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# Participatory action research with adults with mental retardation : "Oh my God. Look out world."

Rita Marie Valade
*University of Louisville*

PARTICIPATORY ACTION RESEARCH
WITH ADULTS WITH MENTAL RETARDATION:
"Oh my God! Look out World!"

By

Rita Marie Valade, RSM
B.A., University of Michigan, 1975
M.S.W., Catholic University, 1982
M.A., Washington Theological Union, 1992

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A Dissertation Approved on

March 11, 2004

by the following Dissertation Committee:

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Daniel P. Wulff, Ph.D.

---

Ruth Huber, Ph.D.

---

Sally St. George, Ph.D.

---

Andy J. Frey, Ph.D.

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Nathan R. Sullivan, M.S.W.

**DEDICATION**

This dissertation is dedicated to all persons who have mental retardation and feel

that their voices are not heard. I pray that this research endeavor offers hope

and encouragement for persons to gather, reflect, and challenge structures and

systems that they experience as demeaning and oppressive.

**ABSTRACT**

Participatory Action Research with Adults with Mental Retardation:

"Oh my God!  Look Out World"

Rita M. Valade

May 8, 2004

This dissertation is a participatory action research project with adults with

mental retardation who reside in Louisville, Kentucky.   It explores some of the

history and ideologies that frequently have hindered persons with mental

retardation from being regarded by others as unique individuals with various

abilities.  It investigates dynamics of social ostracism and the resultant silence,

inclusive of the social work profession's relative absence in the field of mental

retardation.  Furthermore, it explores various aspects of research with persons

with disabilities, and with persons with mental retardation in particular.  While

there have been multiple studies about persons with mental retardation, very few

actually include their voices.  This dissertation attempts to offer a corrective to

this and offers persons with mental retardation a vehicle for their opinions,

actions, and voices.

A participatory action research design and methodology is offered

involving two phases of the study.  The first phase involves interviewing 25 adults

relative to their personal concerns of things they would like to see changed in

their lives. These interviews reveal that the adults' concerns are as varied as the individuals themselves. The second phase focuses on a ten-month process in which nine persons from the original 25 agree to commit to a group experience in which they decide upon a common issue, their structure, and other group needs. They then work together on how best to address the issue, enact their plan, and communally reflect upon the experience. This group decides to focus on the paratransit system in Louisville and through a process of hard work and commitment, decide to invite the director of the system to attend to their group meeting as the focus of their action. The director attends their group, answering their questions and engaging in an extended conversation about their concerns. The dissertation includes a session-by-session reporting on the group gatherings, in addition to insights gained through facilitator's peer supervision experience. It concludes with reflections on the applicability of PAR in social work practice settings and future research needs.

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# CHAPTER 1

# PROBLEM STATEMENT

Persons with mental retardation are fully human persons. All possess unique constellations of personality traits, physical and emotional characteristics, ideas, personal history and context that taken together, shape them. Similar to the rest of humanity, they possess strengths and weaknesses. The reality is however, that because their less developed ability resides in their cognition, their sense of personhood has been questioned throughout the years (Castles, 1996). Engaging in a participatory action research (PAR) project with adults with mental retardation however, promotes a different vision: one of persons actively engaged as they identify and address a problem that concerns them toward the goal of enhancing the quality of their lives.

As a means toward this vision, this dissertation will address some of the history and ideologies that frequently have hindered persons with mental retardation from being regarded by others as unique individuals with various abilities. It will further explore dynamics of social ostracism and the resultant silence, inclusive of social work's relative absence in the field of mental retardation. It will also address various aspects of research in general and with persons with disabilities in particular. A participatory action research design and

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methodology will be offered and the results of an eleven-month process will be shared.

This first chapter will explore the importance of paradigms as they permeate our perspectives and ways of being. Flowing out of this broad framework, various elements that impact specifically upon persons with mental retardation will be explored, beginning with the importance of cognition within our western mindset and intelligence as a social construct. A discussion of social ostracism of persons with mental retardation including the phenomenon of "othering" (Riggins, 1997) will follow. The power of language that shapes reality as a social construction, will then lead into some reflections on the collective silence of persons with mental retardation. In this light, as a source of knowledge, personal experience has tended to be minimized which enhances a reliance upon experts to inform and direct families of and persons with mental retardation. This background establishes the context and rationale for choosing to engage in participatory action research with adults with mental retardation.

### Paradigms

Paradigms are the accepted model or pattern through which we operate, organize and make sense of the world (Kuhn, 1962/1996). They are frameworks through which we both see the world and in turn, how this constructed world shapes what we see. They emerge out of socially accepted ways of being and in turn, foster these ways of being to the exclusion of alternatives (Kuhn, 1962/1996). They are composed of what we want to see, what we expect to see, what we hope to see (Gergen, 1991). The concept of a paradigm intimates a

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social constructionist perspective on knowledge and meaning. Knowledge is socially constructed in that it evolves through interaction with others (Berger & Luckmann, 1996; Gergen, 1999; Greene & Lee, 2002; Heron & Reason, 1997; Laird, 1993). Anything we know comes from within a context (Laird, 1993). Knowledge is never construed in a void. What we know, how we know it, and why we care to know something reflect the shared paradigm of our lives.

Lives are then organized around its basic principles, and interpretations are made according to what is experienced and seen (Bruner, 1990; Kuhn, 1962/1996). Paradigms let us know how to play life's game and how to be successful in it. If one does not follow the rules of a shared paradigm, then results could be said to be unsuccessful (Kuhn, 1962/1996). In other words, we are so shaped by our paradigms that whatever we determine as good or bad, adaptive or maladaptive depends upon the paradigm in which one is immersed (Gergen, 1991). Seeing what makes sense to us and what we perceive as truth and reality in turn reinforces the paradigm out of which we operate. And yet, it is exactly when pieces of data or results do not correspond to the expected, that over time, the paradigm begins to crumble and lose its dominance (Kuhn, 1962/1996). When pieces of the puzzle no longer fit in our paradigm, our eyes are able to discern other elements of life that went unnoticed before. A new paradigm then emerges, incorporating new interpretations and envisioning a framework that more successfully guides and predicts dynamics than the previous paradigm (Kuhn, 1962/1996).

Paradigms exist at various levels and are not clearly deciphered. There are personal paradigms, familial paradigms, professional and cultural paradigms, just to name a few. Like culture, we always see things edited by a definite set of customs and institutions and ways of thinking (Benedict, 1934) which is another way of conceptualizing paradigms. These ways of thinking are embedded deeply in us and are not trivial inclinations or opinions that, given new information, can quickly be changed.

Because of the strength of paradigms in our lives, when and if something is observed or experienced that does not fit into our operative paradigm, then it is generally suppressed, ignored, or made the exception because it challenges the expected (Heron & Reason, 1997; Kuhn, 1962/1996). For example, prior to meeting and befriending someone with a physical disability, the world may be experienced as inhabited by persons who are able-bodied, and those who have physical disabilities are seen as the exception and are marginalized. Once a person with a physical disability enters into one's life, the dominant paradigm is likely to shift. Accessible buildings, sidewalks and bathrooms become a priority regardless that the majority of persons who are able-bodied do not need them. Once considered exceptions to the rule, persons with physical disabilities become integral into a new paradigm of total accessibility of all persons to public buildings and facilities. In other words, to challenge the expected is to encourage a reconceptualization of the entire paradigm or pattern/system of understanding and behavior (Heron & Reason, 1997).

If an operative paradigm states that adults with mental retardation are "disabled," then the norms within the paradigm will support acting in accordance with this conceptualization. Important values within many countries (but clearly within the U.S. paradigm) are the ability to work and be independent (Bobo, 1991). Within this paradigm, existing social service institutions would focus upon the condition(s) that interfere with operationalizing these values. Research endeavors would focus upon the degree to which the identified condition impairs the individual and promotes or undermines the dominant paradigm. Because of the questions asked, the research results will reinforce the observer's perception that persons with disabilities have limitations and lacunae and these will then reinforce the paradigm (Heron & Reason, 1997).

An alternative to the dominant paradigm's approach might be to acknowledge and focus upon the wide range of abilities persons possess and not just focus upon cognitive abilities that impact employability, as is it is conceived in the present. Funding would follow the values of the paradigm. For example, job coaches for persons with mental retardation currently are available through the Federal Government's Department of Vocational Rehabilitation. To be successful, many persons with mental retardation may need job coach support longer than the prescribed six-month window. If the operative paradigm truly valued both persons with mental retardation (and others who would benefit from ongoing assistance) and employment, then the job coach system would be more fully supported, allowing for the individualization of services based on actual need.

## Cognitive Intelligence and Personhood

Western culture has been tremendously shaped by the philosophies of Plato and Aristotle who associated reason, humanness, and human value (Stainton, 2001). Building on the Greek tradition of the importance of logic and rationality, Cartesian dualism postulated envisioning the world in mutually exclusive categories such as mind/body and emotion/cognition. It became integral to the emerging Western paradigm of the rational mind as paramount in decision-making and culture shaping. Descartes' infamous summation of existence, "I think, therefore I am" (Copleston & Copleston, 1994) leads to the consideration that the ability to think rationally is primary when considering a person's existence. While this statement is provocative and articulates a truth within the dominant paradigm, it appears to limit existence primarily to cognition.

Other ways of knowing, such as emotions or sensation are minimized within the culture (Griffin, 1988). Knowing is an integrative and social process that involves the whole self engaged in feelings, emotions, memory, and a curious mind (Freire, 1998). While these other components of knowing are important (e.g., picking up social cues, ability to love and care for others) and interact with intelligence, it is intelligence that is accentuated. There are no social scales or assessments taken as seriously as intelligence quotients that assess cognitive abilities. A person's ability to love or relate are not considered within the dualistic Cartesian framework.

## Social Construction of Intelligence

Professionals interested in the study and treatment of persons with mental retardation at the turn of the 20th century struggled to devise methods of assessing cognitive abilities (Smith, 2000; Trent, 1994). Binet, a psychologist in France, arrived at a series of tasks and questions that when combined, offered objective, measurable and quantifiable results. However, he also insisted that rather than being static, intelligence was to be considered a flexible and adaptive process that could be further developed through a combination of good health and supportive educational structure (Wolf, 1973 as quoted in Trent, 1994). As the test and its revisions became more prevalent in the early 1900's until the present, the attitude toward intelligence as changeable and adaptive became replaced by an attitude that it was static, permanent, and absolute. What was seen initially as a helpful tool for educators to better teach, the I.Q. score became reified as absolute as it was envisioned as a totally objective truth (Trent, 1994). Accordingly, it was claimed that subjectivity played no role in the assessment process or results. The culture, expressive or receptive language abilities, dialect, or physical abilities of the person being tested or of the tester played any role in the final I.Q. score. The score was considered to be immutable (Trent, 1994).

Intelligence is socially constructed and relative, as are the means through which the levels of intelligence are assessed. What is intelligent behavior in one culture may be considered backwards in another (Nuttall, 1998). To emphasize

this point, Trent (1994) noted the relativism of intelligence categories within the North American culture:

In 1973, with the stroke of a pen, the American Association on Mental Deficiency changed the criterion for "mental retardation" from one to two standard deviations below the I.Q. norm. As the change in definition accompanied changes in consciousness and funding, many people who had been officially considered mentally retarded were by the end of the decade freed from the label and from the accompanying structures of state control. (p. 270)

According to the *Diagnostic and Statistical Manual* of the American Psychiatric Association (1994), there is a continuum of levels of cognitive impairments within our culture. There also appears to be a continuum of full personhood along similar lines as evidenced by the social ostracism and dehumanizing conditions that persons with mental retardation have endured throughout the centuries in the U.S. and other countries. These dynamics will be explored next.

### Social Ostracism

The history of the treatment of persons with mental retardation reflects an evolving ideology. Throughout the ages, persons with cognitive impairment have been regarded as deviants, idiots (Andrews, 1998; Howe, 1848/1993; Miller, 1996), feeble-minded (Gelb, 1995), imbeciles, asexual children (Denno, 1997; Taylor, 2000), and insane. Often, because Western philosophy has promoted rational thought as the unique characteristic distinguishing humans from the rest

of creation, persons with mental retardation have been likened to vegetables, animals, or sub-human. Many studies demonstrate how people with mental retardation or other disabilities feel stigmatized and rejected by society (Edgerton, 1967; Lynch & Hanson, 1992; MacMillan, Jones, & Aloia, 1974; Zetlin & Turner, 1984). In addition, according to Taylor (2000), people with demonstrable stigma are seen as "not quite human" and are often reduced in our minds from a whole and usual person to a tainted, discounted creature.

The ancient Greeks and Romans placed persons with disabilities on the countryside, left on their own to survive (Morris, 1986). Persons with disabilities have been noted in literature and history since the writing of Deuteronomy in the Hebrew Scriptures and Plato's *Republic*. The ancient Judeo-Christian tradition regarded persons with disabilities as indications of God's displeasure with the parents or the tribe. In the New Testament, people with mental or physical disorders were declared possessed (Mackelprang & Salsgiver, 1996).

Religious ideology continued to play a significant role in the theories of and approach to mental retardation. The etiology and treatment of persons with cognitive impairments often focused upon sin and grace, major themes prior to modernism. By nature, humanity was filled with corruption. This perspective traces back to the biblical story of Adam and Eve and the origins of the doctrine of original sin. Persons born into poverty and/or with disabilities were considered to be indications of God's displeasure with humanity, and perhaps the family/individual in particular (Axinn & Stern, 2001). In *The Causes of Idiocy* (Howe, 1848/1993) the author, a renowned social activist and liberal reformer of

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his day, articulated the prominent theory that idiocy could be eliminated in a few generations if people followed God's laws more faithfully.

By the 1850s, prior to the Civil War, a few special residential schools were developed to assist persons with mental retardation as a means to address "idiocy" as a social problem and to offer alternatives to jails and almshouses in which many were committed (Trent, 1994). This began the movement from living at home or within the local community towards institutionalized living. The goals of these schools were laudable: to train persons to return to society. Unlike the poor houses in which persons with cognitive impairments were often kept from society coexisting with persons who were simply poor, or were criminals or mentally ill, these schools attempted to help through skill-development and religious instruction.

Integral to this era was society's growing consciousness of and interest in claiming some social responsibility for persons who were vulnerable. The limited success of habilitation towards the goal of return to the broader community through gainful employment resulted in a shift in attitude that persons with mental retardation not only would be assisted in institutions, but that they should reside there apart from society. Persons with almost any form of cognitive, emotional, or physical impairment were considered unable to care or provide for themselves (Smith, 2000). In many cases this was true, but the societal attitude that persons with mental retardation should be protected and isolated from society helped to bring about the attitude that they are to be feared and society also must be protected from them (Mesibov, 1976). According to Trent (1994) due to a variety

of social factors, this fear of persons with mental retardation grew within society throughout the first half of the 20th century and was fueled by the professional world, shifting their approach to persons with cognitive impairments from that of "pitiable but potentially productive" persons of the antebellum years, to that of "menace of the feebleminded" in the early part of the 20th century:

By the First World War, the image of feeble minds created by professionals in the previous decades had shifted to a view of mental defectives that unlike previous views began to penetrate American consciousness. More than a shift of labels, the new term [menace of the feebleminded] suggested new meaning and the necessity for a new social response. The pitiable, but potentially productive, antebellum idiot and the burdensome imbecile of the post-Civil war years gave way to the menacing and increasingly well-known defective of the teens . . . was the increasing insistence that mental defectives, in their amorality and fecundity, were not only linked with social vices but indeed were the most prominent and persistent causes of those vices. Graduating from being merely associated with social vices to being their fundamental cause, mental defectives became a menace, the control of which was an urgent necessity for existing and future generations. (Trent, 1994, p.141)

For these reasons it was important to separate them from mainstream society. Some of this fear was reinforced by some of the directors of the large institutions operative at the time. The more persons these institutions cared for, the more powerful they became (Trent, 1994). Some of these directors

perpetuated and reinforced the attitude of the "menace of the feebleminded" as a means to increase the populations of their institutions (Trent, 1994).

As this separation between mainstream society and the institutionalized grew, so did theories supporting it. A common understanding of "feeble-mindedness" in the early 1900's was a theory called degenerationalism. This theory attempted to integrate religious creationism, the newly established discipline of psychiatry and evolutionary thought that resulted in a new classification of "moral imbecility." An indirect result of this was that people with mental retardation were stripped of their humanity and associated with crime and poverty. In essence, symptoms were confused with causes (Gelb, 1995).

Fear of "moral imbecility" and a growing sense of paternalism intermingled during this era resulting in a two-edged sword relative to care. No doubt many persons with cognitive disabilities suffered greatly when no caring assistance was available within society outside of their families. But on the whole, persons with cognitive impairment gradually lost any freedom of choice that had been afforded them prior to this era. Persons were placed and retained in schools/institutions regardless of their own desires. While these institutions were considered progressive in the latter half of the 19th century due to the shift from allowing persons with cognitive disabilities to fend for themselves, the treatment within these institutions was generally less than caring and person-centered (Axinn & Stern, 2001). Limited discrimination was made among persons with various impairments and the era of institutionalization began in earnest of all persons who looked or acted differently than what was considered normative.

Fearing reproduction of genetically imperfect and immoral persons, sterilization of women became normative by the 1920s (*Buck v. Bell,* 1927). By 1931, 27 states had enacted sterilization laws (Trent, 1994). Sterilization was a common procedure done mostly to women with mental retardation who lived in institutional settings until the 1970s.

This overview of some reference points regarding the treatment of persons with mental retardation was meant to make conscious the level of discrimination and prejudicial attitudes this population has borne over the years. Stereotypical and pejorative attitudes continue into the 21st century. Persons with mental retardation in the U.S. are often considered little more than perpetual children (Sulpizi, 1996), as persons to be pitied and granted charitable kindnesses (Goodley, 1997; Stainton, 2001) or aborted as fetuses (Stainton, 2001). Whether treated as children, deviants, imbeciles or criminally moronic, they are and have always been individually as diverse as the general population with needs, desires, dreams, and abilities. The struggle for full rights as human beings continues to this day.

### *Othering*

A related dynamic, othering, occurs as the result of being socially ostracized. "Othering" is a term used to express the reality of keeping oneself separate and distinct from another, as in observer and observed (Riggins, 1997). While it is used towards all groups, it is a term more frequently used in relation to a person or population considered to be of less value than the one making the judgment.

Persons who present as different from what is considered to be culturally normative tend to be grouped and sub-grouped according to the characteristic that distinguishes them from others: persons with mental retardation, fat people, tall people, homosexuals, Croatians, nuns, or animal lovers. As human beings, we tend to classify and organize our perceptions into categories in the process of integrating information (Gagne & Medsker, 1995). Patterns and commonalities are noted. Stereotyping and prejudice can also easily result. Differences can either be totally discounted (as when a personal characteristic does not fit the stereotype) or become the main focus.

Despite the far intellectual and functional ranges within the diagnostic label of mental retardation of the DSM-IV (American Psychiatric Association, 1994) persons with mental retardation have been grouped together en masse. This reflects the othering phenomenon that is institutionalized within our culture. "Outsiders do tend to perceive Others as a homogeneous category except for those few individuals who are known personally" (Riggins, 1997, p. 5). Grouping persons according to characteristics allows dismissal of their individuality and their voices.

Since cognition is highly valued in our Western society, it seems that those who do not fit intellectually into the societal norm become one-dimensional components of a large stereotypical pattern. In addition, all persons struggle with some dimension of life or expectations, but generally are viewed within the context of their entire range of abilities. If a diagnosis of mental retardation has been made, however, persons tend to be seen only as their category.

Individuality is discounted. It is as if the I.Q. score supersedes any individual constellation of gifts and struggles or their nuances. Assessments do not tend to be very individualized, thereby grouping persons according to their I.Q. scores, which in turn minimizes the rest of their personalities and gifts. In short, they become "othered" through the assessment results and are often known more by their label than their personal attributes (Castles, 1996).

### Language

Language is a powerful cultural medium. Once considered only a tool for communicating one's thoughts, the power of language to shape and alter our reality gives expression to cultural phenomenon and philosophies that permeate the words we choose (Derrida, 1995). Male-oriented, exclusive terminology meant to refer to all human beings reflects a philosophy prominent in society that being male is normative and being female is the exception. *Having* mental retardation expresses an attitude that mental retardation is a condition or attribute a person possesses, one of a myriad of possibilities that when integrated with others, constitute a unique and total person. *Being* mentally retarded intimates that one's existence, a person's *being*, is retarded. It has moved mental retardation from a condition to the person's essence (Castles, 1996). Persons with mental retardation do not tend to be viewed as persons with lives, but rather as their diagnosis. As a group, they have been the object of ridicule, pity, contempt, avoidance, and/or sympathy. Their diagnosis has been and continues to be heard pejoratively on playgrounds or street corners as

children or adults call each other "retarded" or " retard" when hurling insults. Having mental retardation clearly stigmatizes and therefore "others" persons.

Like many other linguistic nuances, the linguistic difference between *having* and *being* is rooted in a particular culture, within a specific local context that cannot be easily translated. Different languages have different idioms and phrases to express their experiences and philosophies. The speaker is more a conduit of the culture than an autonomous agent (Kvale, 1995). Language is both a carrier and creator of cultural mores (Lather, 1991).

As reflected by the language used, persons in comas or similar states, whose cognition has been undetectable by today's scientific methods, are often regarded as being "vegetables" or in a vegetative state. The choice of terms reflects the importance of cognition as paramount to personhood. If persons' cognitive abilities are determined to be less than the culturally determined acceptable range, then their personhood comes into question (Gruning, 1996).

### Silencing

Persons with mental retardation have struggled to find their voices and to have them heard. Since the 1970s and the advent of deinstitutionalization of persons with mental retardation in the United States, there has been a growing self-advocacy movement to promote the rights and citizenship of this population. It is a means through which persons are claiming their places in society (Wehmeyer, Bersani, & Gagne, 2000). Self-perception is integral to the advocacy approach with which persons with mental retardation engage. If persons perceive and experience themselves as victims of personal tragedy,

then their self-advocacy will follow suit. Their advocacy stance may plea for charity or pity. If however, individuals conceptualize themselves as intact human beings possessing rights and responsibilities, regardless of any particular disability they may have, their self-advocacy will reflect this perspective (Aspis, 1997; Goodley, 1997) and will raise the standard for assistance from charity to justice. To demand services based upon their rights as citizens not as persons to be pitied brings the conversation and subsequent activities into a different light and will elicit a different level of response. Pity and charity tend to lead to temporary measures. The self-advocacy movement continues to gain momentum among persons with mental retardation and with strong endorsement from other supporters, encouraging and training persons to speak on their own behalf, whether it is in a mayor's chamber or to a care provider (Amado, 1996; Cone, 1999; Miller & Keys, 1996; Mitchell, 1997; Wolfe, Ofiesh, & Boone, 1996). Claiming their rights as citizens can lead towards a consciousness and paradigm-jolting reaction that may result in a law as pivotal as the Americans with Disabilities Act of 1990.

The Americans with Disabilities Act of 1990 (ADA) is evidence of the growth of the disability movement and its collective voice. This law prohibits discrimination of people with disabilities (including mental retardation) relative to employment, public accommodations, transportation, and telecommunications (U.S. Department of Justice, 1990). The Olmstead decision (*Olmstead v. L.C. and E.W.*, 1999) interpreted Title II of the ADA. It requires states to administer their services, programs, and activities in the most integrated setting appropriate

to the needs of qualified individuals with disabilities. This was an important decision for persons who advocated for an increase in funding and support for community-based services.

But even within the disability rights movement, persons with mental retardation are relatively silenced as a group. They are not as claimed within the disability movement as are those primarily with physical disabilities (Chappell, Goodley, & Lawthom, 2001; McClimens, 2003). Physical disabilities often do not impair intellectual functioning and in this way, do not challenge the concept of personhood. McClimens (2003) poignantly reflected, " . . . the battle to assert their humanity" (p. 40) was the primary challenge for persons with intellectual disabilities within the disability movement.

Another aspect of silencing occurs subtly because the majority of adults with mental retardation live within their family of origin (Smull, 1989). It is generally assumed that adult children with mental retardation living with family members are receiving the care necessary for a quality life and that their needs are being met. However, it is also not unusual for adults with mental retardation to feel overprotected, perceived as immature, and/or infantilized (Blum, Resnick, Nelson, & St. Germaine, 1991; Resnick, 1984; Sulpizi, 1996) as long as they reside with their parents. There have been numerous studies on the effects of parents and families as primary caregivers of persons with mental retardation (Hayden & Goldman, 1996; Hayden & Heller, 1997; Heller, Hsieh, & Rowitz, 1997; Mahon & Goatcher, 1999; McDermott et al., 1996; McDermott et al., 1997; Pruchno & Hicks, 1999; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997) but

few studies focus upon the actual family members with mental retardation. This reality seems to be an apt metaphor for the silencing of persons with mental retardation: many conversations around and about them, fewer listening to their voices directly.

The silence of the voice and experience of persons with mental retardation is operative in research as well. In general, while studies about mental retardation are legion and impossible to count, very few report on the actual opinions, desires, or experiences of persons with intellectual disabilities (Hagner, Helm & Butterworth, 1996; Heller, Pederson & Miller, 1996; Lloyd, Preston-Shoot, Temple, & Wuu, 1996; Sample, 1996; Ward & Trigler, 2001). A book titled *Doing Disability Research* and published by the Disability Press in Leeds, England in 1997 (Barnes & Mercer, 1997) demonstrates this point. It is a very fine compilation of qualitative research studies with some of England's strongest researchers in the area of disabilities. Of the 13 chapters, most of them research reports, only one is related to persons with learning difficulties/mental retardation and this focused on the children of parents with learning difficulties/mental retardation. It was clearly a valid study in its own right. However, the voices of persons with mental retardation were not heard, only their children. The discussion of this book here is to reiterate the points that mental retardation is not as claimed within the disability movement as are other disabilities, and that even a book focused on researching people with disabilities does not directly engage persons with mental retardation. Their voices are unheard.

Even fewer studies include adults with mental retardation in the design and implementation of the study. It is not unusual to study a population without having them included in the design or have any say in the reliability of the results, trusting in the established norms for scientific studies to generate the validity needed. For a population that has been denied the fullness of their humanity, inclusion in mainstream society, and their voices, the moment is overdue to include them in as many aspects of the research agenda as is possible.

### Expert Approach to Services

Experts in the field, those with academic backgrounds schooled in the scientific and theoretical paradigm of their discipline, in combination with bureaucrats within the existing systems, have been the primary designers of social delivery systems (Allard, Howard, Vorderer, & Wells, 1999; Axinn & Stern, 2001; Trent, 1994). Good intentions and some best practice principles may have been the impetus toward development of the service, but like research, rarely were those most affected by the service consulted or included in the process of developing services (Gilson, Bricout, & Baskind, 1998; Trent, 1994). Recipients of a service may have been considered too subjective or ignorant to offer any valid input. In other words, one's life experience and insights were not highly valued.

It could be argued that this expert approach to services has flowed from a positivist life stance that has dominated the North American attitude toward science and research, and has ultimately affected social services. The positivist stance posits that valid knowledge is that which can be scientifically studied and

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mathematically determined (Maguire, 2000). Subjectivity, as in personal experience, is usually restrained and regarded as something to be avoided.

This dynamic has been true relative to the development of most social services focused upon the needs of oppressed and poor persons (Axinn & Stern, 2001). It is definitely the case for persons or families of persons whose cognitive abilities are less than that which is considered normal. To offer valid input into their own care would be unthinkable (Trent, 1994). Allard, et al. (1999) reflected upon this dynamic.

> Psychiatrists knew best, and their advice and experience influenced the developing system of services. As new professions developed to respond to the needs of people with retardation, they were guided by the philosophy of the time: that professionals, particularly doctors, knew best about working with people with retardation, that parents had no particular wisdom to offer, and that people with retardation were passive recipients of services designed and provided by others. To view parents of children with retardation as people with rights was foreign; to consider that people with retardation had rights as unthinkable. (p. 77)

There are some serious consequences to this expert approach as illustrated through an informal conversation with two mothers of adults with mental retardation and the executive director of a residence for adults with mental retardation (B. Barrett, S. Esser, & D. Kern, personal communication, July 15, 2003).

The first consequence of the expert-approach is the unintentional undermining of family supports and the knowledge that families possess about their family member with mental retardation. We all have different needs at different times. Whether it is carrying something heavy, writing a complex proposal, or grieving the loss of a loved one, we all benefit from assistance and support. Likewise, persons with mental retardation generally benefit from supports that assist them on an individual basis according to their unique needs (Wehmeyer & Patton, 2000). In this light, it is a misnomer to speak of services to or with adults with mental retardation without some consideration of the depth of dedication that families or other significant relationships have demonstrated over the long haul in the individuals' lives. In many respects, both the individual and the family are an integrated support system for themselves and a system in need of support from the larger service delivery system (Turnbull & Turnbull, 2000). The discourse in the field of mental retardation services promotes an equal partnership between service providers and persons with mental retardation and their families (Cooney, 2002). However, rhetoric and reality often conflict. As Deborah Kern, MSW, the executive director and service provider shared in our conversation,

> The reality is, however, this does not seem to happen on a regular basis. There is initial talk of partnership, but it usually ends up that the professionals have more authority and the families defer. Then the families get confused because the professional often seems to have a hidden agenda, whether it is philosophy or treatment approaches, lack of

follow-through or some other personal style that results in the family and the individual trying to get their bearings from yet another professional perspective. (D. Kern, personal communication, July 17, 2003)

As a parent shared, "You have to learn how to dance to their tune. If you try to advocate for your child, then you can become known as a 'problem parent'" (Sandy, personal communication, July 17, 2003), thereby fearing that your child's funding could become jeopardized.

The concept of "social credit" then arises. Those families and/or recipients of services who are liked and easy to work with can risk some level of advocacy on their behalf without great fear of losing the funding stream. Those who have spent their "social credit" through asserting their needs or other methods may run a higher risk of losing services, being regarded as "non-compliant" or "difficult to work with." As funding is limited and each service has waiting lists, there is always a fear that if people complain too much, the service provider may find reasons to cease serving them (D. Kern, personal communication, January 19, 2004).

Persons who are considered to be experts (e.g. professionals) are given various levels of authority, particularly when they are the gatekeepers to funding. Both Sandy and Beth, parents of adults with mental retardation in Louisville, speak of their experiences of ultimately questioning their own observations, assessments, and knowledge of their children, whether as minors or as adults.

You are so vulnerable to people considered to be in power . . . the professionals in the field. You question your own abilities and that of your

child all the time. I can't tell you how many times I have felt incompetent in parenting because we have had so many different people tell me or us what we did wrong. (Beth, personal communication, July 17, 2003)

A second serious consequence of the expert-approach is the inflexibility of regulations without seeing the situation in full. The experts have the authority to enforce current regulations but not necessarily offer alternatives to remedy complex reality. When there is a poor fit between the services and the lived needs of the population, this expert-approach to service development and delivery tends to blame the population rather than adjusting the delivery system (Wright, 1993). The following story explicates this point.

Sandy told the story of a friend of hers, a single mother who has an adult daughter with cerebral palsy (CP) and mental retardation. Over the years, while working full time, this woman has successfully raised her children and her daughter with CP. The mother and adult daughter still live together. Within the past few years in order to keep her job, the mother has had to leave for work before her daughter was picked up by the city's handicapped-accessible transport system for her day program. The mother and the day program sought out early morning alternatives for the daughter but none were found. Both the mother and daughter had come to know and trust many of the drivers.

When the mother began to go to work before her daughter was picked up, an informal agreement was made between the drivers and both the mother and the woman with CP. The drivers would come into the apartment, help the woman with CP get on her coat, then bring her out to the van. This system

worked for quite a while until one day in July 2003, the van driver walked into the apartment as usual but found the woman struggling to get her pants on after a bout of diarrhea. Understandably scared of repercussions and false allegations, the van driver backed out the door, called the van company who in turn called adult protective services.

The mother was contacted at her job and an adult protective services (APS) investigation was launched. When the mother asked the APS caseworker about alternatives to leaving her daughter for a few hours alone in the mornings, the caseworker responded, "You made that decision when you decided to keep her." Both the caseworker's tone of voice and the words were devastating to the mother. The insult was leveled against the mother for choosing to not abort her child or place her in an institution. This represents an attitude that persons with special needs do not belong in the community, nor should the community have to provide for them. In other words, the caseworker blamed the mother for the existence of the woman with CP and the fact that she was living in the community.

The "expert" approach of the APS caseworker did not attempt to address the fact that the system was not sufficient or flexible enough to fully address the needs of persons with special needs and their families. The caseworker then sternly told the mother that she would be watched closely and that the consequences of any slip up on her part would not result in the daughter being taken from her, but in the mother going to jail. Through either angle, the mother and daughter would be lost to each other should the mother "slip up." This is an

example of blaming the population in need of services for the lack of fit, rather than adjusting the service delivery system to the real needs of the population the system is established to serve.

Another friend with cerebral palsy and mental retardation spoke of multiple incidents with the medical profession in which her self-knowledge was consistently disregarded. Unable to bend forward from her wheelchair or extend her arm without a strong assistant, she was chastised for not being cooperative with helping the nurse draw blood. Also, despite advance notice to the staff that she could not transfer onto an exam table, she was scheduled for her physical exam in a room unable to fit her wheelchair and without an adjustable exam table. The nurses blamed her. As she aptly stated to me, "I have mental retardation, but I am not dumb! I know my body." (J. Koch, personal communication, April 2, 2003)

While there are no doubt vast numbers of compassionate and helpful professionals involved in the service delivery system, there is often very little room within which they can adjust the structure of the system to help meet the real needs of the persons they desire to serve. In addition, these personal stories help demonstrate just some of the problems that persons with mental retardation and their families encounter in dealing with the current expert-oriented service delivery system in the United States. Minimizing the experience and personal knowledge of both individuals with mental retardation and their families, it is assumed that professionals are in charge and usually they have been given power to assert authority (Allard, et al., 1999). It is important that the

voices of persons with mental retardation can be heard more clearly and with respect. This research project aims to provide this opportunity.

### *Summary*

This chapter explored the power of paradigms and the role of cognition in the Western mindset. Some persons present with limitations in their cognitive abilities and as a result, are socially ostracized from mainstream society, are "Othered." Language as both a conduit and shaper of culture and attitudes was then discussed. The silence of this population's voices is experienced, among other ways, through the attitudes toward services for persons with mental retardation that have focused on the importance of the role of experts and minimized the role of the personal experiences of those most affected by the service. Having articulated some key elements that highlight the issues surrounding persons with mental retardation in our society, we will now move toward a deeper reflection upon situating this research project squarely within the realm of the social work profession and participatory action research.

# CHAPTER 2

## REVIEW OF THE LITERATURE

In the previous chapter, various dynamics were explored that when combined, situate persons with mental retardation within a paradigm that tends to exclude them from mainstream society. This literature review will explore in depth the social work profession's relative absence in addressing the needs of persons with mental retardation despite its commitment to persons marginalized by society. It will also investigate literature related to participatory action research, and research with persons with disabilities, specifically mental retardation.

### *Social Work Profession*

In this section, the profession of social work will be discussed in light of the needs of persons with mental retardation by exploring some of the service needs of the population, social work employment, professional literature, and education. As of March 2000, it was estimated that 5.4 million persons (2%-3% of the U.S. population of 275 million (U.S. Census Bureau, 1998) have mental retardation. According to a personal conversation with the Executive Director of the American Association of Mental Retardation, approximately 1.9 million (.7%) were actually involved in the U.S. service delivery system for people with disabilities (D. Croser, personal communication, March 6, 2000). In 1992,

Hayden (1992) found an estimated 186,000 people with mental retardation in the U.S. on waiting lists for housing and other services. In 1999, that number had risen to 250,000 persons (U.S. Department of Justice, 1990).

Despite the needs that these statistics represent, the social work profession appears to have been relatively silent in the conversation of services toward persons with mental retardation. Dr. Gunnar Dybwad (1999), an internationally known advocate for persons with mental retardation reflected:

> [It is] strange, the lack of responsiveness of the social work field in general to the problem of mental retardation, even in the face of extraordinary manifestations of public interest. Where was the social service department? Safely barricaded behind the roadblock that protects the bureaucracy in what is known to sociologies as system maintenance. (pp. 81-82)

The living arrangements of persons with mental retardation may help explain some of their "invisibility." Prior to the 1970s, many resided in institutions and were cared for by the state. Since deinstitutionalization, most live with their families. In fact, the majority of persons with mental retardation living in non-institutional settings are cared for primarily by a family member and/or live with their parents or siblings (Smull, 1989).

While not representing all social workers in the U.S., the National Association of Social Workers (NASW) is the professional organization for social workers. According to a 2002 randomized survey of its 155,000 members, approximately 4% (620 social workers) identified that their principle work was

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with persons with disabilities (M. Smith, personal communication, July 15, 2003). The NASW does not break down the categories of disabilities into subsections so there is no way to assess how many are committed to persons with mental retardation as one of their service foci.

It is impossible to assess the ways in which individual social workers have been involved in the field of mental retardation but an analysis of literature published in journals primarily geared towards the social work profession yields some information worth noting. Through a meta-analysis performed in 2001 by this author, of the 450 social work-related journals included in the *Social Work Abstracts* online database, 24 specific social work journals were identified. Of these 24 journals, only 49 articles over a 20-year time span addressed mental retardation or developmental disability as their subject matter. In contrast, 101 focused upon homelessness, 342 focused upon mental illness or the mentally ill, and 505 on the elderly.

A subscription to *Social Work,* the official journal of the National Association of Social Workers, is included in the membership fee of NASW. It has the largest distribution of the social work journals, reaching 155,000 members (National Association of Social Workers, 1997). A glaring absence of articles pertaining to mental retardation in this journal could be interpreted as a reflection of social work's involvement with the needs of persons with mental retardation. Of the 1609 *Social Work* articles registered in the Social Work Abstracts online database, 182 articles (approximately 11%) were focused on children or adolescents. Only 8 articles (.04%) focused upon mental retardation.

Not knowing about the myriad faces of mental retardation hinders social workers from understanding how to best obtain, understand, and verify information for effective treatment. Persons with mental retardation then are at a higher risk for misdiagnosis or ineffective treatment because the professionals do not always feel adequately equipped to serve them (Sulpizi, 1996). This dynamic in turn impacts social policy because persons with mental retardation remain an unknown and/or invisible entity to professionals who are in positions to advocate for, with, or on their behalf.

Social work, particularly in its conscious development as a therapeutic profession post Abraham Flexner's reflection that social work did not possess a unique enough body of knowledge to be considered a true profession (Austin, 1983; Butler, 1992), grew more and more focused upon persons' abilities for insight as a prerequisite for change. This focus upon personal insight and the presumptive cognitive abilities to engage in insight-oriented therapy may have played a subliminal role in distancing the profession of social work from the world of persons with cognitive impairments. Whatever the etiology, the reality is that the profession of social work has not embraced mental retardation or persons with disabilities in general as a foci of service.

Persons with mental retardation tend to be a mystery to many professions, particularly social work. The question remains, "Why are they so unknown?" Schools of social work do not educate students about mental retardation regularly in their curriculum (DeWeaver & Kropf, 1992; Liese, Clevenger, & Hanley, 1999) so future generations of social workers will remain ignorant of the

strengths and needs of this population. Perhaps it is due to apathy toward persons with mental retardation, or there is a professional stigma attached to working with this population, or maybe there is a lack of personal contact with persons with cognitive disabilities, persons with mental retardation remain invisible. Another possibility is that there is an assumption that all needs of persons with mental retardation are being met through the educational or developmental disabilities agency of the state. The 1975 Individuals with Disabilities Education Act (IDEA) (Public Law 94-142, 1975) requires states that receive funds under the act to have policies that ensure all children with disabilities will have access to free, appropriate education. The educational system has been the primary implementer of this Act, inclusive of its 1997 revisions and improvements. The profession of social work may have decided, whether consciously or unconsciously to focus its energies on other populations in need rather than persons with mental retardation who appeared to have received much Federal attention. Despite IDEA, which focuses upon children, minimal attention has been paid to adults with mental retardation.

### Participatory Action Research

At the heart of action research is the process of connecting research with action (Argyris & Schön, 1991). Participatory action research builds on this premise and involves participants both as subjects and co-researchers. It is not enough for the participants in the research endeavor to be merely advisory, consultative or consumer-responsive, but to be integral to the project (Fals-Borda & Rahman, 1991; Kemmis & McTaggert, 2000; Pederson, Chaikin, Koehler,

Campbell, & Arcand, 1993; White, Nary, & Froehlich, 2001; Whyte, 1991). It aims to make a difference in the everyday lives of everyday people in their local settings. Or, as Maguire (2000), when reflecting on PAR, succinctly summarized its imperative: "dig where you stand" (p. xv).

Participatory action research has been the method of choice for a growing number of researchers interested in connecting research with concrete enhancement of the participants' lives (Fals-Borda & Rahman, 1991). Through the participants learning and generating new knowledge, which is the heart of research, and using this knowledge towards improving some condition in their lives, knowledge and action will be connected in an emancipatory way.

PAR rejects the notion of the division between researcher and the researched, the powerful and the powerless, and promotes the validity of the lived experience of persons who are oppressed (Fals-Borda & Rahman, 1991). It has been used throughout the world in various settings among a myriad of groupings of people yearning for emancipation. For example, it has been used among indigenous farmers in India who were struggling to retain the use of their forests and land (Selener, 1997); with members of worker cooperatives in Spain (Whyte, 1991); in educational settings in California (Selener, 1997) and Iowa (Brotherson, Sheriff, Milburn, & Schertz, 2001); among farmers in Peru (Rhoades & Booth, 1982) and Mexico (Smith, Willms, & Johnson, 1997); among women seeking to improve the quality of life in war-torn Guatemala (Lykes, 2001); and among persons with disabilities (Heller, Pederson, & Miller, 1996; Kitchin, 2000; Oliver, 1992) including persons with mental retardation (Ward & Trigler, 2001).

Beginning with the participants' lived experiences and knowledge of the struggles of their own lives, they engaged in cycles of study, reflection, and action in order to address the problems they confronted.

Participatory action research is a combination of research-orientation, adult education, and sociopolitical action (Fals-Borda & Rahman, 1991). It is emancipatory by nature in that it involves the persons most affected by the decisions of the research agenda from the beginning of the project (Lloyd, Preston-Shoot, Temple, & Wuu, 1996). Their lived experience and knowledge are instrumental in the process of deciding upon the problem, investigating what they need to learn in order to help solve the problem, and implementing some form of action based upon their learnings and experiences (Kemmis & McTaggert, 2000; Sample, 1996; Selener, 1997). According to Selener (1997), PAR has two goals: solving practical problems at the community level; and creating shifts in the balance of power in favor of poor and marginalized groups in society.

PAR does not offer one particular strategy with which to engage in the research endeavor. With the focus upon personal involvement of those most affected by the outcomes of the study, collaboration is essential. I have chosen to shape this PAR project with adults with mental retardation around the cyclical pattern of Kemmis and McTaggert (2000). They highlighted seven dynamics of PAR. Their first premise is that PAR is a social process. Noting that oppression is a social problem, it is important for persons to actively pursue solutions to their struggles within a social context. Society has fragmented social units to the nth

degree, leading people to believe their problems are only their individual issues. PAR helps to break through that sense of isolation. Secondly, it is also participatory, encouraging all those involved in the problem to become part of the resolution process. Thirdly, it is practical and collaborative. Based upon real problems experienced and named by persons affected by the problems, its methodology is centered in the development of practical and useful knowledge. In order for it to be PAR, it must be as collaborative as possible. The process is also emancipatory for all involved. This fourth criterion reflects that the liberation from a socially created problem is ennobling and energizing for persons. Learning new skills associated with various forms of study or research may hopefully help participants in future situations.

The fifth characteristic of PAR according to Kemmis and McTaggert (2000) stresses an attitude of critical inquiry. This means more than criticizing the current situation. It means trying to look at the problem from a variety of angles and to assess which avenues will offer some form of resolution. Being recursive is the sixth point and infers an attitude and practice of reflexivity and dialogue (Whyte, 1989). Both learning and action occur, demanding reflection upon the entire experience. It is important to take time and energy to ask the questions about what has been learned, what worked, and what did not. The challenge is then to continually bring the insights back into dialogue with the other co-researchers to communally learn from each other, and as preparation for the next phase. Furthermore, the perspective with which researchers and others enter into critical reflection on their own role and the purpose of their

research or work (their practice) makes a tremendous difference relative to the outcomes they experience or desire.

Finally, Kemmis and McTaggert (2000) assert that PAR aims to transform both theory and practice. It aims to mutually influence both entities, highlighting that neither can stand alone:

Participatory action research thus aims to transform both practitioners'

theories and their practices and the theories and practices of others

whose perspectives and practices may help to shape the conditions of life

and work in particular local settings. (p. 598)

According to the Kemmis and McTaggert approach, participatory action research will take different approaches dependent upon the contexts, people involved and affected, and issues confronted. However, there are some key features of PAR. These "steps" are dynamic and interrelated. It is generally envisioned to be a spiral of self-reflective cycles of:

1. Planning a change,

2. Acting and observing the process and consequences of the change,

3. Reflecting on these processes and consequences, and then

4. Replanning,

5. Acting and observing, and

6. Repeating the cycle.

Seymour-Rolls and Hughes (2001) in their research utilized the Kemmis and McTaggert (1988) approach to PAR. Using the reflection, planning, and action/observation cycle as the basis of the research process, they offered

helpful and simple definitions of each phase. Reflection occurs when the research participants join together to reflect and arrive at a shared concern or problem. Planning includes discussions among the participants and critical examination of options. Action is utilizing the plan to achieve the desired outcome or improvement. Observation can be considered the "research portion" where results or changes are made. Some activity occurs in which the participants strive to learn new information (e.g., through a questionnaire, interview, or other means of observing reality or studying the problem further). Therefore, action and observation often occur simultaneously. They further note that the actual beginning of a PAR project may be difficult to pinpoint. It could begin when a conversation occurred or as an idea long before any activity is initiated. However, Seymour-Rolls and Hughes (2001) claimed the research officially begins only when the group gathers and acknowledges a shared concern. They noted that groups usually move through two cycles at the minimum but usually need more to attain their goals.

Data are often collected and analyzed through various methods of record keeping such as journals, photos, transcripts of group processes and member-checking (Fals-Borda & Rahman, 1991). It is through these sources of data that the research story can be chronicled and retold.

It appears then that participatory action research is the most plausible and emancipatory form of research with which to engage adults with mental retardation. It offers a corrective to the social ostracism and othering, silencing, and expert approach to the lives of persons with mental retardation that can

shape their lives.  In contrast to other forms of research, PAR emphasizes and builds on the self-knowledge and personal experience of those most affected by a shared concern.  Furthermore by its very nature, PAR can be engaged in regardless of the cognitive or intellectual capacity of its participants.  It is a methodology that facilitates involvement to the extent that its co-researchers are able and interested.  Because of its inclusive spirit, its participants are offered an experience of social inclusion and the phenomenon of othering does not dominate the project.  All co-researchers are full participants and bring the gifts they have to offer.  No voice is silenced.  All participants are equal and vital.

### *Research and Persons with Disabilities*

Persons with disabilities have been the subject of voluminous medical experiments and studies.  It would be impossible to even approximate the volume of literature throughout the ages that has focused upon the existence of persons with disabilities in general.  There are multiple journals and books dedicated to the topic.  However, as one person with a physical disability once commented:

> . . . there is so much being written and so much being researched, again, again, and again about disability.  The whole thing is ludicrous.  You could fill this hotel with reports and research studies and research papers that have been done in the past ten years - but what's the progress for people actually on the ground?  It's very, very small.  And that's one of the most annoying things that all these studies, all of this research – where does it actually lead in the long run?  Some of it can be used by governments to

defend what they want to defend. A lot of it is written in such a way that it is very academic. I have problems with some of the academic work as I don't think it relates really to what life is like for people on the ground. (Kitchin, 2000, p. 29)

This section will explore a variety of literature on the topic of PAR with persons with disabilities. It does not pretend to be an exhaustive exploration as the numbers of PAR studies with persons with disabilities has increased over the years. Research involving the direct experiences and opinions of persons with disabilities is growing. The disability movement, coupled with an increase in the use of qualitative methodology in the research field, has assisted in this development (Barnes, 1992; Gilson, Bricout, & Baskind, 1998; Kitchin, 2000; Oliver, 1992). However, there is a somewhat tacit understanding that the term disability more references physical impairment than cognitive. It has been acknowledged that persons with mental retardation, while being claimed in some fashion within the movement, are regarded less frequently and with less passion than those fighting for the rights of physically involved persons. Persons with physical disabilities do not tend to align themselves with persons with mental retardation (McClimens, 2003). Their focus is not on their cognitive abilities and claiming their rights to exist, but on the physical limitations placed on them by an inaccessible world (Oliver, 1992). Reflecting upon the dynamic between the two groups, McClimens (2003) expressed the challenge that faces persons with mental retardation, a dynamic that does not tend to be the primary struggle with persons whose cognitions are intact but their bodies may have more limitations

than the dominant norm expects. "Their struggle is actually more basic. It is the struggle to 'assert their humanity'" (McClimens, p. 40).

Ethical concerns of research with persons with disabilities were surfaced by Von Tetzchner and Jensen (1999) and Minkler, Fadem, Perry, Blum, Moore & Rogers (2002). Von Tetzchner and Jensen (1999) challenged researchers to reflect ethically upon involvement with persons with communication problems. The ethical charge to "do the right thing" is extremely important when engaging people who struggle to express themselves. The concern relates to the power differential that tends to exist between professionals interacting with people with disabilities. For persons with disabilities there is the possibility that their ability for expression is reduced and for the speaking partners, the great possibility of misunderstanding the others' intentions. Due to a variety of possible factors such as the professional not being familiar with the other's communication system (e.g., eye blinks, subtle nods, and finger movements), impatience to take the time to wait for a complete response, or failure to check with the other person to see whether the professional's interpretation is correct, the professional can easily misinterpret the other's intended communication. Too often, Von Tetzchner and Jensen (1999) noted, the professionals' interpretations and agendas rule the interaction.

Minkler et al. (2002) reflected on ethical concerns related to disability research, noting the struggles that can surface in a PAR process. In this study, members of a disability rights advocacy group disagreed on some critical social issues that resulted in a splintered group. White (2002) promoted the notion that

the golden rule should be also applied to research. No research should be performed on anyone if the researchers themselves would not be willing to undergo the same process.

Barnes (1992) was supportive of research among persons with disabilities but particularly focused upon the role of qualitative research. Of the research directly involving persons with disabilities, the tendency among researchers is to use a qualitative approach. He noted seven problems related to qualitative research studies among persons with disabilities. Barnes himself has a disability and was employed by the program that he studied. He struggled with all these issues and worked toward a model of "emancipatory research." These seven items offer a caution for all researchers, particularly related to persons presenting with any form of special needs and are worthy of note:

1. The researchers tend to be unlike the studies' participants, which needs to be acknowledged.

2. Researchers may have a propensity towards not being fully honest when conducting a study as to the study's audience, goals, and other agendas.

3. General reporting focuses upon the present without acknowledgement of the past and its impact upon the study.

4. The general presence of the researcher impacts upon the situation and this presence may alter respondents' natural behavior.

5. There is a tendency to rely more heavily upon and over-use the more verbal participants. Results therefore, tend to be skewed.

6. In Barnes' opinion, there is sometimes an insistence on conclusions with which respondents disagree but that the researcher perceives as reality.

7. There is a tendency of non-disabled researchers to over-empathize with respondents with disabilities, thereby losing all sense of objectivity in the research endeavor.

Kitchin (2000) reported on a qualitative study involving 35 persons with a range of disabilities (physical, sensory, cognitive) living in Ireland. They were asked various questions about their experiences with research. While not a PAR project per se, the results of the study surely support struggling with PAR as a preferred modality. Kitchin (2000) reported that there is clear evidence that although persons with disabilities have been studied, they themselves have been excluded largely from the disability discourse and the political processes that impact and shape policy. The respondents felt that the "expert" (traditional) model of research is violating, alienating, disempowering and disenfranchising toward research participants who are disabled. The research participants placed their knowledge into the hands of the researcher to interpret and make recommendations on their behalf. They felt that researchers compound the oppression of disabled respondents through exploitation for academic gain. According to Kitchin (2000) then, research that excludes persons with disabilities from its various stages, and then leaves the population without any feedback, assistance, or voice should no longer occur.

Kitchin (2000) found that the opinions of disabled people mirror the recent arguments forwarded by disabled academics concerning the need for emancipatory and empowering research strategies. In particular, the respondents articulated a need for inclusive, action-based research strategies, in which disabled people are involved as consultants and partners, not just as research subjects. The participants did not expressly advocate only for research conducted by researchers with disabilities, but they felt that their experience and knowledge was valuable and should be acknowledged and respected by researchers.

Zarb (1992) challenged researchers regarding the emancipatory nature of participatory action research. Not all PAR does appears to be emancipatory. He postulated that in order for research to be so, it must abide by reciprocity and empowerment. Reciprocity indicates that the solutions to the problems being studied are helpful to both the researchers and co-researchers. Empowerment means that the co-researchers actually learn how to do the research and decide what needs to be done. Zarb further noted that simply by assuring participation and involvement of persons with disabilities does not necessarily equate with emancipation. Challenging elements of the traditional research process that may seep into a PAR project, he posited four points upon which the PAR researcher could reflect: the actual level of participant control, any movement in actual empowerment, the involvement of persons with disabilities in critiquing the process and results, and the disposition of the results. These points offer a

checks-and-balances framework through which a practitioner can strive to retain genuine participation of all persons throughout the research endeavor.

In their experience of engaging people with disabilities in a PAR endeavor, Balcazar, Keys, Kaplan and Suarez-Balcazar (1998) noted that it is important for people with disabilities to take an active role in shaping the agenda for rehabilitation research that impacts upon them. The authors offered some principles and challenges in conducting PAR with persons with disabilities. In addition to the points made by many other researchers in support of PAR, they suggested that there is the opportunity for a more accurate analysis of the social reality of persons with disabilities, and an increased awareness of the participants' own personal resources and abilities. Balcazar et al. (1998) noted that gaining entry into and developing participatory relationships could be very difficult, as well as the relinquishment of control on the part of the initiating researcher to the wisdom of the total group. The authors also noted that the length of time a PAR endeavor usually demands is more time than participants are willing to give.

Beamish and Bryer (1999) reflected that engaging in a PAR process is very time and energy demanding. An ongoing commitment to communication and documentation of communication with participants is difficult to sustain. But the authors believed it was the only way to help foster authentic, localized action outcomes.

## PAR and Adults with Mental Retardation

Research focused upon adults with mental retardation has been plentiful throughout the ages (Bray, 1997; Park, Meyer, & Goetz, 1998). The use of participatory action research methodology within the field of mental retardation appears to be growing. In preparing for this literature review, there were no articles that surfaced before 1985. The majority of articles specifically addressing PAR and mental retardation have been written since 1989 (Sample, 1996). After extensive probing, only two actual research studies (Sample, 1996; Ward & Trigler, 2001) were located that took the reader through a major portion of the PAR process. Other articles alluded to having engaged in PAR, but these two were the only ones that overtly reported the project.

Pederson, Chaikin, Koehler, Campbell and Arcand (1993) reflected on their experience of using a PAR approach in leadership training, but they did not report on the process per se. They shared valuable insights into the process from their perspectives. Freedman (2001) offered important ethical considerations when engaging in research with persons with mental retardation. Gathering information on what questions to ask through a focus group, Heller, Pederson and Miller (1996) interviewed a variety of self-advocates at a national conference for persons with mental retardation on the topic of involvement and comprehension of research and trainings.

Two studies that surfaced using PAR as the primary approach for their work will complete this section. In the first article, Ward and Trigler (2001) worked intimately with a People First steering committee composed of persons

with developmental disabilities in a PAR project. Secondly, Sample (1996) reported on a study that focused upon persons with mental retardation in relation to their occupational and leisure needs.

Pederson et al. (1993) reflected on their personal and organizational experiences through the efforts of the Rehabilitation Research and Training Center of the Consortium Coordinating Council in Cincinnati with adults with mental retardation. Being concerned that the focus and design of research projects have generally excluded the voices of those most affected by the results, they engaged in a PAR study with participants at their center. The resultant focus of the group was to develop leadership skills and facilitate their voice in arenas where mainstream policies and decisions are made. Through their review of the literature, they concluded that it is "not that consumer involvement in research does not work. The issue is that it is seldom tried" (p. 278).

Noting that PAR is about change, Pederson et al. found that it is not enough for researchers and planners to be merely responsive to consumers, nor to utilize them only in advisory or token roles. They discussed that if an approach is truly reflective of a PAR strategy, then the persons most affected by the outcome and facilitators must work as equal partners. This included the initial work of recruitment in the group, problem identification, participation in its resolution and dissemination of the outcomes. The results of the study offered a more reflective and thorough approach to leadership training and preparation for both boards/committee memberships and participants with mental retardation.

Their conclusion was that real life results can occur when consumers' involvement is viewed as valuable.

Freedman (2001) reflected upon some of the ethical components of research with persons with cognitive disabilities, particularly informed consent. She asserted that extra pains must be taken to assure that all participants comprehend the procedures, dynamics, compliance issues, and potential consequences and risks of any study. After reviewing a variety of research done to persons with mental retardation over the years (e.g., Nuremberg and three U.S. studies), Freedman's (2001) work reflected upon the struggle between autonomy/self-determination of the individual and the protection of the vulnerable. After careful exploration of legal precedents, Freedman found that there were no clear Federal guidelines to protect the special interests of persons with mental retardation. According to Freedman, the guidelines issued by the federal government in 2000 (and currently in effect as of 2003), were not specific as to procedures to follow when working with this population (Department of Health and Human Services, Office of Human Resource Protections [OHRP], 2003). There were and are no established standards, measures, or mental status tests that assess the specific capacity of individuals to provide consent for research participation.

While not specific and prescriptive, OHRP (2003) does articulate three areas that must be addressed in giving informed consent when engaging in a research study with persons with mental retardation. These areas include the individual's cognitive capacity, the information needing to be conveyed, and the

individual's ability to freely choose. An important consideration is not to assume incompetency. These three considerations support an individualized approach to discerning a person's cognitive abilities and competency to make a free choice to engage in a particular study. Each individual has unique cognitive and integrative abilities. Interpretation of the individual's ability to freely choose is left to the discretion of the research team within a specific context for a specific purpose.

To engage in research with persons with mental retardation, Freedman (2001) offered some points for the initiating researcher to reflect upon to better assure the ongoing ability of the participant to freely choose to remain or leave the study. She posited that it is extremely important to speak the language best understood by the participant. In addition, there should be an ongoing informal consent loop whereby the participants are reminded they can discontinue their involvement in the research and to see if any new questions have arisen. According to Freedman, the initiating researcher should be as concrete as possible and elicit emotions and values, not just focus on the facts of the consent or anticipated research.

Freedman supported participatory action research as the only research used to engage persons with mental retardation. She maintained that PAR's emphasis on consumers shaping the research agenda and ongoing involvement with the entire process helps to preclude the possibility of research abuse or conflicts with ethical issues around ongoing informed consent.

Concerned with the level of consumer involvement and comprehension of concepts in research and self-advocacy trainings, Heller, Pederson and Miller (1996) engaged in a participatory action research project with adults. The study had two phases: a focus group and subsequent individual interviews. Through offering a focus group on consumer involvement in research and training at a national self-advocacy conference, 17 consumers articulated issues relevant to the topic. Their experiences and thoughts helped the primary researchers frame questions for more in-depth, personal interviews in which 22 individuals subsequently participated. The questions were open-ended, allowing for more in-depth sharing. Only persons who had previously engaged in research or self-advocacy trainings were interviewed. They allowed the participants to self-select, not engaging in any form of assessment of their cognitive abilities. The group consisted of persons highly involved in advocacy efforts, many high school graduates, and some possessing drivers' licenses.

The results revealed that very few persons who have engaged in research or self-advocacy trainings comprehended or retained understanding of some basic concepts (e.g., informed consent) relevant to these areas. The authors identified four barriers to fully understanding and participating in trainings and research. The first was the use of complex language of professionals or the format of the information. Handouts and other reading materials were not the best format for most of them. The best was a combination of all forms of communication: phone reminders, repetition, and videos mixed with written materials. The second issue related to socio-emotional and self-respect issues.

This pertained to researchers' tendency to focus upon the disabilities of their co-researchers rather than their abilities, a stance of superiority of the professional over the consumer, and other emotions pertaining to feeling their opinions are often ignored. The third area was logistical difficulties. The lack of transportation to meetings in addition to inaccessible buildings and a lack of compensation for work missed or travel and food hindered involvement. Lastly, persons often had personal support difficulties. This pertained to support persons who were under involved and do not take the time or have the patience to explain concepts to the consumer. It should be noted that over involved support persons were not found to be helpful either. These people have a tendency to speak for the consumer without checking what the consumer desires to say.

The authors articulated some concerns of genuine collaboration in the research process. In agreement with Campbell, Copeland and Tate (1998) and Elden and Chisholm (1993), Heller, Pederson and Miller (1996) asserted that it was very important to be attentive to the power differential that may be present and operative. Collaboration, both in attitude and in process, can offer individuals with mental retardation opportunities to engage in the research process as fully as they are able. It encourages and supports individuals to learn new information, voice their opinions, and help interpret research results. Furthermore, including persons who will be most affected by the outcomes helps to develop more usable information.

Heller, Pederson, and Miller (1996) concluded their work by reflecting that the most difficult thing for professionals to do who engage in research with adults

with mental retardation is to change the way in which they use their knowledge and skills.  It means to:

1.  Avoid use of jargon,

2.  Encourage participation by consumers,

3.  Listen to their ideas and opinions,

4.  Attempt to bring out their abilities and capabilities,

5.  Provide adequate support (but not overbearing; keep a balance),

6.  Use accessible buildings, and to

7.  Develop a deeper level of patience, understanding, and trust.

The authors concede that working with adults with mental retardation means additional work, but they also contend it is worth it.

The Steering Committee of People First, a national self-advocacy movement of persons with mental retardation/developmental disabilities wanted information to focus their self-advocacy efforts more effectively and to develop strategies to recruit new members.  They invited the services of researchers Karen Ward and Jordan Trigler (2001) to help them.  Participatory action research was the methodology of choice.  The committee (composed of persons with mental retardation) chose to conduct a quality of life survey among the organization's members at an upcoming conference.  They decided that they themselves would be the primary interviewers, assist in the data analysis and disseminate the results.  In the end, the committee did not use the data learned from the survey, but the authors asserted that the learning was nonetheless rich.

Ward and Trigler (2001) shared their experiences and some of the struggles of the research endeavor and their recommendations were pertinent to this study. First, they encouraged the initiating researcher to take extra time to orient and teach the stakeholders about the entire research process. It was difficult to engage the interest of the committee members in the data analysis process. Numbers, statistical relationships, and their meaning were difficult for the co-researchers to grasp because of their cognitive disabilities. Also, the committee members struggled with extrapolating meaning beyond their own interest or experience. The statistical results were discarded if the committee did not find the results of the data analysis interesting or relevant. Despite their initial goal of engaging in the research to improve their recruiting efforts, the committee disregarded data encouraging them to move toward recruitment of teens and adults still in school settings. Ward and Trigler noted that the Steering Committee consisted primarily of middle-aged adults who expressed little interest in the needs of younger persons with mental retardation. A particular example of need was the transition between school involvement with its multiple supports and life as an adult in the community. The Steering Committee was not interested in providing advocacy in this area of need, so disregarded the results of their research.

Secondly, Ward and Trigler (2001) stressed the need to clarify research roles early in the process in order to encourage full ownership of the research endeavor. The committee members worked diligently on the development of questions for the life satisfaction survey. "They evaluated validity and necessity

of each question in the context of their own lives" (p. 58) and worked to make sure the questions would not be misinterpreted by other respondents. However, according to the authors, trying to give self-advocates primacy in decision-making resulted in some serious methodological problems that compromised the results. The final survey was felt to be awkward, unclear and was prone to misinterpretation. In some regards, the authors felt they minimized their own expertise in order to maximize the voices of the co-researchers. In the end, Ward and Trigler suggested that it is important to clarify the areas of expertise each person possesses, including that of the initiating researchers, and to build on that early in the process.

Negotiating the anticipated time commitments was the third point made by the authors. It was important to acknowledge that the PAR process takes a long time. It was also important to articulate the necessity of all stakeholders to remain involved over the long run. The authors shared their experience of committee members not showing for meetings and becoming involved in other activities during the conference. The result was that people without disabilities conducted most of the life satisfaction interviews and gathered the data for the study. The fourth and last recommendation was to start small when engaging in PAR with adults with mental retardation. The authors wondered if interest would have remained in the project if it had only lasted a few months. In conclusion, the authors noted the richness of the experience, particularly in the development of the questionnaire and training of other persons to interview conference participants. Ward and Trigler concluded that despite its methodological

struggles, PAR is a valuable process with which to engage persons with mental retardation.

Sample (1996) reported on a PAR project with adults with mental retardation relative to their occupational and leisure needs. An occupational therapy agency coordinated the project that was a three-year study. They utilized and adapted the PAR model of "Farmer-back-to-Farmer" of Rhoades and Booth (1982). The focus of this project was on the transition into community life from school. At the time of the project, the author noted the emergence of two different but related streams of opinion. Both the persons with mental retardation involved in the agency and their families expressed a need for recreation and leisure activities. In addition, research indicated that supported employment was not increasing their participation in the community, or increasing the number and quality of friends as had been originally asserted by the developers of community employment.

The initial phase of the research was more quantitative in methodology and approach. Several research and service providers designed the study, with input from family members of young adults with developmental disabilities. The study was to help with recreation/leisure activities for adults from both sheltered and supported employment settings, and then to measure changes in quality of life as the result of the intervention. They collected large amounts of data but none of it seemed to be "getting at the issues." The participants' desires, abilities and disabilities were so different that any programmatic changes in the long run did not seem to help.

According to Sample (1996), some agency staff attended a national conference in which PAR with persons with disabilities was presented. The staff returned to their agency with enthusiasm to stop the current study midstream and to transition toward a PAR approach. Using a feedback loop and struggling to remain faithful to the PAR perspective, they realized that they needed to include persons with mental retardation in the early stages of data collection and other aspects of the research design. (They did not originally because they began the research prior to exposure to PAR.) The research team acknowledged the need to include residential service providers into the process who had been initially overlooked. Additionally, recognizing that persons with mental retardation have varying degrees of capabilities, the team decided to allow for differential participation according to the persons' abilities. It was observed that when the consumers were unable to follow the flow of the conversation or process, they turned to family members in attempts to have something articulated on behalf of the individual. (Consonant with this study, Hagner, Helm and Butterworth, 1996, also found this to be true.) The dissemination of the results was done in a fairly traditional manner, with minimal participation by the consumers of the services.

Their conclusion was that PAR is the most appropriate research approach to working with persons with mental retardation as it is designed to assist marginalized and disenfranchised groups. The process of PAR is empowering in itself. Sample (1996) wished that they had attempted the study with consumer participation from its onset. The agency learned a tremendous amount about what the consumers wanted and needed. An anecdote may be helpful. They

learned unexpectedly that consumers wished to go to meetings for some of their recreation and leisure activities. Meetings were determined to be empowering and enriching. Part of the agency plan then, was to help consumers learn some of the mechanics of meeting attendance and to connect them with committees and other organizational roles in which they may become contributing members.

### *Summary*

In summary, participatory action research is an emerging approach to research among persons with disabilities, including mental retardation. In order for the process to be a PAR endeavor, persons most involved in the effects of the outcomes must be involved in the initial problem selection and solution. Practitioners of this approach are cautioned to be aware of the power differential between the formal researcher and participants/co-researchers, lest the same dynamics of oppression are experienced in the PAR process as are experienced in the world. PAR takes much time and energy. Because of the length of time involved, conducting PAR with persons with disabilities (particularly with mental retardation) may result in a loss of interest on the part of the participants prior to the study's completion. Severe differences of opinion among the group may occur and each group must grapple with its resolution according to its abilities. It is important for all participants to monitor their interactions with persons with communication difficulties. Sensitivity to interrupting or misinterpreting persons with communication impairments must develop. When family members or other adults are present, persons with mental retardation tend to be less vocal and involved. It is essential that professional jargon not be used and that language

be as concrete as necessary when engaging persons with mental retardation in PAR. It is also helpful to facilitate transportation and to utilize accessible buildings.

There was only one study (Ward & Trigler, 2001) that worked with adults with mental retardation exclusively, sans parents or caregivers. They attempted to utilize the tenets of PAR and though they struggled and the process was not considered perfect, they advocated it as a preferred research methodology for persons with mental retardation. In this light, the next chapter will address the chosen methodology of participatory action research exclusively with a group of adults with mental retardation, with the exception of the initiator of this study who does not have mental retardation.

This chapter offered a review of the literature pertaining to the absence of the social work profession in the field of mental retardation and participatory action research, particularly among adults with disabilities. The social work profession, longstanding supporters of the rights of persons disenfranchised from mainstream society, has been minimally involved in securing the rights and advancing the causes of persons with mental retardation. As a social work dissertation, participatory action research presents as the best methodology with which to engage adults with mental retardation in a research endeavor.

Participatory action research was then explored, highlighting its general themes of inclusion of those most affected by the outcomes of the research, full participation of its co-researchers, methodological flexibility, and its recursive nature. The discussion then shifted to traditional research with persons with

disabilities in general, then moved specifically to research with persons with mental retardation. Concluding this review was an exploration of the sparse but pertinent literature pertaining specifically to PAR with adults with mental retardation. This last section highlighted various challenges and learnings of prior PAR research endeavors focusing upon the ethical, the emancipatory, and the concrete elements of previous experiences.

# CHAPTER 3

## METHODOLOGY

Participatory action research (PAR) is an emancipatory form of research focused primarily upon the empowerment of persons who are disenfranchised (Fals-Borda & Rahman, 1991; Kemmis & McTaggert, 2000; Selener, 1997). It offers a framework through which persons participate in all stages of the design and implementation of research in order to benefit from the results they have helped fashion. PAR works from a premise that persons know themselves and their needs best. It contributes to the existing knowledge base through its rigorously monitoring its interactions, choosing interventions, and chronicling the results of the research endeavor. Its methodological approach acknowledges the role of the investigator or facilitator as integral into the research project. There are no illusions that there is an objective scientist or observing ethnographer who is being value- and personality-free. The research initiator becomes an integral part of the learning and research process, joining energy, history and expertise to the research endeavor (Selener, 1997; Whyte, 1989).

This chapter will discuss the various components of this two-phase project of engaging in PAR with adults with mental retardation residing in the Louisville, Kentucky area. In line with PAR's acknowledgement of the role and influence of the initiating investigator, a personal introduction will be included to assist

understanding the perspective and potential "threats to rigor" (Delgado-Gaitan, 1993). This will be followed by a brief section about the genesis of this study. An overview of the initial research methodology, including the University of Louisville's Institutional Review Board concerns, selection of the co-researchers, the study's two different phases, length of the study and a graphic representation of the study, will follow.

Consistent with PAR's inclusion of the initiating researcher into the study, from this point on I will speak in first person when indicated. This is to reinforce the subjectivity of all research, but particularly in this study with its focus on giving voice to all participants.

### *Introduction of Initiating Researcher*

My name is Rita Valade and for the past six years I have resided with seven other adult women. These women work, cook, clean, volunteer, support, argue, go on dates, and attend the ballet, ball games and family gatherings. In other words, they engage life fully. They also have mental retardation. We live within a broader community called Day Spring located in Louisville, Kentucky. Day Spring has two different residential locations within a mile of each other. The setting in which the women and I live has two very home-like houses, inclusive of two dogs on 13 acres of mostly timbered land. The men's house is approximately 100 yards from the women's house and each house has seven residents. We each have our own room but share everything else, not unlike a family home. A mile away is the other property upon which 18 residents reside in a 12-unit apartment building. In total, there are 32 persons with mental

retardation who live on Day Spring properties in addition to a married couple who live in their own condominium offsite while receiving ongoing support services.

The Day Spring community is composed of the residents but also includes family members, friends, board and committee members, and staff. We work hard to maintain appropriate levels of communication among us towards the goal of strengthening our community bonds. The concept of community is not a euphemism to us. It is something that we consciously work to enhance. It operates on all levels.

In addition, encouraging the voices of persons with mental retardation is an integral aspect of our daily life together. The process of vacation planning is a good example. The persons with whom I live have decided to take annual vacations together. This has now become a tradition as it has occurred for the past seven years. The residents and any interested staff come together for an initial meeting to discuss places of interest and possible dates. We all encourage any idea as valid. Destinations are discussed and through voting and consensus, the list is narrowed down to a few locations. A committee is formed of resident and staff volunteers to investigate the options decided upon. A subsequent meeting is called and data are presented relative to such things as cost and activities to do at the destination. A discussion ensues and a decision is made with which we can all live. Subsequent meetings entail logistics, including the selection of roommates, food to bring, and which vehicles to take. This process strongly encourages all residents to develop ideas, share their thoughts, and negotiate the final decisions. The staff persons, who have agreed to join the

residents for vacation, share in the decision-making processes, yet acknowledge that it is the residents' desires that should prevail. Objectivity or professional distance is not operative. Many residents do not comprehend the various abstract concepts, the value of money and numbers or quantity/volume (e.g., the value difference between $20 and $45). They have learned to rely on others to guide them in decisions pertaining to costly items. In this way, other residents who do comprehend these concepts, in addition to staff, help guide other residents in discerning what vacation they would be able to afford. I have learned over the years however, that whenever the executive director who also lives on the property or I voice our opinions, the group too often defers to our thoughts. In light of this lived experience, I have begun to be less verbal relative to vacation ideas. I enter into the conversations and decisions, but hold back so as to not squelch the creativity that may come forth. In other words, I have come to acknowledge that the residents have given me power and authority and I wish to grow in judicious use of this role.

While not directly employed by Day Spring, I share intimately in the daily life that abounds around us. I am involved in its various committees, attend all birthday celebrations and frequent parties, and have come to know all 34 residents and some of their friends and families very well, in addition to many staff. In other words, this is my home. The people with whom I live offer much support and richness in my life.

I am also a Sister of Mercy and a social worker. These two elements are crucial in better understanding my desire to build community and my interest in

this research.  I have been a Sister of Mercy for 27 years.  If I had to do it all over again, I would re-choose this life of commitment to God and social justice within a worldwide network of other women striving for similar goals.  Being a Catholic nun, I have also been subjected to various forms of stereotyping.  Nuns have been the objects of ridicule throughout my lifetime.  We have been made to look mean and harsh, uncaring, angelic, insipid, out of touch with reality, and stupid - despite the fact that we are among the most highly educated group of women in the world.  The educational, social welfare, and health care systems taken for granted in the United States were largely begun and shaped by pioneering Catholic sisters (Stepsis & Liptak, 1989).  Since being in the community, I have engaged in innumerable congregation-sponsored workshops challenging many of the "isms" of our current day.  I have been shaped in a paradigm promoting emancipation for the oppressed, equality of all persons, and living in harmony with creation.

I have been a social worker for almost as many years as I have been a Sister of Mercy.  These two dynamics interplay within me and have shaped me profoundly.  Social work has been the natural outflow of my strong convictions that were shaped prior to and supported since entering the Sisters of Mercy. Encouraging the voice of the voiceless, challenging systems that oppress, and promoting human dignity and self-worth are strong values.  It has been my personal experience, and that of many other social workers with whom I have worked and befriended, that none of us had any substantive professional information or training about persons with mental retardation or any other form of

disability other than mental health or medical conditions. It is for this reason that I engaged in some research on the social work profession's involvement with persons with mental retardation. I wished to either validate or dispute my own experience on the topic.

Perhaps one of my strongest convictions is communicated through my consistent use of people-first language. Throughout the years, I have resisted calling people by their diagnosis or social need. I became aware that we too easily lose track of the reality that we speak about human beings when we talk about "the homeless," "schizophrenics," or "the retarded." The condition comes to mind, not persons who are living in the reality of the condition. As long as society can speak of conditions, then each uniquely human face is blurred into the conglomerate of the condition.

My life of ministry has focused upon hearing the voices of those whom society has muted, particularly persons who are homeless and who have mental illnesses, and now persons with mental retardation. I have ministered in Baltimore, Washington, D.C., Detroit, Benton Harbor, Michigan and now Louisville. Living in community with adults with mental retardation for the past six years, for me, is a natural outgrowth of my commitment to live community. I have done so for 22 years with other nuns. It felt right to do so now with the people of Day Spring.

The executive director of Day Spring is also a Sister of Mercy of the same era as myself. She is also a master's level social worker with a background in special education and work with persons who are hearing impaired. By lived

example and multiple conversations, she has taught me much about the various issues surrounding mental retardation. She has also profoundly influenced the ways I have experienced life with adults with mental retardation.

### Genesis of this Study

I became interested in this dissertation idea through a combination of factors. Through contract work with The Council on Mental Retardation, a local advocacy organization in Louisville, I became aware of various efforts addressing the needs of persons with mental retardation in Kentucky. Severe under funding was the initial effort that connected me with The Council. (Kentucky is ranked 48th in the nation for funding services for persons with mental retardation [Braddock, Hemp, Parish, & Westrich, 1998].) Through my involvement at Day Spring, The Council on Mental Retardation and my other community members, I became aware of multiple issues that persons with mental retardation face daily.

In the last half of the last academic semester of my doctoral courses, I encountered participatory action research as a research methodology in a survey course on qualitative research methodologies. Participatory action research offered an integration of my life's energy, commitment and work. It promotes the values that have shaped my life. I began to mull over the possibility of organizing my dissertation research through a PAR approach. I spoke with a few of the doctoral faculty and they responded with a supportive nod to continue pursuing this model of research.

My involvement with The Council introduced me to various self-advocacy trainings sponsored by The Council for adults with mental retardation. It was a

natural movement to ask if some of these training participants were willing to talk with me about their concerns and things they would like to see changed in their lives. In an attempt to keep communications open and to test out my idea, I met with the advocacy trainers and the administration of The Council about using PAR with some adults with mental retardation. They were supportive and in fact offered me the use of their downtown office, a wheelchair accessible space for our meetings free of charge.

Through my years of overhearing various problem solving conversations in my home at Day Spring, I began to hear a difference in the residents when they relied on staff to solve a problem or if they themselves tried to solve it. The staff at Day Spring work very hard to not direct the residents, but rather try to help them think through alternatives to solutions to their concerns. Unless the result would be a danger to self or others, or would go contrary to the goals the residents established for themselves on an annual basis, whatever decisions the resident makes is what is upheld and supported. I find this a very helpful and adult-oriented approach. But when the residents are on their own, their approach to problem solving is as unique as the residents involved.

My personal experience is that the residents come to some resolution that satisfies them. The resolution may confuse me or be a choice I would not make, but they are pleased and move on. One particular moment crystallized my observations and subsequent reflection. While watching a basketball game of our favorite local team, some of the women with whom I live wondered by how much our team was winning. No staff was around and I was in my room.

Through my wall, I heard one woman talk through the use of her calculator to figure out the lead. A quick calculation in my head resulted in an approximate lead of 20 points. The women however, concluded through the use of their calculator, that our team was winning by 113 points. They were pleased and resumed watching the game. I fought an impulse to open my door and tell them the "real" score differential. I was glad I resisted. I reflected upon how satisfied the women were for arriving at and solving a problem on their own. It was not a situation of potential harm and there was no need for them to know my perspective, which would have of course inferred their calculation was wrong. I walked to the kitchen a few minutes later, passing the basketball game enthusiasts. They excitedly told me that our team was winning and I smiled, pleased to be a part of their lives.

The difference between the two scenarios, with or without staff involved in the problem solving process led me to contemplate facilitating a group of adults with mental retardation in which no support people would be involved. This would mean no family members, no personal attendants, nor staff people would be present. In other words, the persons most affected by the issues would be the ones who would problem solve and decide how to address them. All participants, except for me, would have equivalent experience and status. This is the essence of participatory action research. This is a project that would help to integrate my life's work and values.

## *Study Overview*

In this section I will explain the initial research plan and its associated details. It will be presented as something that I had planned as a seriously thought-through methodology. It has been my experience in reading qualitative and action research studies that, in their reporting, little attention has been given to how the research was planned, inclusive of its details. It is one thing to claim that the direction of the research endeavor is totally dependent upon the participants. It is another thing to acknowledge that the initiating researcher had some sense of an anticipated flow of the research project. In PAR, as in other action and qualitative research that involves persons' personal investment in the process, the difference between what was anticipated and what actually occurred is as important as the final moment of action or insight.

In order to understand its richness, it is important that the reader comprehend the overall plan as prefigured in my mind, as informed by my experience of living with adults with mental retardation, my academic background, my personal hopes and the wisdom of mentors. Knowing the initial plan will allow the reader to understand my perspectives, thoughts, and steps through which trustworthiness of the endeavor can be judged. It is part of the PAR process to lay bare insofar as possible, the strengths and biases of the initiating researcher and available resources. In this light, the remainder of this chapter will be written as the research plan that I conceived. The fourth chapter will explore what actually happened in the course of the research endeavor.

## Research Plan

This PAR project was designed to include two stages of participant involvement. Wanting to first uncover some of the issues that adults with mental retardation saw as important in their lives, interviews with 25 adults with mental retardation who live in the community were to be performed through an open-ended format. A compilation and analysis of the issues surfaced were to identify one or two specific concepts or problems that a subsequent group would then address. The second phase would consist of inviting 8 –12 persons from the initial group of 25 to form an ongoing group to address the concern(s) surfaced by the total group. It was planned that no one else would be present for the gatherings but the co-researchers and I because of the propensity of caregivers and family members to be more verbal than the persons with mental retardation (Hagner, Helm, & Butterworth, 1996). Caregivers and family members were not to be included in the process. This distinguished this study from other PAR endeavors with adults with mental retardation that surfaced during my literature review. The anticipated goal was to collectively address the problem issue through whatever means the group would determine.

## Institutional Review Board

Prior to engaging in the study, ethical and legal considerations were to be reviewed and approved by the Human Studies Committee (HSC), the University of Louisville's Institutional Review Board (IRB). Because PAR is a seldom-used research method for U.S. universities, the study design included two phases, and that adults with mental retardation are considered to be a vulnerable population,

special care was needed to address the IRB concerns. As will be addressed

later in this chapter, special consent forms would need to be devised, adapting

the university's approved informed consent format to more basic concepts and

language. Obtaining permission of the legal guardians of some adults with

mental retardation was to be integrated into the adapted consent form. The use

of PAR as the chosen methodology with this population would be addressed in

the application. It was also anticipated that the presence of Dan Wulff, Ph.D. as

primary investigator and myself as co-investigator would be needed at the IRB

meeting in order to respond to questions.

### *Study Design*

In this section, I will focus upon the actual research design as devised in

light of the learnings of previous research and PAR methodological frameworks.

First I will identify the research question and the recursive research cycle chosen.

This will be followed by a discussion of the anticipated flow of the project and a

description of the process by which persons will be invited to participate. The

financial aspects of this project will then be addressed. The two different phases

of the study will then be explored more in depth, inclusive of concerns related to

informed consent. From this will flow a discussion of the importance of the group

experience relative to decision-making. To complete this section, the sources of

data and its analysis will be addressed.

### Research Question

The question that led this research project was: What issue does a group of adults with mental retardation want to change in their lives and how do they wish to go about doing it?

### Research Cycle

The study design was to be an adaptation of Kemmis and McTaggert's (2000) model of participatory action research of repeating cycles of:

1.  planning a change (planning)

2.  acting and observing the process and consequences (action)

3.  reflecting on these processes and consequences (reflection)

4.  repeating the cycle along time

These steps are interrelated and should mutually influence one another throughout the process. It was to be assumed that each PAR project will look and move differently with different groups, contexts, people involved and affected, and issues confronted (Heller, Pederson, & Miller, 1996; Kemmis & McTaggert, 2000). Because of this, it is important to inform the reader of the anticipated flow of this project.

### Project Flow

Unlike many other forms of research, time is not something to be controlled but rather is embraced as a natural occurring element of life within the PAR context (Kemmis & McTaggert, 2000). However, since this was to be a time-limited study, the design or flow of the research would be within the context of breakdown by months between January 2003 and January 2004.

The design (see Figure 1) consisted of a series of interconnected circles with a brief description of the anticipated activities for the month. The timeline was conceived in order to offer some level of structure for the participants and myself, and for me to be able to complete some of the research process in time for graduation requirements. The process was planned to begin in January 2003 with the preparation for the study, through February and March where I planned to select and interview 25 persons to solicit their experiences and opinions on what issues concern them and that they would like to see changed.

After the interviews were to be completed, I intended to invite 8 –12 individuals to participate in the ongoing problem solving group. I decided on the group size based on a variety of reasons. From experience, having 8 – 12 group members seemed optimal for developing a close working relationship particularly geared toward problem solving. Also, I did not know where we could meet together that would be accessible for all participants and within a small budget. A group larger than 15 persons may have demanded a space I could not afford.

The content and flow of the group process was planned to be totally dependent upon the group's decisions and desires. In the research diagram, I marked the activities according to months but the group may have wished to meet more or less frequently and that would have become the revised design. I stressed that, due to the fact that this project was "part of my homework" in order to complete my dissertation in 2004, the official timeline would be limited to January 2004. If the group would decide to disband within a few months, then that would be the end of this research endeavor. If the group wished to continue

Figure 1

Participatory action research with adults with mental retardation: Study Design



January 2003: Rita plans outline of research process with dissertation committee (consent process, human studies concerns, identifies 25 adults with mental retardation to interview).

February 2003: Rita interviews 25 persons; surfaces primary issue of concern

March 2003: Based upon input, 8-12 persons invited to become PAR group and begin process together as co-researchers.

April 2003: Process and action dependent upon group decisions.

May 2003: Process and action dependent upon group decisions.

June 2003: Process and action dependent upon group decisions.

July 2003: Process and action dependent upon group decisions.

August 2003: Process and action dependent upon group decisions.

September 2003: Process and action dependent upon group decisions.

October 2003: Process and action dependent upon group decisions.

November 2003: Summarize group experiences and prepare for write-up of research.

January 2004: Write-up of experience reviewed by group. Formal conclusion of PAR experience for dissertation purposes. Group may continue if so choose.

beyond the timeline, then I would commit myself to being a group member. However, I planned to complete the last group experience of this PAR project by January 2004 in order to complete the academic requirements for graduation in May 2004.

Although data analysis would be ongoing, I anticipated that the November 2003 meeting would be a summarizing gathering. During December I would plan to write up a draft summary to be presented to the group for one last meeting in January 2004 for their input and feedback. I anticipated that the group might also take some time to discuss dissemination of the information learned, experience shared and action taken to address the concerns upon which they agreed.

*Participants*

I planned to identify persons as having mental retardation if they had received services from agencies specifically serving this population. Most agencies serving adults with mental retardation require that their participants provide some proof of cognitive impairment that occurred during the developmental years (i.e. before the age of 22). This proof comes in the form of a psychological assessment or statement that the individual has a Full Scale I.Q. of 70 or below.

I expected to choose the participants for both the first and second phases of the project based upon a combination of personal knowledge and participant demographics. I struggled with what percentage of my total sample would be from Day Spring. I decided that in neither grouping would there be more than 50%. It had been my experience that people at Day Spring, already having

quality housing and supports may be less likely to be concerned about or knowledgeable of some of the serious pressing housing, transportation, and service shortages of which those living in other settings may be aware. Yet, I planned to include some of my community partners in this research because I wanted to work along side them in a joint project, and, I enjoy being with them. In addition, I reflected upon PAR's acknowledgement and encouragement of tapping familiar resources and persons with whom a relationship already existed (Balcazar et al., 1998). I felt my friends in community at Day Spring would offer a perfect entrée into a PAR relationship.

Furthermore, I wanted to include persons with various abilities. I decided I would need to choose persons with whom I could converse directly, either through verbal conversation, an eye-blink system for yes/no questions, or through communication boards. I realized that this would tend to eliminate persons whose receptive and/or expressive communication abilities and styles were unknown to me. I felt that the time needed to learn a new person's communication system would be too time consuming for the group and me. I was uncomfortable with this decision, but I felt it was the best I could do given the concrete limitations of time and energy. In addition, I decided to invite people who live in the community, not in institutional care. Through my experience and conversations, there are differing needs and dynamics present between the two groups. In this way, I desired to shape a problem solving group who may share more community-based issues than those residing in institutions.

It takes a certain ability to think abstractly to be able and name something as a problem and to envision a solution. Whether this ability was reflected in I.Q. scores or other cognitive assessments was not relevant. Persons were to be invited into the problem solving group if they expressed a desire to join and help share in attempting a resolution to the problem. However, my instinct told me that this ability to think abstractly might eliminate the possibility of group members who possessed lower cognitive abilities. Throughout all of this however, no mention of I.Q. scores would be made.

### Research Journal

In PAR, the process of the research endeavor is integral to the proposed outcomes or results (Balcazar et al., 1998). In this vein, the work that was to be done for the first interview or the first problem solving group would be reported in a journal dedicated to this project. This journal would be a method of data collection through which I planned to note everything that I observed and did within this process. This ongoing tool was to assist me in reflecting upon various activities and offering space for self-scrutiny and reflection, components that were very important to the research endeavor.

### Financial Considerations

Costs of transportation, phone, and food agreed to by the research group were to be absorbed by my personal funds set aside for this study. If more funds were needed than what was available, financial problem solving would become integrated into the content of the participatory action research cycle of

reflection/planning/action. Personal snacks would be the expense of the individual.

**Phase One**

**Selection of participants.** The first phase of this two-phase study was to involve speaking with 25 adults with mental retardation to ascertain their opinions and concerns about things that trouble them in their lives. I planned to select persons according to certain characteristics in order to obtain a purposive sample of some diversity within the mental retardation community. Persons may have multiple characteristics. As these categories are not mutually exclusive, I intended to be able to interview:

1. At least 5 persons who use wheel chairs

2. At least 5 persons employed

3. At least 5 persons residing in apartments/houses

4. At least 5 persons residing in family homes

5. At least 5 persons residing in group settings

6. At least 10 males

7. At least 10 females

8. At least 2 persons of color

I planned to ask 5 persons from Day Spring and approximately 7 other persons who I know outside of Day Spring to meet with me. Furthermore, I intended to ask if any of these 12 persons knew others with mental retardation who would be willing to speak with me. I also planned to ask The Council on

Mental Retardation and the executive director of Day Spring for referrals, requesting that they speak to the individuals prior to my contacting them.

*Consent.* In contacting the potential participants, I intended to ascertain if they had legal guardians. If they did not have guardians, we would schedule meeting times and places. The informed consent process would begin as soon as we were settled into our meeting place. It would involve two aspects: a verbal explanation and a signed consent form. The verbal portion would include an explanation of the informed consent form, point by point. If potential participants wished, they could have trusted persons present during the explanation of the consent process and/or the entire consent process and ensuing conversation. Once potential participants indicated comprehension of the consent, a signature of the consent form would be requested and signed carbon copies would be given to the particular participants.

If any of the interviewees did have guardians, I would schedule individual appointments for both the guardian and the potential participant to read the consent form and answer any questions they had. A second appointment would be made between the potential participant and myself to actually engage in the interview process for the study. If any participants were not sure if they had a guardian, I would ask their verbal permission to contact a family member to find out the information. If they refused to allow me to contact a family member, then I would not pursue interviewing them any further. If, when met, a person realized that she/he did have a guardian, then we would stop our interaction and I would take them home, asking permission to contact the guardian.

The consent form would lay out the anticipated goal and process of the first phase of this study, making a reference to the second phase that would occur later. Confidentiality of the interview would be stressed, noting that no one would know what the participant feels or says directly. All information would be combined with the opinions of the other respondents. It would also be stressed that they could discontinue the conversation at any time without negative consequences. To ensure comprehension of some of the basic points of the two-page consent form, a short three-question form would ask the potential participants if they understood that I was going to school at the University of Louisville and this interview was part of my homework; that they could stop our conversation any time they wished; and that this information was to be kept secret/confidential. Each participant would be requested to sign this three-question final form.

*Interviews.* The interviews would be unstructured, casual interactions. As a means to assure privacy, comfort and enjoyment on the part of the interviewees, I planned to ask each interviewee her or his preference of place where we could talk, away from family or other parties known to the individual. I suspected we would most likely travel to a local fast food restaurant or coffee house where I would treat them to a meal and/or beverage of their choosing. It has been my experience that persons with mental retardation enjoy the experience of going somewhere to eat or drink. Upon settling down away from any other customers, I planned to explain the University of Louisville consent form. After that process was completed, I suspected we would engage in some

informal chatting to transition from the formal consent process to surfacing and discussing issues concerning the individual.

I would then ask each participant a variation on, "Think about your life. Does anything bug you? Is there anything you would change if you could?" I intended to have taken verbatim notes as much as possible. For those who may not have any ideas, I would try to probe their daily activities and attempt to listen with a "third ear" to problems that they may have encountered or worries they had of which they were not aware. I suspected that each interview would last 30 minutes on average.

*Data analysis.* Upon completion of all 25 interviews, I would compile the essential issues that were surfaced by all the participants. The issue(s) that received the most repetition and attention would become the topic(s) to be addressed in Phase Two of this study. The data would be written up and included in the final report.

*Phase Two*

*Selection of participants.* The second phase of this study would involve inviting 8 – 12 persons from Phase One to engage in an approximately ten month project addressing the main issue(s) that surfaced from the first phase. Selection would be based upon the participant's interest in continuing involvement in the project, time available, interest in the topic surfaced from Phase One, personal characteristics for a sense of diversity within the group, and my intuition about who might work well together.

Personal characteristics for this phase of the project would include a mix of

1. Women / Men
2. Wheelchair use / self-ambulatory
3. Literate / non-literate
4. No more than five members to be from Day Spring

The assessment of literacy would be informally made during the initial interviews of Phase One. Since the ability to read among adults with mental retardation cannot be assumed, I felt it would be important to have a group with readers and non-readers to challenge us to think broader than the written word as a means of communication. It was also to be an important reminder that the normative ways of communicating (newsletters, flyers) were not always the most effective method for adults with mental retardation (Heller, et al., 1996; Pederson, et al., 1993).

*Consent.* The consent process for Phase Two would build upon the relationships established in Phase One. It would be a similar albeit expanded, consent process. I planned to explain that the goal is that approximately 8 – 12 adults with mental retardation would become a core group to engage in the research project (i.e. to study something that bothered them and to figure out a way to change it). It was anticipated that the group would meet at least monthly to reflect upon previous activities and experiences and to plan future activities toward addressing the primary concern/problem. The group sessions would be videotaped for record keeping and review by four professional consultants and myself who would watch the tapes in a peer supervisory manner. These peer

consultants and the videographer would be requested to read and sign confidentiality agreements protecting the identities and information shared in the group. Dan Wulff, Ph.D. as principal investigator and the IRB of the University of Louisville would also have access to the tapes if they felt they had just cause.

Because of the time involved in this second phase of the research (approximately 10 months), potential participants who did not have guardians would be asked if they wished to identify a primary caregiver/family member with whom they wished to help them make the decision as to whether to participate in this study. A meeting of the potential participant and caregiver/guardian if requested by the potential participant, and myself would occur with a similar format of Phase One of this study. The anticipated project would be explained and signatures would be required indicating comprehension of and agreement with the consent. If they had a guardian, a definitive appointment would be made to explain the anticipated process and duration of the PAR problem solving group.

*Group decision making.* As mentioned above, it was anticipated that the group would meet at least monthly to address the concern gleaned from Phase One. The fact that this would be "our group," consisting only of adults with mental retardation and myself as facilitator would be stressed. Any decisions would be made together as much as possible. I planned to ask for suggestions as to location, day and time preferences, and length of our gatherings. After the first two gatherings, I hoped that the group would decide if they wished to continue or to disband. The group would decide upon the frequencies of the

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gatherings, what should be held confidential and what could be told outside the group, and what if any, group rules should be established.

Throughout this study, I would work diligently to help establish a milieu in which the co-researchers would have an experience of personal empowerment. By involving them in all the decisions to be made after my choice of group members, I hoped that each member would feel that her or his thoughts and perspectives were valuable and important. With no familial or staff presence, I suspected that it would take a while for the co-researchers to realize the importance of their desires and ideas. Furthermore, I suspected that it would be a while before the group would stop turning to me for many decisions but I would continue to place the authority back into their hands. Personal empowerment would be made manifest in their decision-making capacity in all stages of the research process. The participants would have chosen the subject of concern on which they wished to focus from Phase One, chosen the path upon which they wished to proceed to address the concern, reflected on their experiences, chosen from different interventions should they discern a better angle, had input into the final report, and hopefully, had experienced an enhanced and empowered sense of self. People-First, an advocacy group of adults with mental retardation asserts: "Nothing about us without us." This would be the approach of this research and was integral to the expected benefits received by the subjects/participants.

***Videotapes and peer supervision.*** In an attempt to assure that I as

facilitator would not dominate or control the group process (Balcazar, Keys,

Kaplan, & Suarez-Balcazar, 1998), the group sessions would be videotaped and

reviewed by four professional peers and myself after each session. I felt it would

be walking a tight rope: attempting to balance my experience, expertise and

authority that some of the individuals in the group have already given to me, with

being a simple member of the group, attempting to facilitate the process (Ward &

Trigler, 2001). Acknowledging the propensity of acquiescence among many

persons with mental retardation (Finlay & Lyons, 2002), I would strive to keep my

own suggestions minimal and to have offered the group ideas only when they

were having difficulties moving through a point.

The peer supervisors and I would review large segments of each videoed

session prior to the next group meeting. If they agreed, I would use copies of

their notes for further reflection. Notes of their comments and our discussion

would be taken and integrated into my research journal. I anticipated that each

supervision gathering would last approximately 90 minutes and would be

scheduled at their convenience.

***Data analysis.*** Data analysis was planned to occur through a variety of

modalities. Because of the nature of participatory action research, group

dynamics per se are not usually its primary focus of analysis. The focus of the

research would lie in its cyclical and ongoing reflections, plans, and actions

(Figure 1). Through peer supervision of the videotapes of each group session,

these trends (or their absence) would be noted and brought back to the group for

input. My personal journal, the notes from the peer supervisory sessions, the videotapes, and group reflection, planning, and action movements would be the primary sources of data analysis.

Through the videos, I planned to track the group members' concerns, the level of verbal involvement of all the different participants, and observe my own role. I would also reflect upon and note trends and other dynamics that I found interesting through examining my personal journal, and the learnings and reflections from the peer supervision sessions. Particularly, I would reflect upon the questions posed by Barnes' (1992) model of emancipatory research with persons with disabilities. I would also discuss the concerns of Balcazar, Keys, Kaplan, and Suarez-Balcazar (1998) about gaining entry into and forming participatory relationships in addition to the importance of the relinquishment of control on the part of the initiating researcher. I would plan to share these reflections with the group and request feedback. In addition, together we would process various group dynamics and learnings of the experience in general, and on the action the group took to address their concerns.

As can be seen, data analysis in participatory action research involves the personal immersion of the researcher and co-researchers/participants into the research process. While all was considered to be subjective analysis, for this project it would involve much personal, peer supervisory and group reflection upon our experiences, learnings, decisions and actions. Since the focus of this research was to be the group itself and its members, it would be their insights

and stories that would tell us if in fact the overall research endeavor helped them in their lives.

*Summary*

In this chapter, various aspects of engaging in participatory action research with adults with mental retardation were discussed. Acknowledging the importance of identifying the initiating researcher's perspectives, I offered a personal introduction. Even though PAR is a methodology that is focused upon and led by those most affected by the outcomes, I felt it was naïve to act as if I, as the initiating researcher, did not have some sort of plan in mind. I outlined the two phases of the research plan and how I foresaw it unfolding, including the required process with the University of Louisville Institutional Review Board and the necessity of consent forms. In Phase One, I had anticipated interviewing 25 various adults with mental retardation who lived in the community. We planned to meet at the location of their choice. I wanted to learn from them what areas or concerns they had that they felt needed to be changed. I had then planned to take the top issue(s) from the information gleaned in the first phase and invite 8 – 12 persons from the initial 25 interviewees to form an ongoing group to problem-solve around the identified issue(s). Built into this second phase were the uses of a suggested timeline, videotaping the group sessions, peer supervisors who would review the videotapes with me to help me as initiating researcher not dominate or miss important group dynamics, and ongoing feedback to the group. This was what was planned as the general approach to this research experience. The next chapters will tell the stories of what actually occurred.

# CHAPTER 4

## RESULTS

"I have the same needs as everyone else. I just have a few more."

Sue, a participant in Phase One

This chapter will outline the research experience as it unfolded. I will first note the university's approval of the research in general, and the informed consent forms. Following that, I will address a concern that this research project not interfere or undermine The Council on Mental Retardation's efforts for leadership training among adults with mental retardation in the Louisville area. Next will be a section entirely devoted to the specifics of Phase One of the study: (a) a description of the selection of interview participants, (b) the required consent process, (c) the actual interview experience, (d) the two themes that emerged and, (e) a discussion on the use of the term *mental retardation* will be followed by a summary.

The next section will be focused upon the specifics of Phase Two: group membership; the consent procedure; financial considerations; selection of peer supervisors; introduction to the group members; the group process overview; and finally the thick descriptions of the group sessions and the subsequent process of peer supervision and integration. A summarization of the experience concludes this chapter.

Consistent with the reporting of participatory action research, I will intertwine events with my voice and the voices of participants and other collaborators. The chronology will be drawn primarily from my PAR journal that includes information from the personal interviews with the research participants and my experiences and observations of this research from its inception.

### *Institutional Review Board*

A provisional approval from the University of Louisville's IRB was granted in January 2003, pending the revision of some forms. Formal approval was granted on February 14, 2003, which marked the beginning of the project (see Appendix A).

### *Council on Mental Retardation*

Prior to direct contact with research participants, I met with April Duval, the executive director and Sarah Estes, the associate director of The Council on Mental Retardation, an advocacy organization in Louisville, Kentucky. The Council has been in existence since 1952 and is an important resource in issues related to persons with mental retardation. A recent development of The Council has been the establishment of the Leadership Institute, a division designed expressly for the development of self-advocates through training and leadership mentoring. The Council had offered self-advocacy trainings prior to the establishment of the Leadership Institute and I was contracted to evaluate the training. I came to know some additional persons with mental retardation in the greater Louisville area through my connection with these trainings.

I left the conversation with The Council's leadership feeling some support for the project, but also unsettled. I felt as if they did not find my PAR project possessing much merit. At the same time, I wondered if, because of their years of advocacy within the mental retardation community, they might have "been there, done that," and perhaps had their own experiences of their attempts to help develop a completely advocate-driven group. Regardless, relationships among us remain strong and there was interest in the progression of the group.

I then met with the director and special projects coordinator of the Leadership Institute for information sharing. I felt a strong need to make sure that my research project would not interfere or compete with the efforts of the Leadership Institute. We realized that by the time I would be engaging a total group for the second phase of the project (March/April, 2003), their series of trainings would be completed. Therefore, there was no competition relative to inviting some of the same people for each project. The concepts behind participatory action research are similar to those of the Leadership Institute and they were very supportive of my efforts. They even offered use of their wheelchair-accessible office for our group meetings free of charge.

It was important to establish a spirit of collaboration and non-competition with The Council on Mental Retardation and its Leadership Institute. Our professional and personal relationship was important to maintain. As they are and have been strong advocates for and with persons with mental retardation, I did not want this PAR project to be seen as interfering with their efforts or draining them of their pool of potential participants for their programming. As it

so happened, the timing of this project fit perfectly between two different

programs and therefore was not in any way conflictual. That done, I officially

began to compile a list of adults with mental retardation who may be interested in

telling me things that bothered them and what they would like to see changed.

### Phase One

The research was performed in two phases. In the first phase I engaged

25 adults with mental retardation in the greater Louisville, Kentucky area in

individual interviews. The purpose of these interviews was to learn of the issues

that concern persons with mental retardation in the Louisville area. It was

important to attempt a broad sampling of persons who possessed different

characteristics and demographics. In this section I will address issues

surrounding my choice of persons to interview. I was true to my original design,

having spoken with persons with a variety of demographic characteristics. A

discussion on the content of the interviews follows. While the interview

participants did not identify one specific issue, two themes emerged. An

exploration of these themes and the rationale for not choosing to begin the

second phase of the research based on either of these themes is offered. In

addition, the use of the term, mental retardation, offered some specific

challenges. Some of these challenges are also addressed.

### Interview Participants

My initial plan was to begin with some persons I knew personally and to

ask them to supply me with names of other friends they thought would be willing

to speak to me. However, this snowball sampling method did not work. My

experience with persons with mental retardation has led me to suspect that while many regard others as good friends, they do not work at keeping in touch with each other. Friendships among persons with mental retardation are not necessarily with other persons with mental retardation. When I would ask the participants in the study for some of the names of their friends, most became silent and could not name people outside of those with whom they live. This experience confirmed my own previous observations. Therefore, the snowball approach to soliciting other participants did not occur. Ultimately, participants came from persons I knew personally or from other professionals who worked in the field.

The sample for Phase One was composed of persons I knew from Day Spring (7) and from other sources (18), totaling 25 participants. The group consisted of 13 women and 12 men. The age range of the interviewees was 19 – 52 years old. Two participants were African American with the remainder being European American. Seven persons lived in housing sponsored by residential providers for persons with mental retardation, ten persons lived with their families of origin, and eight lived in other settings (one home owner, two in their own condo, two in an independent apartment; and three in HUD housing based on their physical disabilities). Eighteen were employed (one was employed full time and 17 were part-time). Three walked with assistance, six used wheelchairs exclusively and 16 walked without assistance. Two of the respondents were a married couple. Table 1 summarizes the demographics of the group of 25 interviewees for the first phase of the study.

**Table 1**

*Summary of Sample Demographics by Gender*

| Age | Women (13) | Men (12) |
|---|---|---|
| 19 – 30 years old | 2 | 1 |
| 31 – 60 years old | 11 | 11 |
| **Race** | | |
| African American | 0 | 2 |
| European American | 13 | 10 |
| **Housing** | | |
| Housing supported by residential providers | 4 | 3 |
| Own Home/Condo | 2 | 1 |
| Renting Apartment / Live Singly | 1 | 1 |
| HUD – sponsored apartment building | 3 | 0 |
| Family of Origin | 3 | 7 |
| **Employment** | | |
| Full Time | 0 | 1 |
| Part Time | 9 | 8 |
| Day Program | 1 | 2 |
| None | 3 | 1 |
| **Physical Mobility** | | |
| Walks with Assistance | 1 | 2 |
| Uses Wheelchair | 3 | 3 |
| Independent | 9 | 7 |

If I already knew the potential participant, I contacted the individual on the phone or in person if the opportunity presented itself. For those persons whom I did not know, I requested that the referral sources ask the potential participants for their willingness to speak with me about this project. From the feedback I

received from the individuals, all of the potential participants trusted their referral sources and my Day Spring connection and agreed to participate. In addition to either knowing me or my Day Spring affiliation, the fact that I was doing something connected with the University of Louisville (UofL) lent importance to the project. For many persons residing in the Louisville area, the University of Louisville Cardinals sports teams are a source of pride and strong allegiance. More than once did potential participants exclaim pride in being part of anything connected to UofL, including those who were diehard University of Kentucky fans. At the very least, the UofL affiliation offered an icebreaker for all participants previously unknown to me.

It is important to note that all potential participants expressed an eagerness to participate in my study. I was not sure if the persons I invited would want to commit themselves to an ongoing group focused upon problem solving. It seemed many of the persons I interviewed were already quite busy with various activities and the addition of another one might not have been of interest. I was very touched that all agreed to join the group. The majority expressed some surprise that I needed their help for my homework assignment (the term I used to refer to my dissertation). Sharon[1] typified the response I received. She was a woman with a hearing impairment in addition to mental retardation and responded with wonderment to my invitation to talk about things that bothered her and that she would like to see changed. "You need MY help for school? Is that what you said? Uh...sure... I'd love to help you out. Do you want to talk right now?" Most of those residing in their family homes were pleased that I wished to

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[1] All names used in reporting Phase One of the study results are fictitious.

talk with them and not their parents. Those who resided with their families asked me to explain to their family member(s) the nature of the research project. James was an individual I had never met but had heard about since he was a co-worker with a Day Spring participant. He had heard that I wanted to talk with him through our mutual friend and agreed. He asked me to explain it to his mother, which I did on the phone. His mother was very pleased with my inclusion of her son in the project. "I think this is exactly what he needs . . . to get more involved with people." All family members with whom I talked were very supportive and interested in what the research would surface.

### Consent

I asked all potential participants if they had a guardian and only two out of the 25 interviewees did. This was consistent with my own experience that the majority of adults with mental retardation who resided in the community did not have guardians. Generally their families continued to guide any decisions they made, but legally individuals were their own agents. If the person did not have a guardian, once the participant and I settled into our places at the location of the participant's choice, we read through the consent form together, answering any questions along the way. Once I had a sense the person understood what she or he was agreeing to, I would double-check through asking the three additional clarifying questions requested by the University IRB. These questions clearly asked if the participant knew that they were connected to a study through the University of Louisville where I was a student; that the participant could stop the interview at any time with no negative repercussions; and that nobody would

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know what she or he said, with the possible exception of my advisor and the IRB at UofL. All persons readily signed the consents and I gave them a carbon copy of their signed consent forms.

There were two people who had guardians. An additional woman was not sure. The first person had a guardian as he had no living family member. A friend was his official guardian who helped him with any legal or financial aspects of his life in addition to offering support and love. I asked him if he was interested in meeting with me. When he expressed interest, we made an appointment with his guardian to explain this first phase of a more extensive research project. Both readily agreed to his participation in being interviewed and the appropriate informed consent papers were signed and we went to a local coffee shop for our interview.

After the initial phone conversation to establish the meeting, another woman who lived by herself in her independent apartment with two dogs and who cleans houses to supplement her disability-based income, was not clear if she had a guardian. She called her sister while I was with her and learned that she did in fact, have a guardian. Another meeting was scheduled with her guardian for the following week. When I arrived at her apartment, her sister, brother-in-law, and family friend had brought snacks and transformed it into a social visit. The potential participant desired to have everyone involved in this endeavor, so I explained this first phase of the research process within the context of the entire project to the group. This visit lasted approximately an hour. It was very pleasant to meet a major part of the participant's social network. The

group, including her guardian-sister, appreciated the fact that I was interested in her sibling's opinions. After the informed consents were signed, the participant and myself made yet another appointment to meet individually to ascertain her thoughts on what bothered her that she would like see changed. On the third visit, I learned that she could think of no issues. I sighed as I left her apartment, thinking of the energy expended and in the end, she could think of nothing that bothered her. The researcher in me was a bit frustrated, but the social worker in me rejoiced that she had support, independence and no complaints about life. Even with this sense of contentment, and her higher level of cognitive abilities, my instinct was that she had a more limited sense of self-agency than some of the other interviewees I visited. Prior to this I had more or less subconsciously connected cognitive abilities with self-agency.[2] This experience challenged that assumption.

While inviting another woman to talk with me for this project, she stated that she did not have a guardian. We made an appointment and drove to a local coffee house where, once we got settled, she told me she was not sure whether she had a guardian. With this news, I told her we could not talk about what I had planned. I immediately changed the subject of our conversation to a variety of other topics such as her love of dogs and her work. The topic switch was so clear that I found it comical. I consciously avoided any topic related to her concerns or things she wished to change in her life, even if they spontaneously surfaced from her. When we returned to her apartment, she called her mother to

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[2] Self-agency connotes an ability to act and think independently; the ability to advocate on one's own behalf.

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ask if she had a guardian. Her mother told her she did not have one. At this point the woman handed the phone to me. She wanted me to explain to her mother why she suddenly was interested in her guardian status. I told her mother about my research project and her mother was very gracious and pleased that I would ask her daughter for her opinions. Her daughter and I rescheduled another time to meet to discuss her concerns.

### Interview Experience

Generally, after the initial phone calls to the potential participants and sometimes their request to tell family members, the potential participants and I established dates to meet. I would arrive and if I could transport them in my car, I asked them if they wanted to stay where they lived or go out somewhere. Of the 19 persons who did not use wheel chairs, 16 requested to go somewhere else to visit. According to their choice and availability, interviews were held at local fast food restaurants and coffee houses. I would purchase the menu item(s) they desired as an expression of gratitude for their time and willingness to share their expertise with me. I took beverages to those whom I could not transport in my car or who wanted to meet in their homes.

Each of the conversations lasted approximately 30 to 60 minutes as planned, depending upon the individual's input and verbal abilities. Three of the participants had cerebral palsy that impacted their speech. All encouraged me to ask them to repeat themselves, rather than not being understood. These interviews tended to last a bit longer due to my inability to easily understand them.

The interviews were intentionally informal and unstructured to encourage open and creative thinking. I asked participants, "Is there anything that bothers you . . . that bugs you . . . and that you would like to see changed?" I was aware that the question was very open and that people would have to struggle to think about something so vast. Yet, I was cognizant of the potential that any suggestions I made may influence their own thinking processes and I wanted to avoid that dynamic as much as possible. As could be expected, some persons had immediate answers; others pondered the question quite a long time. When it appeared that no answer was forthcoming, I would attempt to offer some areas to reflect upon such as: at your job? at home? your program? These usually spurred a few comments which, when asked to elaborate, surfaced issues that they wish could be changed.

I completed all 25 interviews within six weeks. As the interviews progressed, no one clear issue surfaced among the majority of the respondents. I grew nervous that I would not have one or two clear concerns to which I would invite individuals to work together to address in an ongoing group for Phase Two of the study. After reflecting upon the ongoing results of the interviews, I realized an amazingly obvious reality: All persons spoke from their own perspectives and vantage points and were concerned about issues that interplayed in their personal lives. There was no ongoing, overarching "issue" related specifically to mental retardation or the condition of having mental retardation. The issues that were raised were concerns with which many people struggle. "Everyone seems to speak out of her or his own place and experience. This 'sub-population' has

less in common with each other than with the rest of the world" (R. Valade, personal journal entry, April 1, 2003). Those without work wished for a job. Those persons without meaningful employment wished for a better job or job coach to help them. Those with aging parents worried about the health of their parents. Many of those living with their families wished for more independence. Some felt lonely and desired more friends. A few persons were worried about the state budget cuts and its impact on the services they receive. Another was concerned about the impact of the bombing of Iraq and pollution concerns. Someone was sad because her dog had just been put to sleep and she wanted her dog back. A few worried about their health insurance or Medicaid funding, and one woman wanted the latest Britney Spears CD.

Throughout the experience, none of the individuals expressed any desire to change their "disability," whether it was mental retardation and/or physical abilities. No one spoke of a desire to walk if currently unable, or a desire to speak more clearly if her or his speech was currently difficult to understand by others. This learning flew in the face of societal attitudes that promote pity towards persons with disabilities. For whatever reasons, the 25 persons I interviewed were not struggling to change themselves into something society considered to be "whole." I did not pursue this line of questioning with any interviewee. I did not notice this pattern until deeper reflection on the total experience. I surmised a few possible reasons for this. The adults with mental retardation and/or physical disabilities I interviewed might have already struggled with self-acceptance earlier in their lives. Another possibility might have been the

acknowledgement that nothing could be done, so there was no need to think of their limitations in response to my questions pertaining to changing something that bothered them. The third, but not in the least, reflection on my part was that what mainstream society calls a disability, was not considered to be so by the interviewees. They are as they are. Perhaps the reason no one spoke of changing anything about themselves might have been a combination of all of the above, or none of the above. These were simply my reflections.

Throughout the interviews, I struggled to listen to the interviewees with a "clear" mind. I was very conscious of not trying to interpret their concerns through my experience or vocabulary. Knowing that is impossible, that every interaction is filled with subjectivity and screens, I worked very hard to simply listen and not make connections for them or broaden out their concerns with other examples. I worked on being present and writing down what THEY said in their own words and constructs. I tried to avoid use of my concepts or other means of remembering or interpreting their concerns. As already reported, the interviewees had their own individual concerns with a few repetitions among them. As a result, no one specific issue repeatedly surfaced from among the persons interviewed. I felt at a loss because there did not appear to be a specific issue upon which to build an ongoing group around for the second phase of the research project. Table 2 below represents the areas of concern as expressed by the interviewees. Respondents may have had more than one issue and therefore the total number is more than 25.

**Table 2**

*Identified Issues and Number of Times Mentioned*

| Issue | Total each |
|---|---|
| More independence; Supported housing; TARC 3 (Louisville's transportation system for persons with disabilities) | 6 |
| Loneliness/Desiring more companionship | 4 |
| Physical disabilities accommodations; Aging Parents | 3 |
| Better jobs/job coaches; State budget issues; Illness of family member | 2 |
| Medical transportation issues for persons who use wheelchairs; Better media coverage of advocacy activities; Vocational training; Society's focus upon being disabled; State waiver for services for persons with mental retardation; War in Iraq; Prettier Environment; Britney Spears CD; Better staffing; Death of a pet. | 1 |

*Emergence of Two Main Themes*

While no one specific issue surfaced from among the majority of the 25 persons interviewed, two different broad themes gently emerged from the collection of interviews performed. While the information came from the interviews, from "between the lines" of the conversations, I felt I was the one who named them, not the participants themselves. Because of this, I did not feel comfortable basing an ongoing group on either of these themes because they were not explicit issues that were spoken by the interviewees. These two themes focused upon the desire of being treated with respect and complaints about the transportation system for persons with disabilities.

*Respect.* The first theme of being treated with respect began to emerge by the third interview. George reflected that as an adult felt more or less respected, but as child, he was teased a lot and felt pretty alone. Sue who also has arthritis, scoliosis, congenital anomalies and walks with assistance noted, "When you have a disability, you're not seen . . . you don't have a thinking process. Even at church, if I'm not standing up, I don't exist. You're judged as soon as you are seen. All I want is to be seen as a real person."

Mary Beth reflected poignantly, "I'm slow but I'm not stupid." This sentiment became an important theme for many interviewees. Having quite involved cerebral palsy, Clare, a middle-age woman who uses a wheelchair, reflected on her experience of having physical disabilities in addition to mental retardation. She told a variety of experiences about visits to the doctor. She has learned to bring her attendant to appointments because the nurses neither know, nor ask her, how to change her clothes. The medical staff also tends to look to the attendant for information rather than at Clare herself. She was never given a PAP smear because the doctors decided it could not be done. Only within the past year has a doctor figured how to position Clare in order to successfully examine her. Clare had called the doctor's office in anticipation of an appointment to remind them of the need of a larger exam room so her wheelchair could fit, only to be placed at the doorway of an exam room with no space for the chair or an exam table that could be lowered to accommodate her.

With her right arm tight up against her chest from the muscular tension of spastic CP, health care professionals have scolded her more than once to extend

her arm for blood pressure checks or for drawing blood work. Unable to extend her arm, she has been accused of being non-cooperative. She attempts to explain her physical abilities and is often dismissed, as if she does not know her body. This type of experience has repeatedly occurred to all of the interview participants with physical disabilities. As Louise reflected, "Sometimes when people see my wheelchair, that's all they see. They act then as if I've got no mind whatsoever."

For persons without physical disabilities, being disrespected can be as painful. Dahlia shared some stories of being the source of ridicule at work. She reflected that she could tell the difference if people are teasing her in kindness or meanness. A few years ago John, a 19-year-old man experienced overt harassment at work. Working at a reputable restaurant in Louisville, kitchen help often called him names and one tried to hold him and turn him upside down. The management did nothing about it. He also recounted other experiences at school where he was the object of ridicule. He is glad to be out of school. He reflects that his life is calmer and he is treated "pretty nice" at his current job.

Joe, who works full time and "does carts" at a local mega store, told me a few different stories of being disrespected by other staff, including management. One story specifically related to being not considered for an inside position. Joe can read, write, and is strong and healthy. He is perfectly capable of working in the stock room, but has been twice overlooked when positions opened. Joe has been with the company for approximately three years and has been hoping to move indoors rather than collecting and pushing carts in the lot through all sorts

of weather.  He attributes this issue to the fact that he has a disability.  He knows

he needs the job and therefore does not file any complaints.

Some of the interviewees reflected upon the difficulty in finding

employment.  Many use the services of a local vocational program that supplies

job coaches to help them learn and retain jobs.  Some interviewees felt

disrespected by their job coaches who do not return phone calls, are otherwise

inaccessible, and from whom they have not heard for extended periods of time

(weeks and months).  Yet, at the same time, they do not want to complain

because they are afraid of losing the little benefit they receive from their job

coaches.

*Transportation.*  The second theme of complaints about the

transportation system for persons with disabilities revealed itself later in the

interview process, after speaking to approximately seven interviewees.  I began

to realize how many persons had various complaints about the government-

sponsored transportation system for persons with disabilities. The paratransit

service in the Louisville area is called TARC-3 (Transit Authority of River City.)  In

five out of the total of 25 interviews, complaints about TARC-3 explicitly surfaced

after being asked about what was bothersome.  Some of these complaints

focused upon being given "No Show" memos when in fact the customer was

waiting but the van went to the wrong location; being on the van over 80 minutes;

for those in wheelchairs, their tie-downs not being secured appropriately and

subsequent rolling with the van's movements; rude drivers; and vans not showing

up when scheduled.  Most of the time however, complaints were interwoven into

the context of chatting prior to and after the interviews. Initially I did not note the informal complaints because, living at Day Spring with the vast majority of residents being dependent upon TARC-3, I have often participated in similar conversations. I have found that these types of conversations have become part of the disability culture in the Louisville area.

The general bus system for greater Louisville is known as TARC, and since the early 1990s, after the enactment of the American with Disabilities Act of 1990, TARC-3 has provided lift vans and other vehicles to transport all persons with disabilities. This system provides door-to-door service. TARC contracts with two other transportation companies to actually provide the service. TARC-3 does the scheduling and quality monitoring. At least one day in advance, persons call TARC-3 to schedule their rides. There is a half-hour window in which the passenger must be available 15 minutes prior to and after the scheduled pick-up time. Drivers are allowed to wait for five minutes for their passengers. Customers may be on a van for up to 80 minutes as it is a shared-ride system. There are a variety of other rules and norms surrounding riding TARC-3 in which the interviewees were well versed. According to its Director, as a transportation system, TARC-3 averages 2300 rides per month, costing approximately $23 per ride. TARC-3 customers pay $1.50 or $2.00 per ride dependent upon time of day (K. Dennison, personal conversation, August 26, 2003).

Sometimes people recounted rude drivers who spoke disrespectfully to them. Tim who has cerebral palsy, communicates through a message board on

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his lap, and uses a wheelchair, reflected, "I've tried them but they were late and rude, or didn't even come. When I called and complained, nothing happened." When Tim expressed more criticisms regarding TARC-3, I realized I began to dismiss his complaints as being too demanding. I have a friend who does not have any "disability" who relies on city taxis because she does not drive. This friend periodically comments about her struggles with scheduled taxicabs being late, rude drivers, and the cost of a ride. In my journal I reflected upon this reaction of mine - - how my dismissal of Tim's complaints was probably what he and many others have experienced throughout their lives. I began to realize how impatient I get when a service is not rendered well. Then I reflected that if I am not satisfied with a product or experience, I choose another option, whether that be another restaurant, car dealership, hairdresser. In my journal I wrote on March 5, 2003:

> I wonder if that is part of the issue . . . choice. I have many choices and can exercise these choices when it is to my convenience. People who have disabilities often do not have any other options. There is no alternative to TARC-3, especially if you use a wheelchair. Despite the ADA laws, our world is still so inaccessible to persons in wheelchairs. And for persons who cannot navigate the complexities of public transportation because of cognitive problems, TARC-3 is the only way for them to get around independently. I feel humbled by my own growing awareness of how limiting I have been in my attitude toward persons with disabilities. I guess I have locked them into a box. I realize I have felt that they should

not expect to live as mainstream a life, with options and easy mobility choices . . . like the way I live.

Ron, a soft-spoken man who uses a wheelchair told about a driver who told him, "You don't tell me how to drive this bus. I'll get you home when I get you home." Another time the driver did not lock his chair properly and Ron jostled and rolled with every movement of the van. When Ron asked the driver to secure the locks, the driver told him "You'll be okay until I get you home." Ron was very afraid during that ride. He recounted the feeling of helplessness when being totally dependent upon others to assure his safety. He has learned to be pleasant at all costs, so as to not anger the drivers upon whom he is so dependent.

These and other complaints became integrated into the interview process as a whole, however most of the participants expressed appreciation for having a transportation system, even if there were problems with it. Many of those who spoke directly about TARC-3 volunteered information about other pleasant experiences with nice drivers and on-time service.

### Use of "Mental Retardation" Terminology

Another perspective that the interviews revealed was the difficulty around articulating the diagnosis of mental retardation and the preferred focus upon physical disabilities. As mentioned before, the primary criteria for persons in this study was that all participants had mental retardation. As many programs that serve this population require verification of the diagnosis (a diagnosis given prior to their 22nd birthday), I felt it was not necessary to require further proof.

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Participation in schools and programs particularly geared toward persons with mental retardation was sufficient verification for this study.

The informed consent form for this study specifically used the term "persons with mental retardation" in the purpose section. When participants or I read the consent form out loud to assure comprehension, almost all stumbled over the use of the term mental retardation, including myself. I became uncomfortable with reading "mental retardation" aloud and found myself glossing over it very quickly. I noted and internalized most participants' body language and found my own behavior reflective of a discomfort with the term. I began to realize how the term is given to persons of a given cognitive and social assessment by other persons who do not have the same issues. In other words, in the United States, persons most affected are not the ones naming their own reality. While aware of my discomfort, it was not until the 14th interview that I realized I had shifted from reading "mental retardation" to "disability." I had picked up the discomfort persons with mental retardation have with the label.

When Clare, the 14th interviewee, called a few friends to ask them if they wanted to participate in the study, these friends had physical disabilities but not mental retardation. I realized my own collusion with the social awkwardness of using mental retardation when directly addressing persons diagnosed with it. It was far easier for others and me to focus upon physical disabilities rather than articulating a focus of my study as being on those with intellectual disabilities. At that point, I realized that I had begun to shift from the term "mental retardation" to "disability" at approximately the seventh interview. I corrected my action and

resumed articulation of the term "mental retardation" when reviewing the informed consent form. I felt awkward using the term, and I noticed that some participants visibly reacted to the term, but I knew I must be as clear as possible.

Another trend surfaced within the interview process. Persons who used wheelchairs focused upon physical disability issues. They seemed to be able to think of things that needed changing along the lines of physical accessibility, mobility, and other related issues. Persons without physical challenges seemed to have had a harder time articulating personal concerns that needed addressing. With the exception of the one participant noted earlier, all interviewees did eventually arrive at some areas of concern, but both the process and the result were different between persons with or without physical disabilities.

### Conclusion of Phase One

At the conclusion of Phase One, while there were a variety of issues, there was no one specific issue articulated that bothered the majority of participants. However, there were two themes that emerged: respect and TARC-3. The original design of the study was to use the issues learned from the interviews as the starting point for Phase Two's ongoing reflection/planning/action cycle. Despite the original PAR design of using the information gleaned from the 25 interviews as the start-off point for Phase Two, I did not feel that there was enough of a groundswell of interest in any specific area that people wanted to change. They told many stories that I interpreted as illustrative about being disrespected and about problems with TARC-3. With the exception of six persons who desired a change with TARC-3, the participants themselves did not

articulate these issues as something they wished or felt they could change. Because of this, I did not want to presume their interest in working toward changing these two areas of concern as the basis for Phase Two of the study when 8 – 12 participants would be invited to join in an ongoing group to address a specific problem.

In this section, I shared the experience of interviewing 25 adults with mental retardation to ascertain their opinions on issues that disturbed them and that they felt needed to be changed. In the next section I describe the transition from Phase One to Phase Two.

### *Transition between Phase One and Phase Two*

Throughout Phase One, I explained the full spectrum of the research project to each participant. They learned of the two specific phases: the interview process of listening to the concerns of 25 adults with mental retardation in the Louisville area; and the development of an ongoing group to address some issue that surfaced through the initial interviews. Participants tended to react to the notion of an ongoing group through expressing an interest to join the group, or polite disinterest. I noted these reactions as offering some criteria for invitation to form the ongoing group.

Initially, I intended that the individual interviews would provide the data upon which to offer a focus for the ongoing group. As the interviews drew to a close, this design did not feel appropriate. As noted previously, two trends were noted (being treated with respect and TARC-3 complaints) but there were no issues that dominated the minds of the interviewees upon which to build an

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issue-group. In addition, I grew to realize that once in a group, people are affected by others' thoughts and opinions. I realized I could not assume that individual issues would be the same as group or collective issues. Another concern was group membership. While the vast majority of the interviewees told stories related to one or both of the trends, no dominant or common theme emerged among those who verbalized a desire to participate in the ongoing group. These dynamics complicated the linear and logical notion of the second phase building directly upon the data of the first phase.

In this section I focused upon the experience of interviewing 25 persons, inclusive of the logistics, demographic characteristics and financial considerations. While I distilled the overall themes of being treated with respect and TARC-3 problems, the results did not clearly identify any one specific issue among those who expressed interest in forming an ongoing group. With this phase completed, I moved into the second phase of the study: the formation of an ongoing group to address a concern that is in need of change.

### Phase Two

In this section, I explore various components of the second phase of the PAR project. I will first address group membership, followed by the consent process we underwent. The financial expenditures and the final peer supervision arrangements will be explained. This will be followed by thick descriptions of each group meeting, succeeded by a synopsis of the reflections of the peer supervisory sessions, our notes from those meetings in reviewing the videotapes, and my journal.

### Group Membership

With the above concerns in mind, I contacted 12 out of the 25 persons initially interviewed to invite them into the ongoing group. I had anticipated I would need to interview more than 12 but each person expressed an eagerness to join the group. One woman invited another female friend who I had interviewed (but did not think she was interested). In total, 13 persons agreed to commit to membership in an ongoing group.

Group membership was explained as clearly as possible. Participants would be committing themselves to gather approximately once a month, more or less dependent upon the decision of the group. I intended only to facilitate the group, and that the group members identified issues, discussed, and made the decisions themselves. No family, staff, or personal aides were allowed (if possible.) Attempting to relay information gleaned from the professional literature, I noted that when I read information about groups with adults with mental retardation, it was usually family and staff persons who spoke, more than the individuals most affected by the decisions (Hagner, Helm, & Butterworth, 1996).

I shall never forget the emotion and delivery behind Donna's[3] reaction to this point. Having cerebral palsy that affects her speech especially when she is tired, Donna generally sits in her wheelchair with her shoulders leaning forward, her spine curved and her head bowed down. She is in her late 40s and has

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[3] Previous to this point, all names of the 25 interviewees were fictitious because the participants signed consent forms that specified that they would not be named or identifiable during Phase One of this study. In Phase Two, the participants requested that their given names be used in reporting their experiences. For an introduction to the group members, see *Introduction to Group Members* section. From this point on, all names used are the real names of the participants.

purchased her own home.  Because she cannot find home care aides, her 80-year-old mother moved in to help provide care.  We met in Donna's kitchen.  I spoke of the group and that the group itself will make all decisions from deciding upon what topic to be addressed to actually doing something to address the issue.  Donna slowly raised her head, looked me straight in the eyes and clearly said with a bit of a smile, "I've been waiting for something like this all my life."  My heart skipped a beat.

Jackie was interested but admitted that she had become quite busy with advocacy work.  She was encouraged to share her opinions and expertise by a few different local organizations focused upon advocacy with and on behalf of persons with physical disabilities and/or mental retardation.  Yet, she felt it would be a different experience to participate in a group composed exclusively of persons with disabilities.  She smiled and told me, "I like the idea."

I had encouraged everyone to think about the serious commitment they were making: meeting over the course of 10 -12 months.  Regi told me, "Don't worry Rita, I'll be there.  I want to do this real bad . . . Do you hear me (with a smile on his face)?  REAL bad.  I'm so glad I get to be in the group."  Cindy told me "I wouldn't miss it for the world.  This sounds great!"

***Consent***

I met individually with each potential group member to discuss the nature of the commitment and to complete the consent forms.  As this was a very different commitment than that of the first phase, it was necessary to obtain a separate consent for this second phase.  Informed consent forms were discussed

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and signed by all group members. Only one of the invited group members had a guardian. Regi and I contacted his guardian who supported Regi's desire for involvement and the informed consent form was completed.

Initially I was concerned with informing the family members of the ongoing and regular participation of the group members. Only one member, who resided with his parents, asked me to explain the group to his mother. The other 12 simply told me that their involvement was their decision and that they assured me they would tell their families but that they were capable of making this level of decision. They would inform their families and if the families desired, they could call me for more information. None of the families contacted me. I have since encountered various family members who expressed gratitude for the interest their member had in the group. Three family members of different group participants specifically shared with me that they thought the personal connections made in the group were beneficial, even though they were not exactly sure of the group's content or purpose. They also expressed a tacit trust in any group in which I was a part and that was held at the Leadership Institute. Both of these connections, my own personal history within the Louisville mental retardation community and The Council on Mental Retardation lent credibility to the group in these family members' minds.

### Financial Considerations

An integral aspect of the research design included financial considerations. While the design was open to unlimited dreams, finances were not. However, any transportation, food, or housing costs that directly resulted

from the group's reflection, planning and action within the approximately 10 month commitment would be paid out of my personal funds through the Sisters of Mercy community. The community was willing to pay the group's expenditures should they decide upon an action that required funding. I did not wish to announce this budget, because I felt it was necessary for the money to be spent only if the group's dreams and plans demanded such expenditures. With a combination of the use of a cost-free meeting location and TARC-3, costs were kept at a minimum. I paid for the round trip fare for all who rode TARC-3 for the meetings along with beverages, and meeting supplies. I also paid for the videotapes, and a video highlighting various parts of our group along with the cost of transcribing the videos. In addition, a donation was made to The Council on Mental Retardation's Leadership Institute for the use of their space.

**Videotape, Peer Supervision and Journal**

As envisioned in the initial research proposal, the group sessions were videotaped and these videotapes were the core material for my peer supervision sessions. Participants relaxed into the presence of the video recorder and the operator who was a professional from within the mental retardation community and with whom all expressed comfort and who signed a confidentiality agreement (see Appendix B).

In the initial research plan, I had anticipated asking four persons to offer ongoing peer supervision. I struggled to identify four persons who would have the time and interest in scheduling meetings over the length of the research. Two persons readily agreed to assist me and I decided that because of their

interest in the population and PAR, they would be able to offer me the input I needed. Julie Shaw Cole, MA is an expressive therapist and is known within the disability and mental retardation communities. David Peterson, MSSW teaches social work at Spalding University and is also a social work doctoral student at the University of Louisville. Dave's expertise is in ethics and supervision. We met between group sessions and reviewed the videotape of the previous group, paying special attention to my facilitation and group dynamics. Both signed confidentiality agreements (see Appendix B).

I integrated the use of peer supervision into the research plan to be a means of monitoring my own input and to establish trustworthiness that the group's decisions were genuinely their own, not mine. Julie, Dave and I kept notes of our conversations and their reflections. Their notes are another source of data. In addition, at the second peer supervision session, we decided to have transcripts made of the videotapes. Transcripts helped us in a variety of ways. A written record aided the supervisory session by having easy access to previous interactions and freeing our energy to focus upon dynamics and intonation rather than primarily focusing upon the participants' words, particularly those we struggled to understand. The transcripts were also a ready source of reference, more accessible than returning to videotapes to recall group interaction.

Transcripts were not originally included in the research design because of the cyclical nature of participatory action research and its emphasis on group decision-making and action. Group dynamics, while important in a global sense, are not the focus of analysis for PAR. The transcriptionist was a professional

secretary and office manager who was well versed in confidentiality concerns. We agreed upon a fee per tape and she signed a confidentiality agreement (see Appendix B).

### *Introduction to Group Members*

At the conclusion of the entire research experience, the group members asked that they be named throughout my "book." They expressed pride in their work and desired recognition for the hard work they did. I contacted the university's human subjects committee, requesting a change in the participants' consent forms, declining anonymity through making public their identities in my dissertation and on a video of highlights of their experience. The university committee approved the change in consent (see Appendix D). From this point on, all those identified gave permission to use their real names. Other persons had expressed interest in joining the group but did not follow through. In the narrative that follows, the persons who did not become active members of the ongoing group are not referred to by name. I now offer a brief introduction to each person who remained with the group until the end (see Figure 2).

1. Regi Lewis, 33, works at a local popular restaurant and loves to go out for coffee and to have dinner with his friends.

2. Ray Goodman, 46, works at a local coffee house, rising at 4:30 to get the coffee and muffins ready for his early morning customers.

3. Cindy Cusick is in her late 30's, works at a grocery store and is involved in almost every sport Special Olympics offers and loves working on her computer and cruising the internet.

4. Adrian White, 21, works at a local grocery store and has a passion for music, singing and playing keyboard.

5. Donna Caudill, in her late 40s, proudly owns her own home and is very involved in a variety of recreational and advocacy activities.

6. Michael "Todd" Esser, in his early 30's loves everything to do with the University of Louisville Cardinals, the Minnesota Vikings and his former high school, Manual.

7. Jackie Koch, in her early 50's, lives by herself and is very busy with a variety of local advocacy groups and is proudly pursuing her GED.

8. Theodia Johnson, Jr. (TJ) is in his late 20s, works with Regi and would love to pursue some form of a career as a cartoonist.

9. Mary Ann Lewis, in her 40's, works at a residential center for senior citizens and loves being involved in political advocacy.

*Figure 2.*
Names and pictures of Group Members in Phase Two.
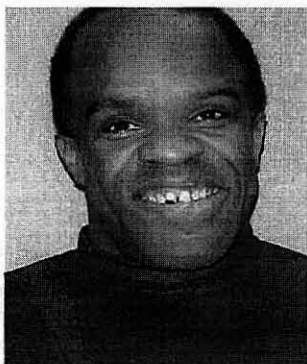


| Regi Lewis | Ray Goodman | Cindy Cusick |
| Adrian White | Donna Caudill | M. Todd Esser |
| Jackie Koch | Theodia Johnson, Jr (TJ) | Mary Ann Lewis |
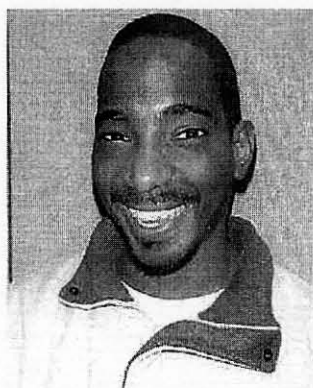
## *Group Process Overview*

In chronological order, this section will articulate the flow of the group process over the course of the nine sessions between April 2003 and January 2004. Each of the nine group sessions will be discussed integrating group interaction through the use of the video records and transcripts with peer supervisory input and my own reflections. I had planned to use pseudonyms for the participants. When in the seventh group session I spoke about writing this up, I told the group I would use fake names to protect their identity. After a discussion, the group decided that I should use their real names.

After establishing that the Leadership Institute had available space and time, I phoned each new group member for suggestions of dates. A date was agreed upon. I sent flyers and made phone calls to all the participants announcing that the first group meeting was to be held on April 24, 2003.

### *Group 1 (April 24, 2003): Reflection on Experience*

The group assembled as planned at The Council on Mental Retardation's Leadership Institute office on Witherspoon in downtown Louisville. This initial gathering lasted one and a half hours, from 7:00 p.m. to 8:30 p.m. As it was spring, the days were growing longer and we would not have to be gathering in the dark of winter. It appeared that the best time to have the gathering was a weekday evening. Many of the participants preferred to leave their weekends free. Trying to juggle various schedules from Special Olympic events to church gatherings, Thursday seemed the best day. Some of the participants were late

because TARC-3 drivers did not know the location of Witherspoon nor the Leadership Institute despite having been given the address.

Cold sodas and straws were available for the participants. I made the decision to not offer food during our meeting unless the participants decided to make arrangements for subsequent meetings. I felt that food may have been a distraction during the meeting and, from my experience, clean up could have presented a problem.

*Group experience.* Persons gathered, made their soda choice and sat wherever they desired. I had made placards with their names printed large. There was a nervous air in the room as some persons met for the first time and all were wondering what was going to happen. I also was nervous for the same reasons in addition to the fact that I had a lot riding on the 'success' of this group. I was not sure what 'success' would mean, but I was anxious about my role in this entire endeavor (R. Valade, personal journal, April 23, 2003).

The video camera was set up and began running as the group settled in. The transcripts chronicled a variety of interactions from among the participants and myself: a dentist's recommendations relative to use of a straw for a woman with cerebral palsy to help lessen the development of cavities as dental work is so difficult to accomplish; a hot air balloon ride celebrating the upcoming Kentucky Derby; and a grandmother's hospitalization. People tried to make connections with one another. "Did you go to the Drop-In at Illinois Avenue?" and "My mom was in the same hospital room as your grandmother was."

I knew that three group members would not be present for this first meeting, so I was expecting ten persons. Once everyone was present, I stood in the middle of the circle of tables around which the participants were seated. I planned to facilitate this initial gathering because I knew they agreed to come together to help me 'with my homework' through working through an issue they agreed and planned to address. I began the group by suggesting we take some time to introduce ourselves and get to know each other a bit. Persons went around the circle saying their names, where they lived and what they liked to do for fun or hobbies. I was not actually surprised, but was very touched at the respect that all the other participants had for each other during the introductions. Pertinent and clarifying questions were asked and smiles given easily.

Approximately half way through the introductions, a woman entered the office introducing herself as Adrian's mother. I introduced myself and verbally stumbled. I knew a major goal of the group was the independence of the participants and that family members and others were not to be present. She had dropped off her son and found a parking place and had come into the room to wait until the end of the meeting in order to bring her son home. The office itself was simply one large room with cubicle dividers, so there was no other space for her to wait. Suddenly, clarity came from within me and I offered to bring her son home from the meeting so she would not have to wait for him. Having interviewed her son in the first phase of the study, I knew exactly where they lived. The mother smiled and seemed relieved to be able to go home, not to wait for one and a half hours until the end of the gathering.

I was glad for the quick and satisfying resolution to the issue of another's presence during the meeting. I processed it with the group, repeating the importance of trying to meet alone. "I kind of feel like I was mean about not letting her (the mother) stay, but I really want to see what we can do by ourselves." Donna (a 47-year-old woman with cerebral palsy) looked up and said very clearly, "No, you're not [being mean]. It's a good idea." I saw other heads nod in agreement with Donna's comment and so I relaxed a bit from the interaction with Adrian's mom.

Introductions resumed. A light hearted conversation among many of the participants ensued when Donna told us she was excited to be going on a hot-air balloon ride the next day. It was a balloon basket made for wheelchairs. She then talked about wanting to hire a personal care attendant but had not been able to so far. Various participants offered to use any of the connections they had (at work, at their day program, at their church) to help locate a person to work for Donna.

As the introductions continued, there appeared to be a more relaxed atmosphere present. Informal interactions and teasing began to emerge as normative. It appeared that the group, including myself, began to enjoy the experience more. Some of the participants' speech was affected by cerebral palsy and many of us struggled with understanding what they said. I made a conscious decision to not automatically translate their speech. I was hoping that if other participants could not understand, that they would ask for clarification.

I introduced myself as the last participant. I also asked the videographer to introduce herself also, even though she would not become an interactive part of the group, her presence was important and therefore needed to be acknowledged. Also, as she has known many of the people with cerebral palsy for many years, she was helpful when we struggled to understand them.

I then began to tell the story about the background of this research in which they were a part. I reiterated, "The purpose of this group is going to be a chance for us to try to address some problem that we all agree on . . . that we will just use our own thinking to try to help solve that problem or to fix the problem or to make it better . . . It is a group for us and about us, no one else." Two lived out in the county and found it hard to arrange for transportation. The third was not able to come because a good friend of his was very sick. The group listened very attentively to me as I gave my introduction to the group focus, stressing that the group, not I, had the authority to decide upon its future and direction.

I asked the group if they wanted to establish any sort of group rules, ways we want to be and work with one another. I suggested the first rule as a way to begin the brainstorming by asking the group if anyone could come to our meetings with a gun. "No" was the resounding reply. "Safety first" and no violence was the consensus of the group for our first rule. After that, the suggestions kept coming from the members. Adrian suggested, "Be respectful." Respectful would mean being kind and considerate with "no nasty tone of voice." Be nice to each other with no cussing aimed at each other was another idea.

The group decided it was okay to use a cuss word when describing something, but not to call each other bad names.

Todd, a 32-year-old man with cerebral palsy had not been a particularly religious individual. He recently underwent surgery that resulted in complications of toxemia and a systemic infection that almost killed him. He was near death a couple of times. His recovery was a wonder and he has since pondered death and why he did not die. He has also struggled with the purpose of his life and why he continues to live. He suggested that our group always begin with prayer, especially for those group members who could not be present. I checked with everyone around the room and all participants heartily agreed to begin each group session with a prayer.

Adrian further suggested another group rule, "No making fun of people." TJ agreed, "Like for example, you shouldn't say, go up to another person and tell that person that he or she is retarded." There was general agreement in the group on this rule also, with a sense of assent that prior rules had not elicited. Mary Ann reflected, "I really like that. People calling people retarded is really not nice." TJ responded, "It makes me madder than I don't know what when I hear that." Mary Ann further shared:

> Well let me tell you about the time when somebody called me retarded. I was at school. I was at my high school and I was in a classroom with very violent people and mean and hateful people. I was getting ready to get on the elevator to get ready to go home. The kid had the notion to tell me that I was a MF retardo [sic] because my parents . . . because I was born

that way.  And I went home crying to my mom and my dad.  Was I really

born that way? Why did they . . . how come it had to be me?  And it just

really hurted [*sic*] me.

The group remained very attentive.  Donna asked if any teachers heard about it

or got on the students that called her that.  Mary Ann said, "No, the teachers

didn't do anything about it.  But my mom had him expelled or fired."

TJ expressed displeasure at the consent form that he had signed in

preparation for participating in the group.  We had gone through the consent form

in his home a few weeks prior to this first meeting.  I had read the entire consent

form out loud about the group being for persons with mental retardation, but it

must not have registered.  TJ shared, "I looked on that paper, you know, I didn't

know what that word is, so my brother helped me.  It said 'retardation.'  I didn't

like the word that much."  I asked if he understood it now.  He replied, "Yeah, I

know what retardation is.  I just didn't know what the word was, yeah." He then

looked out at the group and said, "And if somebody says you're retarded, you

need to tell them 'I'm not retarded.  I'm just a person with disability problems'."

TJ's buddy, Regi replied, "But I'm used to mine.  I'm used to mine, though.  I was

born this way.  I'm used to mine." TJ's response was quick and steady. "You

don't have to get used to anything like that though.  You're just an individual

living with a disability.  You make me laugh everyday." I felt this discussion

touched upon an emotional level of stigma that I have sensed since living at Day

Spring.  It showed itself during my unwitting struggle with the consent forms as I

would read the words 'mental retardation' and felt the cringe within the

participants and within me. During the group session, I wondered if they would want to focus on changing the term 'mental retardation' to another construct. Secretly, I hoped they would want to take this on.

Jackie moved us on from this topic, indicating her frustration with the medical profession:

You know, another thing we might want to address is not a rule or anything . . . But the way the doctors . . . some of the way the doctors don't think you know what you are talking about . . . Experiences like when you go to the doctor they don't ask you, they ask your parents or they ask your . . . well they ask anybody else.

There was a chorus of agreement from among the group. Many then shared their assent all at the same time. It really struck a chord with the participants. Sandy continued:

It just doesn't happen at doctor's offices. It happens everywhere. Just today. I've never been to this dentist's office, the one at Hazelwood [state residential facility for persons with severe mental retardation and physical complications in Louisville] . . . and he came and he asked Tina [caseworker] what was my disability . . .Instead of asking me, he asked her. And sometimes I get the feeling when people call on the phone they don't like the way I sound on the phone. They feel like they don't want to talk to me because, you know they put that label on me . . . They said, 'I don't want to talk to you. You act too retarded or something like that'.

At this point I was making two separate lists on large newsprint itemizing what the participants were saying, whether it was a group rule or a potential topic for group action. Mary Ann raised another issue that bothered her. She would like to see the development of college classes for persons with disabilities. Adrian supported that concept as Mary Ann continued to say, "College classes . . . so handicapped people can be whatever they want to be . . . like lawyers and doctors." Todd gently interjected that he did not think this was realistic. "We have to come back to earth. I can't be a doctor. I can't be a lawyer and people like that." A variety of persons began responding and it was difficult to hear any one point being made. I then suggested we have a group rule of only one person talking at a time. The group agreed. It appeared that the individuals in the group were not in agreement with people's potential to become doctors or lawyers. I did not pursue it then because I was still contemplating establishing group norms. Since the group was interested in generating areas of struggle that they would like to see changed, we kept a dual focus at this point in the gathering.

Todd expressed a concern for the way life was for persons with disabilities before he was born. He emphasized the progress that has been made and that things could be worse. I asked him if things could be better for people now. He was not sure. Some of the participants who were older than Todd spoke up. Donna remembered being with Arthur Campbell (local disabilities activist) in 1979 demonstrating against TARC to have accessible buses with wheelchair lifts. "Yes," she said, "things were much worse than today."

At this point it was almost time for the meeting to end as TARC-3 vans were starting to arrive to take people home. The group decided to meet again and that in fact, weeknights were preferable. Expertise relative to when to schedule their TARC-3 rides for the next meeting was offered by many of the participants to each other. Various TARC-3 complaints were expressed by a number of persons at this point. I was feeling a bit nervous because we had not established if we would have a next meeting, and if we were going to have another meeting, when would that be. People were busy talking about TARC-3. Seven out of ten participants who relied on TARC-3 for transportation were beginning to look for their vans. The other three participants rode with the camerawoman or me.

The group unanimously decided to meet again. Negotiating for our next meeting was quite difficult with ten persons. Finally we agreed upon Monday night, May 12. The time would remain from 7:00 to 8:30 p.m. at the Leadership Institute. Donna and Jackie simultaneously offered to call everyone in the group two weeks in advance to remind them of our upcoming group meeting and to schedule their TARC-3 rides. I asked the group if they would like that and if it was okay for Donna and Jackie to have all our phone numbers. All nodded in approval.

In the midst of concluding the meeting, Debbie (camerawoman) received a call that a friend of many of the group's participants was in the hospital and was nearing death. P. was a participant at a day program for adults with cerebral palsy and other special needs located in Louisville. He was approximately 40-

years-old and many people knew him since they were children.  People knew P. was sick, but did not know that he was dying.  All expressed gratitude to know about his health status and many were beginning to make plans to go to the hospital to see him that night or the next day.

*Videotape, peer supervision and journal.*  In reflecting upon the meeting in my journal, I wrote about the chaos that happened at the end of the gathering.  The announcement of P.'s deteriorating health broke apart any authority I may have thought I had in the group and left me feeling unsettled. Yet, I knew that I would have wanted to know about a friend's poor health.  P. died a few days after our gathering.  At the funeral home and funeral mass I saw many of our group members.  Each one expressed gratitude for having been told about his condition while we were together in our meeting.  For some persons, the support of being with other friends helped with the sadness of the news and assisted them in preparing for P.'s death.

Through reviewing the videotape in peer supervision, Dave, Julie and I gained some new insights into the group's first gathering.  By noting what we interpreted as non-connected responses to some of the comments made by members with cerebral palsy (CP), it seemed that not everyone understood what was being said.  I made a note to encourage everyone in the group to ask others to repeat themselves if anyone could not understand a comment.

The PAR group exuded a lot of energy when discussing issues that rang true to their experience, particularly being excluded from conversations about themselves.  In supervision, we discussed possible reasons persons without

mental retardation try to make persons with mental retardation invisible through not directly addressing them. It seemed that people without mental retardation sometimes (often?) viewed persons with mental retardation as less than human, not knowing how to address them or interact with them. This then results in the lack of basic human courtesies such as speaking directly to them, asking their opinions, and requesting their input on issues pertaining to themselves are suspended.

Furthermore, in watching the video of the group meeting, it was very apparent that the group social skills of the members were highly developed. Persons waited for each other to finish speaking, regardless how long it took them due to their physical challenges. Participants stayed to the topic and none dominated the group. Only two persons said nothing spontaneously, Ray and Cindy. I planned to monitor this to ensure that they felt they had a chance to engage the group in subsequent gatherings.

I told Julie and Dave about my struggle with the consent forms relative to the term "mental retardation" and substituting it with the generic term "disability." I shared with them how mental retardation tended to be included in the disability literature only tangentially and that when the term "disability" is used, it generally connotes physical challenges rather than cognitive challenges. Because of this, I would have to be attentive to distinctions that may be in the group between those with physical disabilities and those without.

Regarding my role, I struggled with how to define myself within the context of the group. Feeling enlivened by the principles of PAR, I so wanted simply to

be a member of the group, offering my own insights and thoughts as an equal partner. Yet I was cognizant of the authority I possessed among the members and with the group as a whole. It sounded absurd to have to admit, but I also had to acknowledge that I do not have mental retardation.

I was reminded of three of Barnes' (1992) elements of emancipatory research endeavors. The first insight reflected the reality that in most cases, initiating researchers are unlike the research participants and this difference needs to be acknowledged. The second characteristic I recalled stated that the presence of the researcher impacts the behavior of the participants. And the third element spoke of the tendency of non-disabled researchers to over-empathize with research respondents with disabilities. I came to a greater appreciation of Barnes' wisdom. However, my role confusion did not resolve after this first group session. That would take a few more meetings.

The peer supervisors felt comfortable with the way I was with the members of the group and that I did not seem to dominate or interfere in the group's processes. Dave's written reflections noted, "Rita did not ignore any one comment and she was very patient. Respect for each member of the group was evident. The introductions took a long time, but the participants were not hurried." They felt sitting at tables in a square with name cards placed before each member was a good arrangement. The video was of a good quality and the videographer was able to capture some group dynamics and interactions that an audiotape would have missed.

### *Group 2 (May 12, 2003): Reflection on Experience*

I was not sure who would return to the group. A few weeks prior, I drove to Donna's house and gave her the phone list of the group participants. I felt nervous abdicating all responsibility for meeting reminders to Donna. I did not know Donna well, and did not know if she would follow through on her offer to phone everyone. Not sure how to best proceed, I also sent out flyers to all participants, reminding them of the May 12 meeting and to schedule their TARC-3 ride. I remembered the learned wisdom of Heller, Pederson and Miller (1996) who reflected that the written word is not always the best medium through which to communicate with persons with disabilities. But, it was the easiest way to assure that the participants would receive a reminder in case Donna did not contact everyone. Through individual conversations with each, I knew that the three persons who were absent from the first meeting would not be participants in the group. Our number then shifted from a group of 13 to 10. I had anticipated that there would be some withdrawals from the group. It just seemed to be a common experience to lose some people in the initial stages of a new endeavor.

*Group experience.* The group gathered and many thanked Donna for the phone calls they received reminding them about the meeting and to schedule their rides. I felt relieved and learned I could trust Donna to follow through on responsibilities she undertook. One woman who attended the first gathering was not present for this second meeting. No one had heard from her. Donna stated that she did not have an answering machine so she could not leave a message.

Regi said he had seen her at the day program and the woman indicated she would like to be part of the group, but could not attend that night. Regi volunteered to pass any information on to her on our behalf. Many of the members knew this woman and knew she had some family pressures, particularly with her mother. Mary Ann was also absent. I expressed concern about persons dropping out of the group. It was my hope that members would talk to someone in the group if they would make that decision. So far the only members I knew who were not coming were the three mentioned earlier.

As one of the group rules was to begin each meeting with a prayer, we took a moment and a member led us in prayer. The prayer mentioned spoke of respect. Once completed, TJ looked right at me, turned to his friend Regi, and said, "Be respectful to each other . . . like I can't knock Regi upside the head." The group broke out in laughter and bantering. I felt it was a terrific way to begin our gathering.

Once everyone settled, I spoke of the observation made during peer supervision to encourage clarification if persons did not understand each other in the group. All agreed. We then reviewed the rules we had agreed upon in the first meeting: begin with prayer; take turns speaking; the word 'retarded' is not to be used in the group, especially in a derogatory manner; safety first, and treat each other with respect. Donna asked about the issue of confidentiality. The group talked about what that meant and its implications. We came to an understanding that it meant "keeping things secret," especially if it is something personal that is shared in the group. If we, as a group, would decide to visit our

state representatives, that information would be public information. From the looks on some persons' expressions, it seemed that a few did not understand the difference between personal and public knowledge. I asked if, at the end of each group, we should take some time to decide what was personal or public information from our meeting. Some heads nodded, but then Todd spoke up, "You have to use your judgment. I don't think you have to go overboard." The group then agreed that we would try to use our judgment rather than take time at the end of each meeting to decide what was personal or public information. Confidentiality then became a group rule.

Interspersed throughout the meeting, there were a few requests by two members of the group for assistance with their beverages. I tried to encourage others to assist with this, but the two people in need asked me to help them. Later I learned that neither one of them trusted the others' abilities to help with the beverages. Neither wanted to hurt the feelings of the other members, but there were specific techniques to helping that they were not sure the others knew.

The conversation then shifted to identifying issues. I attempted to reiterate the topics we surfaced at the last meeting: the term 'retardation', doctors' offices or other places where people don't talk to you but whoever is with you, and some sort of 'college' for persons with disabilities. This topic stirred many spontaneous reflections. It seemed people did not share in Mary Ann's previous belief that we could become doctors or lawyers. "I don't mean to be

negative, but I have been working on my GED since 1989 and I don't know if I will ever get it but I am still trying," shared Jackie.

I suggested we "take it down a notch" and think about a formal education setting after high school. I asked Todd about his experience at the day program he attends. "The program . . . it doesn't get you back to school. They don't teach you math or reading or science. I don't know a program that teaches like that." "I need something like a computer class or something like that," responded Donna. "I'd like that . . . like the experience of high school, but for adults" said Todd. Jackie then interjected, "I enjoy working the process and with the person I work with. She is from Jefferson Public Schools." She was referring to her GED program.

TJ had been silently taking in this conversation. He asked the group, "But what if we DO want to be a lawyer or cartoonist? I'd like to be a cartoonist. I'd like to be a cartoonist . . . some day be in comedy." No one had a direct response to his question. Adrian asked if anyone knew a tutor knowledgeable of dyslexia. "Miss Aunt Helen," Regi replied with a smile:

Oh . . . Miss Aunt Helen. I'm learning how to read. She teaches me on Monday, Wednesday, and Fridays. We use 'Hooked on Phonics'. Yes, that works good. She just comes three days a week when I don't fall asleep on her.

The group laughed. They had already teased Regi about closing his eyes during the meeting. Jackie then offered to ask her GED teacher about any program for people with dyslexia on Adrian's behalf.

The conversation shifted to the difference between getting a diploma and receiving a certificate. Todd had wanted a diploma from his high school. Some of the members were unclear whether they had diplomas or certificates of completion. Neither Ray nor Cindy had spoken during the meeting, so I asked them directly to talk about their high school experiences. They both went to the same school.

I asked if there were any other areas of concern for the group. "They make fun of you if you're wearing a hearing aid," interjected Cindy. The conversation shifted to group members having been ridiculed by others. Jackie then shared:

Kids make fun of me in my wheelchair. The parents are very bad about it. They don't understand that we are as normal as their children and while we are in wheelchairs, they're afraid we have something contagious and won't listen or even talk to us.

Todd then shared his experience with the Louisville-based Crusade for Children. He had been a poster child for them years ago. At its inception, the Crusade had been a movement to raise consciousness about and money for persons with disabilities. When a local television station began to sponsor it, it shifted the Crusade's emphasis to children only. Todd expressed frustration that "we still have needs. But don't get older! They won't help if you're over 19 years old."

The topic of being ridiculed resumed. Adrian reflected:

Like there's this one time when I worked at this one restaurant and you know . . . and when I would go back to the back office I would have to go through the kitchen and back there were people back in the kitchen. They would really mess with me and really get on me. Like calling me names and scaring me and just messing with me. I had to resign from that job. And the managers . . . they didn't do anything about it.

Cindy then added her experience of being made fun of at work because she had a disability. Todd added:

Same way at Papa John's. They change the bosses and that made all the difference. That boss, he didn't know how to work with disabled people. It was a good job, but the boss one time came to work with me. He didn't even know how to work with me.

Ray, who tended to be very quiet and usually did not offer his thoughts spontaneously talked about his experience. It was very hard for me to hear. I had known Ray for many years:

I've been bugged a lot. Ever since I was born. Yeah . . . I went through school . . . made a lot of friends and everything, but there's this bunch of kids that made fun of me and I just had a hard time with that and they're still doing it. I also had this one boss who was very abusive. I mean not physical but verbal and he would cuss me out every day for no reason. I was around 20 years old.

Adrian reflected on his experience in middle school where he was placed in a learning disabled classroom because he did not do well in the regular classroom:

You know, the other kids were in there because they had behavior problems and some of these students were like streetwise kids. I mean there were some students that were friendly . . . but these other kids just messed with me and throw things at me and called me names and all throw stuff and the teachers didn't do anything about it. And so I got mad and did things back at them and I was the one that got in trouble for it.

The group was very attentive to each story shared, with heads nodding in understanding and dismay. It was apparent to me that these stories needed to be shared. Cindy, Adrian, and Ray did not often volunteer to speak in the group, but their spontaneity belied the connection they felt with others in the group about being disrespected and taunted because they had disabilities.

As the stories ended, I reintroduced the 4 areas of concern thus identified. I was conscious of group members who could not read, so I repeated many things that I had written down on the newsprint to refresh everyone's memory. When I got to TARC-3 as an issue, problems were shared. Jackie told of her experience from the day before:

I had a 9:30 pickup. I was out there at 9:10, before the 15-minute window. Anyway, another person was waiting for TARC-3. He had one at 10 and it showed up but mine didn't and the driver called in for me. My driver was a block away. I waited until 10:10 . . . I waited an hour and when I called

they told me there still a block away and they should be there shortly.

They never came.

A few different members shared techniques of noting the reservation agent's name, and the time and date the reservation was made. But even with that information, there is still no guarantee people will be picked up.

Time was drawing to a close for the group. When asked, the group agreed they wanted to keep meeting. We were able to set a date for Thursday, June 13. Interspersed with TARC-3 arriving, members cleaned up and continued to tell stories of their experiences with TARC-3 from the previous month.

*Videotape, peer supervision and journal.* Julie, Dave and I met on June 9, one day prior to the next meeting. Once again, we were in awe of the attitude of respect and patience evidenced in the group as a whole. People genuinely listened to one another, waited their turn to speak, asked each other questions, and easily laughed together. There was an increased sense of familiarity and ease among the group members. We also spoke about some of the assumptions that others may have of persons with mental retardation: that they are not appropriate and they are childish. Just watching the video challenged those assumptions.

Dave challenged me to the use of two different terms. The first term, "drop out" related to my concern about persons leaving the group without informing anyone. The connotation is negative and could intimate failure, as in "high school drop out." The second term, "take it down a notch" related to adjusting Mary Ann's image of persons with mental retardation going to a special

college to become lawyers and doctors. The phrase connoted a service that was 'less than' what other persons can access.

Also, Dave was initially concerned that I was too directive in my facilitation. He noted that I relaxed a bit and grew in patience as the meeting unfolded. Julie tapped into this dynamic with her own observation about the fine line between keeping on task and allowing the group to be free-wheeling. I noted that I was talking too fast and was concerned I was talking through others. Upon reflection, I recalled feeling anxious about moving the process along during the first part of the group. I then began to relax when I reminded myself that this group belonged to the members. I remained confused regarding my exact role in the group. Was I a facilitator? Was I a member? Did my opinion count? Should I offer my opinions? How much should I work toward keeping the group on task towards a decision and movement towards addressing an issue they raise? My role was a serious struggle for me.

Dave indicated some concern because the only two people of color, Regi and TJ, both African Americans sat next to each other for both sessions thus far. I noticed that, but I also knew that they were good friends from work, and socialized together on weekends. Seating of the group was pre-arranged to some degree, assuring space for those in wheelchairs to be able to navigate around a very tight space. Regi and TJ gravitated toward the same place, the first one saving a seat for the other.

I was aware that I was the focus of attention. My journal reflected this point:

I am hoping that as the group continues, I will not be so much of the focus. But I guess that will depend on how the group matures, how I define my role, and what type of time we have available. We will just keep walking the walk. The group does seem to be gelling and they came in with stories about some areas of concern. Some of them have been thinking about the focus of this group in between groups. That feels great!"

All three of us commented upon the energy of the group when topics of concern were being discussed. The members' attentiveness and involvement in the process spoke directly to the importance of the issues that have been identified. All spontaneous comments have related to at least one of the four major topics: TARC-3; continuing education; treatment by the medical profession; and the term, "mental retardation."

To help our own process, we decided it would be helpful to have transcripts of the group sessions. We struggled with understanding Todd, Donna, and Jackie and felt it was important to devise ways of overcoming our disability of not speaking their language. Transcripts would help.

### Group 3 (June 10, 2003): Reflection on Experience

The date set from the last meeting had to be changed due to not having foreseen that I would be out of town on June 12. The day after May's meeting, I was leaving the country for three weeks and did not have time to contact every member of the group by phone prior to my departure. I sent out flyers noting the change and I prayed people received the flyers. Upon my return, I phoned everyone and told them of the date change. I am grateful I did. Many did not

either get the flyer or did not pay attention to it. I spoke with Donna and she had not received the flyer. When I spoke of the change in date, she expressed regrets that she was not able to attend the meeting because of a conflict with other plans she made. I had seen Mary Ann prior to this meeting and she assured me of her continued interest in the group. I was nervous if people would be attending this meeting because of the date confusion.

*Group experience.* Despite the date confusion, for which I apologized, eight members were present. Sandy did not come and we agreed as a group that she may have made a decision not to continue with us, but we would welcome her if she chose to return. Donna had asked me to audiotape the meeting so she would not miss anything. I suggested we loan her the videotape, but I wanted to check with everyone first. All agreed to let Donna see the video. (I took it to her within the week.)

After prayer, I asked the group to talk about understanding each other. There was agreement that there are times when we struggle to understand each other, particularly Todd, Donna, and Jackie. All three said they would rather repeat than to be misunderstood. I asked the group for help, noting on the previous videotape that some of the members more readily understood each other than I could. We agreed to ask for clarification if we are confused.

The group then immediately got into discussing issues when Adrian began to recount a very long TARC-3 trip that took him far from his destination in order to drop off another passenger. Adrian had scheduled the TARC-3 to travel

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between his home and piano lesson, an approximate distance of 3 miles. The trip was so long he missed his piano lesson.

Jackie was quick to tell him he should have scheduled his ride earlier. Cindy then recounted how she was on the van for two hours last week, knowing that 80 minutes was the maximum allowable. There was some discussion relative to where the fault lies: the driver or the scheduler? Todd wanted to make sure that people did not blame the drivers for problems with scheduling. "They just do what the manifest says," he said.

At this point many people were talking at the same time, recounting problems and offering opinions. I reminded folks of our rule: only one person speaks at a time. Mary Ann then shared her concern about the frequency of being late for work because of the TARC-3 schedule. Jackie responded by telling her she also needed to schedule her ride earlier, allowing for a possible 80-minute ride. Mary Ann defended herself, stating that she had scheduled it early enough, "but we went clear out to LaGrange and by the time we got back, it was pretty late."

Feelings were intense in the group. Jackie was talking about the rules when the others were sharing problems. Sometimes it is not appropriate to arrive somewhere over an hour early. Two persons said that they were discouraged from hanging around work for an additional hour waiting for their shift to start. Todd was a stalwart fan of his former high school football team. He has never missed a game. He offered:

You have to pray to God so that you're not late or not too early when you
go to football. You take your TARC real early and then real late, about 10
o'clock as your window. One night, this is funny, one night we were
freezing. My best friend and I went to a ball game. We were watching
football all wrapped up. We had to sand there and wait and they turned
the lights out!! Yeah!!! (he laughs) They turned the lights out! Oh my
God!! It was so dark. I said, "I hope they see us . . . I hope TARC-3 sees
us! And . . . and, you'll love this, we were next to a graveyard!!! Let's face
it; you have to live by the TARC schedule.

"You can't really say nothing to the driver," reflected Cindy. The
discussion shifted to no-shows. If persons receive more than three no-shows in
a month, their service may be temporarily terminated. People receiving no-
shows when they were at the designated spot and the assigned time was a
source of anger and frustration.

In an attempt to help the group focus, check on my own observations and
interpretations thus far, and to help the group decide upon a topic, I reviewed our
first two groups. The first meeting focused upon coming together as a group:
introductions, group rules, and establishing if we would continue to meet. Some
issues were surfaced during that first group also. The second meeting was
focused a little more on group rules, especially confidentiality, but was also more
in depth on the issues of continuing education and being treated with respect.

With that said, Jackie shared about a recent attempt at a bone scan at
which she was chastised for not stretching her arm across an exam table for the

test.  Jackie's CP. has contracted the muscles in her arms and back, preventing her from stretching and bending.  Her arms can be pulled, but she cannot, by her own volition, bend them forward more than a few inches.  She reflected:

> But the doctors don't take my word that my arms do not go out that far when I'm laying flat on my back.  They think I don't know what I am talking about.  They don't take you seriously.  And the nurses at the doctor's office wouldn't give me the address where the test would be done.  I have to schedule my ride two weeks in advance to make sure I get the right time.  The nurses told me I would get it in the mail.  They think I can just hop in my automobile and get there.

Mary Ann replied,  "Sometimes I wonder if these doctors and nurses think we're stupid."  Todd has an athetoid type of cerebral palsy.  His muscles are in constant movement, especially his upper torso.  He squealed retelling this story:

> When I was in the hospital, the nurse made me laugh one morning.  I was sleeping.  He walked in and said "Good morning. How are you?  Let me take your temperature. Where do you want it?  Do you want to take it in your arm pit or your mouth?"  He decided it would be in my mouth. He said, "Open up."  I thought, "Oh God, it's going to be a long day!" "You put it under your tongue."  I said, "Oh no! I don't want to eat it."  He said, "Okay, open up."  I said to myself, "You're going to be sorry."  They think you're stupid.  He was a nice nurse, he just didn't know much about wheelchair people.

In reviewing the other issues that people surfaced in the group, I for the first time heard discouragement about effecting any change. When I mentioned "mental retardation," TJ said, "You can't basically do nothing about it." When I tried to encourage him to dream, he replied, "What good is that going to do?" Again Regi responded, "I'm used to it." I then mentioned the issue about medical staff not acknowledging people with respect. TJ said again, "How are we going to do that?" Todd replied, "I don't know, but you take a big, big issue. It's not going to be a piece of cake. I'd like it to be, but its not going to be one."

As was the style of the group, each time I attempted to repeat the four issues, others had comments or stories to share about each concern. When I repeated TARC-3 again, Jackie expressed a concern that she was not interested in civil disobedience. She spoke of Arthur Campbell, a longtime activist on behalf of people with disabilities in the Louisville area, especially relative to public transportation. Jackie shared that she did not want to be tied to a bus or be part of a demonstration. Todd however, excitedly said that he would love "to live on the edge and land in jail." When I attempted to summarize Arthur Campbell's historic approach to advocacy, the group indicated they were not interested in that form of activism. I asked them to make sure I was interpreting their nonverbal cues. With the exception of Todd, none wanted to engage in civil disobedience regardless of the topic chosen.

Every instinct in me indicated that the group was ready to move toward a decision about what issue they wanted to address. I found it difficult to help them keep focused, but once we began to indicate preferences, the group's attention

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was dead on. I asked the group if they felt they were ready to make a decision. They all agreed to try. I told them I would name all four areas one at a time. Persons were encouraged to vote for whatever issues they wanted to try to change. They could vote for as many as they wanted.

The first topic was dealing with the term "mental retardation." After a bit of a discussion, Regi, TJ, Mary Ann, and Cindy wanted to work on that issue. Six members voted to address the problems with the medical profession. Only one person wished to pursue continuing education as an issue. The issue of TARC-3 was the next topic. Six people immediately indicated interest. Ray, who is not eligible to ride TARC-3, having been told he is capable of navigating the city bus system had not voted for any of the items. I asked him if the group decided to work towards a TARC-3 issue, if he would be willing to help out. He agreed. TJ, who did not have a long list of complaints about TARC-3, agreed to join the group if that was the group's decision.

It seemed from all angles that the group had in fact, made the decision to work towards addressing concerns about TARC-3 service. I checked with everyone to verify that everyone felt comfortable with the decision. All nodded their heads in agreement. The group broke out in spontaneous applause.

As our time was drawing to an end, we agreed on July 17th as our next meeting date. I had some flyers ready for the date to be written in as a visual reminder of our next gathering. Ideas about what to do, who to contact, and other problem solving tactics were beginning to fly around the room as TARC-3 drivers came to the door thus ending our meeting.

***Videotape, peer supervision and journal.*** This was our first session with transcripts in hand. They were a tremendous help in our struggle to understand and track conversation. Julie, Dave and I met on June 25 and we all commented on the genuine humor of the participants as we enjoyed various interactions among them. After hearing the stories of ridicule from the previous meeting, Dave reflected, "I wonder what the connection is between terrible experiences and humor. What role does humor play in general, and with the group specifically?" (D. Peterson, supervision notes).

He further reflected on Jackie's frequently offered advice relative to using TARC-3. She seems to have set herself as the resident expert. We wondered what was behind this. She has had many complaints herself, so she knew that, regardless of following the TARC-3 rules, mishaps sometimes occur and people do not get to their destinations. As this was not a therapy group, but a PAR group, I decided not to pursue these questions with Jackie. I would leave it up to anyone in the group to pursue if they chose.

The return rate was also something of note. Of the original ten persons who participated in the first gathering, nine had remained active in the group. This was our third group and we all commented on the commitment of the members to the group and process. A commitment to me as organizer may have also played a part in their return. While I was uncomfortable pondering this possible reason for the members' return to the group each session, I needed to acknowledge it as a possibility.

I shared my discomfort with having to change the date of the previous PAR gathering. "Fliers are not the best means of communication," reflected Julie in consort with me. Once again, I thought about the wisdom learned through the interviews of persons with mental retardation performed by Heller, Pederson and Miller (1996). Written media is not the best way to communicate. I was not sure what else to do, and despite the problems, I felt it was the only recourse I had at the time.

My role was growing clearer as we watched the group dynamics and discussed it in peer supervision. I finally admitted I was not a full member of the group in the sense of having an equal voice and shared experience. Julie helped me name my own reality: I do not have mental retardation so I do not have a personal experience of living with it. Also, both Dave and Julie envisioned my role as group facilitator, not possessing decision-making powers within the group relative to the choice of issues and the action in which the group will engage. I relaxed upon recognizing my function and identity within the PAR group.

Dave had raised a related issue of my use of "our" or "we" when referring to a variety of dynamics heard from the members. Many of these dynamics related to the experience of oppression, problems with TARC-3, or other aspects of living with a disability. They were not my experiences, therefore my struggle with group membership and role showed itself in trying to identify with the group in ways not genuine. These were very helpful insights. Barnes (1982) spoke directly to two points that relate to this discussion. The first point was that the researcher tends to be different from the participants and that this reality needed

to be acknowledged. It took me three group sessions to finally name my experience, but it directly concurs with Barnes (1982). Experiencing it first hand gave me a deeper appreciation for the tension of being different from the rest of the group. Barnes (1982) also reflected that the researcher could too readily over empathize with the participants, thereby losing all sense of objectivity. I understood his thoughts from a new perspective. I saw this propensity alive within me. I was grateful for the time with and feedback from my peers in supervision. Processing this alone through my journal had not led to the depth of awareness that I came to during our time together.

In reviewing the video and my own journal, I realized how hard I have had worked to not become a problem-solver for the group. That was an ongoing struggle within me from the first session. I felt it would remain an issue as long as the group was active.

### Group 4 (July 17, 2003): Planning

This time I did not do anything to support members' attendance at the meeting. I heard from a variety of group members that they had received Donna's calls reminding them of our meeting. As always, I wondered who would be present and if anyone else decided to leave the group. Eight members were present. Cindy was the only one who was absent for reasons explained below. However, there appeared to be a general chaos operative at the beginning of our time together. People were late and flustered with TARC-3 and other reasons I never learned.

*Group experience.* The group assembled in our usual manner: TARC-3's arriving, people claiming their seats, and choosing their beverages, along with bantering with each other. There seemed to be a growing sense of companionability among the members. TJ said an eloquent and lengthy spontaneous prayer. Afterwards, the group showed its appreciation by teasing him, calling him "Reverend TJ". TJ glowed.

I began to review our process and decision from the previous meeting to focus upon TARC-3 as the issue we wanted to address, checking that all members remained committed to the direction we set last month (Fals-Borda & Rahman, 1991). In the midst of this refresher, I received a phone call from Cindy who had not arrived at the meeting yet. She had told me she may be late because of softball practice and had scheduled TARC-3 to pick her up to bring her to the group meeting. She was in tears. A TARC-3 van drove around the softball area, Cindy had jumped and waved at the van, but did not stop to pick up Cindy. She borrowed a cell phone from the coach and called TARC-3. They told her she was given a no-show because she was not at the field. Despite her explanations, they told her there was no guarantee someone would be back to pick her up. She was very angry and frustrated. She had to figure out how to get back home. Cindy called me back a few minutes later and said that she could get a ride from another friend who was just starting practice, but that she would need to wait the one and a half hours until her friend's practice was completed. But at least, she had a ride home. She was also upset because she did not want to miss the group meeting.

I resumed my attempt to focus the group on their decision to challenge aspects of TARC-3. I thought the current stress that Cindy was in would help stimulate action-oriented conversation and decision-making about a group strategy for addressing TARC-3. But the conversation did not move in that direction at all. In fact, it went in the opposite direction.

Todd began the shift in direction:

I've not had a problem with TARC. They were late once in a while but otherwise things are working. But in 1973 they didn't have buses for handicapped people. They would take you to the doctor, hospital, and that's all. You couldn't go to a ballgame or park or anything for pleasure. You have to take the bad with the good.

I turned to the group and invited any further reflections. Donna offered:

Sr. Rita, you do have to take the good with the bad, but I think they have to train the drivers to hook the chairs in. The other day, I had to go without a strap because they didn't want to take the time to do it right.

Jackie advised that Donna call in the complaint and proceeded to tell Donna the phone number. I felt very irritated by Jackie's constant advice about TARC-3 as if no one else knew how to navigate the system. Also, it was clear to me that calling in complaints did not necessarily solve problems. I breathed deep and reflected back to Jackie what she had said, "It is real clear Jackie, that you really believe about calling in and complaining on the complaint line, right?" She responded, "I can give you that number." I inwardly smiled at her predictable response.

I asked the group to think about the problems that various people had with
TARC-3 since we began meeting, including the current situation with Cindy out in
a ball field 20 miles from home. Regi, Mary Ann, and Adrian commented that
they did not think, "that was right" and that it made them mad. Mary Ann added
that she thought, "We should do something about that." Mary Ann then
proceeded to tell another TARC-3 story that resulted in her not being picked up
from work. After a few phone calls, Mary Ann was told by TARC-3 that no one
would be out to pick her up. Mary Ann made other arrangements with her
mother. As she was getting into her mother's car, TARC-3 showed up and then
they proceeded to give her a no-show. Jackie offered more advice about who to
call to complain.

At that point, I was feeling a "blame the victim" attitude floating in the
group about Cindy and Mary Ann's problems. I attempted to name this dynamic:

> I am hearing that some of you feel that maybe Cindy didn't schedule it
> right, or maybe Mary Ann did something wrong. Maybe they did
> something wrong or maybe there was a miscommunication, but something
> needs to be changed because these problems keep happening.

I realized I was becoming very frustrated at the shift in direction from last month's
meeting. Last month they, especially Todd, were energized about advocating for
change. I was stunned at this attitude shift. Todd continued, "I'm going to be the
bad guy. What if that driver (Cindy's) had an emergency and they couldn't find
Cindy?" Donna interjected that Cindy's van may have been Wheels, a company
TARC-3 contracts. "They close at seven o'clock."

I consciously tried to invite others who had not yet spoken. Adrian commented, "Ah well, I haven't really had any major problems lately except for maybe once in a while." Regi added, "Well, I haven't either, not really though. But last Friday morning, riding the bus, we didn't get there till quarter after nine." TJ commented, "That's because I gave her the wrong directions. Like I said, it goes both ways. It was my fault."

In an attempt to be true to the group dynamics, I tried to put their words into the context of the previous three meetings. It seemed to me that people were concerned about "coming down too hard" on TARC-3. I asked, "Are people afraid to do something about the problem?"

Jackie responded, "Yes, they are afraid that they won't be able to do anything about it. Its not a problem for me because I have done enough and I have been at meetings that they have." I challenged Jackie to think beyond calling in complaints. I asked if there was something else we would feel comfortable doing to address the problems with TARC-3. Donna suggested we call Karen Dennison, "she is the director of TARC-3." I reflected back to the group:

> I am not sure I am hearing from everyone that people would still like to do something about TARC-3. Last month I definitely heard everybody saying that they wanted to do something about TARC-3.

TJ asserted that he had been ambivalent, but Regi had persuaded him to agree to TARC-3 as a focus. I was silent and began to feel even more confused and discouraged. Donna responded by saying, "I think we can do something. I

think we can get Karen here to talk to us." I noted that suggestion. Todd was still uncomfortable with this conversation. I also began to notice Adrian was rocking back and forth, Regi was biting his nails and Mary Ann had her head down frequently. Todd said:

I'm going to be the devil's advocate. I don't think anyone calls in to say I got a good driver. I called a couple of times to say I've had a good driver and we had a good time and we laughed. People, you have to remember, 40 years ago we had nothing.

Donna responded, "I know that Todd. You don't know how I know that. I lived in Bardstown and we didn't have any way to get around. I moved up here so I could get services." Todd continued:

Okay. What if we have too many complaints and they've had enough and say, "we're going to pull out." What are we going to do then? With too many complaints, they'll pull out. You rock the boat too much, they gonna pull out. We'll be up the creek.

That was the issue. Todd articulated a fear that I felt others also shared. I checked with the group and Regi and Jackie agreed they also had felt that fear. Others also nodded their head in agreement. Donna reflected, "That's his fear. You feel like you're at the mercy of TARC-3."

Todd followed:

I feel at the mercy of everybody . . . at Day Spring, at the Mattingly Center. It's okay to complain, but you don't want to rock the boat. I don't want to get sent back home or not have any way to get out on my own.

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I asked if anybody else had that type of fear.  Donna admitted she did, as did Jackie.  Mary Ann did not.  Jackie then looked at Mary Ann and said, "You're able to walk and get in and out of cars.  I know you can get into an automobile, but Donna and Todd and I can't.  We have to be lifted in our wheelchairs."

At that point a TARC-3 driver came to the door to pick up TJ.  We scrambled quickly to arrive at a date for our next meeting as TJ was walking out the door.  Todd reinitiated the conversation by telling the story of a friend of his who had been in an institution all his life without any independence.  Todd was afraid that would happen to him if we did not continue to have services in the community.

I asked the group if anyone thought that because they had disabilities, that they should just accept whatever is offered and to not challenge the system.  After a specific invitation, Ray shared his thinking on the subject:

> I don't ride TARC-3 but I know a lot of people here do and I feel how they feel and everything.  I think sometimes you should complain but other times you should just back off because you know, you know you could lose your ride if you keep complaining.

Adrian declined comment because he felt he did not have many serious complaints about TARC at the moment.   Mary Ann shared the level of anger she felt towards TARC:

> Well, I want to complain.  I want to have a discussion with them.  I want to say, "Hey, look here.  All this stuff has happened to me since I've been with TARC.  Can you please do something about it?"

Jackie encouraged Mary Ann to attend some of the public meetings with TARC-3. Donna repeated that she would like to have someone from TARC-3 come to one of our meetings. "I think they'll try to fix it if they know about it. Yeah, but they don't know. They come to other meetings and that's why its in as good as shape as it is now." Todd quickly responded, "I think you're playing with fire." Regi agreed. Todd continued:

> If we ask her to come, we'd have to be nice to the lady . . . can't go off on her. I feel like I'm preaching and preaching and no one hears me. We have to wake up. We've come a long way.

I challenged Todd. "Todd, I need to ask you this from the bottom of my heart. Does that mean that we're done? That there's nothing that can be improved?" "I don't know. I don't know. I feel sorry for both sides," Todd replied.

At this point we began to run out of time. I suggested we hold off on any decision and to take some time to think about what the group wants to do. Donna suggested that possibly, "if the majority of the group wanted to pursue TARC-3, they could. If there were some people who did not want to, they could just skip that meeting and then come to the next ones. I don't mean any harm."

Todd wanted to apologize to the group "for being the devil's advocate. I'm sorry, but I just feel that way." Donna replied, "Not to make anyone angry, but I'm going to say it anyway. Todd can call his mom and say 'I can't get to so-and-so place.' I can't. My mom is too old and I can't transfer from my chair very good."

Todd was disturbed by this comment and responded:

My mom's getting older and the van's not working. It's not really a choice I have. Without TARC-3, I'm up a creek. No more ballgames, no more going out on my own. TARC-3 is my life.

Regi, who had been silent for much of the meeting, spoke very clearly. He appeared agitated:

This is not going so well cuz [*sic*] the thing that they keep talking about, like we keep saying about TARC-3, you're going to lose your ride, and you're not going to have any ride at all. You're going to make it worse than it already is now. And then how are you going to get around, all of you all? We should just leave it alone. If we invite that TARC lady, you're all going to be without a ride.

Mary Ann was perturbed by Regi's comment and responded, "Well, you haven't been through what I've been through with TARC-3." Regi interrupted Mary Ann with a sarcastic tone of voice, "But that don't mean nothing Mary Ann. That don't mean nothing at all. You go ahead. You go ahead and bring them here if you want to." He thrust his arm down as he said this last phrase and turned his head away from her.

This was the first time any display of anger was so evident. I challenged Regi that I believed he had been disrespectful towards Mary Ann. Todd suggested we "take a deep breath and chill out."

Jackie suggested that we might want to ask some questions of TARC-3 without complaining. "Maybe they could tell us something we don't know already

. . . like information about the computer system or something." Todd reflected that he did not think we were ready to talk about a meeting with TARC. "We have two sides. We've got to work together right now. We've got two sides."

Donna shared that it was hard for her not to try to fix a problem when she sees it. She had trained and worked with Arthur Campbell years ago. "I think we have rights like everybody else does." I invited Ray to share his thoughts on the conversation. "I'm thinking you know, with TARC-3 you have problems, but I think they should just thank God that there is a TARC-3." Regi added, "Just leave it alone." I did not realize how frustrated I was at that point. Todd offered:

I feel bad for Cindy. I feel awful about the whole situation, but you don't want to stick your neck out because you don't want to be afraid you won't get a ride the next time.

I responded directly toward Todd. "So you are saying: Its too bad about Cindy being stuck at the ballpark, but I'm not going to do anything about it because I'm afraid for me." Todd looked back at me, swallowed and blinked. I felt he heard exactly what I was trying to communicate. He responded, "I don't know."

It was clear we were divided and that we did not have a direction for our future. I felt stumped and frustrated. Donna and Jackie both continued to advocate for a meeting with the director of TARC-3, done without complaining but with an attitude of seeking information. As they were speaking, Regi interjected, looking at Mary Ann said, "Sorry Mary Ann. I didn't mean to say what I said." "Well, I forgive you," she responded. "I'm sorry, I just messed up," he replied.

I was deeply touched by the apology and Mary Ann's acceptance of it. At that point, TARC drivers were coming into the door and the normal chaos of departures returned. Todd looked at me and said, "Sr. Rita, you look like you're going to cry." I was touched and embarrassed simultaneously. I did not feel like I was going to cry, but I was exhausted and frustrated that this meeting flowed the way it did. I thanked him for his concern but told him:

I'm not sure how to end this. Other meetings were easy because, you know, we've had a real good spirit among us. Today, there's not a real good spirit . . . I wasn't expecting what happened tonight but I want to say that this is our group and if we are going to work it through, we all have to work it through. Working this stuff out is hard at times.

Jackie was listening and suggested maybe we choose another topic, challenging the medical profession particularly. I suggested we talk about it at our next meeting. Everyone seemed fine with that idea. We would meet again on August 13.

*Videotape, peer supervision, and journal.* As Dave, Julie and I met, I shared how exhausted I was from the previous group meeting. While reviewing the tape, it was evident that all the emotion that filled the evening was not conveyed on tape. Various nervous behaviors such as Adrian's rocking back and forth and Regi biting his nails was evident, but the nonverbal tension was not.

I gave them an overview of my perception of the meeting: how the group seemed split and there was a fear that if they did complain, then TARC-3 would

respond by shutting down. Julie, who was very familiar with the disability rights movement, spoke of this being a relatively common phenomenon. She noted that retaliation is a frequent fear of a habitually oppressed people. She also spoke of the concept of what a local activist called the "dip factor." The dip factor related to the initial enthusiasm a group might have when they discuss challenging something in need of change. The "dip" occurs when it is time to actually do something about it. The enthusiasm wanes and very few remain to actually engage in the change process. So, the enthusiasm of our initial meetings waned as the fear of retaliation surfaced. This made sense and helped to put this 4th meeting into a larger context. She further noted that the women were the ones still interested in addressing TARC-3's problems (Donna, Mary Ann, Jackie) while the men were either neutral (Adrian) or against it (Todd, Ray, Regi, TJ).

We discussed my inner sense of a timeline. I did not realize the strength of the trajectory in my mind regarding how to identify, plan, engage in an action, and process the experience prior to January 2004. I felt ashamed at how much control I desired to have. I do believe if I did not have a timeline, I would have been in a more relaxed state. I felt my surprise at the division among us was naïve on my part. Somehow I had separated my experience with other group processes from this current group. Did I unconsciously believe that this group would not have the same dynamics as any other group of persons because they had mental retardation? I wondered about that. I think I believed it at some level.

Perhaps the TARC issue is too loaded with feared consequences for the group to undertake some action to address its problems. There seemed to be a struggle with Mary Ann's anger with TARC-3. She freely expressed it and did not fear negative repercussions. The men did fear retaliation. I decided I would try to reframe the TARC-3 issue, taking into account the input heard at the last meeting. Some in the group

1. did not want to engage in any civil disobedience;

2. liked some of the drivers;

3. did not believe that problems were the drivers' fault;

4. thought the drivers needed better training to secure wheelchairs; and

5. wondered how the drivers' itineraries were formulated.

Or, the group might in fact want to move toward another topic, one upon which they felt less dependent.

I shared with Dave and Julie that in addition to Todd reaching out to me at the end of the session, both Jackie and Donna called me the next day to see how I was doing. Again, I felt embarrassed that my emotions were so evident. Yet, in viewing the video, I felt I presented as a relatively competent facilitator, albeit a facilitator who felt very invested in the process occurring before her. I wondered if I had, once again, become too invested in the group and less focused upon helping them process and move toward some action.

### Group 5 (August 13, 2003): Planning

Eight persons were present. Mary Ann did not come. Donna continued to call members to remind them of our upcoming meeting. The group seemed to be

in good spirits, greeting each other and telling stories. I had brought some dinner for Donna because she had just come from another appointment and asked me to bring something for her to eat. She ate her dinner during the first few minutes of the group.

*Group experience.* Some bantering among the members returned, especially among TJ, Regi and Ray. After we began with a prayer, I welcomed all back and told them I was happy to see everyone. I named that our last meeting was quite tense. All heads nodded in agreement. I admitted my nervousness and asked if anyone else had been nervous. There were some nods and verbal indications that I was not alone in my experience. Jackie raised the issue about TARC-3, stating:

> I'm not worried about getting TARC mad at me because if they deny me a ride, they can get themselves in trouble. That's one of the reasons I wanted to do it. I want them to hear me about not tying down my chair right. I am afraid that if they don't put the straps on right that they could tear other parts . . . and that would cost them more money if they don't do it right.

Adrian listened to Jackie, then spoke of another incident in the past week when he was on the van for 80 minutes when another passenger was picked up and dropped off in about 30 minutes. All the while, Adrian had been going to a location close to his home. "It just doesn't seem fair to have to be on the van so long to go such a small distance."

Cindy asked if she could read a letter she wrote and sent to TARC-3 after the problems from last month's ball field incident and some other related issues. It was a very clearly written letter, outlining the various problems. It was received well by the group. Personally, I felt proud of Cindy for having advocated on her own behalf. I then shared some of my reflections from the peer supervision session:

I'd like to say some things I thought about after our last meeting. I think that Todd did us all a really good favor by bringing up the fear about rocking the boat too much. You don't want to lose what you have. I also think that some people have made friends with some of the drivers and you don't want to get those drivers in trouble.

Regi agreed to that last point loud and clear. I continued:

Also, I heard you saying that most of the time it works pretty well. But, since the first time we all walked into this room, TARC-3 has been a very big issue. We have heard many, many stories of things that went wrong. But, you also need it everyday, like breakfast, so you don't want to risk losing it or getting your buddies in trouble.

"Right, it's the manifest the drivers have that tells them where they have to go that makes us have long rides on the vans and don't pick us up right," said Todd. I completed my thoughts by saying:

I have heard concerns about no-shows when you were out waiting, about getting to work on time, and being on the van a long time because of the

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manifest.  So, it seems like it is pretty focused on the reservation process and the manifest, not on all of TARC-3.

Group members nodded and smiled.  I felt a renewed energy continue to grow in the group.  Donna told a story about TARC coming 2 hours early for a birthday party at a friend's home.  Cindy added, "They've been getting me mixed up quite a bit and I've been getting no-shows for things I didn't do."  Regi told about a problem but he admitted he had given them the wrong address.  Jackie spoke of ongoing problems with positioning and securing of her chair.  I asked Todd what his thoughts were thus far.  "I'm right on the line.  I don't know which way to go.  I would like to talk about how we can work together about this mess.  I don't want to stay on this line."

I asked the group to think about having a conversation with TARC about the reservation process.  I added, "You might be able to make it better for others because you are not the only ones who are struggling with TARC-3."  Donna replied, "I have friends who are too chicken to rock the boat.  If I don't do it, it won't be done."

After a bit of quiet, I refreshed people's memory relative to this being a research project for the University of Louisville.  I shared that they have been doing some research through sharing their experiences about different problems they have had and thinking about which one they wanted to address.  I let them know they were still free to change the focus from TARC-3 to another topic.  It was up to them.

If we had a meeting, Jackie expressed concern that everyone must act like an adult. A few other members murmured agreement. The conversation shifted towards the meaning of "acting like an adult." It meant listening, being respectful towards everyone, including a TARC-3 guest, and taking your turn at speaking. After that conversation that aired many people's concerns, I asked if the group was interested in addressing TARC-3 concerns relative to the reservation and manifest issues. Regi agreed, as did TJ. Donna raised the issue of the feelings of disappointment and how life has to be readjusted when a ride falls through, is late, or too early. Todd nodded in agreement saying, "It would help us understand more." The rest of the group nodded and/or gave verbal assent.

TJ's ride was expected shortly so we quickly arrived at the date for our next meeting, Wednesday, September 18. He would miss church that night to come to the group. After the date was set, I asked the group how they would like to make a decision. Donna shared, "It wouldn't hurt to ask them if they would like to come to meet with us." We went around the room asking each person her or his thoughts about inviting someone from TARC-3 to meet with us about the reservation and manifest process. Adrian did not care, but would help the group if the group decided to organize a meeting with TARC-3. Regi agreed also, as long as no one would get in trouble. TJ agreed but remained somewhat indifferent. All the rest of the members clearly gave assent to such a meeting.

Adrian then launched into a story about a problem with TARC-3. After the story, I returned the conversation back to some thinking about such a meeting

with TARC-3. "We don't want to mess up nothing. I don't know what's going to happen with the next generation, but it might get better," reflected Todd. Donna added, "Only things that people know about can get fixed." Jackie expressed her concern about drivers not knowing how to secure her chair. I reminded her that our focus would be on reservations, not drivers. She agreed.

We then began to brainstorm the details of such a meeting with TARC-3. There were many suggestions. Ultimately, they decided that Cindy, Donna and Regi would call Karen Dennison, Director of TARC-3 and invite her to the upcoming September meeting. If she could not attend, we would schedule another meeting and Donna would call everyone with a new date. They wanted the meeting to be an informal business meeting with some food and beverages but not a party-atmosphere. The group then began to raise questions to ask Karen. I wrote down the questions as they talked. We compiled a list of nine questions to be addressed. I wrote them on newsprint for all to see:

1. Why are some of the times we request not available?

2. How long can you be on the TARC-3 van?

3. Why do we have to wait 30 minutes and the van only needs to wait 5 minutes for us?

4. Why does my reservation get erased from the computer? If I try to change a round-trip to a one-way trip, sometimes they lose my reservation.

5. Why do the agents get mad when we call to verify that our reservations are still in the computer?

6. Is there any way to verify that I have a reservation?

7. What do the reservation people do when they don't understand me?

8. Signs on the buses say "No eating and no drinking." How come we can't eat or drink but I see drivers eating and drinking?

9. What area does TARC cover?

Donna agreed to call Mary Ann to tell her about the plans to meet with Karen Dennison. She also agreed to talk to Mary Ann about our conversation about acting like an adult and being respectful and appropriate. With that, TARC buses began to arrive. There was a very good spirit among everyone as we concluded our meeting.

*Video, peer supervision and journal.* The peer supervisory session and my journal notes reflected upon the difference between the last two months' meetings. It was only after this recent session that I could clearly see the depth of my fear that the group would not move toward an action in time for the conclusion of dissertation. My journal read:

I was taken by surprise by the July meeting. I was too set in a certain direction of problem solving and was overwhelmed by the momentum that Todd began by suggesting we not take any action against TARC-3. Then our August meeting happened and it all flowed so smoothly. I am relieved, but confused. Did people worry about me and therefore altered their opinions to appease me? Or, was I in fact, able to reflect back an approach to TARC-3 that they had not considered? I also think they were

very afraid that if anyone of them complained too stridently, TARC-3 would get mad and retaliate. I just don't know what exactly happened.

Both Julie and Dave reflected back to me while watching the video, that they did not experience the group acquiescing to me. They spoke openly about their concern over any behavior that would reflect poorly on them and/or would make matters worse with TARC-3. We discussed how important it was that they present themselves well to Karen Dennison. Without laying a surplus of meaning on this point, we reflected aloud how we are all concerned about how we come across to others, especially those we consider to be in power or authority. Having mental retardation is irrelevant to that seemingly human condition. But, having mental retardation may just up the ante a bit more.

I forgot how embarrassed or angry I get when others mentally group me with nuns who performed in a less than compassionate ways or who unwittingly fed into society's stereotype, especially if I consider it to be negative. Dave reflected on how others' expectations of us can tend to govern our behavior. He saw the struggle to provide an informal but business-like meeting with TARC-3 as a means through which the group could assert its purpose and the gravity of the situation, in an adult manner.

In addition to these reflections, this meeting felt like a genuine team effort. Julie noted this dynamic is often present in groups. "Initially everything is nice and easy. Then they move through chaos and tension. But if they are lucky, they can move through that into a more genuine group cohesion." The ease with each other was evident and palpable. While I still remained concerned

about possible acquiescence as described by Finlay and Lyons (2002), the peer supervision helped me see the bigger picture and the sense of organicity of the entire group process.

### Group 6 (September 18, 2003): Action

Due to a schedule conflict, Donna was not able be present when the invitation to Karen Dennison, Director of TARC-3 was extended by phone. Cindy, Regi and I were together when Cindy made the call and spoke with Karen. She invited her to our meeting, told her the date and time and address. From Cindy's report, Karen said she would check if she was free and would get back to us. She asked Cindy for clarification of the exact location and Cindy flustered, handed the phone to me to give her directions. It was a pleasant interaction and Cindy was thrilled that it went so well. Karen was to get back to Cindy if she could attend. A week or so later, after not hearing from Karen, Cindy called her back. Karen would be present at the group meeting on September 18.

**Group experience.** The energy was high among us. Cindy made brownies, Donna made finger sandwiches, and I brought sodas and some other snacks. Karen arrived early, before most of the group had assembled. She introduced herself and we offered her a seat. She sat in the midst of the group as it assembled. There was enjoyable chatting happening, especially as the food and beverages were passed around.

I gave a bit of a history of our group to Karen in order to place the presence of the video equipment in context. I had prepared a consent form should she agree to be videotaped. The form covered the fact that this group

and meeting was part of a study by the University of Louisville. I included in the consent that the video was for academic purposes but she could have a copy if she desired. She agreed to the videotaping and I gave her a copy of her signed consent form (see Appendix C).

Once all nine group members were present and after the prayer, I asked the group how they would like to proceed. Todd began by introducing himself and asking two questions about how she became involved working with people with disabilities and had she ever taken care of persons with disabilities. Karen answered directly. She had a history of working with people with AIDS in Louisville. I then invited all to introduce themselves. Everyone gave a brief personal introduction, including Karen. The atmosphere was very easy and comfortable. Karen remained in her seat in the midst of everyone throughout the entire evening.

After introductions, I gave a brief overview of our group and that we came together to identify and address an issue that bothered them. I mentioned that the group decided to focus upon TARC-3 and so they decided to invite her to our meeting to have a conversation and that it was not the intent of the group to get any drivers in trouble but rather to focus upon the reservation system. I shared that in preparation for this meeting, the group identified nine questions as conversation starters. I read them out loud to refresh everyone's memory and proceeded to sit down. From there on, Karen and the group interacted non-stop until the very end. She would read a question then answered it. Group members

interacted with comments and questions. The meeting was very business-like yet informal, just as they had hoped.

Karen was very respectful of each interaction and answered each question. She spoke about whom to call if there is a problem, the reservation system, no shows, the difference between dispatch and reservation agents, and every issue that was raised. She listened to narratives of complaints and asked for the dates of the events because she can track back in the computer. Also, all phone interactions are recorded and only she had access to them for 30 days before they are erased. She could check to see where the reservation problems developed: the customer or the agent. At one point Karen said emphatically:

> You are our customers. Each person sitting here at this table is a customer of TARC-3. You are to be treated with dignity and respect and anytime you feel that you are not treated with dignity and respect, you let me know. I am not easy on things like that. And please, don't tell me you don't want to get anybody in trouble. That's your right. That is a right that you have and I feel very strongly about that right and I won't take that lightly. Nobody should be disrespectful. I'm not going to be disrespectful and I'm not going to allow any of you to be disrespected by any staff person of mine not that I know about anyway.

Karen stayed until almost the last person was picked up by TARC-3. We took some time to decide on our next meeting date as October 23. All left with smiles on their faces and everyone thanked Karen for talking with us.

***Videotape, peer supervision and journal.*** There were no notes taken by Julie or Dave. Julie exclaimed that it was "a phenomenal action." Dave just sat there, shaking his head in awe, and said, "No comment. What a terrific experience. It was worth the work to get to that point." I had to agree. I felt terrific during and after our meeting with Karen. I could hardly contain myself because despite my quandaries about my abilities and role, the group forged ahead. Nine persons were invited, came together, committed themselves to the group process and struggled through tension, fears and disagreement, to come through on the other side and challenged a system upon which almost all (except Ray) are dependent on a daily basis.

It was upon reflection that I realized anew the power of a group if they decide to work together. I was in awe that no one left the group after the fourth session. I was reminded of Balcazar and colleagues' (1998) experience that sometimes PAR demands more time than participants are willing to give. The people around the table with Karen were persons who knew their own experience, had reflected upon it, and knew how they wanted to address it and did it. These elements are the essential participatory action research pillars. They did it!!!! Now, on to reflection of their action!

### Group 7: October 23, 2003: Reflection upon their Action

Prior to our meeting, I saw Donna at a local restaurant. Once again, what she said touched me profoundly. She felt our meeting was a great success, then as she pulled her head up to strain to see my face said, "So, what are we going

to do next?" I looked at her and told her it was up to her and the group. She just smiled in response.

**_Group experience._** All members were present with the exception of Mary Ann. The group gathered with our normal style: TARC-3s arriving, people getting their beverages, finding their seats, and greeting each other. There were casual comments about how good people felt from last month's meeting with Karen. Overall, the group members liked her and felt she was very respectful and helpful.

Once everyone was settled, Donna and Jackie both shared their previous experiences that Karen was far more respectful at our meeting than at other times they had encountered her. Many members of the group, including myself, looked surprised. Jackie shared, "It was right here (Leadership Institute) that we had a meeting with her before but she wasn't as nice." No one else in the group pursued this point. I felt that it was not our experience from last month's meeting, and none had any more to say on it, including Donna and Jackie.

Cindy shared her thinking, "She made everything so clear . . . like some questions people asked, she answered really nice." "I think it was a help," added Todd. Then he continued, "I think we did one bad thing, we didn't get all the questions answered." When I reflected that she went down the list and addressed each one we had on the newsprint, Todd remarked, "Yeah, but we did not get a real answer about what happens when you get an operator that doesn't understand you. So I guess, I turn around and call Karen? I don't know." Jackie offered the phone number to Julie, Karen's assistant. I saw a few group

members try to find pens to write down the numbers Jackie was repeating. I asked the group if they would find it helpful if I would make cards with the TARC-3 phone numbers on it so they could keep in their wallets. All nodded, even Jackie and Donna who know the numbers by heart. "Yeah, but sometimes people can't understand me and it would be good to have them look at a card to get the right number," Donna said.

Cindy reiterated how clear Karen had been in her answers and she was grateful. I asked the group, "Do you feel that you made a difference in your life because you had that meeting." There was collective agreement with heads nodding and utterances of "Yeah." Todd shared, "She made a big difference with me. They have to deal with the whole city of Louisville and southern Indiana and central Kentucky. That's a lot." Adrian offered

Ah, well, one question that I don't think she really gave an answer to and that's the question that why do we have to wait up to 30 minutes and the driver only has to wait 5. She didn't really say why." Cindy thought that maybe Karen didn't have enough time to answer because people were getting ready to leave. In attempts to draw other people into the conversation, I invited the others to speak. Regi had fallen asleep and was teased back into alertness by TJ "I think it (the meeting) was good," TJ said. Ray nodded in agreement. I reviewed all they had done:

> You came up with the issue you wanted to deal with. We talked about a lot of other issues: respect, going to the doctors' office and stuff like that. And you decided on TARC-3. You all made that decision. You decided

that you would invite Karen. You came up with the agenda, I didn't. You did the inviting. You brought food. You made it a comfortable atmosphere. You came and you had your questions ready. You talked to her. You did it all.

Cindy, full of energy offered, "I think we deserve a hand on all we did." Applause followed accompanied by smiles. I agreed. Cindy continued, "I think she really liked my brownies." There was more nodding and smiles.

I raised the issue of the video being a good resource for us and possibly for TARC-3. I wondered what they thought about offering a copy to Karen to be used as a training tape for the drivers and other TARC-3 personnel. Donna, Jackie, and Cindy all verbalized agreement with the idea. Donna suggested we call her first to see if she would like it. Todd replied, "I think we should go down and give it to her, to hand it to her. That would be cool and we can see her office." I asked the group if they would like someone to do that for us. All indicated agreement. TJ shared:

I agree. It might inspire the drivers to understand that not all disabled people are individuals like us. Some people look at the disabled individuals and just assume because he's disabled or disadvantaged he's mentally ill.

I was reminded about someone I interviewed back in February who said to me that she felt that whenever people see a disability, "its kind of like I disappear. All they see is my disability, not my personality." Todd agreed, "No, they don't see you. Sometimes when they see someone in a wheelchair they back off."

I then asked the group if they thought we could have done our meeting any better. Donna offered, "I don't see how we could have done it any differently. I think it went over a whole lot better than I ever dreamed or thought it would." Todd thought that maybe they should not have dwelled on each question, but moved on to more discussion. "Other than that, it was great!"

I then took some time to offer my experience of the group. I highlighted the commitment people made and that they continued to return, meeting after meeting, even after the tense one we had. They made a decision and worked through the struggle of working as a group. They devised an approach that would facilitate an action relative to TARC-3 with which they could all live. They did all the necessary requirements for the type of research we were doing: a repetitive cycle of reflection, planning, and action. I told them they had been UofL researchers!

Further, I shared with them that I had read about a hundred articles and books, and only a few had folks with mental retardation doing this kind of research. "Are we going to be in an article?" Todd asked. "Yes, after I finish writing the book," I replied. "Oh my God! Oh my God!! Look out world!" Todd excitedly squealed. TJ looked very serious. "If you use my name, use my real name, Theodia Johnson, Jr." I told them that I was writing about our experience but was using fake names. "Why?" they chimed. "Just in case you get a bad grade?" Cindy asked. Smiling, I said, "Oh no. My teachers are very happy about what you have been doing. "Well, I think our names should be in the book. We have worked hard," Cindy said. Regi said, "it won't bother me a bit to use my

real name." I went around the room to obtain everyone's opinion. They all agreed.

I told them I wanted them to know what I have said in my "book," so I would talk about it at our next meeting. Todd asked, "When you present this paper, can we all come?" "Absolutely," I replied enthusiastically. "Can we take a picture to go in the book?" Cindy asked. Again, smiling, I asked each group member if a photo with her or his name be should be included in the book. They all agreed. "We did something real big. We did something people didn't think we could accomplish."

Cindy interjected, "I learned a lot being in this group. I learned about all the things we talked about. We got to talk to each other about a lot of different things." Todd offered, "I learned to help each other out." I asked what they would like me to include in my book. "It was fun. It was fun for people to get together and to talk," said Todd. Regi offered, "I think you did a fine job, Sr. Rita. We talked about a lot of things and I came back because I just wanted to keep updated." Cindy thought of something else, "I was thinking about like you could put in your book that Cindy helped organize the thing about Karen Dennison. Me and Regi helped with the phone calls." I assured her I would include this point.

I then asked others why they kept coming back. "I kept coming back because you are my friend," said Cindy. Donna reflected:

I'm like Cindy, but that's not the only reason. This group helped me to talk about some things that bother me. I wanted to keep coming back because I'm involved in a lot of disabilities things and we were talking

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about things that interested me. And, there wasn't any staff folks. Not that having staff is bad. A lot of times it is really important and necessary. But it was nice just having us together.

Adrian shared, "The reason I kept coming was because I wanted something to do to get me out of the house. Jackie kept coming back "because I made a promise and I do what I have to do to keep my promise." I asked her if it was helpful. Her honest reply was "sometimes." She continued, "Other times I was too tired to talk about things."

As we were drawing to a close, we established December 4 as the date for our next gathering at which I would share some of what I had written so far. I asked if people would like to see some of the videos of themselves from previous meetings. They all agreed to my offer of compiling a video of the best parts of our time together. They also suggested that the next meeting be more of a Christmas party than just a meeting.

*Videotape, peer supervision and journal.* When we met and began to review the video, I was very aware of the honesty of the group members. Dave, Julie and I all remarked about the critical thinking skills of some of the group members in deconstructing the meeting with Karen. We reflected upon the different impressions Karen made with Donna and Jackie and wondered if the informal yet business-like tone our group helped establish an atmosphere of conversation rather than antagonism. Dave noted that our group did not demand a resolution to the problems that were raised. It was more of an information-seeking conversation into which Karen relaxed.

Both Julie and Dave commented on how I had grown as the group facilitator. They noted the change after the tense meeting in which the group was split. The group members were not the only ones who matured when confronted by and moved through pain and anxiety. My fear of dominating the group gave way, over the group sessions, to a more integrative facilitation. I did not use "we" as much when speaking about issues. I acknowledged myself as separate from, yet intimately connected with the group experience and its members. I spoke less as group members spoke more. I was more comfortable making suggestions or offering my opinions, trusting in the group's own ability for honesty and critical thinking.

In addition, we all thought it was very empowering for the group to decide to use their real names, with pictures included for the dissertation. Plus, they wanted to attend my defense. I had secretly hoped they would want to join me because without them, the dissertation would not exist. I was thrilled that they brought it up themselves.

### Meeting 8 (December 4, 2003): Reflection

Donna called in advance to let me know she would be absent for this meeting. I had thought this would be a party. I brought a copy of the incomplete dissertation and the wallet-size cards with TARC-3 phone numbers on them as promised from the last meeting. As people were gathering, a TARC-3 parked across the street. We saw it was Jackie and were dumbfounded that the driver would not turn around and let her off on the proper side of the street near the entranceway where there was a curb cut.

***Group experience.*** It was apparent that only Cindy remembered that the group planned to have a party. No one but Cindy brought any food. After the prayer, the group began to ask Jackie about her interaction with the driver. She told us all the plentiful details as there were a series of problems, including that the driver did not believe that she knew where the meeting was (they had passed us). Without permission from her, he took control of her power chair and attempted to jump her over a guard in the floor of the bus, jarring and scaring her tremendously. There were other problems within those five minutes. By the time she got into the room with us, she was exhausted and furious. Her experience and the group empathizing with her, prompted more stories about TARC-3. Todd and Mary Ann had a problem with TARC-3 also and were late for our meeting. Adrian shared that he had been given a no-show that he did not understand. He called Karen Dennison who spoke with him and erased the no-show from his record. Adrian felt very empowered.

I asked if they wanted to do anything as a group in response to the problems Jackie and Todd had tonight. After a long conversation, Jackie asked if I would call TARC-3 on her behalf. I was surprised by this request, as Jackie is so knowledgeable about TARC-3. She thought if an "AB" person called, she would get a better response. I did not understand her:

> 'AB' is what I call able-bodied. Sometimes I feel I am not listened to and I need someone who they will listen to better. That's why I asked you to help me with my problem with the Medicaid cut for my personal care attendant last month.

My heart dropped, yet I thought she was probably right. Cindy suggested writing Karen an email. Regi said he wanted to help too. Jackie did not have a computer, but I would bring Cindy and Regi to Jackie's apartment with my laptop and write and send the email early next week.

With this our time was drawing to a close. The problem with Jackie's ride here consumed most of our time together. I showed them the dissertation and read from some parts of our first gathering. I also highlighted the fact that a quote from Todd will be right after the title. "Oh my God, I'm quoted!" he exclaimed. I told them the date for the dissertation defense (March 11, 2004) and that I would help them arrange for their attendance, not wanting to trust TARC-3 to find the location on university campus or the timing of their arrival. We established January 26, 2004 for our last meeting where more details will be discussed.

Jackie asked if we could continue meeting after January 2004. Mary Ann supported the request also. The group talked about it a bit and there was a level of ambivalence present. The majority of members was silent about remaining a group or indifferently shrugged to indicate their willingness. I recounted that we had all agreed to continue to meet until this January so we would want to see if people really wanted to commit to the group after January. I also said that I would be very willing to continue to meet after my schoolwork was accomplished if they desired. If it were still an interest, then we would make arrangements for future gatherings at our January meeting.

***Video, Peer Supervision, and Journal.*** I felt the gathering was quite chaotic with many sub-conversations, bantering, and some serious conversations occurring simultaneously. I am not sure if it was only I, but I had a sense that the group was winding down and going through its transition towards closure and ending. Because of the nature of this meeting, I did not schedule Julie and Dave for peer supervision. I reviewed the video and my perception of the meeting was verified. It was a festive and enjoyable evening with some serious content. I was delighted to know that Cindy and Regi wanted to join together to support Jackie in writing a joint email to Karen Dennison relative to the negative TARC-3 experience. I felt there was a progression from advocating in isolation towards a more communal effort. And I was happy that Karen responded to Adrian so affirmatively.

I personally felt that the timing and energy for this group was nearing an end. If there were to be a more enthusiastic interest indicated at the next meeting, I would happily continue to facilitate their meetings.

### Meeting 9 (January 19, 2004): Celebration

Prior to what we know now was our last meeting, I needed to address the university's human studies committee requesting permission to change the consent forms for the group members, responding to their request to use their real names and pictures in the dissertation. They agreed to the revocation of confidentiality for purposes of the dissertation. I also encountered a minor difficulty relative to the timing of my approval to conduct research through the university. I had been approved to engage in this PAR project for one year. The

year would conclude on January 22, 2004. With that in mind, after contacting all the group members, we were able to reschedule our last meeting from January 26 to January 19, thereby completing the research prior to the deadline. I was able to obtain signatures on all the revised consent forms.

I reviewed all videotapes of our eight sessions and marked them for a compilation video of the entire group experience. I went to a local video editing service and sat for hours re-taping the selected segments. I brought this video to this group.

**Group experience.** This was truly a fine conclusion to our 10-month collaboration. The group members arrived and chose their snacks of choice. We had the tables and chairs positioned for all to clearly see the television in preparation for viewing the group video. Todd asked if my book was going to be on the Internet. I told him it would be listed with other books like mine. I said:

> So when other people want to find out if people with mental retardation
> can come together, decide on a problem, and figure out how to address
> the problem, they will find my book. And what is the answer? Can people
> with mental retardation come together to work on a problem together?

"Yes . . . absolutely" was the group response. We then talked about my dissertation and their role in it. I reiterated that there were only a few articles about people with mental retardation getting together to decide on a problem and figuring out a solution. People asked for further clarification about the meeting we will have with my "teachers at UofL." I attempted to explain the concept of a dissertation defense. "We'll make sure you get a good grade, Rita" Cindy said.

All I could do was smile and nod in response, knowing that without the commitment of the nine members, I would not be where I am today. I told them I would be in contact with everyone before March 11 and that between the vans and drivers I had access to, everyone in the group would be provided transportation. I did not want to rely on TARC –3 for this very important day. Many in the group laughed out loud, agreeing with me.

I asked the group what we wished to do next and they wanted to watch the video. After turning it on, people were thrilled to see themselves and each other on the television. I left the video on throughout the rest of the evening. However, after all had seen themselves at least once, it lost its appeal overall. I had a sense that people were a bit disappointed in it because it lacked special effects or a "Disney-like" style. The video was literally the top half of group members sitting at the same tables in the same room in which we had become ever so familiar. Once in a while someone would indicate some tracking of the video. "I remember when we talked about that," said Donna. TJ asked, "Lets just watch the best parts, the parts with me in it." Everyone laughed quite boisterously in response.

As people were chatting and eating their snacks the videographer, who had brought a still camera, took individual pictures of each group member for inclusion in the dissertation. Towards the end of our gathering, the videographer asked if anyone had anything special with which they wanted to conclude our time together. "I think we accomplished something very important about TARC-3. I think we helped a lot of people in the city because we had that meeting,"

shared Todd. "I just want to say I was glad to be able to be a part of Rita's group and I'm looking forward to March 11," Cindy said. "I want to thank Sister Rita for including me in the group," said Mary Ann. Regi expressed gratitude to have been included in the group. No one mentioned the continuation of the group. TARC-3 vans came for the members and it felt like a fine closure to a powerful experience.

*Videotape, peer supervision, and journal.* While I did have parts of our time together videotaped, I did not have it transcribed because it was a party but I did include excerpts in the final edition of the video. I felt relieved that the experience was terrific. I felt uncomfortable that most of the responses had to do with it having been "Rita's group." Regi had thanked me for "a wonderful program." I wonder how much conscious impact this experience had on the individuals in the group. It was transformative for me. I can only hope it was also for them. I learned more about the world of persons with disabilities and adults with mental retardation in particular, and myself.

*Conclusion*

In this chapter I told the story of the entire research process, inclusive of the peer supervision and reflections on rigor suggested by the literature. I began with the details of establishing the project within the context of the University of Louisville and the greater mental retardation community in Louisville. This was followed by a description of the first phase of the research, that of interviewing 25 adults with mental retardation to ascertain their thoughts about any issues that disturbed them and which they would liked to have seen changed. No one

specific issue emerged from this first phase but was nonetheless a learning experience and a process that offered a space for their voices to be heard.

I then explored the selection of the group members, the consent process and the financial considerations of having engaged in an ongoing research endeavor. This was followed by thick descriptions of each gathering of the PAR group. All group experience descriptions were succeeded by integrative reflections of the video, peer supervision, and journal entries that combined, helped me continue to grow in honesty and faithfulness to the principles of PAR.

Having reported on this one encounter of PAR, I will now move toward a general discussion of this experience in light of some reflections of authors previously cited who helped shape my own approach. The applicability of this approach to research in practice settings will be also explored.

# CHAPTER 5

## DISCUSSION

Throughout every aspect of this research experience, I have attempted to integrate a variety of aspects of my life as a social worker intimately involved with adults with mental retardation. This chapter will continue this endeavor through weaving together some of the reflections and learnings gleaned from engaging in PAR with adults with mental retardation. I begin with a focus on some of the authors who helped shape my consciousness of PAR as an emancipatory methodology that encourages people to think and plan ways to improve their lives. Some of these authors offered some guidelines against which PAR could be measured. I will further reflect on some inward challenges that I faced within the context of my total experience in this project. I then proceed to offer some thoughts on the applicability of PAR in social work settings. I will then conclude my thoughts with ideas for further participatory action research projects.

### *Reflection on the Literature*

As a conclusion to this chapter, this section will reflect upon some of the literature on PAR, particularly with persons with disabilities. Particularly, I wish to highlight the insights and challenges of Barnes (1992) and Balcazar and colleagues (1998).

Barnes (1992) specified seven points to consider when engaging in research with persons with disabilities. These seven issues focus upon the identity of the researcher as different from the participants, the researcher's level of honesty about the project, focus on the present; presence of the researcher altering participants' behavior, a reliance on verbal participants, the conclusions reached may be different than those of the participants; and the potential of over-empathizing with the participants.

In this research project, I endeavored to abide by Barnes' (1992) observations. As noted throughout the first three peer supervision sessions, I struggled with my role. Was I a facilitator or a group member with equal status? Through my journal entries and peer supervision, I was challenged to and ultimately was able to firmly claim my distinction within the group and my over identification with the group members. I used the terminology of "we" and "us" much less, gradually shifting towards "you" when I spoke about life experiences and group decision-making. I retained "we" and "us" relative to the entire group that included me as part of the experience.

I had no doubt that my presence altered the behavior of the individual group members, especially initially. Just as I was shaped by the individual personalities and group dynamics, so I suspect they were also, because of my presence. As time passed and as I internally clarified my role, I felt ease among members to speak their truth, even if it may have disturbed me. A clear example of that was in the 4th meeting when the group was split on pursuing TARC-3 as a focus for their action.

Beginning with the initial interviews of Phase One, I tried to be totally honest about the PAR process and my attempts to help organize a group who would identify an issue and pursue its resolution. Everyone knew I was a student at the University of Louisville, that I was connected with Day Spring, and that we would agree to meet until January 2004 when my official research would be completed. I also sincerely meant my intent to stay with and help the group should they decide to continue after that date. In November, I realized my enthusiasm was waning, and though I would have abided by my promise, I was relieved that no one pursued group continuance on a serious level. I believe that from October on, I was not overtly honest with the group about my loss of energy to continue it.

Upon reflection, I also found myself relying upon verbal participants to keep the conversations going and for direction setting. Even though it was difficult at times to understand everyone, all persons in the group were physically capable of understandable speech, inclusive of word formation and volume. We just had to listen a little more attentively to some. Ray was the most silent of all the participants. It was difficult to evoke verbal responses from him. But, this was also Ray's personality outside the group. All the others were easier to verbally engage in the conversation. I repeated myself frequently, using different words to express my point in the hope that persons could understand me. In retrospect, I felt that some people had been quiet because they were struggling to comprehend the speaker. All I can say is that we (and I) did the best we could.

Each group member came to be known within the group as a whole person. Unlike other forms of research that may observe one aspect or slice of a person, of her or his life, PAR offers space for persons to share themselves inclusive of their interests and fears. Also, reporting PAR includes the narrative and thick descriptions of the interactions and the evolution of the entire experience over time, including its history.

The primary conclusion that was reached by engaging in participatory action research with adults with mental retardation is that it works. Barnes (1992) offered a valid concern that the conclusions reached by the researcher and the participants may differ. In this instance, the group members felt it was a good experience and that although many could not put words around exactly what they learned, they had no doubt that they learned. I totally concur. Upon reflection, I felt that this experience of PAR met the standards of engaging in research with adults with disabilities established by Barnes.

Balcazar, Keys, Kaplan, and Suarez-Balcazar (1998) highlighted some important aspects of engaging in PAR with persons with disabilities. They felt it was important within a PAR framework for persons with disabilities to come to a greater awareness of their resources and abilities, that gaining entry and relinquishing control on the part of the initiating researcher may be difficult, and finally that there may be concerns about the length of time needed for the project.

I hoped that the persons in the group felt they grew in self-awareness of their abilities and resources. That would be very difficult to determine overtly. I would fear that even asking the question would result in a positive answer

regardless of the person's experience, due to a propensity to acquiesce (Finlay, 2002). Yet, growth in personal power was something I believed happened, at least among some individuals. Adrian contacted Karen Dennison, the director of TARC-3 to inquire about a no-show. He had never done that before. Cindy emailed Ms. Dennison on occasion about various problems.

All members shared that they kept returning to the group because they were learning and enjoying the process. They expressed pride in their work, desiring to use their real names in my dissertation and wanting to attend my defense. And a growth in self-confidence in their ability to effect change was evident when they all agreed to meet with TARC-3, even with their fears of possible repercussions. Todd, who did not have a tendency to be involved in self-advocacy events prior to this group, continued to come back. A few weeks after the conclusion of the group I asked him why he returned to the group each meeting. He told me he appreciated being with and problem solving among his peers without others telling him what to do.

For me, living in a residential community of adults with mental retardation for six years, gaining entry and acceptance into their world was exceptionally easy. It was a blessing that PAR encourages researchers to operate from within the world in which you live (Maguire, 2000). However, Balcazar et al.'s (1998) point about relinquishing control on the part of the initiating researcher was a serious challenge and one I do not think I accomplished. I continuously struggled with two powerful dynamics. The first dynamic was balancing between being the initiating researcher with a timeline and allowing the process to take its natural

course. I felt I kept the balance to some degree, and I know I did the best I could, but I felt I wished I could have done a better job.

The second dynamic was balancing between granting others control yet not knowing their abilities, memory, or interest level to complete the tasks. While I felt it was no favor to expect more from an individual than that person was interested in or capable of offering, it was also no favor to expect or ask for less. I had dreamed I would have had the skills of patience and discernment to know when and how to encourage others to take more responsibility for the group. As it was, I felt I did not have the time to engage others in some aspects of the group, as I would have desired. For example, to make a one and a half hour video from 20 hours of tape took much time and concentration. I had wanted to invite group members to help me decide, but that felt to be too daunting a task to coordinate and I did not have the time (or required patience, most likely) that would be needed to organize and consult for each video clip decision. So, I retained the authority and asked for their evaluation of the finished product.

I felt whenever possible, I did try to relinquish control over the group. Donna became our monthly reminder of the meetings. Cindy invited Karen Dennison to our group meeting. The group decided upon the frequency, time and dates of our meetings. They also decided upon the issue they addressed and how to address it. These I believe were the most important areas in which I would have had to relinquish control if this endeavor was in fact, PAR.

Finally, Balcazar and associates (1998) spoke of their concern that the time necessary for a PAR project may demand more than the participants might

be willing to give. I do believe that it would have been difficult to keep group members invested for much longer. As it was, they were initially interviewed in February and March of 2003 and remained active in the group until its conclusion in January 2004. Their commitment and continued involvement was a consistent gift to this project.

Selener (1997) asserted that PAR has two goals. These goals were solving practical problems at the local level, and creating a shift in the balance of power in favor of the poor and marginalized. Those goals felt overwhelming upon first review. Reading about how indigenous peoples worked with governments to reclaim land and other massive endeavors offered a daunting vision of PAR. In a much smaller scale, this project, in it own ways, addressed Selener's (1997) principles. The adults with whom I worked named a local problem with which they had first hand experience on a daily basis (Kemmis & McTaggert, 2000; Sample, 1996; Selener, 1997). How the balance of power shifted more towards those who were marginalized will remain unknown. I cannot conjecture the impact our meeting had on the director of TARC-3. However, I suspected (hoped?) that all members in the group grew in their own sense of self-advocacy and personal empowerment (Zarb, 1992). By having claimed their voices throughout their experience together, their own personal power was strengthened, therein affecting a shift in power.

The emphasis upon which I chose to focus with the previous authors was the emancipatory element of PAR. Growing in awareness of persons' own self-agency is a powerful result of any intervention, research or clinical. As long as

persons most affected by the results are integral to the design and implementation of an endeavor, empowerment occurs.

### *Inward Challenges*

With the above said and strongly believed, an area of ambivalence surfaced from within me. A basic premise of PAR is systemic change as the result of the persons most affected by the problem having an integral role in shaping and enacting the resolution of the problem. As a result, its focus is not on interpersonal or group dynamics. My experience challenges this premise a bit. I am left wondering, "What really has changed as the result of our group process, action, and reflection?" There are still problems with TARC-3 and we have no way of knowing if the problems are fewer (or greater) since our September meeting with its director. There was no dramatic or visible change as the result of our interaction.

When the group was deciding to have a meeting as the form of action about TARC-3, I admitted to myself I was disappointed. I realized I had hoped for a more dramatic posturing to help make public the dysfunctions of the system. I felt a meeting would not seriously alter the status quo. I believed the group would have been more "successful" within the systemic-change paradigm of PAR if they had chosen other actions. Having to let go of my own expectations and desires was and remains a difficult challenge for me. I am not sure what was changed. I can hope that TARC-3 is slightly different because of the personal interaction between Karen Dennison and the group members.

I was also aware of my own desires that group members would own the focus and intention of the group as one of self-advocacy. I wished, at the end of the experience, group members had used language of appreciation toward each other more than towards me, and that they had indicated more of a group identity.

Furthermore, I found myself reflecting upon the fact that the majority of the group members most likely possessed cognitive and social abilities that when combined, constituted an interactive group able to focus on a task. Even with this level of competency, I begrudgingly admitted my struggle to allow members to operate at the level of their abilities and not to expect more (or less). There were times I desired more critical thinking or creative problem solving. In this light, when I claim that PAR works with persons with mental retardation, I wonder if there are those for whom it would not work. I know this question is more complex than only cognitive abilities. Are there interactive, cognitive, cultural, social, or emotional factors that would hinder genuine and free participation in a PAR project? I suspect there are. Prior to engaging in the writing, planning, doing, and reflecting upon this entire PAR project, I may have too easily fallen into believing that cognitive abilities were of primary importance. I could say that no longer. As persons are combinations of myriad variables, through this experience I can far more easily see how any group involvement needs all the variables its members possess.

## PAR, Social Work and Mental Retardation

Participatory action research is a viable tool for both research and client empowerment within practice settings.  Group work has been an integral form of intervention within the social work profession since its inception (Addams, 1910/1998; Richmond, 1917/1965) and can offer mutual support, networking, collective advice, and other benefits to its members (Yalom, 1995).   The social work profession has claimed service to persons oppressed by society as a major focus of its attention. The National Association of Social Worker's Preamble to the Code of Ethics (NASW, 2004) states:

> The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed and living in poverty.

Furthermore, the profession purports to base its work upon the six values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence (NASW, 2004).  It would not be too far of a stretch to state that PAR follows a similar philosophy.  It would therefore follow that combining social work and PAR could enhance both social workers' practice and their clients' sense of self-agency.

PAR's emphasis on group members as co-researchers helps to equalize the power differential that traditionally exists between clients and workers. Furthermore, it de-emphasizes the "expert approach" that can tend to alienate and further disenfranchise the client population.  Clients' self-knowledge and

personal experience, when combined with others who are invested in affecting some change in a mutually agreed upon problem, can bear tremendous fruit in a PAR reflection/planning/action cycle. In addition, encouraging the development of clients' sense of self-agency and personal power are important aspects of the profession and of PAR.

Participatory action research does not adhere to any one particular methodology, nor does it separate out research from lived reality of the people most affected by a social problem, be they social workers or clients. It does take patience, time, client investment, and a willingness to let the clients lead, elements that are sometimes difficult to find. However, I feel it is an approach to research that is very applicable in daily life and the knowledge learned would be relevant to the real lives of social workers and their client systems. For these reasons, there seems to be a natural fit between PAR and social work.

Furthermore, I wish to encourage social workers to become more knowledgeable of and interested in service with persons with mental retardation. This population has many of the characteristics of an oppressed people as reflected upon in Chapter 2. The goals and values of the profession of social work, in addition to skill base and emancipatory perspective of service could lend themselves towards improving the lives of persons with mental retardation. The use of PAR would be but one suggestion.

### *Further Research*

In addition to encouraging more use of PAR in social work settings, I also encourage further research with persons with mental retardation. Persons with

mental retardation who reside in institutions are often more physically and cognitively challenged than those who live in the community. Engaging them in a PAR project could reveal some tremendous insights.

I admitted taking a lead in this entire project. A future PAR project could engage some persons with mental retardation from its inception. This small group would help decide who to invite, how to coordinate the effort, and various other details of a group project. In addition, part of the goal would be to help them take more leadership in the endeavor. I found myself reflecting upon how I as facilitator remained the focus throughout the project. What if I had taken some time to help mentor someone else to take on aspects of the role?

I believe that more PAR studies involving persons with mental retardation would be the most important recommendation for future research. True to PAR, it would be up to each unique group of people to decide how it would decide upon a focus issue and how they best engage in the reflection/planning/action cycle of the research project. Each project would offer a variety of insights and learnings as unique as the individuals involved.

As noted earlier, the disability movement has tended to focus upon the rights of persons with physical complications. More research that highlights the various abilities of persons with mental retardation would offer a vehicle to allow their voices to be heard. While all publications are encouraged, I believe it would be very helpful if future research could be published in research journals other than those exclusively dedicated to the concerns of persons with mental

retardation. As long as their voices are not heard in the mainstream journals, they will remain unknown as the capable people they are.

## Conclusion

This chapter contained some points of reflection as stimulated by some researchers who helped shape my practice of participatory action research in light of the project just concluded. I then shared some thoughts on the apparent natural fit between and applicability of PAR within social work settings. Suggested areas for future participatory action research with adults with mental retardation concluded this chapter.

## Summary

This was a powerful experience. The articulation of the cultural prejudices we have towards persons with mental retardation in the first chapter helped to offer a backdrop and rationale for engaging in PAR with adults with mental retardation. Chapter two established the social work profession's relative absence in the field of mental retardation, despite social work's commitment to serve persons who are vulnerable and without social power. Combined with my personal story, this then offered further impetus as to why I chose to engage in research with this population. However, I did not want to perpetuate the social ostracism or the silencing of their voices in my research. Participatory action research offered an approach that encouraged the empowerment of persons through involvement in all phases of the cyclical research process of reflection/planning/action (Kemmis & McTaggert, 2000). I wanted to be part of the solution. Chapter three offered my plan to attempt such an adventure.

The fourth chapter however, tells the real story of the process. Focused upon the group members, it was filled with quotes and stories of the nine people who were willing to commit to the 10-month PAR process. They deserve a profound bow of gratitude and I am in awe for their ongoing commitment to the process. Without them, I would be less than who I am today. I also want to believe their action made a chink in the armor of TARC-3 and perhaps helped to increase the sensitivity of the director and those she has spoken with about her experience. The fifth chapter was an attempt to offer some further reflections upon the experience in light of some previous PAR researchers' wisdom. I consciously reintroduced the social work profession and encouraged our deeper involvement with persons with mental retardation and to use PAR within practice settings.

And finally as I conclude this dissertation I breathe a deep sigh and say: What a challenge. What a relief. What a gift.

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# Appendix A
## Original Consent Forms for Phase One and Phase Two

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**Participatory Action Research with Adults with Mental Retardation**

**Participant Informed Consent for Phase I**

### Introduction and Background Information

You are invited to participate in a research study. Research means we work hard to try to learn more about certain problems or things. Dr. Dan Wulff and Rita Valade, doctoral student, and the University of Louisville Kent School of Social Work are the study sponsors. We are connected with the University of Louisville, Kent School of Social Work. They agreed to let us do this study. Rita is going to talk with 25 persons with mental retardation in the Louisville, KY area. She will talk to the people where they want. This will take about 30 minutes for you.

### Purpose

The purpose of this research study is to learn what issues about your life concern you or that you would like to see changed or made better. We think you know your problems the best and want to find out what you think. This is part 1 of a big project.

### What we will do *(Procedures)*

We are asking you to take about 30 minutes to talk with Rita Valade about anything you would like to see changed in your life. Rita will talk and listen to you and 24 other people about things they would also like to see changed. Rita will talk with different adults with mental retardation around the Louisville area at places where they would like to meet. She will want to talk to a lot of different people with different needs. She will start with 10 people she knows and will ask them who else she should talk to. She will take notes to help her remember what everyone says. Then, she will find out some of the important things many of you are worried about and would like to change. If you can refuse to answer any question you do not want to answer.

### Possible bad things that could happen *(Potential Risks)*

You will be asked to think of a problem in your life that might make you sad. We don't want you to think that we are going to change everything to make it better. Right now we need to listen to what you think.

### Good things that can happen *(Potential Benefits)*

Some good things may happen if you talk with Rita. Rita and Dr. Wulff will learn what are the kinds of things you and lots of other people with mental retardation are worried about. After Rita has talked with you, you may be asked to take part in a second part of the study.

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**Keeping what you say a secret** *(Confidentiality)*

Dr. Dan and Rita will try really hard to keep what you say a secret but we can't make an absolute promise that everything will always be kept secret. Your parents, or family, or friends will never know what you tell Rita. Although we cannot promise to keep everything you say a secret, there are laws that protect this kind of secrecy. Some people at UofL who are in charge of this study (the Human Studies Committee, members of my dissertation committee), or other appropriate agencies may look at Rita's notes. Otherwise, all information will be held privately to the extent permitted by law. If Rita writes an article for a magazine, your name will never be used.

**Free to do this or not** *(Voluntary Participation)*

You are free to talk to Rita or not. You can also stop talking with Rita anytime you wish. No bad thing will happen to you if you stop before we are done talking.

**Your Rights and Contact Persons**

Do you have any questions? Did you understand what Rita and you are going to do? If you are really clear, we are going to ask you to sign your name to let us know you understand. If you have any questions about the study, please contact Rita at 634-1537.

If you have any questions about your rights as a research subject, you may call the Human Studies Committees office (502) 852-5188. You will be given the chance to discuss any questions about your rights as a research subject, in secret, with a member of the committee. These are independent committees made up of people of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. One of the committees has reviewed this study.

**Information about Rita's notes**

Rita will keep all your information in a locked file cabinet in her office at Day Spring. No one will be able to get it except Rita. After Rita talks to everyone for this study, she will destroy her notes. This will happen by May, 2004.

**Consent**

You have discussed the above information and agree to voluntarily participate in this study. You have been given a copy of the consent.

| | |
|---|---|
| _____ | _____ |
| Signature of Participant | Date Signed |

---

*Guardian/Family Member permission:*

*By signing this form, I am agreeing to allow _____ to participate as a full member of this research study. I understand that the participant or I can revoke this approval at any time.*

| | |
|---|---|
| _____ | _____ |
| Signature of Guardian/Family Member | Date Signed |

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| | |
|---|---|
| _____ | _____ |
| Signature of Investigator: Rita Valade | Date Signed |

Phase II consent. Date written 01/08/2003, p. 2

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### Participatory Action Research with Adults with Mental Retardation
### Participant Informed Consent for Phase II

**Introduction and Background Information**

You are invited to participate in a research study. The word research means that we try to learn more about certain problems or things. Dr. Dan Wulff and Rita Valade, doctoral student, and the University of Louisville Kent School of Social Work are the study sponsors. They agreed to let us do this study. Rita is going to invite about 10 persons to meet for about 10 months to work together to help fix a problem in their lives that they all agree upon.

**Purpose**

The purpose of this research study is to help around 8-12 adults with mental retardation figure out ways to make a problem in their lives get better. We will also learn what things work and what does not work in trying to make the problem get better. We hope that others will be able to learn from our experience and try to change things in their lives that worry them.

**What we will do** *(Procedure)*

We are asking you to become part of a group that will meet at least every month until January 2004. The group meetings will last about an hour. Rita Valade will be part of the group. We will think about the problem that we've agreed to meet about then try to do something about it as a group. Everyone will be able to talk about what they think will work. The group will decide what we will do. Different people in the group may do different things in between group meetings to try to better understand or help out the group make the problem better. We will meet at a place where the group agrees. It will be accessible for people in wheelchairs.

**Possible bad things that could happen** *(Potential Risks)*

We can't think of any bad things that will happen because the group will decide what to do. We will not do anything illegal or dangerous. Other people may talk about what we have said and you may be disappointed that we will not be able to change things.

**Good things that can happen** *(Potential Benefits)*

Some good things can happen if you agree to join the group. You will be part of a group that is going to try to change something. You may learn some ways for self-advocacy, to speak up for yourself and to help others in the process.

**Keeping what you say a secret** *(Confidentiality)*

Because this is a group process that will result in something being changed, what you say will not be a secret in this part of the study. But, we will all work very hard to keep our group discussions private and not repeat what we talked about. You understand that you should not discuss group conversations with others outside the group *unless the group decides differently*. The group meetings will be videotaped for Rita to help the group better. The videotapes will be reviewed by a team of 4 professionals who will help Rita better understand the group dynamics and to make sure that Rita's ideas don't take over the group.

Phase II consent. Date revised 2/4/2003, p. 1

**Keeping what you say a secret** *(Confidentiality)*

Dr. Dan and Rita will try really hard to keep what you say a secret but we can't make an absolute promise that everything will always be kept secret. Your parents, or family, or friends will never know what you tell Rita. Although we cannot promise to keep everything you say a secret, there are laws that protect this kind of secrecy. Some people at UofL who are in charge of this study (the Human Studies Committee, members of my dissertation committee), or other appropriate agencies may look at Rita's notes. Otherwise, all information will be held privately to the extent permitted by law. If Rita writes an article for a magazine, your name will never be used.

**Free to do this or not** *(Voluntary Participation)*

You are free to talk to Rita or not. You can also stop talking with Rita anytime you wish. No bad thing will happen to you if you stop before we are done talking.

**Your Rights and Contact Persons**

Do you have any questions? Did you understand what Rita and you are going to do? If you are really clear, we are going to ask you to sign your name to let us know you understand. If you have any questions about the study, please contact Rita at 634-1537.

If you have any questions about your rights as a research subject, you may call the Human Studies Committees office (502) 852-5188. You will be given the chance to discuss any questions about your rights as a research subject, in secret, with a member of the committee. These are independent committees made up of people of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. One of the committees has reviewed this study.

**Information about Rita's notes**

Rita will keep all your information in a locked file cabinet in her office at Day Spring. No one will be able to get it except Rita. After Rita talks to everyone for this study, she will destroy her notes. This will happen by May, 2004.

**Consent**

You have discussed the above information and agree to voluntarily participate in this study. You have been given a copy of the consent.

_____          _____
Signature of Participant                                            Date Signed

*Guardian/Family Member permission:*

> *By signing this form, I am agreeing to allow _____ to participate as a full member of this research study. I understand that the participant or I can revoke this approval at any time.*

_____          _____
Signature of Guardian/Family Member                       Date Signed

_____          _____
Signature of Investigator:  Rita Valade                       Date Signed

Phase II consent. Date written 01/08/2003, p. 2

**New Questions Per HSC**

After explaining the consent form, all study participants will be asked the following questions to help determine if in fact, they understand the important points:

### Questions to Determine Understanding of the Project
Phase I

I have some questions for you:

1)    Do you understand that I am (Rita is) a student at the University of Louisville? Do you understand that our talking together today is part of a research study that is connected with her homework for school?

2) If you don't like talking to me (Rita) can you stop anytime you want?

3) The things we talk about today will be kept secret as much as possible. Do you think that's true?

### Questions to Determine Understanding of the Project
Phase II

I have some questions for you:

1) Do you understand that Rita is a student at the University of Louisville? Do you understand that joining our group for the next 10 months is part of a research study that is connected with her homework for school?

2) If you don't like being in the group, can you stop anytime you want?

3) The group is going to try to work together on some problem but it may not solve or make the problem go away. Is this true?

# Appendix B
## Confidentiality Agreement

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### Confidentiality Agreement

As the undersigned, I understand that any information regarding the participants or the identities of the participants that is disclosed to me as a consultant to the research study titled Participatory Action Research and Adults with Mental Retardation conducted by Rita Valade and Dan Wulff, PhD through the University of Louisville, Kent School of Social Work is confidential. I am fully aware that the law protects this confidential information and that I am absolutely prohibited from making any disclosure of this information. I hereby agree to adhere to the law of confidentiality of participant information and will refrain from disclosing any participant information.

I have received a copy of this agreement.


_____          _____
Consultant                                Date



_____          _____
Researcher: Rita Valade                   Date

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**Permission to be videotaped**

As a guest of the group, I understand that I am participating in a research study sponsored by the University of Louisville and being guided by Dan Wulff, Ph.D. and Rita Valade, doctoral student. The group with which I am about to meet is also participating in this research project

Furthermore, I understand that the video tape will be used only for Rita Valade's personal use as pertains to the research project and will be stored in a locked cabinet until such time as it is destroyed by May 2005, unless you agree to other arrangements.

I have been given a copy of this consent.


_____          _____
Karen Dennison                           Date


_____          _____
Rita Valade, witness                     Date

# Appendix D
## Revised Consent Form for Phase Two

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### Participatory Action Research with Adults with Mental Retardation
### Participant Informed Consent for Phase II

**Introduction and Background Information**

You are invited to participate in a research study. The word research means that we try to learn more about certain problems or things. Dr. Dan Wulff and Rita Valade, doctoral student, and the University of Louisville Kent School of Social Work are the study sponsors. They agreed to let us do this study. Rita is going to invite about 10 persons to meet for about 10 months to work together to help fix a problem in their lives that they all agree upon.

**Purpose**

The purpose of this research study is to help around 8-12 adults with mental retardation figure out ways to make a problem in their lives get better. We will also learn what things work and what does not work in trying to make the problem get better. We hope that others will be able to learn from our experience and try to change things in their lives that worry them.

**What we will do** *(Procedure)*

We are asking you to become part of a group that will meet at least every month until January 2004. The group meetings will last about an hour. Rita Valade will be part of the group. We will think about the problem that we've agreed to meet about then try to do something about it as a group. Everyone will be able to talk about what they think will work. The group will decide what we will do. Different people in the group may do different things in between group meetings to try to better understand or help out the group make the problem better. We will meet at a place where the group agrees. It will be accessible for people in wheelchairs.

**Possible bad things that could happen** *(Potential Risks)*

We can't think of any bad things that will happen because the group will decide what to do. We will not do anything illegal or dangerous. Other people may talk about what we have said and you may be disappointed that we will not be able to change things.

**Good things that can happen** *(Potential Benefits)*

Some good things can happen if you agree to join the group. You will be part of a group that is going to try to change something. You may learn some ways for self-advocacy, to speak up for yourself and to help others in the process.

**Keeping what you say a secret** *(Confidentiality)*

Because this is a group process that will result in something being changed, what you say will not be a secret in this part of the study. But, we will all work very hard to keep our group discussions private and not repeat what we talked about. You understand that you should not discuss group conversations with others outside the group *unless the group decides differently.* The group meetings will be videotaped for Rita to help the group better. The videotapes will be reviewed by a team of 4 professionals who will help Rita better understand the group dynamics and to make sure that Rita's ideas don't take over the group.

Phase II consent. Date revised 1/15/2004, p. 1

The person who runs the video camera, the four professional reviewers, Dr. Wulff and others at the University of Louisville who are connected to the study (Human Studies Committees, members of the dissertation committee) will be able to review the videotapes if they think it is important.

I do not want my participation in this group to be a secret. I want to be given credit for my work in Rita's dissertation and I want Rita to use my real name and include my picture in her dissertation. I also want her to add a videotape of highlights of our group meetings that we can all use. I also want Rita to ask me about using my name again when she publishes an article or anything else about our group. I can change my mind any time I want.

### Free to do this or not *(Voluntary Participation)*
You are free to join this group or not. You can also stop the being in the group anytime you wish. No bad thing will happen to you if you stop before we are done meeting as a group in January 2004.

### Your Rights and Contact Persons
Do you have any questions? Did you understand what Rita and you are going to do? If you are really clear, we are going to ask you to sign your name to let us know you understand. If you have any questions about the study, please contact Rita at 634-1537.

If you have any questions about your rights as a research subject, you may call the Human Studies Committees office (502) 852-5188. You will be given the chance to discuss any questions about your rights as a research subject, in secret, with a member of the committee. These are independent committees made up of people of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. The Committee has reviewed this study.

### Information about Rita's notes
Rita will keep all your information in a locked file cabinet in her office at Day Spring. Only Rita will be able to get to her notes. After the group is finished in January, 2004, Rita will take all the information we learned and write up her school homework, called a dissertation.

### End of the Group
By January 2004, the group will be finished. However, we may decide to continue to see each other and/or keep working on things together. The group will decide that around Thanksgiving time this year, 2003.

### Consent
You have discussed the above information and agree to voluntarily participate in this study. You have been given a copy of the consent.

_____          _____
Signature of Participant                                           Date Signed

> *Guardian/Family Member permission:*
>
> *By signing this form, I am agreeing to allow _____ to participate as a full member of this research study. I understand that the participant or I can revoke this approval at any time.*
>
> _____          _____
> Signature of Guardian/Family Member                        Date Signed

_____          _____
Signature of Investigator                                          Date Signed

Phase II consent. Date written Revised 1/15/2004, p. 2

CURRICULUM VITAE
# Rita Marie Valade, R.S.M, M.S.W., M. A.
3439 Illinois Ave.
Louisville, KY 40213
502-634-1537

## EDUCATION:

1999- 2004 **Doctor of Philosophy,** *University of Louisville, Kent School of Social Work*, Louisville, KY. Dissertation: Participatory Action Research with Adults with Mental Retardation.

1990 - 1992 **Masters in Theology,** Concentration in Systematic Theology; *Washington Theological Union*, Silver Spring, MD; Thesis: Ecclesiology of Catherine McAuley, foundress of the Sisters of Mercy.

1984 - 1985 **Post-Masters Certificate in Social Administration,** *University of Maryland*, School of Social Work and Community Planning; Baltimore, MD.

1980 - 1982 **Masters in Social Work,** Concentration in Mental Health; *Catholic University of America,* National Catholic School of Social Services; Washington, D.C.

1972 - 1975 **Bachelors of Arts,** Majors in Psychology and Sociology; with Honors; *University of Michigan*, Dearborn, MI.

## EMPLOYMENT:

2003 – 2004 **Assistant Professor**: *Spalding University*, Louisville, KY; School of Social Work.

1999 - 2003 **Instructor,** *Spalding University,* Louisville, KY. Have taught as adjunct in religious studies and adjunct and half-time in social work. Have taught in both Masters and Bachelors levels. Have also had duties that included administration, liaison with Spalding Social Work Association, and coordinator of field placements and instruction for B.S.W. students.

1992 - 1999 **Vocation Coordinator,** *Sisters of Mercy-Detroit,* Farmington Hills, MI. Duties included individual counseling, psycho-social assessments, recruitment, and administration.

1992 - 1996 **Adjunct Instructor,** *University of Detroit Mercy,* Social Work, Detroit, MI.

1984 - 1990 **Mental Health Coordinator,** *Johns Hopkins Hospital,* Department of Psychiatry's outreach program Health Care for the Homeless, Baltimore, MD. Duties included direct service as a psychiatric therapist with individuals, couples, and families; administration; program development; staff supervision; public speaking; field supervision of M.S.W. students.

1986 - 1987 **Private Practice,** *Arundel Psychiatric Associates*; Glen Burnie, MD.

1982 - 1984 **Outpatient Psychiatric Therapist,** *St. Luke Institute*, Suitland, MD. Chemical dependency treatment program which also addressed general psychiatric work with individuals and families.

1982 - 1984 **Graduate Instructor**; *Washington Theological Union*, Washington, D.C. Pastoral Studies Department.

1980 - 1982 **M.S.W. student field placements**: Adolescent Unit, *Area C Community Mental Health Center*, Washington, D.C; and the *Green Door*, psychosocial day treatment program for people with chronic mental illness.

1977 - 1980 **Co-Director;** *Catholic Community Center*, Benton Harbor, MI. Duties included administration and casework. Conceptualized and organized the area's only soup kitchen through grants and community organizing.

## MAJOR PRESENTATIONS:

"Enabling the Social Worker in Accessing the Mental Health System for the Client",
     **Arundel County Department of Social Services**, Annual Meeting; June, 1989.
"Interdisciplinary Approach in Caring for the Homeless Mentally Ill", **Hospital and**
     **Community Psychiatry Annual Meeting**; New Orleans, LA; October, 1988.
"Social Work Concepts in Treating the Homeless Mentally Ill", Annual Meeting,
     **American Public Health Association, Annual Meeting**, New Orleans, LA;
     October, 1987.
"Providing Mental Health Services to the Homeless", **National Association of Social**
     **Workers, Maryland** Chapter; September, 1987.
"Introduction to Mental/Mental Illness", Annual Conference, **Department of Social**
     **Services, State of Maryland**; May, 1987.

## CREDENTIALS AND HONORS:

1984   Academy of Certified Social Workers (A.C.S.W.) (continuous)
1984   Licensed Clinical Social Worker (State of Maryland)
1988   Direct Service Award, State of Maryland Department of Mental Hygiene
2001   Licensed Clinical Social Worker (State of Kentucky)
2002   Spirit of Day Spring Award

## MEMBERSHIPS AND COMMUNITY INVOLVEMENT:

**Sisters of Mercy**, Regional Community of Detroit.
**National Association of Social Workers** (since 1982)
**American Association of Mental Retardation**
**Council on Social Work Education**
**Day Spring:** For the past 6 years, I have lived in community with adults with mental
     retardation in Louisville, KY and am involved in various issues related to mental
     retardation.
**Casa Guadalupana:** Board of Directors since 2002.
**Passport Health Services of Kentucky:** Partnership Council Board and Chair of
     Quality Membership Access Committee since 2001.

(3/30/2004)