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ABSTRACT

Intended for educational researchers, the paper stresses the importance of disseminating research knowledge to parents, particularly to parents of handicapped children. Barriers to disseminating research knowledge to parents include the low priority of this activity among members of the academic community, the trickles down theory of dissemination whereby the parents are among the last to receive information, and the scarcity of appropriate dissemination vehicles geared toward parents. Ethical and practical reasons for overcoming these barriers are considered, such as the importance of arming parents and advocacy groups with information to back up their attempts to get programs for handicapped children. Among suggestions are the placing more emphasis on the values underlying research efforts, lobbying for federal funds to disseminate research to parents, and creating linkages with existing parent organizations. (SB)

Dissemination of Research to Parents:
Issues, Barriers and Future Directions

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Introduction

The importance of communicating with parents regarding what is known about children and their development hardly needs emphasis. For parents of handicapped children, the need for information is even greater. Major changes in law, such as the passage of P.L. 94-142, and in practice, such as deinstitutionalization, have meant increased responsibilities for parents of handicapped children. A major assumption upon which new law and practice is based is that parents have the knowledge and skill to make sure their children get a proper education. There is research evidence which suggests that parents do not have knowledge and skills to fully exercise their rights and responsibilities. For instance, a recent observational study of IEP Conferences (Goldstein, Strickland, Turnbull, & Curry, 1980) indicated that parents played a very passive role in these conferences. During the 45 conferences observed, parents spent on the average only 8% of the time they talked discussing placement issues (Goldstein, 1979). Other evidence suggests that parents may not be discussing placement issues because they do not have information to do so. A nationwide survey we recently conducted with 100 parents of handicapped and non-handicapped kindergarten children indicated that 90% of the parents of handicapped and 80% of the parents of non-handicapped would like more information about mainstreaming. We can infer that if parents are supposed to be actively participating in placement decisions, are not doing so and do not have information on placement issues, then a major need exists.

Parents' needs in terms of these increased responsibilities can be viewed as being twofold: one is for information about new laws and practice, and the other is for skills in how to act on knowledge. For the purposes of this discussion, I will focus on the first need - the need for information. First, I will present what I feel to be some of the barriers which make disseminating research knowledge to parents a hard task for researchers. Following this, I would like to make a case for why it is increasingly important for us, as researchers, to work at overcoming those barriers to reach the parent audience. The last section focuses on suggestions for future directions.

What are the Barriers to Disseminating Research Knowledge to Parents?

Disseminating to Parents is a Low Priority for Researchers

Perhaps the greatest barrier to disseminating research information to parents is the low priority which this activity has for members of the academic community, the place where most researchers reside. This low priority relates, in turn, to several other issues - one being the dissemination models used by some research institutes. To illustrate this point I would like to show a model developed by Joe Sanders, Communication Specialist at Frank Porter Graham Child Development Center, to guide the dissemination efforts of a major research project there.

Insert Figure 1 about here

The order in which audiences are reached is as follows: scientific community, practitioners, educated lay public, including parents, and the general public. (This could be referred to as the "trickle down theory of dissemination".) This figure makes it clear that the content of the information disseminated to parents has gone through various stages of review and simplification. The process represented by this model is quite useful in insuring that parents receive valid and reliable information. Unfortunately, the safeguards provided by this model impose a definite barrier: that is, parents are among the last to receive information. Unless a project is directly geared toward the development of materials for parents, rarely is time and money left at the end of a research project to translate and synthesize research findings for the parent audience.

In addition to there not being time and money available, there is a clear absence of status associated with disseminating to parents. For the most part, the academic careers of researchers heavily depend upon two closely related things. One is the ability to attract money for conducting research and the other is publishing in peer-reviewed journals. The implications of this are far-reaching and have not done much to enhance the parent-researcher relationship.

First, there is not much of an incentive for researchers to make the extra effort to reach the parent audience. Second, the major factor affecting the content of most research and the methodologies employed is whether or not certain academic expectations can be satisfied. The extent to which the research will provide any directly useful information for parents is not a factor often considered. Third, the methodologies we use, while perhaps elegant from a statistical standpoint, may leave parent participants feeling frustrated or not listened to. A mother, seasoned by 2 years worth of participation in various research studies, made this comment to me at the end of of an interview which was conducted as part of a descriptive study which we did:

> "I'm so glad someone's talking to me instead of giving me forms to fill out and questionnaires. Last time I said, 'there are no answers to any of these questions.' They really should do some checking before they ask some of these questions, because some of us don't even know what you're talking about because of the language the questions are stated in. I've got a handicapped youngster . . . talk to me on my level."

Related to this issue are the scarcity of appropriate dissemination vehicles geared toward parents. The major periodical for parents of handicapped children is The Exceptional Parent - a journal which I feel is an excellent source of valuable, practical information for parents. Unfortunately, the incentives for researchers to publish in this journal are few. It is generally not considered to be peer reviewed and it is operated on such a small scale that there is a very slow turn around time for having an article published. In addition, this magazine reaches less than 1% of the estimated number of families of handicapped children.

Popular magazines are another possible means of providing information to parents. They offer the advantage of being able to reach a large audience but, again, have the disadvantage of not carrying weight or prestige among the academic community. When knowledgable persons do not take responsibility in this area, the results can be disatrous. Family Circle, a magazine sold in grocery stores everywhere, had a recent misleading and unnecessarily pessimistic article on birth defects. In this article it was stated that "there is no treatment for Down syndrome children" and "retardation is irreversible and untreatable."

Another important vehicle becuase of distribution potential is commercially published books. The survey mentioned earlier which we conducted with 100 parents of young handicapped and non-handicapped children indicated that parents prefer printed materials over TV and PTA meetings as a way of receiving information. A larger nationwide survey on parents' informational needs by Sparling, Lowman, Lewis & Bartel (1979) indicated that books were identified as the most frequent "first choice" print materials. Parents of non-handicapped children have fared well in this area. A trip to any bookstore reveals numerous books on parenting. Parents of handicapped children have done less well. Small publishers who typically publish books for small audiences, such as parents of handicapped children, have limited marketing capabilities. These books usually don't find their way to the shelves of local bookstores.

Probably the largest body of information for parents of handicapped children is that which has been published and distributed through government agencies and private foundations. Unfortunately, there is no centralized clearinghouse for parents to use in order to obtain this information. Basically these publications remain an untapped resource for most parents.

Another possible way of disseminating information to parents is through conferences. This is a major way that researchers and practitioners share information with each other but has not been used as a way of providing research information to parents. Parents rarely attend professional conferences and professionals rarely attend parent conferences, such as those sponsored by the Association of Retarded Citizens. Again, there is little prestige or reward for researchers to do so, and with travel funds becoming more limited, it is unlikely that this trend will be reversed.

Why Is It Important For Us, As Researchers To Communicate to Parents?

I feel that there are both ethical and practical reasons why, for our own survival, we must try to overcome these barriers and pay more attention to the parent audience. First, I would like to focus on why I feel it is ethically important. In our often frantic attempts to obtain funds for research we sometimes lose sight of the basic principles or values underlying our research efforts. What is the basic purpose of conducting research? To discover and organize knowledge. Why do we do that? We want to discover knowledge as a means to an end - as a way of understanding and improving the world around us. In terms of the handicapped, we conduct research in hopes of enhancing the potential of handicapped persons. As professionals we have adopted certain assumptions for treatment which we feel do enhance the potential of handicapped children. One is the value that handicapped children whould live with their families and receive community-based treatment. We feel we have accomplished this when handicapped children are not institutionalized; but have we really? In a sense we have shifted the burdens of responsibility and care from the professional community to the family. They are clearly the key to the success of community-based treatment, but have we left parents out on a limb by not providing them with practical and important research information. When we do not disseminate to parents, then research becomes an end in itself - not a means to an end. We have an ethical responsibility to see that this does not happen by making sure that parents receive research information.

Not only are there ethical reasons why we should pay more attention to parents, there are practical reasons as well. Up until this current administration, educational research could be conducted successfully with little attention to either the public or the pocketbook. As mentioned before, the conduct of a research effort was largely concerned with satisfying academic expectations. We have not in the past had to justify our work to consumers. Times are changing. As stated by Schutz in a December 1981 article in the Educational Researcher, "in our current 'era of limits' the basis for judging the success of an educational research project is going to increasingly be its justified contribution to publicly endorsed goals." (Schutz, 1981).

We are at a critical time - although it is generally felt that the Administration is still considering educational research to be a part of the federal rôle in education, it is uncertain the extent to which research activity will be funded.

Where can we turn for help? I feel that we must develop support for out research activities among the general public. Parents in the past have banded together for causes and clearly have made an impact on policy decisions. Educational research has not been a rallying point for parents in the past because they have not seen the connection between research and their children. We have not shown it to them. Now we have an important opportunity to remedy this. With block grants being the direction of funding efforts, important decisions will be made at state and local levels. It is more important than ever to arm parents and advocacy groups with informtion to back up their attempts to get programs for handicapped children. Parents need us now and we need parents. As one parent with whom I recently spoke stated - "if I just had a one page summary of information on the cost effectiveness of early intervention to present to the local school board I think I could persuade them to set up a program." I contend that we need to do a better job at listening to what parents want and at providing them with this information.

Future Directions

What can be done to help overcome these barriers to make disseminating research to parents a valued and respected part of the research process? First, I would suggest placing more emphasis on teaching a philosophy of science in research training programs. By providing students with opportunities to think about and identify the values underlying the way research is conducted, it is more likely that their later research efforts will be a means to an end and will provide some direct benefits for consumers.

A second way of enhancing dissemination to parents in the future is to lobby for federal funds to do so. A reward system would be extremely helpful. Perhaps targeting a certain percentage of research as being client-centered and earmarking funds for dissemination (a sort of affirmative action policy) would be one way of rewarding this activity.

Another way of securing funds for dissemination to parents is by forming more linkages with State Departments of Education. According to P.L. 94-142, state agencies have responsibility for providing training for parents - most school systems have not acted on this responsibility. If universities, with their knowledge base, could link up with state departments, who have the mechanism to secure funding, then the barrier of lack of funding could be overcome.

Another potentially useful linkage for researchers is existing parent organizations. The National Association for Retarded Citizens has a research and development division with a paid staff, along with a network of interested parents around the country. Bringing together the resources which researchers and parent groups have to offer is a way of potentially strengthening both groups and getting what some people call the "ivory tower" back down to a gress roots level.

When research knowledge is shared, used and valued by parents, then we will be able to count on support from this group and we will develop a broader and more effective constituency in support of educational research.

References

Goldstein, S. The effect of two intervention strategies on parental participation in and satisfaction with the IEP Conference. Unpublished doctoral dissertation, University of North Carolina, 1979.

Goldstein, S. Strickland, B., Turnbull, A., & Curry, L. An observational analysis of the IEP Conference. Exceptional Children, 1980, 46, 278-286.

Schutz, R. E. The conduct of educational R & D in an era of limits. Educational Researcher, 1981, 10(10), 13-18.

Sparling, J. J., Lowman, B. C., Lewis, I. S., & Bartel, J. M. What mothers say about their informational needs, Vol. 1. A final report to the Administration for Children, Youth & Families. Chapel Hill, N.C.: Frank Porter Graham Research Center, 1979.

Figure 1

A Model for Information Flow Through a Series of Communications Activities