆ ***Leverage Marketing Resources***

UCEDDs must seek out marketing/dissemination resources including their affiliated University or host organization, e.g. Hospital, as well as other organizations with mandates to reach the same audience, to leveraging available resources as a way of cutting costs, sharing expertise, etc.

B. Network Level

◆ *Develop a national brand*

AUCD should actively involve itself in promoting communication about marketing and dissemination throughout the network and work to transform the network of UCEDDs into a national brand known for its excellence in serving individuals with developmental disabilities. A marketing committee could be developed to explore branding concepts and strategies for the network. Such a brand should be flexible and accommodating to the needs of the various UCEDDs within the network. Through an enhancement of its brand, UCEDDs will in turn enhance their own brands.

◆ *Provide technical assistance to UCEDDs*

AUCD could create a monthly column in AUCD Wired Newsletter devoted to showcasing marketing, dissemination, utilization, models, lessons learned, good resources and best practices; and, could establish a dissemination listserve/discussion group exclusive to that function for its members. In addition, a technical advisory office could be created, accessible to the Network which could provide hands-on, practical advice to researchers in all phases of the product lifecycle process. AUCD could also secure a national public relations firm, if it has not done so already, to assist in publicizing its successes and raising awareness among parents, providers, and policymakers.

◆ *Establish a product clearinghouse and commercial contracts for distribution*

AUCD could explore the formation of a collaborative UCEDD marketing division to commercialize and market applicable UCEDD products. Too often products and replicable models are not shared across the network and duplication of products results. AUCD should consider development of a clearinghouse or listing of UCEDD resources to assure their widespread use and replication. Through this division formalized relationships could be developed with appropriate commercial publishers, magazines, video distributors, etc., in the interests of broadening the reach and exposure of UCEDD products.

◆ *Explore/develop corporate relationships*

Many non-profit and for-profit corporations are potentially interested in the intellectual property the UCEDD Network is able to offer. If AUCD were able to establish relationships with these entities as a means of broadening and/or funding dissemination endeavors it would provide a possible solution to the perennial problem of maintaining active dissemination after the expiration of the funding grant. Through the central office AUCD could secure corporate sponsor(s) to support dissemination and utilization efforts either for the entire UCEDD portfolio or on a per product basis.

◆ *Work with Federal-funding agencies to formulate specific/measurable guidelines*

The National Institute on Disability and Rehabilitation Research (NIDRR) through its National Center for the Dissemination of Disability Research (NCDDR) has established specific language and guidelines for the development and dissemination of products developed with NIDRR funding. NIDRR research grantees are required to address their plans for the dissemination and utilization of research information in their grant applications. In *Developing an Effective Dissemination Plan*, NCDDR sets out steps that could be used to develop an effective dissemination plan. NIDRR emphasizes the participation of people with disabilities and family members in the formulation and conduct of research studies. It also stresses that the end point of NIDRR research is its use

to achieve the full participation of individuals with disabilities in all aspects of education, employment, and community life. The NCDDR model could serve as best-practices for how a product is developed and evaluated, e.g. the product lifecycle, as well as the establishment of RFP grant language to assure that product development/ dissemination results in improved utilization. AUCD could work with grant-funding agencies to define best-practices in formulating more specific and measurable product development and dissemination guidelines.

◆ ***Offer rewards or incentives for exemplary product development***

AUCD could establish, along with its existing annual meeting/conference awards, a competition (peer-reviewed) or award, to recognize exemplary products (e.g., curricula or online training modules, information sheets, consumer education materials, educational videos or movies) that are developed and disseminated by UCEDDs. AUCD could thus showcase exemplary products and could encourage novel ways of offering incentives/rewards to UCEDD faculty members for successful product development/dissemination.

◆ ***Develop Network-wide models and electronic systems for evaluation/ outcome measurement***

The UCEDDs in collaboration with federal funding agencies need to develop a uniform methodology and systematic approach to tracking and evaluating dissemination efforts including exploring the National Information and Reporting System (NIRS) ability to track individual product dissemination outcomes. By identifying common yardsticks, effective dissemination across the entire network can be measured and compared in much more meaningful ways.

C. Federal Funding-Level

◆ ***Establish grant language with a focus on outcomes vs. outputs and define expectations for the development of a dissemination plan***

Grant proposal RFP language must be revised to focus on outcomes vs. outputs. Perhaps the most critical step towards improving dissemination and utilization is to mandate outcomes vs. outputs. Currently most grant funding agencies are perpetuating a flawed model, minimizing overall effectiveness, and continually reinforcing poor strategies and execution by requiring only numbers of products distributed as an overall evaluation of the success of the project. That being said, what became clear in the focus groups conducted under this project, is that some researchers are aware of the superficial benchmarks outlined by the federal agencies, but fear that by not adhering to them they will jeopardize their chances of being awarded the grant. The RFP should be designed with specific objectives for obtaining measurable behavioral change (outcomes) amongst targeted end-users.

◆ ***Grant language should specify a minimum percentage of the budget devoted to dissemination***

If grantees do not include ample funding in grant proposals to support marketing/dissemination the chance of the grantee's ability to achieve significant behavior change or document actual utilization of products, will be impacted. The funding-level should be adequate to assure products developed reach the intended audiences.

◆ ***Reward grant applicants that exhibit a track record for effective dissemination/ utilization***

Grant applicants could be awarded extra points in their grant review if they are able to exhibit a track record for effective dissemination and utilization. By not holding grantees accountable in any meaningful way, there is little motivation to raise the quality of their dissemination activities. Funding agencies need to step up their evaluation activities and make it known that those grantees with stronger track records in effective dissemination practices will receive a competitive advantage on future grant applications, thus further reinforcing these practices.

◆ ***Require documentation in progress reports of milestones and deliverables related to the product lifecycle and dissemination planning***

Require that progress reports document milestones (marketing, dissemination) and provide periodic deliverables to allow the agency to monitor grant progress and modify goals and objectives, if necessary. These federal mandates should be designed with the specific objectives of obtaining measurable behavioral change amongst their targeted end-users.

◆ ***The granting agency could create a more “inclusive” and “open-door” environment and be open to change in project objectives and activities***

Funding agencies should also create a more inclusive and “open door” environment, encouraging grant recipients to approach them with new ideas and/or ways of improving upon the grant as written – even after the initial funding period to present new objectives and activities. Often grants are written with a proposal to conduct a thorough needs assessment at the project outset. This assessment provides the grantee with the opportunity to reach out to the target audience and define their needs. If the needs of the audience differ from what was initially proposed in the grant the grantee should feel comfortable changing the focus of the project in terms of proposed product development. Survey and focus group participants reported they felt compelled to deliver on what was promised or mandated, rather than improve upon it. Such perceptions do not lay the foundation for original thinking or innovation. The granting organization should also provide technical assistance to grantees to promote an openness to change and new direction and offer linkages with appropriate resources, or provision of materials to facilitate understanding of effective dissemination. Periodic communications can be shared with grantees to open communications and share national best-practices models.

◆ ***Provide technical assistance, training and promote information sharing***

Granting agencies could expand awareness of project outcomes through the availability of technical assistance and dissemination of information, e.g. website, newsletter. Training on effective marketing, dissemination and evaluation practices is desperately needed. The primary reason products are not reaching consumers and target audiences is a lack of practice principles for effective marketing. On-site consultations could also be offered to facilitate discussion and assist with problem-solving for dissemination and utilization efforts. Training on effective marketing/ dissemination of products and principles and strategies to assure effective utilization could be offered. Grantee organization must employ individuals to provide technical assistance that have the training and skill-level in basic marketing principles and strategies, to be able to meet grantee TA and training needs.

V. REFERENCES

Administration on Developmental Disabilities (2000). *Roadmap to the Future*, available on-line: <http://www.acf.dhhs.gov/programs/add>.

Hsu, E., Kreutzer, C., Schweers, L. (2004). *Tune Up Your Dissemination Plan: A Marketing Toolbox for University Centers for Excellence in Developmental Disabilities*. Teleconference Series and Self Study Course, USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles: USC, UCEDD.

<http://child.uscucedd.org/ProductsResources/EducationalMaterialsCurricula/tabid/573/Default.aspx>

This self-study curriculum provides the user with an introduction to marketing terminology and strategic models within a non-profit setting. Additional resources and readings are cited at the end of each module. Modules include:

- Terminology and Strategy Tools
- Market Research
- Testing
- Dissemination
- Evaluation
- Integrating Marketing into Grant Proposals
- Internal Marketing in Organizations

National Center for the Dissemination of Disability Research (NCDDR), National Institute on Disability and Rehabilitation Research (NIDRR) (2000). *Developing an Effective Dissemination Plan*. Austin, TX: NCDDR, <http://www.ncddr.org>.

National Institutes of Health, National Cancer Institute (1994). *Clear and Simple: Developing Effective Print Materials for Low-Literate Readers*. US Department of Health and Human Services, Public Health Services, <https://cissecure.nci.nih.gov/ncipubs/details.asp?pid=154>. This 61-page guide outlines a process for developing publications for people with limited literacy skills.

National Institutes of Health, National Cancer Institute (2002). *Making Health Communications Programs Work*. Washington, DC: U.S. Department of Health and Human Services. Available in print and CD-ROM. This handbook presents key principles and steps in developing and evaluating health communication programs for the public, patients, and health professionals. It expands upon and replaces two earlier publications titled Pre-testing in Health Communications and Making PSAs Work. Also known as the “Pink Book”.

VI. APPENDICES

Appendix A: Long Survey

Appendix B: Short Survey

Appendix C: Focus Group Questions

Appendix D: AUCD Annual Meeting Pre-conference Training Survey

Appendix E: Sample Marketing Specialist Job Description

APPENDIX A Long Survey



UCE DISSEMINATION/MARKETING SURVEY



Thank you for linking to our survey. The survey is designed to be completed during a single session (the software will not allow you to save your data for completion during a subsequent session). When you click on the "submit survey" button which appears after the last section, all of the data from your survey will be sent to the host server.

Please contact Laura Schweers [323-671-3862 (9am-5pm pacific standard time), laschweers@chla.usc.edu] if you encounter any difficulties or need clarification while you are completing the survey.



University Center for Excellence

childrens hospital

LOS ANGELES

A. GENERAL QUESTIONS ABOUT YOUR UCE

- a. What are the major content areas in which your UCE specializes?
- b. Does your UCE have a well developed written plan for the dissemination of information?
 - yes
 - no
- c. Are individuals from your target audience involved in writing proposals, identifying needs, designing proposals, conducting projects, evaluating projects and/or disseminating results?
 - yes
 - no

if "yes," please explain briefly:
- d. In general, are individuals from your target audience compensated for their participation?
 - yes
 - no
 - not applicable
- e. Funds for compensating individuals from your target audience come from where? **please select all that apply)**
 - core funding
 - project budgets
 - in-kind funding from the individual's organization
 - not applicable
 - other

if you selected other please specify

B. GRANT WRITING

a. When evaluating possible grants to apply for, please rank the following in terms of their level of importance in the overall decision-making process. (1=greatest, 7=least)

- the mission of your organization
- interest in subject matter
- perceived benefits to the target population
- commercialization potential of the product
- esteem or publicity the project/product will bring to the UCE
- opportunity to leverage existing UCE resources
- potential to leverage old/new opportunities for dissemination

b. In general, do the RFPs you receive require you to include descriptions of the marketing/dissemination plan you will use once the product is completed?

- yes
- no

c. Does your UCE include a line item in its grant proposals to cover the costs of the following for marketing/disseminating the product once it has been completed? (please select all that apply)

- copies
- printing
- clerical
- postage
- graphic design
- marketing specialist/director
- consulting services
- not applicable
- other

If you selected other please specify:

d. If marketing funding is not requested within the grant proposal, how does your UCE fund product marketing/dissemination? (please explain briefly)

C. PRODUCT RESEARCH & DEVELOPMENT

a. Do your project advisory councils provide input on products being developed?

- yes
- no

b. In general, are individuals from your target audience involved during the research/product development stages?

- yes
- no

If "yes," how?

If "no," what are the barriers?

c. What incentives, if any, do you provide to assure target audience participation?
(e.g., transportation, child care, secretarial services, etc.)

d. In general, do you conduct surveys or focus groups with your target audience to help shape products or formats?

yes

no

If "no," what are the barriers?

e. Are the needs and expectations of the appropriate distribution channels (e.g., websites, parent to parent organizations, health fairs, etc.) taken into account at this stage?

yes

no

If "yes," how?

f. Do you enlist the services of a graphic designer (e.g., print, website) to assist in the presentation of your products during product development?

yes

no

If "no," what are the barriers?

If "yes," where does financial support for graphic design come from?
(please select all that apply)

core funding
project budgets
other

if you selected other please specify:

g. Do you conduct any product testing\review with members from your target audience to determine which product attribute(s) is/are most effective?

yes

no

If "yes," how?

If "no," what are the barriers?

D. PRODUCTS

a. Please select the most common types of products that your UCE develops.

- print
- multimedia
- online
- training/workshops
- other

if you selected other please specify:

b. Of the content areas in which your UCE specializes, please specify those areas which generate the most products.

c. Do you advertise any of your products?

yes

no

If "yes," where?

d. We will be conducting small focus groups over the telephone to discuss *in greater detail* - specific product types, dissemination strategies, distribution channels, successes, failures, overall levels of satisfaction, etc. If you would be willing to participate, please provide the following information:

name ~~~~~

telephone number~~~~

email address ~~~~~

E. MARKETING/DISSEMINATING

a. What positions within your UCE have primary responsibility for dissemination activities?

b. Does your UCE generate income through its dissemination efforts?

yes

no

c. How does your UCE monitor and evaluate its dissemination activities?
(please explain briefly)

d. Does your UCE utilize the dissemination activities of other organizations within its network?

yes

no

If "yes," what organizations within your network [e.g., your university affiliation, the national UCE network, other professional affiliation, parent organization (if other than university)]?

If "yes," what activities (e.g., newsletter, listserv, website)?

e. Does your UCE query individuals with developmental disabilities and their families to develop and evaluate products?

yes

no

f. Do you formulate a marketing/dissemination plan for each product?

yes

no

If "yes," what resources (e.g., consultants, UCE policies/guides, textbooks, etc.) do you utilize, if any?

g. Do you set goals (e.g., # of brochures distributed, # of hits on the website, # of CD ROMs purchased, etc.) for each product you disseminate?

yes

no

h. What method of dissemination is most commonly used by your UCE?

UCE website
university website
mailings
multimedia
training/workshops
other

if you selected other please specify:

i. Do recipients and users of disseminated products evaluate your UCE's effectiveness in information dissemination?

yes

no

j. Has your UCE ever received a National Institute on Disability and Rehabilitation Research (NIDRR) grant?

yes

no

If "yes," are you familiar with NIDRR's dissemination requirement?

yes

no

If "yes," please comment on your experiences related to this requirement.

k. Do you or your organization have relationships with any well-established marketing/dissemination/distribution entities that assist in disseminating products developed by your UCE?

yes

no

If "yes," please specify entity name(s) and explain the relationship(s):

entity:

relationship:

l. Have you pursued corporate sponsorships for any of your products or for your UCE as a whole?

yes

no

If "yes," were you successful in securing corporate sponsorship?

yes

no

If "yes," please indicate the name of the corporation and describe the arrangement:

corporation:

arrangement:

F. AFTER INITIAL DISSEMINATION - PRODUCT/STRATEGY MODIFICATION

a. What methods do you use to track the effectiveness of your marketing/dissemination strategy? (please explain briefly)

b. What positions in your organization determine whether or not a product and/or marketing strategy needs to be modified?

c. Does your organization modify your product and/or marketing strategy to improve upon them or to reach another target audience?

yes

no

If "yes," please describe:

If "no," what are the barriers?

d. How do you determine whether or not the marketing/dissemination of a product has been successful?

e. Are product modifications designed to appeal to different ethnic groups taken into account at this stage?

yes

no

f. Does your UCE have established annual dissemination objectives?

yes

no

If "yes," in the last year were you able to meet those objectives?

yes

no

G. ORGANIZATIONAL & ADMINISTRATIVE

a. Does your organization provide the necessary technical assistance and support to assist you in your job?

yes

no

b. Does your organization possess or allow you access to the necessary support/consultative services to assist you in your job?

(please select all that apply)

corporate sponsor

marketing department

marketing consultant

public relations firm/executive

graphic designer

web designer

other

if you selected other please specify:

c. Is someone clearly assigned to promote consumer responsiveness within the UCE and its various projects?

yes

no

d. Does the person assigned have power and influence similar to those who administer core functions?

yes

no

e. How important is it to you that the product is marketed effectively?

(1=lowest, 5=highest)

1

2

3

4

5

f. What incentives, if any, are offered to employees of your UCE for successful marketing/dissemination of its products?

g. The individual in what position, if any, is held accountable if the product is not marketed effectively?

h. The individual in what position, if any, upholds this accountability?

i. How severe is the beating that results from ineffective marketing?

mild

moderate, but not too alarming

cruel and unusual

would rather not discuss

other

if you selected other please specify:

j. In terms of your overall organization, what level of priority is given to completing funded projects? (1=lowest, 5=highest)

1

2

3

4

5

k. In terms of your overall organization, what level of priority is given to completing funded products? (1=lowest, 5=highest)

1

2

3

4

5

l. In terms of your overall organization, what level of priority is given to maintaining input from members of the target audience throughout the process? (1=lowest, 5=highest)

1

2

3

4

5

m. In terms of your overall organization, what level of priority is given to the marketing/dissemination aspect of a product?(1=lowest, 5=highest)

1

2

3

4

5

n. In terms of your overall organization, what level of priority is given to modifying the product and/or marketing strategy after the initial dissemination of the product?(1=lowest, 5=highest)

1

2

3

4

5

o. In general, do you feel you have the necessary resources (e.g., time, manpower, money, experienced staff, access to consultants, etc.) to satisfactorily market/disseminate your product?

yes

no

p. If not, which do you need more of? (please select all that apply)

time

manpower

funding

experienced staff

access to consultants

other

if you selected other please specify:

q. What is the biggest hurdle you face in terms of marketing/disseminating UCE products?

r. What has been the greatest help?

s. What resources, if any, would best assist you in your efforts to better market/disseminate UCE products?

G. ORGANIZATIONAL & ADMINISTRATIVE

a. Does your organization provide the necessary technical assistance and support to assist you in your job?

yes

no

b. Does your organization possess or allow you access to the necessary support/consultative services to assist you in your job?

(please select all that apply)

corporate sponsor

marketing department

marketing consultant

public relations firm/executive

graphic designer

web designer

other

if you selected other please specify:

c. Is someone clearly assigned to promote consumer responsiveness within the UCE and its various projects?

yes

no

d. Does the person assigned have power and influence similar to those who administer core functions?

yes

no

e. How important is it to you that the product is marketed effectively?

(1=lowest, 5=highest)

1

2

3

4

5

f. What incentives, if any, are offered to employees of your UCE for successful marketing/dissemination of its products?

g. The individual in what position, if any, is held accountable if the product is not marketed effectively?

h. The individual in what position, if any, upholds this accountability?

i. How severe is the beating that results from ineffective marketing?

- mild
- moderate, but not too alarming
- cruel and unusual
- would rather not discuss
- other

if you selected other please specify:

j. In terms of your overall organization, what level of priority is given to completing funded projects? (1=lowest, 5=highest)

- 1
- 2
- 3
- 4
- 5

k. In terms of your overall organization, what level of priority is given to completing funded products? (1=lowest, 5=highest)

- 1
- 2
- 3
- 4
- 5

l. In terms of your overall organization, what level of priority is given to maintaining input from members of the target audience throughout the process? (1=lowest, 5=highest)

- 1
- 2
- 3
- 4
- 5

m. In terms of your overall organization, what level of priority is given to the marketing/dissemination aspect of a product?(1=lowest, 5=highest)

- 1
- 2
- 3
- 4
- 5

n. In terms of your overall organization, what level of priority is given to modifying the product and/or marketing strategy after the initial dissemination of the product?(1=lowest, 5=highest)

1

2

3

4

5

o. In general, do you feel you have the necessary resources (e.g., time, manpower, money, experienced staff, access to consultants, etc.) to satisfactorily market/disseminate your product?

yes

no

p. If not, which do you need more of? (please select all that apply)

time

manpower

funding

experienced staff

access to consultants

other

if you selected other please specify:

q. What is the biggest hurdle you face in terms of marketing/disseminating UCE products?

r. What has been the greatest help?

s. What resources, if any, would best assist you in your efforts to better market/disseminate UCE products?

APPENDIX B

Short Survey



UCE DISSEMINATION/MARKETING SURVEY



University Center for Excellence

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LOS ANGELES

In what capacity are you representing your UCEDD?

- As a member of the AUCD Community Education Director Listserv
- As a designated Dissemination Coordinator
- Both

Thank you for linking to our survey. The survey is designed to be completed during a single session (the software will not allow you to save your data for completion during a subsequent session). When you click on the "submit survey" button which appears after the last section, all of the data from your survey will be sent to the host server.

Please contact Laura Schweers [323-671-3862 (9am-5pm pacific standard time), laschweers@chla.usc.edu] if you encounter any difficulties or need clarification while you are completing the survey.

A. GENERAL QUESTIONS ABOUT YOUR UCEDD

- a. What are the major content areas in which your UCE specializes?

- b. Does your UCE have a well developed written plan for the dissemination of information? [yes or no]

B. GRANT WRITING

- a. In general, do the RFPs you receive require you to include descriptions of the marketing/dissemination plan you will use once the product is completed? [yes or no]

- b. Does your UCE include a line item in its grant proposals to cover the costs of the following for marketing/disseminating the product once it has been completed? (please select all that apply)
 - copies
 - printing
 - clerical
 - postage
 - graphic design

- marketing specialist/director
- consulting services
- not applicable
- other

if you selected other please specify:

C. PRODUCT RESEARCH & DEVELOPMENT

a. In general, are individuals from your target audience involved during the research/product development stages? [yes or no]

If "no," what are the barriers?

b. In general, do you conduct surveys or focus groups with your target audience to help shape products or formats? [yes or no]

If "no," what are the barriers?

c. Are the needs and expectations of the appropriate distribution channels (e.g., websites, parent to parent organizations, health fairs, etc.) taken into account at this stage? [yes or no]

If "yes," how?

D. PRODUCTS

a. Of the content areas in which your UCE specializes, please specify those areas which generate the most products.

b. We will be conducting small focus groups over the telephone to discuss – *in greater detail* - specific product types, dissemination strategies, distribution channels, successes, failures, overall levels of satisfaction, etc. If you would be willing to participate, please provide the following information:

name ~~~~~

telephone number~~~~

email address ~~~~~

E. MARKETING/DISSEMINATING

a. What positions within your UCE have primary responsibility for dissemination activities?

b. Do you formulate a marketing/dissemination plan for each product? [yes or no]

If "yes," what resources (e.g., consultants, UCE policies/guides, textbooks, etc.) do you utilize, if any?

c. Do you set goals (e.g., # of brochures distributed, # of hits on the website, # of CD ROMs purchased, etc.) for each product you disseminate?
[yes or no]

d. Do recipients and users of disseminated products evaluate your UCE's effectiveness in information dissemination?
[yes or no]

e. Do you or your organization have relationships with any well-established marketing/dissemination/distribution entities that assist in disseminating products developed by your UCE? [yes or no]

If "yes," please specify entity name(s):

f. Have you pursued corporate sponsorships for any of your products or for your UCE as a whole? [yes or no]

If "yes," were you successful in securing corporate sponsorship? [yes or no]

If "yes," please indicate the name of the corporation:

F. AFTER INITIAL DISSEMINATION - PRODUCT/STRATEGY MODIFICATION

a. Do you track the effectiveness of your marketing/dissemination strategy? [yes or no]

b. Does your organization modify your product and/or marketing strategy to improve upon them or to reach another target audience? [yes or no]

If "no," what are the barriers?

c. How do you determine whether or not the marketing/dissemination of a product has been successful?

d. Are product modifications designed to appeal to different ethnic groups taken into account at this stage? [yes or no]

G. ORGANIZATIONAL & ADMINISTRATIVE

a. Does your organization offer incentives to employees for successful marketing/dissemination of its products? [yes or no]

b. The individual in what position, if any, is held accountable if the product is not marketed effectively?

c. In terms of your overall organization, what level of priority is given to completing funded products? (1=lowest, 5=highest)

1 2 3 4 5

d. In terms of your overall organization, what level of priority is given to the marketing/dissemination aspect of a product? (1=lowest, 5=highest)

1 2 3 4 5

e. In general, do you feel you have the necessary resources (e.g., time, manpower, money, experienced staff, access to consultants, etc.) to satisfactorily market/disseminate your product? [yes or no]

f. If not, which do you need more of? (please select all that apply)

- time
- manpower
- funding
- experienced staff
- access to consultants
- other

if you selected other please specify:

g. What is the biggest hurdle you face in terms of marketing/disseminating UCE products?

h. What has been the greatest help?

i. What resources, if any, would best assist you in your efforts to better market/disseminate UCE products?

H. JOB FUNCTION/DEMOGRAPHIC INFORMATION

a. Please indicate your area of specialty or discipline:

b. Please indicate the university your UCE is affiliated with:

c. What is your position title?

d. Does your position place great emphasis on dissemination, specifically? [yes or no]

If "no," please describe the barriers:

e. Please indicate what percentage of your time is devoted to the following activities: (by percentage breakdown - sum to equal 100)

- % - Grant Writing
- % - Product Research & Development
- % - Marketing/Dissemination
- % - Product/Strategy Modification - Post Initial Product Dissemination
- % - Organizational/Administrative
- % - Other UCE Responsibilities (clinical services, research, training, other)

f. Please indicate your preference as to how your time should be devoted to the following activities: (by percentage breakdown - sum to equal 100)

- % - Grant Writing
 - % - Product Research & Development
 - % - Marketing/Dissemination
 - % - Product/Strategy Modification - Post Initial Product Dissemination
 - % - Organizational/Administrative
 - % - Other UCE Responsibilities (clinical services, research, training, other)
-

I. COMMENTS/SUGGESTIONS

Please use the box below for comments, suggestions, or to address marketing/dissemination concerns which were not represented in the survey. Also, please be on the lookout for the results of this survey which will be posted to the NCEDC listserv!

End of survey. We are grateful for your participation. Thank you!!!

APPENDIX C

Focus Group Questions

1. Just so we're all clear with the terminology, let's talk about *effective dissemination*.
 - a. What does that term mean to you?
 - b. If possible, please provide some examples of *effective dissemination*, perhaps from your own experience.

2. How important is *effective dissemination* to you and your UCE? How is this level of priority made clear throughout your organization?
 - a. Is your organization designed with a marketing/dissemination function in mind?
 - i. Tell us how products are disseminated/ marketed internally.

3. Does your UCE have a dissemination plan?
 - a. If yes, please tell us about it. (Note: Get them talking freely before asking the below follow up questions.)
 - i. How does it define *effective dissemination*?
 - ii. What are its objectives?
 - iii. Does it set measurable goals? Please provide some examples.
 - iv. How does it measure effectiveness?
 - v. Who oversees the execution, dissemination, and evaluation of the plan?
 - vi. Is this plan adhered to across the organization?
 - b. If your UCE does not have a dissemination plan, why not?
 - i. Do you think it needs one?
 - ii. What should such a plan include?

4. Do you formulate marketing plans for your individual products?
 - a. If yes, tell us about those plans. (Again, get them talking freely before asking the below follow up questions.)
 - i. What are the objectives? Please provide some examples
 - ii. Do they set measurable goals? Please provide some examples.
 - iii. How do they measure effectiveness/success?
 - iv. Who oversees the execution, dissemination, and evaluation of the plan?
 - b. If not, why not?

5. Who are your customers/end users?
 - a. How do you know what they want?
 - i. How do you involve end users in the product development process? Please provide some examples.
 - ii. How do you incorporate the concerns of special needs groups that are separated from the mainstream by language, ethnicity, culture, etc.?
 - b. What about customer satisfaction? Do your customers/end users evaluate your UCE's effectiveness in information dissemination?
 - i. If so, how?
 - ii. If not, why not?

6. Who are your distributors?
 - a. What channels do you use to distribute your products?
 - b. How do you know their needs/requirements?
 - c. How do you modify your products to satisfy those needs?

7. How satisfied are you in terms of how effectively you and your UCE disseminate products and information?
 - a. Do you think this is a function UCEDDs should provide?
 - b. Tell us about some of the successes.
 - c. Tell us about some of the failures/frustrations.
 - d. Tell us about some of the challenges that you face.
 - e. What would most assist you in doing your job?

How would you feel about receiving dissemination assistance from the state, regional, and/or national level?

APPENDIX D
AUCD ANNUAL MEETING 2003
PRE-CONFERENCE TRAINING SURVEY

What do you want? How do you want it?

Why should you complete this survey?

- (1.) Under the P3 grant we plan to offer resource materials and training to UCEDDs, integrating marketing as a discipline, addressing marketing, communication and dissemination of products. Here's your chance to customize this training for UCEDDs. Completing the following two-page survey will help us to get a sense of the best format, delivery method and content to meet your training needs.
- (2.) You will inform AUCD on the outcomes of the Pre Conference Training Symposium.
- (3.) Estimated completion time: **10** minutes or less – most of the questions are check-off or Likert scale format.

Immediate gratification – a free gift for completing the survey...

As a token of our appreciation for your input, we are offering a free copy of *Making Health Communication Programs Work*, a National Cancer Institute publication, a practical guide through all stages of planning and executing a consumer-responsive integrated marketing plan with special consideration for the needs of non-profit, health-related organizations.

If you would like to receive the NCI "Pink Book", Making Health Communication Programs Work, please complete the attached survey and print your name and mailing address below.

Which format do you prefer? _____ Print manual **OR** _____ CD-ROM (pdf files)

Name: _____

Title: _____

Specialization/Discipline _____

UCEDD: _____

Mailing address _____

- Check here to be added to the mailing list for new marketing and communications resource/product updates and training/education events

Your name and the name of your UCEDD will not be listed in any forthcoming documents or reports to preserve the confidentiality of your comments.

Please mail or fax to: Ellen Hsu, M.B.A.
Marketing Specialist
USC UCEDD CHLA
5000 Sunset Boulevard, Suite 510
Los Angeles, CA 90027
Fax: 323-671-3835

Additional comments are also welcome at: elhsu@chla.usc.edu

About the Pre Conference Training Symposium Itself: Part 1 of 3

How well do you remember the content presented at the 2003 AUCD Pre Conference Training Symposium, *Developing a Marketing Mindset*? Please check one:

- Very well. Somewhat. Not well Not at all.

What was your definition of marketing before the Pre Conference Training Symposium?

What information about marketing/ recommendations did you find most useful? Please list *your top 3 points*:

1.

2.

3.

Have any specific changes been made at your UCEDD (or are in progress) as a result of your attendance at the training?

Have you shared the information from the training with anyone at your UCEDD or any other organization?

What factors influenced your decision to register for the Training Symposium? Please check all that apply

- | | |
|--|---|
| <input type="checkbox"/> The topic is important to me/ my UCEDD | <input type="checkbox"/> A desire to hear about experiences of other UCEDDs |
| <input type="checkbox"/> A desire to build my skills/ my team's skills | <input type="checkbox"/> Attending another presentation/ meeting that day |
| <input type="checkbox"/> The credentials of the presenters | <input type="checkbox"/> Contemplating a career or role change |
| <input type="checkbox"/> Sponsorship and endorsement of the councils | Other: _____ |
| <input type="checkbox"/> A desire to stay current on issues affecting AUCD | |
| <input type="checkbox"/> A desire to network with other UCEDDs | |

Which of the following describes your dissemination/ community education/ marketing responsibilities? Check all that apply

- | | |
|---|--|
| <input type="checkbox"/> Fund-raising | <input type="checkbox"/> Grant/proposal writing |
| <input type="checkbox"/> NIRS/Data coordinator | <input type="checkbox"/> Principal Investigator/Project Director |
| <input type="checkbox"/> Technical assistance to other UCEDD staff | <input type="checkbox"/> Community needs assessment |
| <input type="checkbox"/> Product/ information development and dissemination | <input type="checkbox"/> Center-wide newsletters, annual reports, UCEDD publications |
| <input type="checkbox"/> Outreach education and training | <input type="checkbox"/> Web development and maintenance |
| <input type="checkbox"/> Conference planning/ coordination | |
| <input type="checkbox"/> Communication/Advertisement | |
| <input type="checkbox"/> Center-wide coordination/collaboration of community education or community services projects | |

Others: _____

Would you recommend this training to your staff/colleagues who couldn't attend in November?

Please check one

- Yes Yes, if their area of responsibility demanded it

- No I don't know

Your Future Interest in Marketing Training: Part 2 of 3

Which marketing topics interest you? Please check *all that apply*

- | | |
|--|--|
| <input type="checkbox"/> Organization-wide marketing/dissemination plans | <input type="checkbox"/> Forming alliances and partnerships |
| <input type="checkbox"/> Development of product marketing plan for the UCEDD | <input type="checkbox"/> Obtaining corporate sponsorship |
| <input type="checkbox"/> Integrating a marketing plan into grant proposals | <input type="checkbox"/> Leveraging university resources |
| <input type="checkbox"/> Marketing research (focus groups/surveys) | <input type="checkbox"/> Advertising, promotions, public relations |
| <input type="checkbox"/> Databases and knowledge assets | <input type="checkbox"/> Contract with public relations/marketing agency |
| <input type="checkbox"/> Copyrights and patents | <input type="checkbox"/> Working with an outside distributor/publisher |
| <input type="checkbox"/> Branding (style, positioning) | <input type="checkbox"/> Pricing |
| <input type="checkbox"/> Distribution channels | Other: _____ |
| <input type="checkbox"/> Forming an effective Board of Directors | |

Your Future Interest in Marketing Training: Part 2 of 3 Continued

Which training/information delivery methods are most feasible for you? Please check *all that apply*

- | | |
|---|---|
| <input type="checkbox"/> National/State conferences | <input type="checkbox"/> AUCD Newsletter |
| <input type="checkbox"/> Teleconferences | <input type="checkbox"/> T/A from AUCD or other UCEDDs with expertise |
| <input type="checkbox"/> Web based training/ CD-ROMs | <input type="checkbox"/> Professional marketing association membership |
| <input type="checkbox"/> Print manuals on marketing communications | <input type="checkbox"/> Hire marketing agency |
| <input type="checkbox"/> Marketing textbooks | <input type="checkbox"/> Establish MBA-level marketing faculty position at your UCEDD |
| <input type="checkbox"/> T/A from marketing experts | Other: _____ |
| <input type="checkbox"/> Electronic resources on AUCD website (pdf) | |

Is there anything we could provide that would help facilitate your participation in any future marketing training or is there a different training format we should consider?

Your General Education/Training Preferences: Part 3 of 3

How do you stay informed about issues that affect your professional life/ career development?

	Use Frequently					Rarely Use	Intend to Use More Often
Peer-reviewed journals	5	4	3	2	1	<input type="checkbox"/>	
Internet/Online continuing education courses	5	4	3	2	1	<input type="checkbox"/>	
Internet/Online reference	5	4	3	2	1	<input type="checkbox"/>	
CD-ROM continuing education courses	5	4	3	2	1	<input type="checkbox"/>	
CD-ROM courses as references/training	5	4	3	2	1	<input type="checkbox"/>	
Telemedicine/Telehealth conferences	5	4	3	2	1	<input type="checkbox"/>	
Face-to-face conferences	5	4	3	2	1	<input type="checkbox"/>	
Consulting with colleagues	5	4	3	2	1	<input type="checkbox"/>	
Print resources such as: _____	5	4	3	2	1	<input type="checkbox"/>	
Other: _____	5	4	3	2	1	<input type="checkbox"/>	

How do you stay current about needs of individuals you serve and parent/caregiver concerns?

	Use Frequently					Rarely Use	Intend to Use More Often
My own observations during clinical visits	5	4	3	2	1	<input type="checkbox"/>	
Talking with parents/caregivers about their concerns	5	4	3	2	1	<input type="checkbox"/>	
Reading materials aimed at parents/caregivers	5	4	3	2	1	<input type="checkbox"/>	
Affiliation with community organizations	5	4	3	2	1	<input type="checkbox"/>	
Other: _____	5	4	3	2	1	<input type="checkbox"/>	

What factors are important in your decision to order educational materials or enroll in training?

	<i>High Priority</i>				<i>Not a Priority</i>
Continuing professional education credits	5	4	3	2	1
Interest in using new technology in training/communication	5	4	3	2	1
Interest in interdisciplinary practices	5	4	3	2	1
Need for self-education on the topic	5	4	3	2	1
Need to train support staff	5	4	3	2	1
Recommendation of a colleague/ professional organization	5	4	3	2	1
Topic is relevant to my practice/programming	5	4	3	2	1
Convenience and accessibility	5	4	3	2	1
Time commitment needed	5	4	3	2	1
Price	5	4	3	2	1
Ability to reference an expert I trust/authority on the topic	5	4	3	2	1
Access to information from a reputable source/organization	5	4	3	2	1
Reputation of funding source	5	4	3	2	1
Other _____	5	4	3	2	1

Other comments (Comments are also welcome at elhsu@chla.usc.edu):

I'd be willing to talk about my experience in more detail. Please contact me at this phone number: _____

Make an appointment with me at this email: _____

APPENDIX E

Sample Marketing Specialist Job Description

Position Purpose and Summary

- Provide technical assistance and marketing services as a part of interdisciplinary teams in various UAP/CHLA clinics, serving children with chronic illness/developmental disabilities.
- Provide integrated health communications services serving children with special health care needs and their families.
- Develop systems for community agencies, care providers, parents and policymakers to make their needs known to interdisciplinary teams at UAP/CHLA in order to produce services and products that are responsive to consumers.
- Evaluate utilization of the aforementioned services and products to constantly improve upon utilization rates and increase fundability of UAP/CHLA teams on State and Federal levels.

Duties and Responsibilities

Service

- Seek Copyrights and Patents
- Coordinate with the Communications Office: radio, print, TV, Internet, press releases
- Negotiating Contracts: video, print
- Hiring/contracting with PR firm
- Negotiating contracts with commercial distributors

Training/ Technical Assistance/Consultation/Continuing Education

- Marketing 101 – understanding the principles of marketing
- Developing a marketing strategic plan for your grant proposal
- Branding and developing an image, mission and vision
- Pricing
- Strategies for product distribution
- Leveraging University Resources: Foundation, PR/Communications, Legal, Graphic
- Design, Branding (style guides), marketing department, student help
- Obtaining Corporate Sponsorship
- Leveraging the power and influence of advisory boards or board of directors

Research

- Hiring/contracting with Formative Research Firms
- Maintaining consumer information/preference database
- Developing product evaluation strategies: Utilization, outcomes and performance
- Establishing databases to track product development/dissemination/ evaluation
- Formative evaluations – focus groups, sampling
- Product Testing
- Finding resources – including AMA and Research firms, video distributors, book companies

Minimum Education/Training Required: Master's degree in Business Administration

Experience Required: 3-5 years in an entrepreneurial environment, non-profit experience preferred