

CASH AND COUNSELING DEMONSTRATION AND EVALUATION

Independent Choices:

Report on Arkansas Focus Groups

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Cash and Counseling Demonstration and Evaluation Summary of Focus Groups Arkansas, April 2000

Introduction and Methodology

In an effort to enhance marketing efforts and increase enrollment in the Cash and Counseling Demonstration and Evaluation (CCDE) in the three participating states, the Robert Wood Johnson Foundation has provided funding to conduct qualitative research (focus groups) with targeted groups thought to have direct contact with consumers who would be eligible for the program. The goals of the focus group discussions are:

- To provide focus group participants an overview of the state-specific Cash and Counseling Demonstration and Evaluation program.
- To provide focus group participants with ideas and ways to identify and refer eligible consumers to **IndependentChoices**.
- To identify those who might be "ambassadors" for **IndependentChoices** among those professionals participating in the focus groups.

The first series of focus groups were conducted in Little Rock, Arkansas on April 4 and 5, 2000. Based on the recommendations of the staff of the state's demonstration, called **IndependentChoices**, it was decided to conduct focus groups, one each with physicians, nurses, social workers and pharmacists. **IndependentChoices** staff provided lists of physicians, pharmacists, and rural health centers across the state that served those Medicaid clients receiving personal assistance services. In addition, the Arkansas Hospital Association provided a list of hospital-based home health agencies, and the names of the directors of hospital social work and discharge planning departments.

Approximately 800 letters of invitation were sent to individuals across the state who were invited to participate in the groups either in person at a research facility in Little Rock, or via conference call. In appreciation for the their time and effort, a modest stipend was offered to those participating in the groups. It is important to note that the letters themselves provided information and education about **IndependentChoices**. An **IndependentChoices** brochure was included in the mailing. The R.S.V.P. form enabled invitees to request more information about the program if they were unable to participate in the group discussion.

Note: Please refer to the Appendix to review a copy of the letters of invitation sent and the Moderator's Guide. The National Program office and Arkansas **IndependentChoices** staff received transcripts of the focus groups that provide a complete overview of the entire group discussion.

Forty-five people participated in the focus groups – 28 on site and 17 via conference call. It is unusual to have focus group participants present in person and by phone at the same time. While such a format could appear cumbersome, it appeared to work very well in the groups, allowing many to participate in the discussion that might not otherwise have been able to do so. (See table below)

GROUP	ON SITE	VIA PHONE
Social Workers	6	3
Pharmacists	8	4
Nurses	9	3
Physicians	5	7

The moderator provided each focus group with an overview of the Cash and Counseling Demonstration and Evaluation and how the project worked specifically in Arkansas. The referral and selection process for **IndependentChoices**, the demographics of current enrollees, and marketing activities for the program were also presented. Throughout the discussion, information and clarification was provided to the participants about the program, including

eligibility, the referral process, impact on other benefits, the evaluation process and program oversight.

In three of the four groups, the Program Administrator of **IndependentChoices**, Sandra Barrett, participated in part of the focus group discussion in order to address specific questions and concerns about the program raised by the participants.

Following is a summary of key findings from each of the focus groups. Each section provides a review of the following:

- Participants' reactions and concerns about **IndependentChoices**. (Note: Given that the primary purpose of these focus groups is to identify ways to further market the Cash and Counseling Demonstration in each of the three participating states, *detailed* discussion about focus group participant concerns is omitted from this report, but is available in the focus group transcripts.)
- Ideas about marketing **IndependentChoices**, both to professional colleagues and to those consumers who might be eligible for the program.

Statement of Limitations: Focus groups afford the opportunity to observe and record spontaneous reactions – perceptions, opinions, and attitudes – from a selected group of participants on a variety of issues and topics. The groups help develop insight and direction rather than quantitatively precise or absolute measures. Therefore this research must be considered in a qualitative frame of reference and the results viewed as exploratory and directional in nature.

Statements in the report noted in *Italics* are actual quotes taken from the focus group transcripts. In some cases, the sentence structure may seem awkward – a result of the spoken word seen in writing.

SOCIAL WORKERS

General Discussion on IndependentChoices

Nine social workers participated in the focus group, six in person and three by phone. All were affiliated with hospitals around the state, with several having additional responsibilities with home health agencies, hospice, and long term care.

- While none of the participants had heard of the term "consumer directed care", they had a good sense of the meaning of the term.

"It would mean that the patient, the consumer, had a lot of input into their care and would direct their care."

"You are in control. / Independence."

- Most of the social workers had heard of **IndependentChoices**, either having read about the program in a local newspaper or receiving information from other organizations, such as the Area Agency on Aging. Two of the participants had been told about **IndependentChoices** by patients.
- However, there was some misinformation about the project and there seemed to be confusion with several other pilot programs also offered by the Department of Human Services.
 - Several had been told there was a waiting list to enroll in the program.
 - It was thought by some that **IndependentChoices** was under the auspices of the Area Agency on Agency (AAA). Others stated that they had received information about the program from the AAA, who indicated they were not happy with the new program.
 - There was also uncertainty about the referral process and eligibility criteria. Some thought it was only for those over age 65.

- Social Work participants cited several **concerns** about the program related primarily to use of the cash allowance, quality of caregivers, and program oversight.

".... whether you are getting what you should get you for your dollar, I would wonder how that is monitored and controlled."

"I wonder about the quality and the consistency of the quality [of the personal assistant]."

"I'm always worried about people being taken advantage of."

- Several participants could think of patients with whom they had worked that could have been referred to **IndependentChoices** and all said it is another valuable resource they can offer to patients who might be eligible.

"In discharge planning...we are always looking for resources for a personal assistant, home health aide, whatever the needs might be to augment what they are getting. It would be presented as one of the options for person care in the home.... for those that we feel might be eligible."

Marketing IndependentChoices

- An overview was given of the marketing efforts for **IndependentChoices** -- the letter from the governor to eligible Medicaid beneficiaries, newspaper articles and public service announcements. While a few had read articles about the program, none had seen the public service announcements.
- Participants named several professional organizations that should be made aware of **IndependentChoices**, such as the state's hospice association, home care organizations and independent living services.
- Consumer/ patient support groups -- such as those for Parkinson's, Alzheimer's, Diabetes, AIDS, and stroke, and advocacy groups such as the Arkansas Disability Coalition are organizations that like to be kept aware of new programs and services from which their members might benefit. Also

mentioned were United Cerebral Palsy, the Easter Seal Society, and the Spina Bifida Association.

- Other agencies or services that go into clients' homes, such as staff from medical equipment companies, would be groups that should be informed about **IndependentChoices**.
- Churches, health fairs, senior citizens centers were consumer venues suggested by the social workers for marketing the program to those who might know of persons eligible for **IndependentChoices**.
- Participants strongly advocated **IndependentChoices** staff meeting *in person* with professionals such as themselves.

"What helps us is to have someone actually come with brochures and talk face to face. People tend to remember things more if you have someone coming and talking directly to you."

- Professional association meetings, conferences, and publications, such as the National Association of Social Workers state chapter and its newsletter, as well as the Society for Social Work Leaders in Health Care could be used as a vehicle for informing other social workers about the program.
- Participants were asked if they would be willing to speak about **IndependentChoices** to any of the venues they had suggested. While they seemed willing to do so, most were emphatic that in order for them to speak about the program, they themselves would have to feel that they have a good grasp of the program. Having talking points and informational material provided by **IndependentChoices** staff would be helpful to them in presenting to others.

"When we speak to groups, we like to have the information and feel like we know what we are talking about, because in our positions, especially in hospitals...we always seem to be looked on as the experts. Therefore, I am not going to speak to a group until I am sure I understand it myself."

PHARMACISTS

Seven pharmacists and one student in training were present for the focus group with four people participating via telephone. Half of the pharmacists were employed by Little Rock area drug stores.

General Discussion on IndependentChoices

- None of the pharmacists were familiar with "consumer directed care", nor had any heard of **IndependentChoices**. However all could see benefits to the program and could think of clients that might be eligible.
- Pharmacists were uncertain that they actually understood personal care -- what services were considered personal care, who provided them, and how much recipients could receive.
- Using the cash allowance to purchase prescriptions not covered by Medicaid was seen as a tremendous asset of the program, as many of these pharmacists cited patients they knew who are unable to fill all the prescriptions they need.
- There was some concern expressed that perhaps recipients might be giving up other services and benefits if they participated in IndependentChoices.

"...my first concern was that they were going to be losing something that they might not have the ability to manage as well as an agency does."

- The potential for abusing the cash allowance and being an employer were concerns expressed about the program.

" The one thing that does concern me is them being their own employer.... taking care of the deductions. I certainly think a lot of them would need a counselor. That role might be a little much for some..."

Marketing IndependentChoices

- Using the state pharmacists association was suggested as a key method to communicate information about **IndependentChoices** to other pharmacists statewide.
- Free clinics, often run by faith-based organizations, should be informed of the program as they serve persons who might be eligible for IndependentChoices, suggested several pharmacists who were aware of such programs in their communities.
- Pharmacists in the smaller communities stressed the importance of having local home health agencies supportive of the program.

"It would be nice to have them [home health agencies] informed and on your side before you try to sell the program."

- Several participants had suggestions for using the video. Having copies to provide to their customers to "check out" and view was one suggestion. Another pharmacist thought showing the video in certain settings such as senior citizens centers would be beneficial.
- An easy way to inform their customers about the program would be to have brochures available to distribute to customers, according to the pharmacists.

"..if we were going to put a brochure out...that answered a majority of their questions... I would want you to have some kind of nice looking rack... I wouldn't want you to send me 500 brochures, maybe 25 or 50 and give me a little placard so I can reorder them. ...not take up much space on my counter. It would need to have somewhere on it saying, 'Do you have an aide that comes into your house? Are you on Medicaid? Ask about this' "

- As the pharmacists were unfamiliar with Medicaid personal care eligibility criteria, they stated it would be helpful to have a simple screening tool or a few key questions regarding personal

care services in order for them to know whom to approach about **IndependentChoices**.

NURSES

Twelve nurses participated in the focus group, nine in person and three via phone. Several practice settings were represented, including hospitals, home health agencies, and community health centers.

General Discussion on IndependentChoices

- About one-third of the focus group participants had heard about **IndependentChoices**, but most of them did not have a clear sense of what the program was about. One of the home health agency nurses had clients in the program.
- While not familiar with the term, participants could readily imagine how consumers would respond to the concept of consumer direction in general and **IndependentChoices** specifically.

"I'm sure they loved it. A lot of people when they are faced with loss of independence feel like they have lost everything. With this kind of program, I'm sure they felt a little bit more in control."

"They might be able to get more for their buck with them being able to choose what services and where to go."

- Competence of the caregivers, potential abuse by the caregiver and the patient not reporting abuse for fear of losing services, were significant concerns of the nurses.

"How do we know that these people are not going to abuse the elderly person?"

"...when they think they are going to lose that care, they will not complain. You take somebody who is 85 years old, they are not going to complain."

"If someone can prove to me that you are monitoring this so tightly that there is no chance of abuse or neglect...then I think it is a wonderful program."

- The nurses were very troubled by the fact that **IndependentChoices** is not regulated in the same way as home health and personal care agencies. There was also concern about appropriate oversight of the agencies providing the counseling and fiscal intermediary services for the program. Several felt strongly that home health agencies should have a role in a program such as **IndependentChoices** and could if they were under less regulatory constraints.

"...why don't we relax some of the regulations...so that we can oversee some of this care and make sure these people are well cared for and still allow them the personal choice?"

"We would love to be able to do these things but we are being regulated to death and don't have the freedoms..."

- Several of the nurses however, pointed out the realities -- and failures -- of agency care including: inability to find personal care aides; no guarantee in spite of regulations that clients won't be abused; inability to be flexible to meet client needs;. For them, there are tremendous advantages to involvement in **IndependentChoices**.

"I would rather see them use somebody that they know rather than the patient having to wait six to eight months."

"...you have a patient with chronic lung [disease] who needs an air conditioner, it is like pulling teeth to find funding for something like that. That piece of it is really wonderful to me."

- Participants were asked why they decided to participate in the focus group, given the strong negative feelings about the program. For some, it was an opportunity to express how they felt about the program. For others, they wanted to learn more about a program that concerned them greatly. While several said they were leaving the focus group discussion more open about **IndependentChoices**, others readily admitted they still had serious doubts.

"I am much, much more positive than I was when I read the brochure. ...I think another way to look at this is they [patients] might let the families provide personal care which will allow someone to come into the home whereas they would not let an agency come in."

"I still don't think it has been proven to me that there is a fool-proof way to discriminate between a licensed agency and a non-licensed situation like this."

Marketing IndependentChoices

Given the breadth and intensity of concerns the nurses had about the program, little time was spent in this session about marketing the program.

- As with the other professional groups, contact with professional associations, such as home health care groups was mentioned by several of the focus group participants as an effective means for educating and informing nurses about **IndependentChoices**.

PHYSICIANS

Twelve physicians took part in the focus group -- five in person and seven on the phone. Four were family practitioners, one of whom is now retired and no longer sees patients. He was invited to attend because of his involvement in the state medical society. Others participating included those practicing neurology, oncology, ophthalmology, and physical medicine.

General Discussion on IndependentChoices

- None of the physicians had heard of consumer direction or **IndependentChoices**, although one doctor did have a patient who is self-directing her care. Several could see the advantages of such a program.

"I think that people might be excited about this. They can involve their family in their care and choose their caregivers."

"For them to be able to determine what they did and what they received."

- As with the nurses, most of these physician participants had strong reservations about the program. Based on their own opinions about the Medicaid program and those receiving the benefit, it was difficult for them to see how someone on Medicaid would be able to manage a program such as **IndependentChoices**.

"...it seems to be a lot of potential for abuse in this program."

"...you are burdening them with more management to try to allocate the funds you are directing them to use in a way they may not be capable of doing."

"You should have a case manager to be sure they get what they are supposed to have."

- It was suggested that there should be certain standards or qualifications to allow participation in **IndependentChoices**, as well as ensuring level of competence of the caregiver.
- Using the cash allowance for items other than personal care needs was a strong concern for the participants.
- Despite the level of pessimism about the program, there were several physicians who could see the potential benefits of the program.

"...you really have no control over what they do with their money. They could tell you one thing and do something else."

"I think it is just a wonderful opportunity. I think you will allow people to empower themselves.... To just say 'gee, we've got people who are just going to abuse the program so we should not have it at all' is just really negative. I think something like this needs to be tried."

"If we can improve the quality of life for some of the people, maybe it will be of benefit."

"I have seen the elderly having to make a decision about where they are going at discharge. There is a choice of nursing home or home.... If a person had the autonomy to choose someone to be there and hire them to be there it would help some of these patients get home instead of the family having to opt for a nursing home."

- Some even thought the physician could be the key to success of the program.

"That is probably the key to success for this program is the physician. ...If a physician gets involved and the physician does a good job and is kind of the triage officer as it were and picks the right kind of people for the program this may be a very good program."

Marketing IndependentChoices

- Given the key role physicians play in Medicaid personal care services, these participants believed that educating other physicians across the state was critical. Face to face presentations were felt to be most effective with attendance at hospital staff meetings and state medical society functions were seen as the most likely venues.
- Several physicians said they would like to have **IndependentChoices** brochures available in their offices that they might share them with patients whom they thought might be eligible for the program.
- Physicians thought it was important that hospital social workers involved in discharge planning and those in rehabilitation medicine be informed of the program.

Conclusions and Observations

- These focus groups provided an opportunity to learn the chief concerns, misinformation and misperceptions professionals have about the concept of consumer-directed care. While some of these can be readily addressed, prejudices towards consumer directed care could create barriers to having some professionals serve as "ambassadors" for the program.
- All of the professionals want and need to have a good understanding of how the program works -- the referral process, eligibility, oversight and evaluation -- in order for them to feel comfortable recommending **IndependentChoices**.

- Nurses and physicians need to be assured that, should they have concerns about someone's ability to participate in the program, those concerns will be heard and addressed by **IndependentChoices** staff.
- Personal contact with **IndependentChoices** staff was strongly advocated by participants in each of the professional groups as one of the most effective marketing and education strategies to professionals. This process actually began during the focus group discussions when the Program Administrator participated in three of the four groups.
- Professional association meetings and newsletters were seen as effective means for reaching other professionals across the state.
- Social workers and pharmacists were enthusiastic about getting more personally involved; they were willing to speak to others about **IndependentChoices**, but not before they felt they were well versed in the program themselves.
- Based on these focus group discussions, it appears nurses and physicians are more likely to market the program only within their own settings.
- The participation of the **IndependentChoices** Program Administrator in the groups proved to be extremely valuable.
- Having someone directly involved in the program helped to diffuse much of the anxiety participants felt about the program and provided them with a strong sense that their concerns were being addressed.
- Many of the professionals who received letters of invitation to participate in the focus groups, but were unable to do so, requested more information about **IndependentChoices**. It is clear from these focus group discussions that the program brochure does not provide adequate information for

professionals. Any follow-up mailings need to explain in greater detail certain key aspects of the program that continually were raised as concerns by these focus group participants -- the referral process, eligibility criteria, oversight and quality assurance. Each professional group also raised issues that could be used in promoting the program to their colleagues, such as physicians feeling they are the most critical component of the team in terms of making the program work; providing brochures to pharmacists for display; and informing social workers that referrals can be made to the program while the patient is still in the hospital.