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ABSTRACT

This paper explores how family stories can be used in the professional preparation of early interventionists working with families of children with disabilities. It provides a rationale for using family stories in training, noting that they are inherently interesting, provide affective awareness, and provide access to understanding multiple realities. The use of family stories in personnel preparation assists students in making connections between theory and practice, gives meaning and purpose to learning, and challenges assumptions. Instructional strategies include inviting family members as speakers, using parent advisors as adjunct faculty, examining case studies of family situations, and reading family stories in literature. (Contains 19 references.) (JDD)

Family Stories: A Pathway to Family-Centered Practice

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Running Head: FAMILY STORIES

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Abstract

The use of stories from families with young children with disabilities is a powerful teaching tool for providing early interventionists with a family-centered perspective. Family stories are inherently interesting, provide affective awareness and access to understanding multiple realities. The use of family stories in personnel preparation assists students in making connections between theory and practice, gives meaning and purpose to learning and challenges assumptions. Instructional strategies including the use of family members as speakers, a Parent Advisor, family situation studies and family stories in literature are discussed.

Family Stories: A Pathway to Family-Centered Practice

The implementation of PL 99-457 (now the Individuals with Disabilities Education Act 1991) has challenged professional preparation programs from all disciplines to provide students with competencies for working with families of young children with disabilities.[1] These competencies include being able to articulate values and principles of family-centered services; to communicate with families in a clear, sensitive and empathic way; to identify family resources, concerns and priorities; to work collaboratively with families to develop family outcomes and goals for the child; to assist families in meeting the needs of their children; and to understand the effect of culture on family organization and function.[2] Our experience of using individual family stories in coursework and practicum supervision has convinced us that stories from families with young children with disabilities are a powerful means of conveying a family-centered perspective to early childhood special education professionals. The purpose of this article is to explore how family stories can be used in the professional preparation of early interventionists working with families. The first half of this article will share our thinking about the power of family stories as a teaching tool and in the second half, we will describe strategies for the use of family stories in training.

Rationale for Using Stories in Training

Stories or narrative accounts are used by many disciplines as means of making sense of one's own and others' experience.[3] The contributions of narrative to teaching and training has recently been recognized in anthropology[4], psychology[5,6], psychiatry[7] and in educational practice and research.[8] We believe that stories as narrative accounts have been used as a strategy for teaching and learning across disciplines, professions and cultures because stories are inherently captivating and interesting, they provide a powerful affective component to learning and stories provide a strategy for understanding multiple realities. We will discuss each of these as a rationale for using family stories in the training of personnel in the area of early intervention.

Stories are Inherently Interesting. Stories have a unique and captivating power over us. In our everyday lives, we enjoy listening to stories that others tell of their experiences as well as sharing stories about ourselves. There is something about narratives that makes telling and listening to stories a universal practice. In fact, it has been estimated that people communicate through stories between 60-70% of the time.[9] An educational expert, Lee Shulman, suggests that, "We, as a species, are apparently wired to listen to, engage in, and remember stories much better than we do with non-narrative discourses".[10(p18)] Anyone who has taught a college course will agree that students pay closer attention to the story of a child, a

family or a classroom than to an explanation of a concept or a theory. Furthermore, instructors recognize the way in which a story can sometimes clarify a point or a principle much easier than a wordy explanation. Without doubt, stories are a strategy for getting student attention and illustrating course material.

Family stories are particularly compelling since we all can personally relate to the concept of family. In our work with students, we have noticed their enthusiasm for oral and written family stories. Like us, our students are consistently intrigued by and enthusiastic about the stories families share in coursework, in literature, or through other mediums. We have observed that listening to stories does not seem like work, and agree fully with Margaret Buchman's belief that "stories make us think about shared mortal questions in compelling but not coercive ways."[11(p493)] In our training efforts, stories have become an enjoyable and personalized way of learning about families.

Stories Provide Affective Awareness. Another reason for using family stories in personnel preparation is that they are a rich source of the affective awareness and understanding needed by professionals, if they are to work in collaboration with families. Collaborating with families requires professionals to be comfortable understanding and responding to each family's individuality affectively as well as conceptually. As Robert Coles suggests, stories have the power to engage both our hearts and minds. They work their way into

"... one's reveries or idle thoughts, even one's moods and dreams"[7(p104)] as well as one's thinking. They force us to respond as human beings.

Theories of adult learning offer an academic rationale for the inclusion of individual family stories in professional preparation. Studies of adult development suggest that adult thinkers take their own subjective feelings and personal experiences into account when confronted with new ideas and try to engage in active dialogues with the multiple perspectives presented in an effort to form a personal understanding of the material.[12] Stories easily lend themselves to such a process. Their personal nature allows students a chance to take into account their own subjective feelings and personal experiences. Older students in our classes tend to relate the particulars of the family stories they listen to in class to themselves and to the families with whom they have worked. For them, listening is an interactive process in which they as listeners interject their own views and expectations as they try to make sense of the storyteller's perspective.[13] Younger students find stories to be a source for broadening their experience base. For them, the families who tell their stories become new acquaintances, contacts, people in their lives, in short, new sources of knowledge about life. For both types of students, stories offer active engagement with ideas and concepts as they force the audience to try and make sense of what they hear

or read in relation to their own views and experiences. Such endeavors naturally lead to learning.

Stories Provide Multiple Realities. Jerome Bruner's explanation for the power of stories offers further evidence for their role in training. In Actual Minds, Possible Worlds, Bruner claims that narratives are the result of a different kind of cognitive functioning, one that helps us order our experience and construct reality as much as a well-formed argument.[5] While stories are not believed in the same way theories are, they do help adults know the family in yet another way, from a different perspective, as a different reality. Thus, training sessions that focus on family stories provide students with not just a break from abstractions and theorizing about families but rather a chance to understand human experience in a new way. For some learners, that might mean access to a family perspective, for others, it offers a broadening of their understanding of the meaning of family perspective. Given the new research on women which suggests that women use multiple approaches to knowing,[14,15] it may very well be that our use of family stories is effective because it provides adult female students (the majority of students in this field) with reason to satisfy their need to understand the opinions and beliefs of others.

Stories as a Training Tool

Underlying family-centered training is an assumption that children must be viewed within the context of their families if appropriate educational, social, and therapeutic services are to be provided and that families must be empowered members of the service delivery team if intervention is to have lasting effects.[16] Several years ago, we began to infuse this family systems perspective into the courses we teach and required our students to have direct contact with families as well as children in their practicum experiences. Recognizing that promoting a family perspective would require more than discussion about and direct contact with families, we began to experiment with other strategies aimed at sensitizing students to the family perspective and helping them feel more comfortable in collaborating with families, including the use of stories.

Our informal analysis of the inherent power of stories in teaching a family perspective to prospective early childhood special educators has led us to think more specifically about the meaning of caring in the profession. We believe stories have been effective tools for us because they are constant reminder of the fact that we are in the business of improving the human condition.[17] Specifically, we think family stories enabled students, and forced us as instructors, to do three things: to make connections between theory and practice, to give meaning and purpose to our efforts and to challenge our assumptions about family/professional collaboration.

Making Connections. Because individual family stories tell of real people in real situations faced with real dilemmas, they more closely approximated the day to day clinical experiences of students. Textbooks, films, lectures cannot adequately portray the complexity of everyday professional interactions with families. The stories to which students listen in class or read at home were very much like the experiences of the families with whom they were working in practicum settings. The professional/family relationships highlighted in the family stories stemmed from a web of interlocking variables and never suggested simple resolutions. In that respect, they were much like the relationships students were experiencing as prospective professionals: full of emotion, dilemmas and complexities. Stories, like hands on experiences, forced students to test out their own thoughts about the issues and to grapple with alternative points of view.

Family stories helped students make connections between theory and practice in another way as well. Just as individual children and families in the world of practice evoke emotion as well as generate thoughts in professionals, stories call up feelings as well as ideas. When ideas and concepts are connected to real people in real situations, students are aroused emotionally and stimulated cognitively. They feel compelled to consider how they might act in similar situations in addition to what they think about it. The need for action encourages them to learn more. For example, students have

shared with us the importance of real family stories in relation to their understanding of family systems theory. Many tell us that the individual family stories they became familiar with in class helped them to understand and see the need for the abstract notions of family dynamics and social ecology they read about in their textbooks.

Through stories, our students recognized the need for knowledge and theoretical frameworks as a source of understanding and a basis for action in helping families. They linked course concepts like intrafamily resources and family functioning style to real practicum experiences with family assessments, interventions and communications. The parents they heard in training became voices who would help them make choices about professional/family practices later.

Giving Meaning and Purpose. The human connections made from the sharing of family stories also give meaning and purpose to professional practice. Lectures and texts fail to remind us sufficiently that families and children are the reason for work in the helping professions. In courses, we become caught up in the theories and abstractions of best practice that inform our professional work. In supervision of practica, we focus on the prospective practitioner's developing clinical skills.

A number of professionals across disciplines, including Robert Coles,[7] have suggested that a certain quality of attention in seeing

and hearing clients enables the professional to serve his/her clients well. They suggest that to help families and children, we need to attend to them as individuals, not as representatives of the theories or concepts we use to understand them. We need to look at and listen to them in a distinct way. In Margaret Buchman's words, ". . . really looking, in an effort at acknowledgment and just discernment that stops us in our tracks and grants the other person as much reality as we and our projects have to ourselves."[11(p494)]

Training prospective professionals to attend in such a way to those they are helping requires teaching something of the real quality of human nature. It is a difficult goal for training, but one we believe can be fostered through the use of real family stories. The sharing of individual family stories is one means of continually arousing student awareness of and exposure to the essence of their profession. While not a substitute for actual collaboration with families, it has potential for developing in students a habit of mind that will enable then to learn from the people they serve in the same way that Coles speaks of learning from his patients as a student of psychiatry. "The people who come to see us bring their stories. They hope they tell them well enough so that we can understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story."[7(p7)]

While individual children and families are ever present peripherally in our thinking about professional work, it takes situations

of a different sort, like the occasion for telling and listening to stories, to put real human beings at the center of our attention. Individual family stories when told directly by those who experienced them serve as vivid reminders of what the helping professions are all about. The nature of the stories families tell make it difficult for us to fit them neatly into our conceptual frameworks or to interpret them simply as variables in an analysis. Just as characters in a novel help us to understand our shared humanity, families who tell their stories remind us persuasively of the immediate purposes of our work. They force us to move away from general hypotheses and try to understand unique perspectives; they offer us a view of families not readily available in other training efforts.

Teaching and learning the legal and ethical rights of families is a case in point. We attribute our students' strong belief in family rights as much to family stories told by those who had to fight for services for their children as to any rights training workshops that we might offer. A consistent theme in many of the family stories shared with our students has been the strong desire of families to be a part of their children's educational decision-making process. It was the voices of these individual families that convinced students of family rights in this arena.

Challenging Assumptions. In addition to connecting knowledge and skills to real world practice and giving meaning and purpose to professional action, stories can challenge us to think through more

carefully our underlying assumptions about the people we serve and the practices we employ. Listening to a family's experiences with another professional can shed light on our own behavior and force us to rethink the approaches and strategies that we use. It can also make us more conscious of the subtle implications in the ideals we espouse. Herein lies another benefit to the use of stories in preparing prospective professionals. Not only are individual family stories "chunks of reality" to appreciate and ponder, they also become food for thought about current practices in our field.

As professionals, we learn to rely on established patterns of behavior, "tricks of the trade", which we acquire through successful interactions with families over the years, some of which may need revision. Further, we may be so passionate about the effectiveness of these practices that we overlook any unintended drawbacks that may accompany them. However, it only takes one family's recounting of a negative experience with a practice or policy to force us to rethink our position more carefully. Thus, individual family stories can contribute to our understanding of special education practice by elucidating and defining problems in them for us. Professionals need to listen carefully to the families served to learn about the real consequences of their actions. Robert Coles suggests, ". . . the ultimate test of a person's worth as a doctor or teacher or lawyer has to do not with what he or she knows, but with how he or she behaves with another person, the patient or student or

client."[7(p119)] Learning to attend to, listen and learn from individual family stories is one strategy for helping prospective professionals learn the importance of caring in practice.

Recently, one student explained that listening to a particular family's story forced her to think about IEPs from a family perspective and to rethink whether or not she was doing the right thing by merely asking the families with whom she worked to approve documents she in fact had drawn up. She and others of us can learn from listening to families and adapt our practices accordingly.

Strategies for Using Stories in Training

The following instructional strategies are examples of how we have incorporated family stories in our curriculum. In coursework, at supervision meetings and during day-long workshops students in our programs are exposed to individual family stories in various ways and degrees.

Family Members as Speakers. While family members are often invited to speak in college classes, at conferences and through book chapters, they are usually asked to do so in light of a particular topic or experience. We too have asked parents to share their perceptions of the parent role on an IEP/IFSP team or to discuss the ways in which a disability impacts the whole family or to suggest what professional practices they have found to be supportive for their family. Colleagues have asked family members to lead workshops on

writing IFSPs while publishers request others to write about building parent/professional relationships.

Less likely, however, are parents asked to tell their family's unique story as a simple chronicle of their experiences -- with freedom to include or exclude information and incidents as they choose and with a sense that in and of itself, the story is worth telling. Less often are family stories considered data for professional learning or documentation of current professional practice. In our preparation programs, we do try to include individual family stories throughout training because we believe them to be relevant to the kind of individualized, interpersonal, family-centered interactions likely to be demanded of students later.

We have found that establishing an informal atmosphere, having refreshments and assuring family members that they have important and worthwhile information to share facilitates interaction between families and students. Whenever possible, we give family members honoraria for their participation and include two or three families to make sharing a more comfortable experience. Family members who have participated in these sessions have given us feedback about how helpful it was to hear other parents or brothers and sisters and some have made new friends through this experience. At times, families have been invited back to up-date us about what is happening in their lives. Arranging these class sessions, often holding them in evenings to accommodate the schedules of families, is time

consuming and sometimes a little anxiety producing. Will this parent have something to tell us? Will this brother or sister become intimidated and not talk? However, we have never been disappointed - each experience has been unique and valuable in and of itself. We recommend that the effect of live speakers cannot be surpassed, however we have also video-taped presentations to be used at later times - a different, but also useful experience for students.

Parent Advisor. A unique strategy for providing a family perspective to our training is the use of what we have called a Parent Advisor. The Parent Advisor is the parent of a child with a disability whom we have hired as a temporary or adjunct faculty and is available to both students and faculty. As faculty we have used the Parent Advisor to assist in planning courses and experiences for students. She has been particularly helpful in arranging for family members to share their stories with us. In an introductory course, the Parent Advisor allows students to get to know one family in-depth by sharing her family story, a story that includes the birth of her second child, her concerns about his early development, the discovery and diagnosis of his deafness and its subsequent impact on her family's life. As follow-up, she also attends later sessions of other required courses to update students on changes in her family and to provide feedback related to discussion of specific topics such as the role of the parent in the assessment process or a parent perspective on service coordination. This individual has become a sounding board

for us that has heightened our sensitivity to what a family-centered perspective really means. The Parent Advisor has described her experiences with us a learning experience that has provided her with a wider perspective, beyond her own, about the experience of families with children with disabilities and has allowed her to take on advocacy roles for other families.[18] We believe that the use of a parent advisor can be a very beneficial way to use a family story for a variety of purposes.

Family Situation Studies. In group supervision meetings for students in practicum, we have used family situation studies based on real family experiences to facilitate dialogue among students as they share similar challenges as prospective professionals. As their clinical experiences increase, students are often asked to bring in vignettes of personal work with families that has been difficult for them. In the discussions of either the case studies or personal vignettes, the emphasis is primarily on understanding the situation from the family's point of view and secondarily for purposes of brainstorming intervention strategies for students to use. This is yet another way that family stories can be incorporated in the curriculum. The current interest in the case study method for teacher education is an exciting development in personnel preparation. Specific resources are available for using case studies for training related to the implementation of family-centered services in early childhood special education.[19]

Family Stories in Literature. Literature has become another source of individual family stories in our programs. Students read a number of published family stories throughout their training. In required courses and seminars, we assign books and articles written by family members of children with disabilities, in addition to the usual texts and research studies. We have found Jane Bernstein's family story, Loving Rachel, (Boston: Little Brown, 1988) to be particularly effective for illustrating a family systems perspective for understanding the effect of disability on the family. Students are asked to read this book and analyze the family structure, subsystem interactions, family resources, and coping strategies of family members. The following books have also been used and we have found them to be excellent sources of in-depth, intimate accounts of parenting a child with a disability:

Dorris, Michael. (1989). The Broken Cord. New York: Harper Row

Kaufman, Sandra. (1988). Retarded Isn't Stupid, Mom! Baltimore: Brookes.

Kupfer, Fern. (1982). Before and After Zachariah. New York: Delacorte Press.

Massie, Susanne and Robert. (1966). Journey.

Park, Clara Calirborne. (1967). The Siege. Boston: Little Brown.

In addition, the Exceptional Parent magazine has been a source of brief, but poignant articles written by mothers, fathers, brothers and sisters, and grandparents. The vignettes printed there often express alterative points of view that might be left untold by professionals in the field. Family stories depicted in books and articles help students to understand their prospective professions more fully.

It is important to mention here that students are guided by questions or instructions as they listen to or read individual family stories in order to facilitate their interpretations of the stories and to maximize their learning from the story. Furthermore, time in class or during seminars is devoted to debriefing and reconstructing any individual family stories told or read to aid students' understanding of the messages within them. Students are encouraged to share their perceptions of the stories with others who heard or read them outside of class. This dialogue among the listeners/readers is as important to learning from family stories as the interactions between storyteller and audience.

In summary, we believe the use of family stories to be an effective element in a training program that provides a family-centered perspective to professionals who will be working with families of children with disabilities. Exposure to family stories also heightens our awareness of the importance of caring for the individual families and children with whom we work. We would suggest that listening to

family stories should be extended beyond pre- or in-service training and could also be used to evaluate what we are doing and how our interactions with families effect them. Listening to family stories is an important learning tool for determining best practices, evaluating program impact and answering important research questions.

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