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Unmet needs: Service issues for
persons who are blind or visually impaired

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ABSTRACT

Five focus groups were conducted as a part of an assessment to identify stakeholder views regarding service delivery needs of persons who are blind/severely visually impaired. Groups were conducted in various urban areas of a southern state and included consumers, parents, and service providers. Analysis of focus group data clustered in four distinct themes or concerns regarding variability in services, outreach, transportation, and service delivery. Results are limited to one state agency and cannot be generalized to a wider audience. However, service providers and administrators may evaluate this information for transferability to other agencies. This project provides an example of focus group research methodology in needs assessment and program evaluation.

Key words: blind, visually impaired, needs assessment, focus groups

Unmet Needs: Service Issues for Persons who are Blind or Visually Impaired

A statewide assessment of stakeholder needs was conducted for a state agency serving persons of all ages who are blind/visually impaired. This needs assessment was designed to acquire an accurate and thorough picture of the agency's strengths and weaknesses. It used focus groups as a key component to obtain findings that might be overlooked using a strictly quantitative focus. The focus groups provided information about stakeholder issues and generated data for program planning and development.

Background

The Rehabilitation Act of 1973 as amended requires an annual statewide assessment of residents' rehabilitation needs (Freedman & Fesko, 1996). States have autonomy in determining the procedure for these assessments, resulting in variation among methods across the country. Although typically completed in-house, states may have an independent entity complete these assessments. Results are reported in individual state plans, submitted to the federal funding agency, and made available for public review (but not widely disseminated). State agencies may conduct additional assessments of program components or services to meet other requirements, or to evaluate the strengths and weaknesses of specific programs.

In an example of such an assessment, a 2008 study (Williams, Dutta, Kundu, & Welch) addressed the service delivery needs of female ex-inmates with mental illness in a southern state which requested anonymity. The state's Department of Rehabilitation Services completed a series of data collection instruments using information from closed

files. Results indicated that consumers' greatest needs upon release included assistance adjusting to their families, their communities, and their disabilities, as well as vocational counseling and guidance. Authors recommended additional training about these issues for agency staff.

Another previous needs assessment (Cherry, Keller, & Dudley, 1991) addressed demographic characteristics, disability status, independent living skills, mobility and transportation needs, and interest in employment among persons who are legally blind in Georgia. Telephone surveys found that older adults experience more difficulty performing tasks of daily living than younger people and were less likely to live with family members or relatives. Authors stressed the importance of inter-agency collaboration to achieve effective service delivery to elders.

In a similar need to comply with this federal regulation requiring a statewide assessment, the state discussed here requested an independent party to evaluate potential gaps in services or unmet needs. Focus groups were conducted as part of this multistage assessment.

Method

Focus Groups

The importance of stakeholder input to evaluate service delivery and service needs is recognized by service providers and funding agencies (Schriner, 1995; Graves, 1991). Focus groups provide a means to obtain information about the ability of agencies to provide services to the populations they serve and to provide a vehicle for obtaining information directly from those receiving services, their families, and others in the service delivery process. This consumer perspective is especially important to assess

policy formation and service delivery (Kosciulek, 1999). Focus group methodologies are also useful for obtaining information regarding specific rehabilitation outcomes (Kluesner & Taylor, 2005). Packer, Race, & Hotch (1994) note the importance of using focus groups to investigate changes in consumer satisfaction standards and outcome measures after policy changes have moved from legislation, to policy, to practice.

Focus groups can provide relevant information about programmatic dynamics and personal perspectives in applied settings (Nyamathi & Shuler, 1990; Packer, Race, & Hotch, 1994; Richard, 2000) because they capture perspectives beyond what participants think about a particular topic or issue. They examine *how* people think and *why* they think as they do about the topics being investigated (Morgan, 1996; Kitzinger, 1994). Focus groups provide an opportunity for members to share unique perspectives. In addition, focus groups are one of the basic elements of participatory action research, a concept promoted by the National Institute on Disability and Rehabilitation Research (Graves, 1991; Schriener, 1995). This participatory element encourages inclusion of persons most affected by the phenomena under study (Verner & Gilbert, 2006).

Procedure

State agency administrators selected five cities for focus groups. Only urban areas were included; however, locations were selected to ensure all geographic areas of the state were represented. Administrators selected and contacted participants from their respective cities. Prior to contacting consumers, the project was approved by the Mississippi State University institutional review board for the protection of human subjects; the research followed the tenets of the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects.

Of the five focus groups, two were comprised of consumers who are blind/severely visually impaired and/or their parents. Persons are considered blind/severely visually impaired if they meet the legal definition of blindness (visual acuity of 20/200 or worse in the better eye with corrective lenses) or have a disabling condition making it difficult to read regular print. Three focus groups were comprised of service providers or agency personnel working with or for the state agency under investigation.

Focus groups were conducted by two experienced moderators within a 10-day period. Neither moderator worked for the stage agency under investigation, had lived in the state, or is blind/severely visually impaired. One person served as the primary moderator/facilitator of each group, initiating discussions, monitoring the flow of discussions, and ensuring that established protocols were followed and objectives achieved. The secondary moderator welcomed participants, managed the audiotaping of the sessions, and took detailed notes.

Investigators explained the procedure, introduced the topics and informed participants that sessions would be audio taped. Participants were reminded that the researchers/facilitators would ask questions to get the discussion started and help maintain a focus on the topic but would not participate in the discussion. Each discussion was strictly among focus group participants and lasted approximately 90 minutes. Participants were provided an informed consent document and a demographic information sheet prior to initiating the session with copies offered to participants. Refreshments were provided.

After introductions, the focus group protocol addressed four major queries: (a) What are your thoughts about gaps in services you have heard about or experienced with this agency? (b) What can you tell me about persons or groups of persons who need services who are NOT receiving them? (c) Do you see needs for services that are not offered? (d) Are there policies that you believe impact gaps in services? After each query was presented, the floor was opened for other comments. As discussion of each query concluded, the facilitator summarized comments and moved to the next query.

Results

Participants

Fifty-seven people provided informed consent and demographic information. Of this number, three were eliminated from analyses for the following reasons: declined participation, not an English speaker, and departed before the group was underway. This left 54 people participating in the sessions.

The participants included 21 males (39%) and 33 females (59%); the agency population is approximately 50% female and 51% of state residents are female. Group participants had an average age of 50 years and a range of 25 to 75 years. Eighteen participants were consumers or parents of consumers of the state agency, 22 were service providers, nine were vendors, and five were members of the Rehabilitation Council or advocacy agencies. Forty-three participants were employed, three retired, and eight were unemployed. Of the 26 participants reporting a disability, 24 have some degree of visual impairment as their primary disability.

Forty (74%) participants identified their race/ethnicity as White, eight (15%) as African American, five (9%) as Hispanic and one (2%) as Asian. The agency consumer

population was approximately 60% White, 24% African American, 15% Hispanic, and 1% other race/ethnicity. In the state, 60% are White, 15% African American, 21% Hispanic, and 4% are other race/ethnicity. Participants averaged 16 years of education as compared to the population the agency served, where 53% had a high school degree or less education; state residents average 15.75 years of education.

Data analysis

The majority of the data for this component of the needs assessment are qualitative. Descriptive quantitative data analysis of the demographics of focus group participants was compiled using SPSS. Statistics include analyzed included frequencies, percentages in categories and a measure of central tendency (mean).

To insure detailed analyses of the focus group data two researchers evaluated detailed notes from the focus groups, first independently and then collaboratively. Each compiled independent notes from the sessions and from the audio tapes. This dual perspective approach provided a measure of inter-rater reliability and assured careful interpretation of the data.

Analysis of focus group transcripts was guided by grounded theory, an inductive approach where codes and categories are developed during analysis, interpretation, and comparison of various parts of the text to one another (Glaser, 1978). These analyses involved coding transcribed statements to reveal recurring themes and prominent concerns of participants across groups. Items were classified into concepts or categories.

Researchers identified emerging themes or areas needing improvement with respect to services and future programs addressed in all focus group sessions. The analysis identified concerns common among the various stakeholder groups represented.

Researchers strived to identify factors that promote an agency culture that emphasizes meeting the rehabilitation, transition, and/or independent living needs of persons who are blind/severely visually impaired.

Results

Focus group participants expressed their perceptions about state services for persons who are blind/visually impaired. Remarks about service delivery were generally positive. Participants in all groups commented that counselor caseloads are too high, thereby straining the ability of the individual counselor to provide services. Participants expressed awareness that counselors must complete a high volume of paperwork which negatively impacts service delivery but is beyond the responsibility of the individual counselor. Participants were aware that salaries are low for counselors and others involved in service delivery for persons who are blind/severely visually impaired, resulting in inadequate numbers of counselors, teachers, etc. Comments about gaps or service delivery needs were clustered in categories: (a) variability in services, (b) outreach, (c) transportation, and (d) service delivery. Each cluster is described here.

Variability in Services

At each focus group session participants discussed the variability in services across the state and in some cases, within local offices. There appeared to be a strong sentiment that some areas of the state and some groups of consumers receive more comprehensive and higher quality services than others.

Participants commented that consumers were not always made aware of the services/goods or choices available to them, sometimes resulting in purchase of equipment that failed to meet their needs or in referrals to less appropriate agencies.

Some participants stated that specific vendors or service providers were strongly recommended and consumers were either not offered other avenues for goods or services or were encouraged not to deviate from those which were recommended. Participants stated that some groups of consumers appeared to receive faster or more comprehensive services than others, though it was believed that this, too, was variable across the state.

The need for consumers to exercise informed choice was stated repeatedly. Participants want the agency to educate consumers sufficiently so that informed choice can occur. Vendors servicing multiple offices across the state reported (and were critical of) differences in procedures across the state. They report that some offices respond in a more timely way, communication varies among offices, and some areas of the state have more programs available. Some participants reported agency staff lacks current information about service delivery options and technology, thus preventing staff from providing consumers with all available options for goods and services.

Queries regarding why this variability in services exists produced responses that fell into three major areas. Participants stated that “local interpretation” of state policy varies, resulting in differences in service delivery depending on that interpretation. Others expressed the belief that the “personality” of the individuals providing services substantially influenced the quality of the services received, noting that some agency employees were more accessible and easier to work with. Finally, some participants indicated a belief that “personal relationships and political connections” were influencing service delivery negatively. Comments were made about potential conflicts of interest, particularly when members of boards were also service providers, or if there were

personal and/or political relationships between these individuals and employees of the state agency.

Outreach

Participants repeatedly expressed a belief that greater efforts need to be directed toward making the public aware of persons who are blind/visually impaired within the community, the services available to that population, and the abilities of that population to work and lead full and productive lives. This lack of information was perceived as having two major consequences.

One major consequence was the failure of persons who are blind/visually impaired to seek services. Participants believe that many citizens are unaware of the help available to them through this state agency. When asked to identify groups for whom information was particularly lacking, they mentioned persons living in rural areas, elders, children in private schools, and persons with multiple disabilities (particularly those who are deaf and blind and persons who are blind with mental illness).

Another major consequence was attitudes among the public and the public's lack of awareness about assistive technology and techniques available to persons who are blind/visually impaired. While employers' attitudes and the resultant difficulty in securing employment were highlighted, many expressed the opinion that a public awareness effort that addresses everyone would be more effective than targeting employers alone. The need for sensitivity training for the public, particularly public service providers, was discussed.

Participants commented that medical professionals and some school personnel appear unaware of services for persons who are blind/severely visually impaired.

Participants stated repeated incidents of ophthalmologists or optometrists who did not refer consumers to agencies serving persons who are blind/severely visually impaired. Some participants reported that teachers in private and public schools also failed to make appropriate referrals.

Improved communication was another issue in the outreach category. Participants expressed a need for improved communication among agency offices, among school providers and agency staff, between agency staff and hospitals and medical personnel, etc. Participants believe that greater communication will result in faster referral and service delivery and more informed consumers

Transportation

Participants stated that transportation continues to be a problem across the state for persons who are blind/severely visually impaired. Persons in rural areas may have no access to public transportation and persons in more urban areas believe the transportation services available to them are unreliable to the point of being unmanageable. Participants said that, although many people relocate to more urban areas specifically to utilize public transportation, the chronic unreliability of the transportation system results in ongoing problems. Both public and para-transit systems were characterized as problematic.

Participants stated that they were provided little information or assistance about how to use or resolve problems with public transportation. Night travel and travel across city or county lines were particular concerns. The inconvenience of required annual certification of handicapped parking decals was also discussed.

Service Delivery

When identifying gaps in service delivery, some participants stressed the need for improved services to infants, children, and youth. For infants, earlier access to low vision screenings and services was mentioned. Some participants believe that additional services to families are needed, particularly education about family adjustment, emotional support, and available services for parents of infants with visual impairments. Children in rural areas were recognized as being particularly at risk due to either the lack or the inaccessibility of services, as were children from families with limited incomes. Although transition programs are available to some, participants believe they are not available to all and some transition programs are more comprehensive than others. Youth need more and earlier training in activities of daily living, college preparation, and computer skills.

Among adults, services were perceived as better for those in urban areas and those with greater social and economic resources than for persons in rural areas, those who are socially and/or economically disadvantaged, or for minorities. Participants expressed a need for more support groups and assistance with adjustment to blindness, more opportunities for supported living, and more comprehensive employment training, particularly advocacy skills. Participants reported that services should be expanded for persons with multiple disabilities, particularly those who are deaf and blind, and for persons who are blind and mentally ill. Difficulty obtaining services for persons who have a visual impairment due to stroke was also discussed.

A particular concern of many participants was the economic need requirement for seniors to receive assistive technology. Many stated that the economic level used is too restrictive and that it is imperative that seniors have greater access to assistive technology. Suggestions for programs that lend assistive technology devices to any

consumer and for programs to loan money to consumers to purchase technology were discussed.

Limitations

Results reported here should be interpreted with caution. Focus group sites were not randomly selected, nor were individual participants randomly selected. The lack of random selection of sites or participants increases the likelihood that results may be biased. The racial/ethnic composition of focus group participants differs substantially from both the general state population and the population of those served by the state agency. The lack of adequate representation presents particular concerns when attempting to identify unserved or underserved populations because the very groups the project seeks to identify are likely not represented here.

Furthermore, participants provided information from individual perspectives, which are influenced by personal experiences and beliefs. While individual perspective is one of the strengths of qualitative research in general and, more specifically, of focus group methodology, these results are limited in terms of breadth and scope; consequently, interpretation should consider these limitations. Individuals and/or groups not represented here may have very different perspectives regarding the need and importance of various service delivery options.

The above results are not reported in any order or by degree of importance. Rather, results were compiled from each focus group and results were integrated to develop a report.

Discussion

While qualitative data is not considered generalizable, readers may review this information and evaluate its transferability to other settings/populations. Quantitative research is necessary to document the scope of the issues discussed here. However, persons familiar with the range of service delivery issues persons who are blind/severely visually impaired often confront will recognize some of the concerns voiced by these focus group participants as frequent topics of anecdotal reports. This information can be used as a springboard for dialogue in other states to determine if similar issues and concerns exist. Collaboration among states with similar concerns may be helpful in developing strategies that address these issues. Furthermore, states whose constituents do not experience these needs may have policies or procedures that (by design or coincidence) address these issues; the potential for replicating those policies or procedures should be explored.

Any time either a group of people who are blind/severely visually impaired or service providers involved with this population gather, the topic eventually shifts to transportation. This widely recognized and documented (Crudden, Sansing, & Butler, 2005; Crews and Campbell, 2001) issue continues to be relevant, apparently in both rural and urban areas. Indeed, persons who are blind/visually impaired have complained that their vocational rehabilitation counselors are not always helpful in addressing transportation barriers (Crudden, McBroom, Skinner, & Moore, 1998). Further research regarding this issue appears warranted. However, even without additional research the need for service delivery intervention at the individual level and the systems level appears clear.

Further investigation regarding variability in service delivery also appears necessary. First, it must be determined whether this is a perceptual issue or whether actual differences do exist. This topic may be difficult to examine given that variability can be manifested in multiple ways and for a variety of reasons. However, it is imperative that agency administrators strive to implement management practices to insure that all consumers have equal access and availability of services. To do so, additional information about how and why variability in service delivery occurs should be collected. A thorough review of agency records to determine patterns in service delivery may be one place to begin this effort.

Outreach efforts were strongly recommended by participants. Efforts to document existing outreach efforts in other agencies and states may be warranted. As state agencies struggle to maximize direct services with limited budgets and increasing overhead costs the importance of implementing cost-effective outreach methods cannot be over emphasized. The *Campaign for Disability Employment*, funded by the Office of Disability Employment Policy/U.S. Department of Labor, offers information and materials free of charge to promote employment for persons with disabilities. Use of these existing materials or development of disability specific materials from a local perspective provides a starting place for increased outreach.

Service delivery to unserved and underserved citizens continues to be a concern. Targeted outreach strategies may achieve the goal of getting these persons into the service delivery system but will not address the issues of availability and quality of the needed services. Exploration of efforts to coordinate services with existing organizations and consumer groups to maximize service delivery should be explored.

Although the focus groups were conducted in urban areas, participants had awareness of and concern for persons living in rural areas. There was a consensus that rural consumers received less information and fewer services and transportation options. The Research and Training Center on Disability in Rural Communities has valuable resources and information concerning rural infrastructure and resource allocation that may provide direction to agencies seeking strategies to improve service to rural populations.

Conclusion

Stakeholders in this state report concerns regarding agency variability in service delivery, inadequate outreach, transportation, and unmet service needs. Additional research, both qualitative and quantitative, is needed to determine whether these issues are consistent with state rehabilitation agencies in other states and with other populations. However, given the consistency of both reported and anecdotal transportation problems, it appears that this particular issue is problematic in other settings and with other populations. Consequently, it represents one potential starting place for initiating systems change.

Voucher programs (Gonzales, Stombaugh, Seekins, & Kasnitz, 2006), training and technical assistance programs (Easter Seals, 2010), and transportation cooperatives (Center for Transportation Policy, 2006) have all documented success in overcoming transportation barriers via networks with multiple service delivery systems but they remain isolated programs without widespread financial support. State rehabilitation agencies are urged to examine their state plans and devise methods to implement a successful intervention or to implement innovative strategies specific to their own

environment. It is imperative that steps be taken to address this longstanding problem that negatively impacts quality of life and impedes employment for persons who are blind/visually impaired.

The issue of variability in service delivery across this state may be one of perception and not reality. However, because it was consistently reported, further examination of the scope and specifics of this variation could lead to changes that improve service delivery. Each agency has the potential to use its federally mandated annual needs assessment as more than an exercise but as a genuine effort to evaluate itself and engage in self-monitoring to identify and address internal procedures that might lead to variability in service delivery. Such an effort would provide each agency a means of determining its most effective procedures are consistently implemented.

Informed choice is no longer a new concept, yet stakeholders in these focus groups believe that their state agency is not doing a good job of implementing it consistently. The Rehabilitation Services Administration funded seven Choice Demonstration Projects (Stoddard, Hanson, & Temkin, 1999) and provided a Self-Assessment and Technical Guide for Fiscal Year 1999 to assist agencies in evaluating their implementation of informed choice legislation. Administrators are urged to review successful strategies and evaluate their suitability for implementation in their own states.

Conduct of focus groups proved to be a valuable methodology in this data collection process. In addition to yielding important information about the status of service delivery, it provided keys to greater understanding of stakeholder satisfaction/dissatisfaction and direction for additional research and service delivery.

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