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ABSTRACT

This paper presents two versions of a "story" about a man with severe mental retardation, one from an interdisciplinary team meeting reviewing progress and service needs, and the other prepared by a group of people who know and care about the man and his family and who sought a better response to his situation. The stories differ in the way they were constructed, in their purpose, in their consequences, and in the assumptions they shape about human development and human service organization. The first version assumes that professional people who share very little of the man's daily life can speak the most important words about him, that the man remains the same person in every situation, that the man will be helped if his deficiencies are exhaustively cataloged, that human services exist to change the man, and that reliable and effective service results from hierarchical structures controlled by rational argument among experts who find preexisting answers by standard examination. The second version was used as the basis for discussion in a personal futures planning meeting in which several people took personal responsibility for action steps. It assumes that the man himself and those who share and shape his daily life should be the primary speakers; that his life can only be understood in context; that capacities, interests, and preferences make the foundation of effective help; that human services exist to assist the man by supporting him, his family, and his friends to develop and pursue community opportunities; and that reliable and effective service results from collaboration across organizational boundaries influenced by shared visions and shaped by negotiation of multiple differences. The paper concludes that individuals in the developmental disabilities field must learn to listen to, to tell, and to act on stories whose theme is action to discover capacity. (14 references) (JDD)

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TELLING NEW STORIES: THE SEARCH FOR CAPACITY AMONG PEOPLE WITH SEVERE HANDICAPS

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Telling New Stories

The Search for Capacity Among People with Severe Handicaps

John O'Brien & Beth Mount

Consider these two stories:

I

Mr. Davis has a mental age of 3 years, 2 months. IQ = 18. Severe impairment of adaptive behavior, severe range of mental retardation. Becomes agitated and out of control. Takes [medicines] for psychosis.

Severely limited verbal ability; inability to comprehend abstract concepts. Learns through imitation. Has learned to unlock the Coke machine and restock it, and to crank a power mower and operate it.

His family is uncooperative. They break appointments and do not follow through on behavior management plans.

II

Ed lives with his mother and sister in [housing project]. Ten of his relatives live near by and they visit back and forth frequently. His father spends little time with him, but two of his sisters have been very helpful when there are crises. His family agree that he will live with one or another of them for the rest of his life.

Ed is at home in his neighborhood. He visits extended family members and neighbors daily. He goes to local stores with his sisters and helps with shopping. He goes to church.

Ed dresses neatly, is usually friendly, and shakes hands with people when he meets them. He is a very big man, with limited ability to speak. When he gets frustrated and upset he curses and "talks" to himself in a loud voice. These characteristics often frighten other people who do not know him well. He has been excluded

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from the work activity center because he acts "out of control" there. He has broken some furniture and punched holes in the walls there and scares some of the staff people very much.

Ed likes people and enjoys visiting in the neighborhood. He loves music, dancing, and sweeping. He likes loading vending machines and operating mechanical equipment. He likes to go shopping. He likes to cook for himself and for other people and can fix several meals on the stove at home. He likes to hang clothes and bring them in off the line. He likes to stack cord wood and help people move furniture. He prefers tasks that require strength and a lot of large muscle movement.

Both of these stories were told to help the same man. But they differ in the way they were constructed, in their purpose, in their consequences, and in the assumptions they shape about human development and human service organization. The group that constructed the first story speaks a different language from the group that enacted the second story.

Contrasts

	<u>Story I</u>	<u>Story II</u>
Why?	• Plan on paper in routine compliance to regulations.	• Plan in action in response to real changes in the person's life.
By whom?	• Written by professional team; person & family members uninvolved.	• Developed through problem solving by voluntary group that knows & cares about the person with person, family members, family friends, & service workers directly involved.
What content?	• Defines service objectives based on evaluation of person's deficiencies.	• Creates neighborhood opportunities based on person's capacities & interests.
What roles for service & person	• Service options & organization seen as constant; service mission is to change person to fit service environment.	• Service workers change their schedule, location, & focus of work to partially assist person to make use of opportunities.
What risks for person?	• Risk of exclusion from community & institutionalization. Missed opportunities for skill development due to irrelevant programming.	• Risk of neglect of support to person & family. Missed opportunities for skill development due to lack of contact with professionals.

An interdisciplinary team told the first story in its required annual review of Mr. Davis' progress. They integrated data from psychological, social work, nursing, speech therapy, and occupational therapy assessments with data about Mr. Davis' performance in the day program. They determined objectives for the next year, recommended additional therapy services, and made a placement recommendation. The team was uncertain about the extent to which Mr. Davis' behavior problems are an expression of psychotic illness and agreed to seek a psychiatric evaluation to settle the question. Mr. Davis was not at the meeting because he had acted out violently that day and staff had sent him home to his mother in compliance with the team's behavior management plan. Though the social worker sent an invitation, no one from his family attended. The meeting took twenty minutes.

A group of people who know and care about Mr. Davis and his family told the second story as part of a collective search for a better response to his situation. The day program director, a friend of Beth Mount, asked her to meet Mr. Davis and his family because he was concerned for Mr. Davis. Beth helped Mr. Davis's mother and sister and two direct service workers organize a personal futures planning group (see the box on the next page for a brief description of the personal futures planning process). Concerned staff people from the day program joined Mr. Davis, members of his extended family, neighbors, and church members at the family's church on a Sunday afternoon. They told stories about Mr. Davis and his family, expressed their concerns for his situation and their ideas about his future, shared information about opportunities in the neighborhood, and came up with suggested next steps. Several people, including program staff, took personal responsibility for action steps and agreed to meet again to review progress, without the facilitator. The facilitator recorded the meeting on large posters, using color coded graphic symbols and quotations from participants. Mr. Davis sat with one of his sisters during the meeting. He asked for, and carried home, the poster that described the group's ideas about his fu-

ture. The meeting took two hours.

Personal futures planning

Personal futures planning is an ongoing problem solving process that begins when a group of people agree to meet and to work in support of a focus person. The process keeps the person at the center. Group members guide the action by a vision of the focus person's gifts, capacities, and interests shared by the focus person and those who know the person best.

Understanding the person's capacities leads to a search for opportunities and resources in their community. Overall, the aim is to strengthen the person's connections to the web of relationships and associations that create community. In this effort, human services assist people as they need assistance to be part of ordinary neighborhoods, workplaces, schools, and community activities; human services do not provide opportunities as a substitute for community.

A personal futures planning group's efforts are organized by personal commitments to take action with or for the person. Many groups find it helpful to set down a personal futures plan which records their account of the person's current reality and vision as well as their choice of strategies. Like any creative action process, personal futures planning groups can benefit from the facilitation of someone with skills in helping people express a vision and make plans to move toward it. But an effective group avoids the trap of making a facilitator into the group's manager.

The group meets from time to time to

- clarify understanding of person's vision**
- share information on opportunities and obstacles**
- develop strategies for moving toward the vision with the person**
- analyze and solve problems.**
- offer mutual support and celebrate positive changes**

For more information about personal futures planning, see Mount and Zwernik (1988), Mount (1987), and O'Brien (1987).

Different Purposes

Professionals told the first story in compliance with state regulations in order to control the routine work of direct service staff. Their story justifies Mr Davis' eligibility for the program and the program's responses to his problem behaviors. It takes existing service arrangements as a given.

People who know Mr Davis and his family told the second story voluntarily in order to discover actions that will reveal capacities in him, in the people who care about him, and in his neighborhood. Their story justifies action to expand his opportunities and learn better ways to support him. It calls for changes in existing service arrangements from the time and place of planning meetings to the mission and activities of the day program.

Different Consequences

The people who told the first story selected objectives for Mr. Davis which would increase his time on task at the assembly contract the center works on, increase his accuracy in performing a letter folding simulation to improve his small motor coordination, and ready him to prepare meals by identifying menu items from pictures of the four food groups. Noting an increase in his problem behavior, they recommended his admission to a psychiatric hospital for evaluation and mental health treatment. Noting his unmet need for speech therapy and his mother's difficulty in following through on required programs, they recommended post psychiatric hospital placement in the regional mental retardation institution for intensive training. While the plan arising from their meeting was being typed, Mr. Davis was excluded from the program in response to staff concern for their safety and the safety of other clients.

The people who told the second story responded to their account of Mr. Davis' preferences and neighborhood resources to deal with the idleness resulting from his exclusion from the day program and the threat of institutionalization. They decided that he preferred hard physical work and work with machines to sedentary tasks requiring fine movements. Within three days, one of his sisters and a direct service staff person had developed an opportunity for him to load soft drink vending machines at three convenience stores in his neighborhood. Within two weeks another sister and a neighbor had begun to create a schedule of lawn mowing, fire wood stacking, and yard work that he and one of his cousin's could share, with occasional assistance from a center staff person. They

recognized his ability to help out at home and encouraged his mother to increase her expectations of regular and reliable performance. They acknowledged that he was a welcome visitor in many neighborhood homes and shared what they had learned about how to understand his communication and deal with his occasional episodes of talking to himself and blowing off steam. They agreed that there was no reason for Mr. Davis to go to the psychiatric hospital or the mental retardation institution.

The tellers of the second story did not aim for perfection, nor have they achieved it. Three years after this process began, Mr. Davis still loads machines and does outside work daily, but these activities do not add up to a full time job and he receives very little cash for his efforts. He remains active and helpful around his house and among his neighbors. He has had no help to improve his ability to communicate, though there have been several unproductive referrals. He continues to talk to himself but has not had a frightening episode in more than a year. A number of the people who gathered at the first meeting still meet regularly to share what they are doing and learning about Mr. Davis and what they might do together next.

Different Assumptions;
Different Organizations

Think for a moment about organizations as systems for interpreting their own actions and their environments (Daft & Weick, 1986): as a set of processes for telling stories about...

...what has happened in and around the organization

...what events mean to organization members

...what to do next

Assumptions about effective organization and human development shape, and in turn are shaped by, the ways human service organizations make sense of their world.

The first story assumes that professional people who share very little of Mr. Davis' daily life can speak the most important words about him. These words

have power because they are objective data, the (often quantitative) results of scientific procedures. Things will be better for Mr Davis if he, his family, and direct service workers, non-experts all, listen to and obey professional plans. The second story assumes that Mr Davis himself, and those who share and shape his daily life, should be the primary speakers. Knowledge and the power to effectively bind action arise primarily from personal commitment, careful listening, and shared action. When available technology is insufficient to cure, the role of experts is to listen and cooperate.

The first story assumes that Mr. Davis remains the same person no matter where and how you meet him. What needs to be known about him is disclosed by viewing him in isolation from his social context (Sarason, 1981). His measured intelligence fixes his potential for development unequivocally and dictates his future (Could, 1981). The second story assumes that Mr. Davis' life can only be understood in context. He is both unable to meet the prerequisites for cooking and able to fix meals. He is both dangerous and friendly. He is both "that big crazy boy" and a welcome guest in some people's homes. He is both unable to speak and a dancer. His potential for development is the product of his efforts and the efforts of his allies and assistants (Bronfenbrenner, 1977). He can only be revealed when people join with him to create his future. In this sense his potential is unknown and unknowable apart from action what he and the others he relies on decide to do together.

The first story assumes that Mr. Davis will be helped if the tellers exhaustively catalog his deficiencies. Their conversation is dominated by what he can't do, what he won't do, and why he doesn't. The second story assumes that capacity, interest, and preference make the foundation of effective help. What he likes, what he wants to do, and his vocation among us centers storytelling and action.

The first story assumes that human services

exist to change Mr. Davis. Accurate classification leads to appropriate placement and good diagnosis leads to proper prescription. If Mr. Davis complies with the prescribed program, he will progress as far as he is able (Biklen, 1988). Services change by learning to do what they are doing better. The second story assumes that human services exist to assist Mr. Davis by supporting him, his family, and friends to develop and pursue community opportunities (O'Brien & Lyle, 1989). Services develop by learning to do new things in new ways (Argyris & Schon, 1978).

The first story assumes that reliable and effective service results from hierarchical structures controlled by rational argument among experts who find pre-existing answers by standard examination (Weick & Browning, 1986). Impersonal statements, standardized scores, quantified objectives, linear logic, and appeals to authority shape the organization. The second story assumes that reliable and effective service results from collaboration across organizational boundaries influenced by shared visions and shaped by negotiation of multiple differences. Answers don't preexist, they are constructed by the way people organize to find them (Maturana & Varela, 1980) and communicated in the narratives people share (Weick, 1987). Personal testimony, graphic images, shared food, music, laughter and tears, and creative action shape the organization .

New Directions:
New Stories

Raymond Kilroy, a wise and vigorous advocate for himself and other people with disabilities, gave testimony to the US Senate about his vision for himself and all people with disabilities (Kilroy, 1987). His vision compels attention to new directions for all of us.

We are moving away from emphasizing my needs toward building upon my capacities. We are moving away from providing services to me in some facility toward building bridges with me to communities and neighborhood associations. We are moving away from programing me and

other people with disabilities toward empowering us and our families to acquire the support we want. We are moving away from focusing on my deficits to focusing on my competence. We are moving away from specialized disability organizations so that we can develop and sustain relationships with people who will depend upon people like me and upon whom people like me can depend.

To move toward this future we must all learn to listen to, to tell, and to act on new stories, stories whose theme is action to discover capacity.

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