

TOWARD A TECHNOLOGY OF BEHAVIORAL SUPPORT FOR INDIVIDUALS  
WITH AUTISM: AN IDEAL INFORMATION SYSTEM

by

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AN ABSTRACT OF THE DISSERTATION  
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information system

Abstract approved: Robert Grover, Ph.D.  
\_\_\_\_\_  
(Chair)

This study examines services to individuals with autism from the perspective of information systems. This case study investigated two exemplary sites in the Midwest where individuals with autism live in their home communities. Data were collected over a 5-month period in seven locations. Participants were 18 key people whose roles with 16 individuals with autism included parents (6), educators (7) and related service providers (2), and administrators (3). Responses from semistructured interviews, observation and questionnaires contained 1299 distinct items of information that formed 65 total categories and six unique elements of effective information systems. Theoretical elements emphasizing the social processes of the sociology of information, behavioral processes of the psychology of information, and organization-managerial processes of information were used to guide the investigation of the actual information systems. Elements of effective information systems included a combination of humans resources and environmental resources: people and published resources, multidisciplinary-collaborative problem-solving, extended family v. professional model of interactions, informational and experiential content, multiple formats of information, and shared environments. A kaleidoscopic model of an information system was extrapolated from the results with implications for future research and practices of educators, social service providers, and information professionals.

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### Orientation to the Study

Autism can be found among people of all social classes, ethnic and racial groups, and nationalities (Mesibov, 1991). According to the 1996 report of the National Institutes of Health, autism exists in the United States at a rate of at least 22 per 10,000 (Alexander, Cowdry, Hall, & Snow, 1996). Approximately 596,000 individuals now experience autism first-hand. Described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) as a life-long disability with an early onset and an organic basis, autism is the most severe of the developmental disabilities.

The primary problem in autism is that the way the brain processes and integrates information results in social problems, communication difficulties, narrow interests and resistance to change (Mesibov, Adams, & Klinger, 1997). When a child is diagnosed with autism, the most often asked questions by parents and educators is, “What do I do now?” The answer to this question requires credible information that will make a positive difference in the life of the individual with autism and that will improve the way parents and professionals educate themselves before making treatment decisions.

The debate about how to help individuals with autism is fueled by a proliferation of information about interventions which reduce or eliminate the biological effects, cognitive consequences and/or behavioral manifestations of autism. Contrary to popular opinion, there is no shortage of information on how to treat individuals with autism. Print and on-line sources abound, containing descriptions of how to help people with autism through education, positive behavioral supports, Applied Behavioral Analysis, facilitated communication, sensory integration theory, play-based therapy, music and art therapy,

various drugs, vitamins and other “natural” substances, special diets of various kinds, and other less known or less popular treatments. This mass of information contributes to the uncertainty and frustration of parents and professionals who realize that something must be done to help an individual with autism but cannot make an informed choice.

A growing body of research investigates the nature of autism and behavioral principles of learning connected to autism in last half of the 20th century including work by Ferster and Demyer (1961); Lovaas, Freitag, Gold, & Kassorla (1965); Lovaas, Berberich, Perloff, & Schaeffer (1966); and by Lovaas, Schribman, & Koegel (1974). According to Lovaas (1987), the purpose of behavioral research and interventions is to divide the problems of autism into separate, measurable aspects of behavior and relate them to present conditions which can be experimentally altered. However, no studies investigate the needs of people with autism as an information systems issue.

This researcher contends that Lovaas’ idea that “helping autistic kids . . . is a matter of construction of a person” (Chance, 1974, p. 76) has too long dominated social science theory and educational practices. As Mesibov et al. (1997) suggested, “Lovass’ theory of ‘build[ing] a person’ suggests that the person with autism is other than--or less than--a person, and it implies that the professional’s job is to change the person” (p. 17). Lovaas later acknowledged that the work of professionals consists of more than attempting “to change” the person with autism. This researcher agrees with Lovaas’ acknowledgment about the work of professionals and suggests that it is possible to help the child with autism to change through non-aversive behavioral interventions, while accepting the responsibility of changing the environment to better suit the child. The work of the

professional should alter the environment to more closely match the diverse needs of people who occupy the environment.

This researcher further asserts that (a) neurological conditions will not allow people with autism to fully overcome inabilities to communicate effectively, develop substantial social relationships, or to determine solutions to problems encountered in everyday life; (b) despite best educational practices and/or medical interventions, most individuals with autism will not survive if left alone; and (c) capable others must always assist people with autism. Therefore, effective information systems are needed to manage details between and among individuals with and without autism.

#### Problem

People who effectively live and work with people with autism are demonstrating that, while interventions do not in medical terms “cure” autism, interventions can change the environment to better suit the individual. In so doing, interventions can help individuals with autism to become contributing members of society. With a changed environment, perceptions of people with autism can be changed.

#### Research Questions

To improve our understanding of what it means “to change” the environment, professionals need to know the following:

Research Question 1: What are the elements of an effective information system that enables parents, educators and providers to help children with autism?

This research is an attempt to identify elements of effective information systems that are currently helping individuals with autism and to use those elements to create new

knowledge about information systems in general. A model of information science by Roger Greer (1984) was used to determine this study's multidisciplinary parameters. Elements of an ideal, effective information system were constructed from a theoretical review of literature related to autism, social processes of the sociology of information, behavioral processes of the psychology of information, and the organizational-managerial processes of information organization management.

Recognizing that all people are in need of effective information systems, results of this study will relate to the field of information studies through the following sub-questions:

Research Sub-Question 1-A: What is the scope in terms of the depth and breadth of an effective information system? These dimensions include professional knowledge, dissemination, diffusion and use of resources.

Research Sub-Question 1-B: What are the functions of various participants within the effective information system?

Research Sub-Question 1-C: What is the organizational-managerial structure of an effective information system?

Answers to these questions are revealed in the results found in Chapter 3 and form the basis for identifying elements of effective information systems in Chapter 4.

#### Definition of Terms

“Information system” as used in this study is a person-centered system that uses creative collaboration to develop a circle of support allowing full participation of members in making life-critical decisions on behalf of school-aged individuals with autism. Using

this definition, a model information system is expected to emerge from the data that reflects the discovery of patterns that connect issues and events of relevance or interest.

Greer's (1984) definition of "information transfer" was used: "that part of the communication process wherein the message is recorded and received by one or more individuals" (p. 2). In this context, "information" is recorded knowledge, that knowledge external to an intellect.

The terms "treatment," "therapy," and "intervention" are used interchangeably in this study to refer to anything that is done to or with a individual that may change the individuals behavior and/or biology, both broadly defined. In contrast to typically developing children who receive "instruction" in schools, children and youth with autism are commonly reported to receive "treatment," "therapy" and/or "intervention."

#### Literature Review In Four Parts

In contrast to an "integrative review" summarizing past research or a "methodological review" concentrating on research methods and definitions, a "theoretical literature review" (Merriam, 1988, p. 62) was conducted to focus on relevant theories which could become a foundation for the problem to be investigated. The literature was not used to form a deductive, "theory-testing study" (Glaser, 1978, p. 31), but rather to build theory where there was none. The goal of the literature review was to locate interdisciplinary theory that has the potential for building new theory about the treatment of individuals with autism within the context of an information system. According to Riley (1963, pp. 5-6), "one cannot exhaust the description of a setting." Therefore, some selection criteria were needed to organize the phenomenon to be investigated.

“A Model For the Discipline of Information Science” by Greer (1984) was used to organize the phenomenon and to form a framework for the study. Greer’s multidisciplinary model permitted the researcher to review literature from disciplines other than psychology and biology, which have traditionally provided grounding theories upon which special education applied research and practice have been based (Bogdan & Kugelmass, 1984; Mercer, 1973; Skrtic, 1986). Greer’s multidisciplinary model provides guiding theories necessary to explore the social-political-cultural context of disability as an alternative to placing the root cause of deviance within the person with autism as has been done in the behavioral and biological sciences.

Greer’s (1984) model describes behavioral processes associated with the fields of information science: sociology of information, information psychology, information organization management, and information engineering. The engineering field and processes were not included as part of this study. Engineering in this context refers to specific aspects of the design and management of databases which were determined by the researcher to be unrelated in this study to helping individuals with autism.

From a synthesis of the literature review, a multiple criteria definition of “effective information system” was constructed to be used in the study as an “ideal type” (Weber, 1904/1949, p. 92) that would emphasize the cultural significance of the social phenomena under investigation. Construction of an ideal type in this study is similar to the work of Schein (1972) who synthesized theories from a number of social scientists to create a multiple criterion definition of a “professional.”

Background theory for this study is presented in the following sections that

correspond with Greer's (1984) fields of information science: social processes of the sociology of information, behavioral processes of the psychology of information, and organizational or managerial processes of information organization management. Each of the three process sections begins with Greer's explanation of the corresponding process and ends with the respective theoretical element of an ideal information system. The three process sections are preceded with a review of literature related to autism. Understanding the complexity and intensity of autism is a prerequisite to discussing what differences an effective information system can make to individuals with autism, their parents, educators and providers. In addition, by focusing on the profound information needs of people with autism, their family members and professionals, a framework emerges for an effective information system that will benefit all people.

### Autism

Autism is a life-long developmental disability characterized by difficulties and abnormalities in several areas: communication skills, social relationships, cognitive functioning, sensory processing and behavior (Baron-Cohn, S, (1998); Simpson, R. L., & Myles, B. S. (1998); Mesibov, G. B., Adams, L. W., & Klinger, L. G. (1997); Happe, F. (1994); Simpson, R. L., & Zions, P. (1992); Baron-Cohn, S., & Bolton, P. (1993); Frith, U. (1991). Once thought to be a result of inadequate parenting, autism research concentrates on neurological, genetic and biochemical explanations for autism. The term "spectrum of autism" was used by Wing (1988) to capture the idea of a range of manifestations of the same disability according to intellectual ability and age.

Since Leo Kanner initially described autism in 1943 based on his study of 11 children



with strikingly similar characteristics, the impairment of autism has been grouped into three areas of functioning termed the “triad of impairment” (Wing & Gould, 1979): reciprocal social interactions, verbal and nonverbal communication, and a restricted repertoire of activities and interests. Today the DSM-IV (American Psychiatric Association, 1994) divides the diagnostic criteria among these three impairments, requiring that a child at least 30 months of age meet at least two criteria from the social category and at least one from both the communication and restricted repertoire of activities categories to be diagnosed with autism. Diagnostic criteria consistent with that of the DSM-IV is also found in the International Classification of Diseases, 10th edition (ICD-10; World Health Organization, 1990). In addition, a new classification system has recently been developed by Zero To Three: National Centers for Infants, Toddlers, and Families (1994). Under this system called the “Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood,” the term “Multi System Developmental Disorder” is used to describe autism in the context of other Pervasive Developmental Disorders.

Individuals with autism function intellectually in the gifted, normal and mentally retarded ranges of intelligence. Approximately two-thirds of all people effected by autism also have a diagnosis of mental retardation. Gillberg (1984) reported that 23% of people with autism have IQs between 50 and 70 and that 27% have IQs below 50. Individuals with low IQs and autism are the least likely to develop communicative language skills.

In addition to overlapping with mental retardation, autism resembles and overlaps with many related disorders, including learning disabilities, Attention Deficit Disorder,

Obsessive-Compulsive Disorder, Schizophrenia, and other Pervasive Developmental Disorders. What distinguishes autism from the other cognitive disabilities is the number, severity, combination and interactions of problems, which result in significant functional impairment. Autism is the composite of the deficits, not any one characteristic (Mesibov, G. B., Adams, L. W., & Klinger, L. G. (1997).

The major problem in autism is with cognition and information processing (Happé, F. (1994). People with autism have difficulties imposing meaning on their experiences. Underlying concepts, themes, reasons, or principles are typically unclear to people with autism. For example, an individual with autism may know that there is a specific time to be at school but not be able to understand why being late is a social problem that affects that individual and other people. People with autism can act on their environment, they can learn skills, some can learn to use language, but they have no independent capacity to understand what many of their activities mean. The severe neurological impairment in autism prevents the individual with autism from drawing relationships between ideas and events. It is as though the world consists of a series of unrelated experiences and demands.

This severe impairment in generating meaning likely relates to several other cognitive difficulties. Individuals with autism are often very good at observing minute details, particularly visual details. What individuals with autism are less capable of is assessing the relative importance of all the details they have noted. Individuals with autism experience a high degree of distractibility. They have great difficulty interpreting and putting in priority the importance of external stimulation or thoughts that bombard them. Some people with

autism look, move and explore constantly as if all sensations are new and exciting, while others deal with the bombardment of external stimulation by appearing to “shut down” their processing and becoming preoccupied with a narrow range of objects.

Individuals with autism, regardless of their IQ score, have relatively greater difficulty with symbolic or abstract language concepts than with straightforward facts and descriptions (Leslie, A. M., & Roth, D. (1993); Leslie, A. M., & Thaiss, L. (1992). Words and facts mean one thing. It is easier for people with autism to understand individual facts or concepts than to put concepts together or to integrate them with related information, particularly when the concepts appears to be contradictory. Individuals with autism have great difficulty organizing and sequencing information. Organizational skills are difficult for people with autism because organization requires the ability to focus on both the immediate task and the desired outcome at the same time. This kind of dual focus is hampered by their concentrating specifically on individual details. In the same way, sequencing is difficult for people with autism. It is not unusual for people with autism to perform a series of acts in illogical, counter-productive order, without their seeming to notice. Through structure that is imposed on the environment by capable others, individuals with autism can learn to perform tasks that can be combined to form routines. However, people with autism often learn skills in one situation but have great difficulty generalizing learned skills to a different situation.

In addition to cognitive deficits, individuals with autism experience certain behaviors that are associated with the biological condition of their brain (Shaw, 1998). People with autism often have very strong impulses and are extraordinarily persistent in seeking out the

things they desire, whether it be a favorite object, experience or sensation. This is a driven quality that people with autism appear not to control. People with autism often experience a high level of anxiety. Some of this anxiety may be caused by a biological condition, but some anxiety in autism may be caused by the difficulties people with autism experience in understanding what is going on around them.

People with autism have great difficulty demonstrating an understanding of information that is known to others through their senses (Cook, D. G., & Dunn, W. (1998). Some people with autism have very unusual food preferences, spend their time watching their own fingers flicking, or rubbing their hands against certain textures. Some people with autism cry when they hear certain sounds or are annoyed by even very soft sounds. Some people with autism appear not to feel pain or to need sleep. In many ways, people with autism through their behaviors indicate that their difficulties begin at the level of sensory processing.

Implications for the study. Autism affects the ways that individuals eat, dress, work, spend leisure time, understand their world, and communicate with others. In a sense, autism functions as a culture in that it yields characteristic and predictable patterns of behavior in individuals with the condition. For people with autism and without autism to live together, two cultures must come together. The role of the parents, professionals and other support providers within an effective information system is to bring together the two cultures in a cross-cultural relationship. Because autism has an organic basis, “being normal” cannot be the goal of interventions. The long term goal must be to create an environment that will be comprehensible to individuals with autism and appropriate for

people without autism. Participants within an effective information system must have a common understanding of autism and the goal for people with and without autism.

Therefore, the most essential theoretical element an effective information system is that the *effective* information system must be focused around a common purpose: a common understanding of autism.

#### Social Processes of the Sociology of Information

According to Greer (1984), the broadest field of concern to the information professional is the sociology of information which begins with information creation and continues through the phases of recording, production, dissemination, bibliographic control, organization by discipline, diffusion, use, and preservation. Knowledge about interventions for autism, like all professional knowledge, is “premised on an underlying discipline or basic science” (Schein, 1972, p. 43). In his analytical treatment of the nature of society dimension, Ritzer (1980) used a “levels of social analysis,” (p. 18) or microscopic-macroscopic distinction to differentiate among metatheoretical positions. Adapting Ritzer’s model, Burrell and Morgan (1979) approached the problem of analyzing professional knowledge grounded in social science thought by relating the nature of science and the nature of society to produce four paradigms of modern social scientific thought: the functionalist (micro-objective); interpretivist (micro-subjective); radical humanist (macro-subjective); and radical structuralist (macro-objective). Each paradigm or “loose collection of logically held-together assumptions, concepts, or prepositions that orient thinking and research” (Bogdan & Biklen, 1982, p.30) identified by Burrell and Morgan is described below.

Functionalist paradigm. According to Burrell and Morgan (1979), the dominant framework for social science in the Western world, functionalism, is grounded in the sociology of regulation, takes a microscopic view of social reality, and studies subject matter from an objectivist point of view. The functionalist paradigm seems to provide rational explanations of social affairs for the purpose of prediction and control. As Ritzer (1980) noted, the functionalist views society as a social system composed of interrelated parts, each of which contributes to the maintenance of the others. In the most extreme case, functionalists argue that all events and structures in society are functional because, if they were not, they would not exist. This premise leads to the conservative bias that all current aspects of society are indispensable to the system and that, as such, “all structures that exist should continue to exist. . . [which] holds out little possibility of meaningful change within a social system” (p. 49).

Interpretivist paradigm. Implicitly committed to regulation and order, interpretivists assume that the social world is cohesive, orderly, and integrated (Burrell & Morgan, 1979). Interpretivists are oriented toward understanding the ongoing processes through which humans subjectively construct their social world (Berger & Luckmann, 1967). The interpretivist is concerned with understanding the essence of the everyday world as an emergent social process. When the social world outside the consciousness of the individual is recognized, it is regarded as a network of assumptions and intersubjectively shared meanings. Burrell and Morgan’s (1979) interpretivist paradigm corresponds to Ritzer’s (1980) micro-subjective paradigm. Social scientists of this persuasion are concerned with understanding the social construction of reality and the way people create

and share meaning.

Radical humanist paradigm. Sharing a view of social science with the interpretivist paradigm, Burrell and Morgan (1979) characterize the radical humanists' frame of reference as the sociology of radical change. Radical humanists' view of society emphasizes the importance of transcending the limitations of existing social structures, which they view as distorting true human consciousness. Society is viewed as being antihuman, as inhibiting human development and fulfillment. Taking a macro-subjective view (Ritzer, 1980), humanist theorizing focuses on a critique of the status quo. Radical humanists focus their analyses on ideological structures such as culture, norms, and values, and are concerned with the influence of these structures on human thought and action.

Radical structuralist paradigm. According to Burrell and Morgan (1979), from the perspective of the objectivist, radical structuralism shares a conceptualization of science with the functionalists, poses a critique of the status quo, and advocates change. Radical structuralists characterize contemporary society in terms of fundamental conflicts that generate change through political and economic crises. Radical structuralists focus their critique upon material structures and are concerned with the consciousness of entire categories of individuals such as races, genders, and socioeconomic classes. They occupy Ritzer's macro-objective frame of reference and approach social science by concentrating on material structures such as law, bureaucracy, technology, and the economy.

Implications for the study. According to Greer (1984), the professional must be concerned with the creation of knowledge as well as the dissemination, diffusion and use

of information. Burrell and Morgan (1979) suggested that the approach social scientists take to creating knowledge depends on which of the four paradigms of modern social scientific thought serves as their metaphysical frame of reference. Underlying assumptions behind professional theories, assumptions, models, practices and tools can be understood when the knowledge the professional uses is located within one, two, three or four paradigms of modern social scientific thought (Skrtic, 1991). Skrtic asserts that professionals need a way to analyze their knowledge base that will bring its anomalies (Kuhn, 1970) to the surface, to prompt the suspicion that something is amiss with the accepted knowledge tradition, thus setting the stage for deconstruction of knowledge. Skrtic further suggests that “to understand what possibilities lie ahead for special education, special educators must understand and more important, free themselves from that which has conditioned, limited and institutionalized their professional thought and action” (Skrtic, 1991, pp. 23-24).

In order for professionals to change their view that the only way to help a person with autism is “to construct a person,” they must first be able to perceive that there is more than one paradigm of social science thought and, consequently, more than the functionalist paradigm from which to create knowledge about helping people with autism. Similarly, professional knowledge about the human condition in general can be changed. Therefore, drawing from these theories related to the social processes of the sociology of information, this researcher formulates the second theoretical element of an effective information system. That is, the *effective* information system must be created and operated by professionals who deliberately deconstruct and reconstruct their knowledge base.



### Behavioral Processes of the Psychology of Information

According to Greer (1984), the information professional operates within an information system in order to enhance the information transfer processes of a specific client population. This goal applied to understanding the elements of an effective information system that enables parents, professionals and other providers to assist individuals with autism requires a knowledge of existing theories regarding assessment of information needs. Assessment of information needs includes an understanding of the behavioral characteristics of the specific population being served, knowledge of theories regarding human nature, and human ability to adapt to environments. In the following section, theory related to assessment of information needs and literature related to human behaviors associated with changing environments will be discussed.

Assessment of information needs. Often called “diagnosis of information needs” by library and information professionals, assessment focuses the professional on specific needs of the information seeker. According to Grover and Carabell (1995), there is no one correct method for diagnosis of an information seeker’s needs. The methodologies used should be determined on an individual basis, defined by the information seeker’s unique problem, contexts, and desired outcomes. The diagnostic processes should be client-centered, holistic, creative and problem-solving. After establishing a rapport and a comfortable environment to conduct the diagnosis, the information seeker’s needs should be established. The professional’s role is to ascertain how the information seeker perceives the problem and is impacted by it. A customized information package can be created when the user’s intended purpose of the information and expected outcomes are

known. Each information user has unique preferences for using information. Depending on the user's learning or cognitive style, a user may prefer oral, written or pictorial, or part or full-text. Some users desire information to be gathered for them while others like to search for themselves. A user's limitation such as time, cost, and need to know should also be determined during the diagnostic interview. Therefore, the *effective* information system must be designed and evaluated from the point of view of the user.

Human behavior. Piaget (1950) stated that intelligence can be regarded from the point of view of the functional situation and of the structural mechanism, together forming the essential property of the operation which characterizes living logic in action. From the functional situation view, behavior becomes more "intelligent" as the pathways between the subject and the objects on which the behavior acts cease to be simple and become progressively more complex. From the point of view of the structural mechanism, elementary sensori-motor adaptations are both rigid and undirectional, while intelligence tends towards reversible mobility. According to Piaget, to define intelligence in terms of the progressive reversibility of the mobile structures which it forms is to say that "intelligence constitutes the state of equilibrium towards which tend all the successive adaptations of a sensori-motor and cognitive nature, as well as all assimilatory and accommodatory interactions between the organism and the environment" (p. 11).

Piaget (1980) further states that "assimilation" (p. 8) may be used to describe the action of the organism on surrounding objects, insofar as this action depends on previous behavior involving the same or similar objects. Psychologically, modifications are entirely functional and are determined by movement, perception or the interplay of real or

potential actions. “Mental assimilation is thus the incorporation of objects into patterns of behavior, these patterns being none other than the whole gamut of actions capable of active repetition” (p. 8). Defined in psychological terms, “accommodation” (p. 8) can be understood as taking place in situations wherein individuals never suffer the impact of surrounding stimuli, but the surrounding stimuli simply modify the assimilatory cycle by accommodating the individual to themselves. As such, adaptation can be defined as “an equilibrium between assimilation and accommodation” (p. 8), which amounts to the same as an equilibrium of interaction between subject and object. According to Piaget intelligence is “an extension and a perfection of all adaptive processes” (p. 9).

Implications for the study. Grover and Carabell’s (1995) research on diagnosis of information needs reveals aspects of assessment that are relevant to understanding the professional functions of key people within an effective information system. From this theory, the researcher formulates the third theoretical element of an effective information system. The effective information system must be designed and evaluated from the point of view of the user.

From Piaget’s (1980) theory of human intelligence, the fourth theoretical element of an effective information system is revealed. That is, the *effective* information system must be maintained through human acts of assimilation and accommodation which prevent the environment’s occupants from suffering the impact of surrounding stimuli.

#### Organizational-Managerial Processes of Information Organization Management

The processes associated with the management of an information organization include the mission and objectives of the organization, policies, strategies and procedures,

implementations of plans, and supervision of the organization (Greer, 1984). Children with autism received service from public organizations such as schools and social and rehabilitation services. The public expects schools as legitimate organizations to look like and to conform to the machine bureaucracy structure (Skrtic, 1991, Mintzberg, 1979; Meyer & Rowan, 1977, 1978). The following sections contain theories related to bureaucratic government, machine and professional bureaucracies, and both loose and tight coupling of employees within organizations.

Bureaucracy. Bureaucratic forms of government began during the Progressive Era in America to control corruption and patronage that existed during the nineteenth century when government decisions were made without benefit of budgets (Wilson, 1989). According to Schorr (1997), reformers advocating merit hiring, objective criteria for contracting, and an end to “clubhouse rule” began to prevail in the early twentieth century as the country evolved from a decentralized agrarian society to an urban, industrialized nation that required efficient government. The bureaucratic reform vision became a compelling system of beliefs that placed the highest value on impersonal exercise of public authority and consistent application of universal rules. “The reformers during the Progressive Era loathed corruption more than efficiency” (p. 70). There was little challenge to the dominant beliefs that public benefits must be centrally standardized and routinized and that lower-level discretion and flexibility would threaten the integrity of public institutions and agencies.

Machine and professional bureaucracy. The type of work done and the means an organization has available to coordinate its work influence organizational structures.

Organizations configure themselves as machine bureaucracies when their work is simple, that is, it can be rationalized into a series of precise, routine tasks that can be fully pre-specified and done by separate workers. Simple work can be coordinated by standardizing the work processes, which is accomplished through formalization, detailed job specifications, precise instructions, and rules (Braverman, 1974).

According to Mintzberg (1979), organizations configure themselves as professional bureaucracies when their work is complex, when work is too ambiguous to be rationalized, prespecified, and formalized. Complex work requires that the people who do it have an extensive knowledge base and an associated repertoire of skills that take a prolonged period of time to learn. Complex work is coordinated by standardizing the skills of the worker which is accomplished through professionalization (i.e., education and socialization). The logic of formalization rests on minimizing discretion and separating theory from practice. Professionalization, in principle, is premised on increasing discretion and uniting theory and practice, which is necessary because complex work requires the adaptation of general theories or principles to variable cases or clients (Perrow, 1970; Schein, 1972).

The means of coordination in an organization influences the nature of the interdependency or coupling among its workers (March & Olsen, 1976; Thompson, 1967; Weick, 1976, 1982). Because machine bureaucracies coordinate their work by rationalizing and formalizing it so that each worker does one part of the total job, their workers, like links in a chain, are tightly coupled. The workers in a professional bureaucracy are loosely coupled because standardization of skills creates a form of

interdependency in which professionals share common facilities and resources but do the entire job alone with an assigned client group. Coordination which is loose is accomplished by everyone knowing roughly what everyone else is doing by way of their common professionalization.

Loosely and tightly coupled workers. Tightly coupled workers are highly dependent on one another because they each do one part of a larger work activity (e.g., building an automobile on an assembly line; making donuts in a factory). Loosely coupled workers are not highly dependent on one another because each one of them does the entire work activity alone. Teachers working in a school are the ideal typical case of loosely coupled workers (Mintzberg, 1979; Thompson, 1967). In this sense, while students ordinarily encounter several different teachers from the start to the finish of the educational process, each teacher controls her/his classroom in an autonomous existence within the school building.

Adhocracy. According to Mintzberg (1979), adhocracy as a type of organization was first recognized in the 1960s when analysts began to notice varying degrees of formalization across bureaucracies (Pugh, Hickson, Hinnings, McDonald, Turner, & Lupton, 1963). This realization eventually led to the recognition of organic organizations (Toffler, 1970). Organic organizations which operate in dynamic and uncertain environments where innovation and adaptation are necessary for survival configure themselves as the “inverse of the bureaucratic form” (Burns & Stalker, 1966; Woodward, 1965). Mintzberg (1979) called the organic configuration “adhocracy” following Toffler (1970) who popularized the term.

In an “adhocracy,” division of labor is achieved by deploying professionals from various specializations on multidisciplinary project teams, a situation in which team members work collaboratively on the team’s project and assume joint responsibility for its completion. Under “mutual adjustment,” coordination is achieved through informal communication among team members as they invent and reinvent novel problem solutions on an “ad hoc” basis, a process that requires them to adapt, adjust, and revise their conventional theories and practices relative to those of their colleagues and the team’s progress on the tasks at hand (Chandler & Sayles, 1971; Mintzberg, 1979). Together, the structural contingencies of collaboration and mutual adjustment give rise to a “discursive coupling” arrangement premised on reflective thought and on the unification of theory and practice in the team of workers (Burns & Stalker, 1966).

Implications for the study. Theories which can explain organization and management of schools and other governmental agencies are necessary for understanding structures which surround key people within effective information systems and the interactions of key people within effective information systems that enable parents, professionals and other providers to help children with autism. Taken together, these organizational-managerial theories provide the fifth theoretical feature of an effective information system. The *effective* information system must supersede traditional institutional structures by creating alternative forms of mutual adjustment.

#### Theoretical Multicriterion Definition of An Effective Information System

Formulated on the basis of a synthesis of theories related to social, behavioral, and managerial-organizational processes, five theoretical elements of an effective information

system were constructed to be used as an ideal-type, an analytic device that would be both sensitive to and capable of relating cultural ideas and actual social phenomena. Weber (1904/1949) advanced the ideal-type as a method of social analysis pointing out that the meaning of social phenomena derives from the value orientation behind human and institutional action and historical events. Weber further stated that the ideal-type could be used as a mental construct, a tool, an exploratory device to expose divergences between ideal and real cases, and to attempt to explain the implications of the deviations in terms of the integral logic of the construct. Applied in this way, Weber's conceptualization of social science is consistent with post-Kuhnian philosophy of science and the notion of paradigms; Rorty's (1989) notions of edification, optional descriptions, and utopian politics; and the method of philosophical pragmatism (Huff, 1984; Kloppenberg, 1986).

Formulated on the basis of the theories found in the literature review, a multiple criterion definition of an effective information system is revealed. The effective information system contains the following elements:

Theoretical Element 1: The effective information system must be focused around a common purpose.

Theoretical Element 2: The effective information system must be operated by professionals who deliberately deconstruct and reconstruct their knowledge base.

Theoretical Element 3: The effective information system must be designed and evaluated from the point of view of the user.



Theoretical Element 4: The effective information system must be maintained through human acts of assimilation and accommodation which prevent the environment's occupants from suffering the impact of surrounding stimuli.

Theoretical Element 5: The effective information system supersedes traditional organizational structures by creating occasions for mutual adjustment to occur.

The researcher used this theoretical construct as an ideal-type in Weber's (1904/1949) sense to emphasize the cultural significance and value orientation of the social phenomena under investigation and in Rorty's (1989) sense as a utopian characterization or optional description for the purpose of edification. A method for comparing these theoretical elements of an effective information system to existing, effective information systems surrounding individuals with autism is discussed in Chapter 2.

## CHAPTER 2 METHODS

To understand the elements of an effective information system that enables parents, educators and care givers to help children and youth with autism it was necessary to use a methodology that would facilitate an understanding of (a) social processes involved in the creation, dissemination and utilization of knowledge about autism interventions; (b) human needs to satisfy or ignore the need for information; and (c) organizational structure that results in interactions between parents and professionals. A methodology that will create new knowledge must also call into question the knowledge, practices and discourses of social professions. The dominant philosophy of science upon which modern education and social service to clients is premised is the positivist epistemology of knowledge. A brief description of the philosophical underpinnings of positivism will provide the background for understanding critical pragmatism, an alternative to positivism, and immanent critique and ideal type, two methods of critical pragmatism used in this study to determine the elements of actual, effective information systems.

### Positivism

In its most extreme form, positivism asserts that sense perception is the basis of all human knowledge and that through objective observations, humans can escape the bias of historical and cultural context and discern facts that correspond to reality. Interpretation and judgment have no validity for the positivist; anything that cannot be observed objectively is dismissed as meaningless (Harre, 1981). Value neutrality is the hallmark of positivism because it is assumed that only neutral observation will allow “the facts to

speak for themselves,” unaffected by the distorting effects of history and context. Science is central to positivism because the scientific method is thought to be the only way to achieve the objectivity necessary to see the world as it really is (Bernstein, 1976; Hesse, 1980; Wolf, 1981). As such, the growth of knowledge is assumed to be “a cumulative process in which new insights are added to the existing stock of knowledge and false hypotheses eliminated” (Burrell & Morgan, 1979, p. 5), a process that, over time, ultimately converges upon the truth about the world. Positivism is the conviction that scientific knowledge is cumulative, convergent, and objective and is the only source of acceptable knowledge about reality.

The positivist model of professional knowledge legitimizes professional practice as the product of a formal, rational-technical process of knowledge production (Schon, 1983). This rational-technical process of knowledge production begins with disciplinary science producing theoretical knowledge which becomes the foundation for applied knowledge and explains and determines professional services to clients. Thus, rigorous professional practice, according to the positivist model, depends on applied scientists developing models, practices, and tools that, given their grounding in the theoretical knowledge of the disciplinary sciences, are themselves assumed to be cumulative, convergent, and objective (Glazer, 1974; Greenwood, 1981).

#### Alternative to Positivism: Critical Pragmatism

For more than 30 years, the legitimacy of positivism has been called into question. “The uncertainty that we feel today stems from the fact that we are undergoing a fundamental change in worldview, one that questions the very ideas upon which our

modern institutions are premised, including the institutions of the professions” (Skrtic, 1991, p. 4). The ideal methodology for a study of this kind, that is breaking new ground in the area of information studies and developmental disabilities, is one that will allow the researcher to realize insight, discovery, and interpretation rather than to engage in hypothesis testing.

Whether this research leads to improving the human condition for people with and without autism depends on the manner in which professional knowledge, practices and discourses are studied and reconstructed. “Reconstruction [of positivism] involves pragmatic choices among alternative theories and practices, a process that can take two forms: naive pragmatism or critical pragmatism” (Skrtic, 1991, p. 44). According to Skrtic, naive pragmatism values functional efficiency, pure utility, or expediency. While it questions professional models, practices, and tools, it unreflectively accepts the assumptions, theories, and metatheories in which they are grounded. As such, naive pragmatism “is socially reproductive, instrumentally and functionally reproducing accepted meanings and conventional organization, institutions, and ways of doing things for good or ill” (Cherryholmes, 1988, p. 151). In the alternative, critical pragmatism approaches decision making in a way that recognizes and treats as problematic the assumptions, theories and metatheories behind professional models, practices, and tools; it accepts the fact that our assumptions, theories and metatheories themselves require evaluation and reappraisal (Cherryholmes, 1988; Skrtic, 1986, 1991, 1995).

Critical pragmatism is premised on philosophical pragmatism, the progressive liberal form of postmodernism associated primarily with Dewey (1899/1976) and with

philosophers such as Rorty (1979, 1982, 1989, 1991); Bernstein (1971, 1983, 1991); West (1985); Davidson (1984); Putnam (1981, 1990); and Quine (1981). Pragmatism is a method for deconstructing and reconstructing social knowledge, practices, discourses, and institutions under conditions of uncertainty, conditions in which it is recognized that there are no independent, cognitive criteria for choosing among interpretations of the social world.

Whereas the aim of modern social inquiry is to justify social practices and institutions by showing that they are based on a true representation of the social world, the goal of philosophical pragmatism is to reform social practices and institutions by reconciling them with moral ideals (Bernstein, 1971, 1991; Rorty, 1982, 1989, 1991). Pragmatism avoids the foundational question of representation by focusing on the consequences of knowledge, on the question of whether, if acted upon, a particular form of knowledge contributes to the practical realization of desirable social values.

As James (1907/1975) clearly noted, pragmatism is a method of settling metaphysical disputes that otherwise might be interminable. Is the world one or many?--fated or free?--material or spiritual?--here are notions either of which may or may not hold good of the world; and disputes over such notions are unending. The pragmatic method in such cases is to try to interpret each notion by tracing its respective practical consequences. What difference would it practically make to anyone if this notion rather than that notion were true? . . . Whenever a dispute is serious, we ought to be able to show some practical difference that must follow from one side or the other's being right (p.28).

The goal of critical pragmatism is not certainty; it does not seek objective knowledge or monological truth. Its goal is education. It is a pedagogical process of remaking ourselves by redescribing our practices, discourses, and institutions in alternative theoretical and metatheoretical languages (Gadamer, 1975). Pragmatism is premised on a continual search for “new and more interesting [ways] of expressing ourselves, and thus of coping with the world. From [this] educational . . . point of view, the way things are said is more important than the possession of truths” (Rorty, 1979, p. 359). Rorty (1979) referred to the task of finding new and better ways of describing ourselves as “edifying philosophy” (p. 378). Applied to the profession of education and information management, it is a mode of inquiry that forces educators and related service providers to face the fact that what they think, do, say, write, and read as professionals is shaped by convention, and it helps to avoid the delusion that professionals can know themselves, their practices, their clients, “or anything else, except under optional descriptions” (Rorty, 1979, p. 379). Rorty (1989) noted that edifying philosophy is

the same as the ‘method’ of utopian politics or revolutionary science (as opposed to parliamentary politics or normal science). The method is to redescribe lots and lots of things in new ways, until you . . . tempt the rising generation to . . . look for . . . new scientific equipment or new social institutions. This sort of philosophy. . . works holistically and pragmatically. It says things like ‘try thinking of it this way’--or more specifically, try to ignore the apparently futile traditional questions by substituting the following new and possible interesting questions (p. 9).

As an alternative to positivism, critical pragmatism provides an epistemological

framework and moral grounding to address the philosophical and political implications practices related to helping individuals with autism. Immanent critique (Antonio, 1981; Benhabib, 1986; Taylor, 1977) and ideal type (Mommsen, 1974; Weber, 1904/1949) are two pragmatic methods of social analysis used in this study to determine the elements of effective information systems.

Immanent critique. A means of exposing the contradictions between claims and conditions, between values and practices, immanent critique is a form of emancipatory social analysis. Immanent critique seeks to free us from our present conditions, to transform the real into the ideal, by describing “what a social totality holds itself to be, and then confronting it with what it is in fact becoming” (Schroyer, 1973, pp. 30-31).

G. W. F. Hegel in Phenomenology of Spirit (1807/1977) presented the history of Western civilization as the progressive development of human consciousness and self-consciousness. Human self-consciousness progressed because humans try to reconcile their claims about themselves (appearance) with existing social relations (reality). Hegel’s method for critically revealing the disjuncture between appearance and reality was the immanent critique. In this way, an immanent critique exposes how the claims of humans do not correspond to their life conditions.

Ideal type. An exaggerated mental construct, ideal type is “formed by the one-sided *accentuation* of one or more points of view. . . . In its conceptual purity, this mental construct. . . cannot be found empirically anywhere in reality. It is a *utopia*” (Weber, 1904/1949, p. 90). Moreover, one ideal type is never sufficient. The more complex the phenomena of interest and thus “the more many-sided their cultural *significance*,” Weber

notes, “repeated attempts to discover ever new aspects of significance by the construction of new ideal typical concepts is all the more natural and unavoidable” (p. 97). Ideal types are not true in an objective sense; they are exaggerated mental constructions, the value of which stems from their utility as expository devices, conceptual tools for analyzing the meaning and practical consequences of social institutional practices (Dallmayr & McCarthy, 1977; Mommsen, 1974; Ritzer, 1983).

Implications for the study. Positivism as the dominant philosophy of science upon which modern education and social service to clients is premised has been called into question. Critical pragmatism was used in this study as an alternative to positivism. Two methods of critical pragmatism were used: immanent critique and ideal type.

Immanent critique is used in this study as it was used by Habermas (1968/1971), Horkheimer (1947/1974) and Giroux (1981) as a means to bring about change through social analysis. By exposing contradictions between the ideal information system and the real information system, this study seeks to transform the real into the ideal. By exposing unquestioned assumptions about practices related to helping children with autism, this researcher hopes to influence self-conscientious parents, educators, related service providers, and administrators to live up to what is actually needed to help children with autism to become contributing members of society.

Theories were selected by using Greer’s (1984) multiprocess model of information transfer to form a framework to organize the work of others on topics such as professional knowledge, human behavior, and organizations. Taken together, these theories became the basis for an ideal, effective information system from which to determine elements of



real, effective information systems. In this way, Greer's model and the new model of an effective information system formed two ideal types used as utopian characterizations or optional descriptions for the purpose of edification.

### Procedure

Qualitative methods of inquiry are especially indicated when the intent is to generate hypothesis or "grounded theory" for subsequent quantitative research tests (Glaser & Strauss, 1967; LaRossa & Wolf, 1875). Utilizing the case study approach, a combination of semistructured interviews, questionnaire and observation was the source of data collection. These procedures were used in combination as Taylor and Bodgan (1984) suggested to strengthen interview and questionnaire data (secondhand accounts of the world) with the firsthand account of observing. The constant comparative text method (Glaser & Strauss, 1967) of data analysis was used to gain a "meaningful picture" (Glaser & Strauss, 1967, pp. 38-39) of the data. It should also be noted that the researcher in this study functioned as a primary instrument of investigation as Guba and Lincoln (1981) point out is essential to being immediately responsive to the context of the situation under investigation.

To locate effective systems in which to conduct research, a panel of three experts was asked to identify exemplary sites based on excellent practices of teachers, providers and parents with individuals with autism. The expert panel was comprised of three individuals: a university faculty member who has frequent and direct interactions with students and teachers in schools; a public school practitioner who is also a parent of a child with autism; and an autism education program consultant of the Kansas State Department of

Education, Student Support Services. Each member of the team was asked to identify a priority list of 5 - 10 potential sites in Kansas which exemplify satisfying needs of children with autism. A total of nine different sites was identified. The researcher reviewed all three expert lists and, with the approval of her dissertation committee, selected the two sites that were named first by all three experts. Both sites were public programs; one was funded by Social and Rehabilitation Services, and the other by the Department of Education.

After contacting the program director at both locations and ascertaining the director's initial interest in the study, the researcher met with the Human Subjects Committee at The University of Kansas, Department of Human Development and Family Living (HDFL), and obtained approval so that the study could be conducted within HDFL affiliated programs. The researcher then made arrangements with each program director to begin spending week days in observation of key people engaged in various roles with individuals with autism.

The first site observed, subsequently referred to as "site one," was a public school in one Kansas special education cooperative serving 12 school districts. At site one, children with and without disabilities attended programming in shared placements. Observations took place throughout two buildings, in three separate classrooms, a play ground, central offices, and on a home visit with providers.

The second site observed, subsequently referred to as "site two," was a not-for-profit, university affiliated agency that serves approximately 150 persons with severe developmental disabilities in two Kansas counties and employs nearly 400 interdisciplinary

staff. One function of the agency is to serve children/youth with autism beyond the school day in individualized, home-based programs. Observations took place in the agency's central offices, work center, and in homes.

Each location became a "bounded system" (Smith, 1978) from which data collection and analysis would be an ongoing process. Theoretical guidelines identified by Lincoln and Guba (1985) including "exhaustion of sources, saturation of categories, emergence of regularities, and over-extension" (p. 350) were used to determine when to stop the data collection processes of the investigation and when to begin data analysis. Given the nature of the disability and the necessity to deliver consistent forms of interaction within an individualized intervention process, each program was viewed as an "obvious instance in action" (MacDonald & Walker, 1977, p. 181).

The study began with observation. According to Kidder (1981), observation is a research tool when it "serves a formulated research purpose, is planned deliberately, is recorded systematically, and is subjected to checks and controls on validity and reliability (p. 264). An observation form pre-approved by the researcher's dissertation committee was comprised of two columns, one for "individual/group dynamics" and the other for "resources." As recommended by Taylor and Bogdan (1984), field notes included verbal descriptions of the setting, the people, and the activities; direct quotations or the substance of what people said; and the observer's comments placed in the margins or in the running narrative and identified by underlining, bracketing, or the initials "OC." In this way, the observer's data deliberately included the researcher's feelings, reactions, hunches, initial interpretations, and working hypothesis.

A semistructured (Merriam, 1988, p. 74) interview questionnaire (Appendix A) was used to gather firsthand insights into the respondents' information preferences, priorities and concerns, and to serve as a means of verifying what was otherwise contained in observation and interview data. Open-ended questions were organized around broad issues pertaining to the social, behavioral and managerial processes which comprise Greer's (1984) model of information transfer. Frequency and duration of topics were indicators of a topic's salience.

Interviews were conducted during non-observation times, at times and locations convenient to the participant. The researcher read each question and allowed the participant to talk until the participant stopped. The researcher listened to what was meaningful to the respondents and pursued issues in later interviews that were relevant to respondents in the first several interviews. This format allowed the researcher "to respond to the situation at hand, to the emerging world view of the respondent, and to new ideas on the topic" (Merriam, 1988, p. 74).

Potential interview participants were determined by the director and researcher on the basis of direct involvement in the information system. Each potential participant was asked by the researcher to complete one interview and one questionnaire. Each person asked to participate agreed to do so, and then read and signed an informed consent form (Appendix B).

The questionnaire (Appendix C), which was pre-approved by the researcher's committee, focused on the type of information and the frequency of information use. Participants were given the questionnaire at the time of the interview. Some completed

and handed back the questionnaire before leaving the interview session and others took the questionnaire home and returned it at a later date.

### Participants

Although children with autism were not considered participants in this study, they were central to determining the key people involved in the information system. An individual with autism was defined as a child or youth having a diagnosis of Autism Disorder, Asperger's Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified, all sub-categories of Pervasive Developmental Disorder described in the DSM-IV (American Psychiatric Association, 1994). Appendix D shows demographic information about children/youth with autism observed in this study.

The key people were identified by the program directors. After the first few days at each site, the researcher further questioned the program directors in order to apply a broad description of "key people" involved with the child and to verify that every key person was obvious to the researcher. A total of 18 key people were identified at both sites who were involved with 16 children ranging from 4 - 12 years of age. The term "participant" is used hereafter to refer to key people who participated by completing an interview and questionnaire. Appendix E shows demographic information about participants. Since the sociology of information processes used in this study emphasize disciplinary knowledge in the creation of knowledge, the disciplinary backgrounds of all the participants, including parents, are shown.

There were 7 teacher participants of three types: certified teacher, uncertified teacher, and paraeducator (support staff). The paraeducator had no higher education experience;

the uncertified teachers had earned graduate degrees in Human Development and Family Living at the University of Kansas, or were enrolled as master's students in that program. Certified teachers were graduates of various education programs and credentialed as teachers by the Kansas State Department of Education. Two master's level teachers (one certified teacher; and a non-certified teacher) served as local autism resource specialists.

All of the administrator-participants had earned graduate degrees and had more than 10 years experience in working directly with children with autism and other developmental disabilities before becoming program administrators. One administrator had been a public school classroom teacher and the other two had taught children, youth and adults with autism in center-based programs. Two of the three administrators were engaged in teaching graduate autism courses and frequent inservice sessions to providers. One administrator reported that she read many current publications related to autism, but her administrative responsibilities have limited her ability to personally share research findings or demonstrate current best practices. This administrator facilitated numerous opportunities for her personnel to attend classes, conferences and workshops and to bring experts to the local community. All administrators reported using knowledge about autism as a point of reference for offering excellent training and learning opportunities for children and youth with other special learning needs.

The two related service providers included a school psychologist and speech language pathologist. Both were local leaders in the area of autism. These providers distinguished their work with children with autism by organizing special interest groups, attending national, regional and local research conference, participating in workshops, and serving

as local experts to assist other related service providers and teachers throughout the districts served by the local special education cooperative. The speech-language pathologist teamed with a local teacher to teach an undergraduate college course.

The parents, 5 mothers and 1 father, were all biological parents of children with autism. These parents were actively involved in programming. All families were presently engaged in home programming or at one time had developed and implemented a home program with the assistance of autism consultants. These parents were viewed by others within the information center as equal participants in the process of helping the child/children with autism.

#### Data Collection

Over a period of approximately 5 months, the researcher collected 131 pages of hand-written observation notes recorded on an observation form (Appendix F), conducted 18 tape-recorded interviews including 4 telephone interviews ranging from approximately 20 minutes to 70 minutes with an average of about 42 minutes per interview, and obtained 18 completed questionnaires. The researcher agreed to keep the identity of students and adults, and the locations of the research confidential. Proper names were replaced with nouns or pronouns (e.g., child, agency, she, he, etc.). Since program information pertaining to an individual with autism is highly personalized to reflect various preferences, priorities and concerns of a certain individual with autism, the perspective of individuals with autism was considered to be embedded within those details shared by and

through the educators, parents and providers. No attempts were made during the investigation to involve or engage the individual with autism in the data collection process.

The researcher made every effort to observe activities without distracting the individuals with autism, their peers or their program participants. This was particularly challenging given the nature of the disability and the specialized structure of physical environments and tasks that are individually planned and used to increase student understanding and productivity. Even though challenged by significant deficits in communication and socialization skills, individuals with autism have the tendency to “gravitate” to people, especially those individuals perceived as being capable or willing to share their structure and communication system. Given the researcher’s skills with non-verbal people and the students’ limitations in ability to discriminate, the researcher took measures (e.g., avoiding eye contact; moving from one location to another depending on the activities of the children; remaining quiet) to observe every aspect of the day while at the same time avoiding direct interaction with the children. Adults in all environments were extremely cooperative in facilitating the inclusion of the researcher and preventing confusion for the children that might have otherwise been created by the researcher’s presence. At no time during the study was there any indication that the children with autism were distracted or concerned that the researcher had joined them in their environments.

Observation notes were generally recorded during the observation time. However, on several occasions such as during a home visit, writing during the observation would have prevented the researcher from being fully immersed in observation of the activities. In



such cases, the researcher made observation notes immediately following the event and before talking to anyone about the observation, a technique suggested by Bodgan (1972). The researcher also spent time during observation days reviewing notes and making additional notes about demographic information, programming, and re-occurring themes and sub-themes.

Due to the intensity of the observation phase of the study, the audio tapes were all transcribed after the observations were completed. Interviews were transcribed in a question-answer format. Once all the interviews were transcribed, member checks (Brotherson & Goldstein, 1992; Morgan, 1988, Turnbull & Ruff, 1997) were conducted to enhance the rigor of the interview mythology and content analysis. Member checks were conducted by mailing a copy of each transcribed interview to each respondent along with a participation form (Appendix G) to be completed by the respondent. The form indicated respondent's acceptance or rejection of the printed text of the interview, and a stamped, self-addressed envelop was included to use when returning the forms. Respondents were instructed to read the text, make changes if necessary, and return the transcript to the researcher. All 18 interviews were approved by respondents with only minor spelling changes and some minor editing of quotes in 5 interviews.

Once a decision was made to end simultaneous data collection and analysis, the information was organized into the case study data base and the case report (Yin, 1984). The case study data base contains tables of demographic information about individuals involved in the research and signed consent forms. The data record consists of two, three-ring notebooks of transcribed interview data and completed interview forms.

### Data Analysis

The interview data were analyzed during six separate stages:

1. The initial interview was conducted and tape recorded. The researcher carefully listened as participants responded to each question.
2. Audio tapes were transcribed in a question and answer format. By doing the transcriptions herself, the researcher listened a second time to all responses, and in some cases, a third or fourth replay of certain sections was heard.
3. Transcriptions of interviews were read by the researcher. Significant comments were highlighted.
4. Transcriptions were read a second time. The researcher cut transcriptions into pieces containing one question and the corresponding answer. Like numbered questions and answers were organized together in data record notebooks.
5. Transcriptions were read a third time, this time from the data record notebooks. The researcher wrote or cut and pasted significant, highlighted quotes on 5" x 8" note cards.
6. Note cards were read. Significant bits of information were typed into a digital data base.

As the notebooks were constructed, all pages were numbered. During stage three, site number, respondent role, question number and topic were written at the beginning of each numbered question. Identical identifying information and page number of notebook data entry were written on each note card. During each stage of analysis, categories, topologies and reoccurring themes and sub-themes became more evident. The most

salient themes were finally fleshed out by using a comparative text technique by Lincoln and Guba (1985) which involved reading short answers and determining look-alike or feel-alike content until all answers were sorted into the data base. Look-alike or feel-alike content was that content containing exact words or phrases or words and/or phrases with same implications.

The researcher read and re-read observation data throughout the five months involving data collection, and made additional notes highlighting key words, themes or topics of importance. The observation notes were used to verify the interview data. Throughout all six stages of interview data collection and analysis, the researcher used the observations notes to clarify responses and to answer the question “Did I see that this is so?”

Data were sorted by site throughout the data collection and analysis process until the final step of “teasing out” meaningful responses when the researcher found data from each site to be so similar that it became impossible to draw analytical distinctions between answers obtained at one site or the other. Therefore, by “constantly comparing one incident or unit of information with another (Lincoln and Guba, 1985, pp. 347-348) the elements of the actual, effective information system emerged from the data. Using the constant comparative method, the data gradually evolved into a core of emerging theory. The results are reported in Chapter 3.

### CHAPTER THREE RESULTS

An alternative to positivism, critical pragmatism was used as the epistemological framework for examining two information systems that were determined by an expert panel to be effective in enabling parents, educators and other providers to help children with autism. Immanent critique and ideal-type are two pragmatic methods of social analysis used in this study to determine the elements of the effective information system. Immanent critique was used to expose unquestioned assumptions about interventions, functions of key people, and local policy and management of information. Greer's (1984) model for the information sciences and the researcher's multicriterion definition of the effective information system became two separate ideal-types from which to compare and contrast the theoretical and real information systems.

The 18 participants in this study generated responses to 14 interview questions and 7 questionnaire items. These responses were used in combination with hand-written observation notes highlighting individual and group dynamics and available resources in 7 locations. Results from interviews, questionnaires and observations are discussed in the following three sections.

#### Effective Information Systems as Seen Through Participant Interviews

A structured interview comprised of 14 questions was designed to reveal underlying assumptions behind the (a) knowledge and applied practices of key people within the information system (social processes); (b) behavior of key people within the information system relevant to the information transfer process (behavioral processes); and (c) local

policy and organizational structure of key people within the information system (organizational-managerial processes). Questions were written to address the processes identified in Greer's (1984) model for the information sciences. Responses to interview questions were, however, overlapping in their potential to address issues related to social processes, behavioral processes, and management-organizational processes of information. Key people within the information system were identified by the researcher and the program director as those adults with the most direct involvement in programming. Key people were invited to become interview participants in the study. After orientation to the study and explanation of the interview process, interview participants were encouraged to use as much time as they needed to answer questions. The structured interview provided the most general responses to the research question "What are the elements of an effective information system that enables parents, professionals and other providers to help children with autism?"

Question 1: Circumstances. Respondents were asked to identify circumstances that led them to seeking information about autism. Responses revealed seven different circumstances which resulted in a need for specialized information: child not developing; student not progressing; educational experiences; needed a job; questions to be answered; wanted to help. Results of question 1 are shown on Table 1. Each respondent described the circumstance as an instance of great urgency, or as a pivotal point that changed her/his direction. Each respondent described the circumstance as an event that stood out as being different from anything she/he had earlier experienced. Information seeking was the first reaction of both family members and professionals.

Table 1

Circumstances That Lead To Seeking Information About Autism

Frequency	Circumstance	Description
6	Child not developing	Infant not progressing through developmental milestones
5	Student not progressing	School outcomes unacceptable
3	Educational experience	College course assignments increased student curiosity
2	Needed a job	Looking for work with pay
1	Questions to answer	Professional role required disability specific knowledge
1	Wanted to help	Improve professional practice to match human needs
<hr/>		
18	total respondents	

Questions 2: Decide and Question 3: Resources. An unexpected outcome of asking question 2, “Once you knew that you needed information about autism, how did you decide what to do?” was that all respondents, without hesitation, said that they began searching for information resources about autism. Responses clustered around 15 resource types in a variety of different formats of information including print, lecture, discussion and digital forms of information. Since talking about the use of information resources was particularly compelling for all respondents, the researcher continued with the structured interview protocol asking question 3 wherein respondents were asked to name all the resources that they have used to discover how to help individuals with autism. Consequently, respondents had two opportunities to name as many forms of information as they could recall. Responses from both question 2 and 3 produced a total of 15 types of information resources. Respondents (18) named from 2 - 5 different resources (average of 2.8 formats).

Table 2 indicates by participant groups the types of information used in problem solving. The type of information is listed using terms stated by the respondents. Telephone book, book store, college classes, university workshops and conferences described information types implied by each stated term. “Program” information was reported to be early childhood screening and home visits by program coordinators. “Conversations” were described as informal discussions with friends, another parent, colleague and/or experts. Respondents reported using both public and university libraries. In addition to professional journals, books and videos, publications by individuals with autism and/or their family members were identified as being very useful.

Table 2

Information Types Used in Initial Problem Solving

Information Type	N=6 Parent	N=7 Teacher	N=2 Service Provider	N=3 Administrator
Program	X			
Conversation	X	X	X	X
Telephone book	X			
Book store	X			
Library	X	X	X	
Professional literature	X	X	X	X
Other literature	X	X	X	
In-service training		X		
Observation		X	X	X
Networked		X	X	X
Trained with consultant-mentor		X	X	
College classes		X		
University workshops		X	X	X
Conferences	X	X	X	X
Learn as you go	X	X		X

Note. Parent group includes mother/father of children with autism. Teacher group includes the paraeducator, certified and uncertified teachers. Service provider group includes the speech-language pathologist and school psychologist. Administrator group includes program directors.



“In-service training” was described as sessions presented on autism to educators at school without students during the regular school year. “Observation” was of classrooms containing children with and without autism and teachers who had been trained to use autism interventions. Respondents described “networking” as taking place within the local community and around the state. “Learn as you go” information included personal experiences with children/youth with autism both with and without support of other knowledgeable persons. Respondents indicated that “learn as you go” information was the only means of determining what to do during certain periods of time even after autism-specific books and experts were discovered.

Parents, teachers, service providers and administrators reported that they had informal conversations, consulted professional literature and attended professional conferences. Parents, teachers and service providers said that reading publications written by parents of a child with autism or by individuals with autism was a valued resource. Teachers, service providers and administrators reported that the most beneficial resources were opportunities to observe other teachers and children with autism in actual school situations, to network with other professionals and to attend university sponsored workshops about methods of teaching individuals with autism. No parent reported observations, networking or attending university sponsored workshops as a known possibility for learning what to do. Administrators were the only group who did not report using either public or university libraries.

Question 4: Interventions. Interview participants were asked to name specific autism interventions used in local programming. Respondents were encouraged to identify all the

interventions that they knew were being used even when the exact name for the intervention was not known. When an intervention name could not be recalled, the respondent was asked to describe the activity taking place using words or phrases typically used during the intervention process. Educators (paraprofessionals, certified and uncertified teachers), related service providers (school psychologist and speech-language pathologist), administrators and parents were all very familiar with various autism interventions and were able to spontaneously describe strategies in general as well as interventions relevant to individualized programming. There were 113 statements in this topic area which clustered around 5 categories ranging in size from 9 to 48 items. Table 3 lists the definition of these categories, the total number of items in each category, and examples of each category.

Terms used by interview participants to describe interventions were easily grouped into categories identified by Skrtic (1991, p. 14) as a hierarchy of presuppositions including theories, assumptions, models, practices and tools. Each term, phrase, idea or concept used by respondents was located by the researcher in one of Skrtic's five categories.

Theories (15 items) were mentioned as a way of clarifying the intent of intervention. One administrator illustrated interventions by saying:

Our interventions are guided by Applied Behavior Analysis. . . that means that we are using behavioral principles to develop programs, measure progress, develop data collection systems to look at a baseline and then measure how we are doing. We are using the principles of operant conditioning: reinforcement, stimulus control. . .

Table 3

Interventions Used in Effective Information Systems For Individuals With Autism

<u>Category</u>	<u>Description</u>
Theories (15 items)	Results of quantitative or qualitative analysis (e.g., Applied Behavior Analysis; operant conditioning; Play-Based Assessment).
Assumptions (25 items)	Something taken for granted (e.g., same thing for each child; improvise; functional skills).
Models (9 items)	Set of plans for replication (e.g., TEACCH; PECS; Social Stories).
Practices (48 items)	Actual application; strategies, methods (e.g., one/one; IEP development; discrete trial training).
Tools (18 items)	An instrument or object used in performing a method or strategy (e.g., schedule, transition tool).

Note. Categories from Skrtic, T. M. (1991). Behind Special Education. Denver: Love Publishing, p. 14. Acronyms include Teaching and Education of Autistic and related Communication handicapped CHildren (TEACCH); Picture Exchange Communication System (PECS); and Individualized Education Plan (IEP).

Multiple theories were identified as contributing to individual programs. An emphasis on utilizing theories from more than one source was described by one administrator in her statement about best practices:

Our intervention overall is based on a philosophy of Applied Behavior Analysis. . We really look to best practices in the field of autism--what has been shown through research, the literature and through people who have been doing this across time, through case studies--what works. Many of those [best practices] we believe are in the field of behavior analysis, but some of them may be traditionally in another field but because of the literature, you can tell that they are effective and we adopt them. We are open to other ideas and maybe people who use different terminology than we would.

The second largest category of responses to interview question 4 included taken-for-granted statements or assumptions (25 items) about interventions. One paraeducator said “. . basically the same technique is used for each child. We just kind of have to improvise it sometimes maybe with each child since they are at different levels.” Respondents also mentioned their assumption that they were teaching children with autism “social skills” or “functional skills.” These assumptions were based on the respondent’s understanding of instruction of typically developing, same age, same culture individuals without autism.

A parent talked about her assumption that both her children with autism need sensory integration theory. Her assumption was based on her knowledge of sensory integration therapy and her own experiences with her children. She reported that:

my daughter still likes deep compression when she is out of sorts. Wrapping her up in a sleeping bag works the best. My son likes rough textures. I have made him a glued sand board where he can rub his hands over it. He can do it himself. . .My son gets sensory integration at least twice a day because he requires it.

When asked to name interventions used in local programs, models (9 items) were named including the TEACCH model (Teaching and Education of Autistic and related Communication handicapped CHildren); Picture Exchange Communication System (PECS) and Social Stories. Statements used by interview participants revealed that while parents and professionals had knowledge of certain methods and desired outcomes of certain models, stated models were not being followed in terms of attempting to replicate the use of instructional methods, materials or environmental arrangements, or evaluations procedures. Model names were mentioned as a way of identifying collections of practices and tools used in local intervention. A speech language pathologist included in a list of various terms “the TEACCH model with the visual strategies.” An uncertified teacher said “we use a lot of TEACCH using work systems, visual schedules, some transition tools.”

The largest category of responses about interventions being used were those identifying practices (48 items). Practices named by respondents could be grouped into teacher practices of two kinds: student adaptations and document accommodations. Student adaptations included re-writing existing curriculum, repackaging instructional materials, and/or creating new materials to match individual needs; instructional strategies such as one-to-one and hand-over-hand instruction; arranging task materials and the

physical environment to tell the child with autism what is expected. Document accommodations included writing individualized education plans, developing student notebooks containing detailed teaching procedures to be followed by everyone instructing the child, and completed and blank data collection sheets.

Parents and professionals talked about practices in same or similar terms of student-centered or teacher-centered activities. Parents and professionals also used same or similar descriptions of interactions with the child with autism. All participants expressed high satisfaction with their involvement in the on-going process of assessing immediate needs, developing and implementing instruction and evaluating the process in terms of student outcomes. No respondents revealed through their statements an anticipated end to this on-going process.

In describing local interventions, respondents mentioned tools (18 items) such as communication schedules; picture cards; tokens such as stickers, pennies, food; picture jigs in which a sequence of steps for a task is displayed on a card using a combination of line drawings, pictures, words and/or numbers. Respondents indicated that tools were an essential part of intervention. According to respondents, tools were determined for use in intervention on the basis of emerging skills of the child and goals and objectives of instruction for each individual child with autism. Emerging skills meant that skill which the child was almost able to do but would not be able to accomplish without some form of assistance. The tools were used to achieve the instructional goals written by parents and professionals in Individualized Education Plans (IEP). Goals for instruction were adapted from the curriculum of same age peers, assumptions of parents and professionals of the

child's need to function within her/his classroom and home, and the child's special interests revealed through the child's responses to experiences and choices encountered in her/his environment.

Question 5: Prior Interventions. Respondents were asked to describe interventions prior to accessing autism-specific information. Although this question was included in the original structured interview protocol, the question was not included in the first 6 interviews as the researcher initially questioned its usefulness. It was added as a means to investigate the researcher's later perception that respondents, when talking about interventions, were indicating that a change had occurred after obtaining autism specific information. Twelve respondents described the period of time prior to accessing autism specific information as occurring from 1-15 years earlier. By relating dissatisfaction with previous interventions, all respondents emphasized that interventions in local programming had improved since accessing autism specific information. For example, one certified teacher said, "We were flying by the seat of our pants. . . using anything and everything we could to basically survive." A parent said, "I just kind of fumbled around; doctors were afraid to get close to the diagnosis." The issue of past practices which included punishment was recalled by an administrator who stated the following:

Years ago that [punishment] would have been handled very differently. People questioned that we were somehow catering to the child and giving them special treatment, but it was really just trying to help the child see that being appropriate, not hitting, not kicking, being ready to learn by sitting quietly, having their hands

on their laps would get them more and something better than hitting, kicking, screaming, biting.

Responses to this question were clear indications that educators, related service providers and administrators had previously doubted their own understanding of autism and the effectiveness of their practices and policies with individuals with autism. Questioning to increase understanding of autism involved discussing theories, practices, methods and tools with other professionals and parents and engaging in conversations with local policy makers about obtaining further training, attending conferences, workshops and observing other programs, changing existing programs and creating new ones where there were none. Respondents' dissatisfaction with their own knowledge and practice and their openness in expressing their dissatisfaction with student progress and lack of outcomes was also emphasized earlier in responses to interview questions 1, 2, and 3.

Descriptions of radical environmental change was another clear indication of a transition from a state of uncertainty to a better understanding of how to help people with autism. This transition is expressed in a speech-language pathologist's statement, "It [intervention] looks different. We were in various sites and we were not doing the same things. We were in the searching mode. I didn't feel very successful."

Question 6: Locations. Items included comments by interview participants that were applicable to the various locations where interventions take place including in the community, at the child's home, and within school activities. Table 4 displays categories for the items (123) mentioned. The most frequently mentioned sites where interventions



Table 4

Intervention Locations In Effective Information Systems

<u>Category</u>	<u>Number of Items</u>
In the community	56
At home	25
School activities	34
Not specific	<u>8</u>
Total items	123

take place were those located in the community (56 items). Common places of importance for teaching children outside the classroom in the community were graphically described including grocery stores, the park, the library, church, and scout activities. This was illustrated in the comments of a certified, special education teacher:

Interventions . . . take place on the bus, classroom, church, summer movie program, swimming lessons, ballet, McDonalds, Field Trips, Dillons, library. We try to work with the parents and find out places that are important for them to go and we try to devise some strategies to help so that they can go there, too. We spend time in their homes to get a feel for what the parents need.

One program administrator further illustrated the importance and innovation of community instruction in her statement that interventions take place “in the natural environments for kids. I think that it is something this field has learned over time.” Considered to be significant in the school (34 items) was the issue of inclusive interventions that enable the child/youth with autism to function in various locations. One certified teacher said, “Intervention takes place in every location. Wherever the child is there is some intervention to get them there. Structure whatever they are doing if they need it, and then [intervention] to get them to the next place. Interventions are going on wherever they are.”

The issue of early intervention beginning at home (25 items) was pointed out in the statement of one program administrator:

You can't even begin to teach if a child can't momentarily join you. Sit down on the

floor, in a chair, bedroom, special room, kitchen, bath room, places where the child would normally be, outside in the backyard or near the house in the neighborhood.

A parent illustrated the importance of making interventions portable in her statement that interventions take place “everywhere and anywhere. I try to make as many interventions as I can as mobile as possible. Every opportunity to train my children into the needs that they have to do, I do whenever I have an opportunity.”

Question 7: Interactions and Question 8: Relationship. Each respondent was asked to (1) talk about her/his interactions with other key people; (2) draw a picture of her/his relationship to the other key people; and (3) describe what the drawing would look like if set into motion. Because four interviews were conducted over the telephone, four participants used words to “draw” a picture of their relationship to the other key people.

Thirteen actual drawings and four verbal “drawings” revealed circular-shaped organizational patterns. One actual drawing was in a mountain-shaped pattern. All eighteen illustrations of the relationships within the information system included the children, parents or family members, school and community educators. While four administrators and one school psychologist mentioned managerial responsibilities for others within the information system, no interview participant described or illustrated her/his relationship to other key people in a superior or subordinate relationship. An administrator described her responsibilities to the school organization by saying:

I don't see it [organizational structure] as a hierarchy. . . . I do have supervisory responsibilities. . . we are kind of intertwined and we overlap. The motion would

probably be going both ways because there is give and take. We are all in this together and the information goes both ways.

All interview participants described a close but flexible relationship to the other key people. One parent emphasized the importance of the child as a member of the information system in her statement that “He [child] would be in the middle of a circle. . .we would gently move him toward where we want him to be. . . like a parachute when everyone is around the parachute. . . all pull one way and it goes up.”

An uncertified teacher when drawing a picture with words first placed parents on the top of a pyramid, but without explanation changed her description of the configuration to an expanding circle with the parents and child in the center and teachers forming a wheel around the outside of the circle.

A parent in a telephone interview used her career responsibilities as a metaphor for her relationship with other key people within the effective information system. She described her role in the information system saying:

I see myself as a project manager. . . like in a business model. . . I am a computer programmer. I don't really train these people [teachers] on what to do. I facilitate the training, the information and the administration that it takes to keep them going. The motion would be back and forth. I give them information in the beginning and now that they are doing a lot more, they are giving a lot of it back to me.”

Examples of the circular organizational patterns described as existing within real, effective information systems are presented in Figures 1 - 4. Drawings by interview participants communicated the importance of the child-family in combination with two

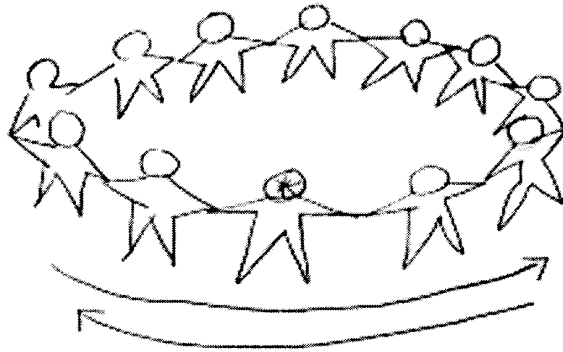


Figure 1. Drawing by a speech-language pathologist. Respondent's relationship to the other key people in the information system is as a connected partner. All the key people are connected, all at the same level. The motion moves the group one direction and then back then at times, back the other direction.

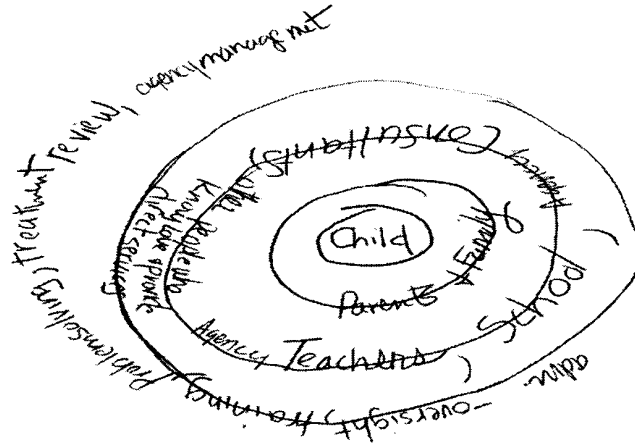


Figure 2. Drawing by an administrator. Respondent's relationship between the other key people in the information system is in the form of stacking, expandable circles. The child is located in the center circle and everyone else is encircling the child and pushing the child as the foremost and most important. The momentum of the outside circles push the child's circle to the top of the stack.

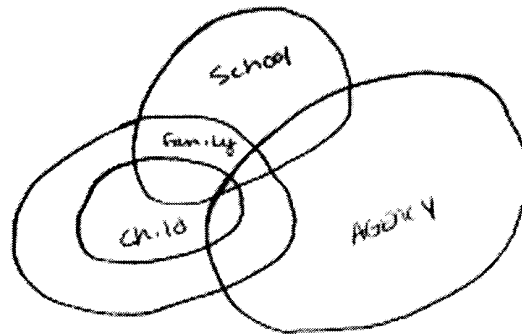
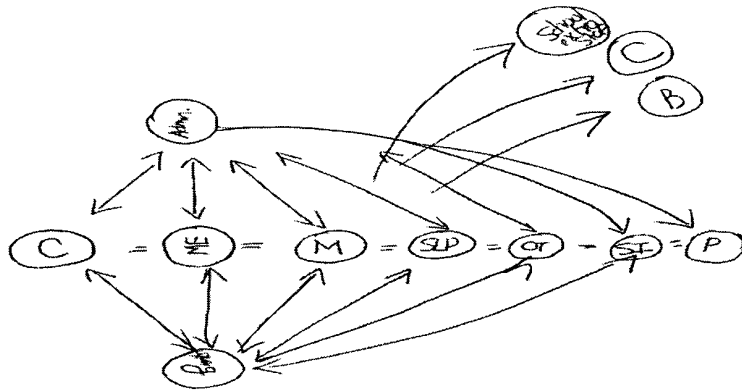


Figure 3. Drawing by a parent. Respondent's relationship to other key people in the information system is a strong relationship between the child and team, and among the team, the principal, and the parents.



**Figure 4.** Drawing by a certified teacher. Respondent's relationship to other key people in the information system. The information system is characterized as a two way, curved street with information flowing both ways between parents and educators. The circles contain codes for individual participants: C=child; ME = the certified teacher drawing the figure; M = District Autism Consultant; SLP = Speech Language Pathologist; OT = Occupational Therapist; SI = School Psychologist ; P = paraeducator; Adm. = Administration; Parent = parents of the child with autism; School Extra Staff = lunchroom help, custodians; B = bus driver.



separate agencies: the school and social and rehabilitation services. Key people within the effective information system are in direct contact with each other having frequent conversations about life-critical issues related to helping children with autism. Life-critical issues included matters pertaining to the child's eating and nutrition; exercise and rest; safety and protection; shelter and clothing; medication, prescribed glasses and/or hearing aide; and physical and mental growth and development. All key people, including parents, are expected and encouraged to agree and disagree in the process of creating individualized instruction and supports. The term "instruction" is used to indicate methods of intervention leading to educational outcomes, and "support" is used to indicate the care given a child with autism when not otherwise involved in interventions. The pleasant relationship key people share within the effective information system was described by one paraeducator as "friendship."

Question 9: Policy. Respondents were asked to talk about local policies that affect children with autism. Responses related to five policy categories: special education law; Social and Rehabilitation Services (SRS) funding; inclusion; public library policy; and school building policy. One respondent reported no policy knowledge. Four participants were not asked about policy because responses to earlier questions indicated that policy issues were unknown. Two respondents reported that there are no policies that affect their work with students with autism. Three reported more than one policy: one respondent mentioned three policies; and two respondents mentioned two each. Table 5 displays responses indicating type of policy mentioned by site and type of participant.

While discussing local policy, an administrator indicated some ambiguity in

Table 5

Local Policies That Effect Students With Autism

Number	Policy Type
5	Social and Rehabilitation Services funding
4	special education law
4	inclusion
1	school building
1	library
2	no policies
<u>1</u>	no knowledge of policies
18 total items	

administrative understanding of how to comply with federal and state education law. She affirmed the school's determination to do the best for children in her statement that "our policy is to follow the law as set out in IDEA (Individuals With Disabilities Education Act). Our philosophy is that whatever it takes to help a child succeed, we're going to try our darndest to do that."

Concern for having adequate funding to provide sufficiently intense services was indicated in an uncertified teacher's statement that "Home and Community Based Service (HCBS) waiver has a big impact because that effects hours of direct care with a child. All parents expressed concern that their child's behavior might at sometime prevent her/him from participation in desired activities. One parent expressed her concern by pointing out that "library policy has not been met with success. . . . the behavioral policy [at a school that her son would likely attend in the future] is kind of 'a three strikes, you're out' form of policy."

Question 10: Ultimate decisions. Fourteen interview participants were asked who makes the ultimate educational decision about children with autism. Table 6 shows answers cluster around three categories of people responsible for making decisions about children/youth with autism: the team (8 items); the parents (4 items), and school personnel (2 items). The category "school personnel" differs from the "team" in that "team" is used to refer to small group of school or agency officials operating together with parents as opposed to only one school employee. While all respondents talked throughout the interview about decisions about children with autism being made on an individualized basis, when asked "who makes ultimate decisions" some responses indicated disagreement

Table 6

Persons Who Make Educational Decisions About Children With Autism

Type of Participant	Source of Ultimate Decisions	Number
teacher (6)	team	4
	parents	1
	school personnel	1
parents (5)	team	1
	parents	3
	School personnel	1
administrator (2)	team	2
related service provider (1)	team	1
		—
		14 total responses

Note. Team = a small group including parents who know and care about the child.

Parents = Mother and/or Father of child with autism. School personnel = School

employees other than and/or in addition to team members.

among participants within each site about who the actual, ultimate decision makers are. It is important to point out that each person who replied “the team” was including parents. However, when “school personnel” were indicated as those making ultimate decisions, parents were not included. A paraeducator said “the teacher, the autism consultant, the principal I’m assuming is involved. . . minute to minute that is the classroom teacher and the paraeducator who is working with the student.”

When parents answered “parents,” the parent indicated that she/he was acting alone. When asked “who makes the ultimate decision,” all except one parent replied “that would be me.” The remaining parent expressed concern that some decisions would be beyond her control at an anticipated, future location in her statement that “I’m afraid that [decision maker] is going to be the teachers who don’t want those kids in their classrooms.” A teacher at the agency emphasized parent decision making in her statement “it is ultimately the parents’ decision what programming they choose to use for their child or what intervention they use in particular. . . we are really a resource.”

Question 11: Mission. The researcher determined not to ask the question about the mission of the school or agency in five interviews on the basis of limitations in respondents’ knowledge related to organizational-managerial issues. While no respondent was able to recite their organization’s entire mission statement, 12 of 13 interview participants tried to state the mission statement on the basis of their knowledge of the actual mission statement and their perception of the mission statement based on experiences within the organization.

All responses (13/13) in this topic area emphasized customizing the program to match the needs of individuals with autism within the context of the child's family. One administrator said, "It [the mission] has everything to do with the child. The mission is to service primarily children with autism, to provide interventions that are best practices. Our mission includes to train people in effective intervention techniques and best practices." A certified teacher said,

The mission of the school is basically to be a service to children and their families and to enable or empower our families to be a vital part of the community in which they live. That fits into exactly what we do with the children with autism and with all the kids here.

A parent articulated the mission of her/his agency:

. . . to our family has been to enable us to provide for [our daughter] the best programming that we can; to help us to understand [our daughter] and her behaviors; who [our daughter] is and what her world looks like, and providing her keys that will help her enjoy life. They [the agency] are fulfilling their mission.

Question 12: Attributes and Question 14: Working. Answers to interview questions about attributes necessary for working with individuals with autism were again restated in responses to the final interview question, "Is there anything else that you would like to say about working with children with autism?" Respondents mentioned 96 items in 11 categories related to attributes. Category descriptions are shown in Table 7.

Answers emphasized that adults who work with children/youth with autism have extraordinary strengths in the areas of knowledge about autism, typical development

Table 7

Attributes Necessary For Working With Individuals With Autism

<u>Items</u>	<u>Description</u>
Affective characteristics (44 items)	Love, patience, caring, tolerance
Rapport with children (13 items)	Compatibility; understanding
Training (11 items)	Performance of teaching techniques and measurement
Background knowledge (10 items)	Of autism; normal language development
Continual learning (7 items)	Unlimited willingness to gain new information; willingness to make mistakes
Experience (5 items)	Time spent with people with autism
Professionalism (2 items)	Confidentiality; recognizing boundaries
Creativity (3 items)	Making original adaptations
<hr/>	
96 total items	

including language development, training in teaching practices, relating to others and acceptance of individual differences. It should be noted that all 18 interview participants included in the discussion of attributes the importance of training in autism interventions and/or the importance of having background knowledge of autism. Three respondents included both issues related to having training and having knowledge of autism.

The speech-language pathologist described the work with people with autism as being “multicultural” in her statement that “ it is like going to another country. The language, the clothing, the food, the environment that they [the child/youth with autism] live in might be different. You have to be accepting of people from different cultures.” A parent described necessary, extraordinary attributes in her statements:

It is not just a ‘today’ problem; it is a ‘forever’ problem. You have to minimize the problem and to enhance their [the child’s] potential. It requires patience, advocacy, a lot of innate love and patience. A background in autism and to know when not having a good day, it is not because the child with autism is trying to make life difficult.

An administrator mentioned extraordinary attributes of people who work with individuals with autism in her statement:

It is a blending of someone who can connect, who can build a relationship with a family and a child without going over the line of being too personally involved, and utilizing their skills and knowledge in teaching techniques embedded in Applied Behavior Analysis to be an effective teacher.

Question 13: Ideal program. Respondents were asked to describe an “ideal program” to support children with autism. One parent and one teacher at site two (agency), and one



teacher at site one (school) indicated that she/he was involved with an “ideal program to support children with autism.” Other respondents said that ideal programs would include typically developing children, quality teachers, access to autism specific information, a combination of school and agency services and supports, and adequate funding.

The need for an ideal program to include typically developing children was indicated in a teacher’s reply that “a school with 75% typically developed kids and the rest with autism” would be ideal. “The goal would be to instruct children with autism,” she said. One director emphasized the need for quality teachers in her statement that the program would include “teachers who are just the best you could find who are continually learning.” One parent described the ideal system in terms of access to information. She said that she would want the ideal program to include “books about autism, about Part H, information about organizations in the local area, names of other parents who have been successful in the different systems and are coping with autism.” Another parent indicated the need for both school and agency support in her reply, “It would look like what we have right now. It is just perfect because we have the asset of school and we have seen incredible progress since HCBS [Home and Community Based Service] funding. The agency is vital.” The issue of available funding in an ideal program situation was also indicated in an administrator’s reply that it would be ideal to have “people to make materials at the teachers’ beckoned call. . . . money to get to training and to bring people in. . . . facilities, spacious learning environment.” Another administrator said that an ideal program would “be flexible and able to fit a different child’s needs; begin as early as possible through working with people who are educating and identifying

children at a young age.”

Question 14: Closure. At the close of the interview, respondents were asked if there was anything else that they would like to say. Two respondents said they had nothing more to say. In addition to re-emphasizing attributes necessary to teach and support individuals with autism and characteristics of ideal systems, respondents said that they wished that there could be more done to help individuals with autism, their parents, educators and providers. One parent emphasized this point by recalling her earlier desperate need to know what to do:

I think that in my earlier years as a mother of a child with autism, I felt so strongly the need for information that I would get irritated at other parents who did not seek information. I can remember the early years when I had no one, I was so tired that just to sit down and read a book on autism or to get the regulations out and start reading the legalistic terminology, I would just fall asleep. I persevered, I tried really hard. . .even when I was tired.

A veteran teacher used the “is there anything else” question to emphasize her own satisfaction in teaching children with autism. She said, “It has been the neatest experience. I am fifty. I thought I had seen it all, done it all. It [teaching children with autism] has given me a boost. . . stimulated by creativity again, given me a whole new look on what I wanted to do.”

The need for early information and increased awareness of what autism is and what to do about it was emphasized in final comments by parents, teachers, related service providers and administrators. One parent illustrated the negative impact of lack of public

awareness as she described the difficulties of dealing with people everywhere who are without knowledge about autism and who nevertheless have suggestions and ideas about “what you should do with your child and how you should treat children with autism.”

#### Effective Information Systems As Seen Through Questionnaire Data

A questionnaire comprised of seven questions was used to gather information from eighteen participants about present information resource availability and preferences. Frequency data from questionnaires were calculated using the Statistical Package for the Social Sciences (SPSS). The information revealed by the questionnaire was relevant to the respondents’ current situation in contrast to earlier interview questions wherein respondents were asked to comment on their initial need to know how to help individuals with autism.

All participants reported having and using published resources. The frequency of using published information resources and people resources each school year is shown in Table 8. Time frames for indicating frequency of use of resources was determined on the basis of universally occurring divisions of time for school-aged children and youth and their families, educators and providers. The data reveal that nearly half (44.4%) of the people completing questionnaires use published information resources about autism 3 - 5 times each 9 week period, and more than half (61.1%) indicated that they use people resources weekly. Two participants indicated “other” terms of publication use. One participant wrote “it is not a regularly scheduled activity but used as needed when a problem arrives. Another participant wrote “usage depends on when working with a

Table 8

Frequency of Information Use In Effective Information Systems

Type of Source	weekly	3-5 times/ nine weeks	3-5 times/ semester	3-5 times/ school year	other
published	27.8	44.4	5.6	11.1	11.1
people	61.1	27.8	11.1		

student with autism.” Published resources on autism include professional journals, handbooks and text books, conference and assessment manuals, videos, and on-line articles. People resources on autism included professionals and others within the information system, university faculty, physicians, parents and family members of individuals with autism, and individuals with autism.

Participants were asked to rank sources of information about autism from 1 (being most valued) to 7 (being least valued). These results based on the experiences of the eighteen people completing questionnaires and of those sources presented on the question indicate the most valued sources of information are journals, university faculty, classroom teacher/program specialists, parents, and personal experiences. Classroom teachers/program specialists received the most number 1 rankings. Television and Internet, and medical professionals received the greatest number of 7 rankings with medical professionals being the least preferred information source.

Participants were asked to name their single most valued source of authority about autism. This question served as a point of reference from which to compare interview responses. Answers to this question were consistent with the participants’ earlier answers with the following sources reappearing: university faculty (2/18), books/journals (3/18), special statewide projects (3/18), administrators (2/18), agency (1/18), parent (1/18), teachers/related service providers (3/18), children with autism (1/18), and no response (1/18). One participant illustrated her preference for research to be the source of authority in her statement “the empirical data from research studies primarily in the field of Applied Behavior Analysis.” All participants reported that they are better able to problem solve

when referring to information resources about autism. Individual format preferences are shown in Table 9. Most participants (14/18) indicated that a combination of formats is preferred. Discussion (3/18) and demonstration (3/18) were also included in format preferences. One participant wrote that “classroom participation” was preferred, and another participant identified “observation” as a preferred format.

Participants were asked for the most important aspect of teaching and supporting a child with autism. Responses (18 items) included people, collaboration, and team work (7 items); emotional responsiveness (3 items); state of the art knowledge on teaching strategies and behavioral principles and techniques, and consistent programming/environment (4 items); providing child with autism communication system, and more self-sufficient behaviors (3 items); and environmental structure (1 item). When asked if these aspects exist in participants’ current situation, 100% of the participants answered “yes.”

#### Effective Information Systems As Seen Through Observation Data

Observation data were collected in a narrative form about individual and group dynamics and resources. The researcher recorded activities of key participants as they were both directly and indirectly involved with children with autism. At site one, observation took place inside and outside of two separate school buildings, in a district office and in one student’s home. Activities included planning, direct instruction and other formal or informal interactions with parents and children. Formal interactions were those

Table 9

Information Format Preferences in Effective Information Systems

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Format	Yes	No
Print	1	17
Lecture	1	17
Discussion	3	15
Digital/electronic	0	18
Demonstration	3	15
Combination	14	4

---

during session time and informal interactions were times before and after session time. At site two, observation took place inside and outside of the agency office, and in homes of children with autism. Observed activities included office practices in the agency headquarters and reception area; client work in supported workshop; instruction of students, and team meetings involving child, parent, school and agency personnel.

Individual and group dynamics. In the observation category related to individual/group dynamics (413 items), an emergent theme was that key people within the information system perform formal and informal functions. Dual functions provided by practitioners to families and children with developmental disabilities were determined by Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell, and Siegel-Causey (1990) to be "formal (i.e., knowledge, capable, and professional) and informal (i.e., emotionally responsive)" (p. 95). By adding a category for management issues, the researcher was able to locate each observation entry about individual or group dynamics in one of five categories including: knowledge, capable, professional, management, emotionally responsive. Table 10 shows categories and category descriptions of the activities of key people within effective information systems. There was a strong uniformity between the answers provided by participants during structured interviews and what was observed by the researcher and recorded in the observation note on the topic of functions of key people within the information system.

The category labeled "capable" was the largest in this topic area (180 items). Consistently, questions during the interviews related to behavior processes of the psychology of information emphasized awareness of practices applied by educators and



family members with children with autism. The student-centered activities and teacher-centered activities articulated in interviews were found repeatedly in observation notes. A student-centered practice by a teacher was described in an observation note stating that “the teacher creates visually clear materials so task materials will tell the student what to do.” A document-accommodation kind of teacher-centered practice was illustrated in the observation note that the “teacher studied a pre-recorded session on video tape to learn exact instructional strategy of the previous teacher for calendar activities with students.”

Except for several statements by administrators about theories of learning associated with interventions and studies describing the effectiveness of Applied Behavior Analysis in improving the behavior of children with autism, interview participants tended to make few, if any, conversational connections between theories of learning and their practices with children with autism. The second smallest category in formal functions, knowledge (51 items), contained observation notes that revealed extensive synthesis of theories related to interventions. Awareness of a research-based understanding of autism was illustrated in the note “uncertified teacher knows that there is potential for improvement and progress ” and “teacher believes in discrete trial training but feels she has to know when to quit, when it works or not, and then to continue skills but within many different activities.” Knowledge-based activities by key people were indicated in the notations: “The teacher and speech-language pathologist teach a communication development and disorders class for a local junior college,” and “Administrators have written a teacher curriculum and are currently doing a pilot study with five teachers.

Table 10

Activities of Key People Within Effective Information Systems

<u>Category</u>	<u>Category Description</u>
Capable (180 items)	Teacher behavior with children/youth; awareness of practice
Management issues (87 items)	Planning, implementation of activities related to doing the work, fill the gaps
Emotionally responsive (80 items)	Emotions (e.g., friendship building, caring, sadness, frustration, empathy)
Knowledge (51 items)	Scholarly awareness of autism, child development, curriculum
Professional (15 items)	Leadership, mannerisms with other adults
<hr/>	
413 total items	

Note. Categories adapted from Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell, & Siegel-Causey (1990). Examining the Individualized Family System process: What are family and practitioner preferences? Topics in Early Childhood Special Education, 10(1), 78-99.

These administrators teach a 3 credit hour graduate course at the university each semester.”

There were strong indications in both interviews and observation notes that participants consider placing task materials in a certain configuration and arranging the physical environment based on individual student needs to use the space as critical to increasing productivity of students with autism. Notation in the observation notes describing individual tasks and work areas in homes and classrooms illustrate the importance of task and environmental structures for both high and low functioning students with autism. High functioning students were those who had good spoken language and were readers. Low functioning students were those with little or no spoken language, those with little if any ability to read words, and those who could not be left for even short periods of time.

While the category “professional” (15 items) had the fewest items related to formal functions of key participants, management (87 items) had the second highest number of items. This reflects a strong tendency among key people to create organizational operations that reflect a certain high sensitivity to human needs and to being accountable for actions with children and with adults within the system. A teacher’s leadership role was reflected in a notation stating “uncertified teacher has a vision of where she is going with her student.” Another notation reveals the researcher’s awareness of the teachers’ image: “Teacher is casually but professionally dressed; paraeducators are more casually dressed.”

The management of children and planning time was meticulously balanced. Notations describing management included:

“Teacher and paraeducator arrive early to discuss how things went yesterday and to talk about special features of today; organized instructional materials.”

“Almost no talking among adults during instruction. Each instructor engages directly with students in one-to-one instruction.”

“During preparation today paraeducators looked at the student’s daily lesson plans located in student notebook and asked the teacher about the instruction that would take place today. The paraeducators know a great deal about the details. The paraeducators’ questions of the teacher are about specific aspects of how to use specific instructional formats.”

Emotional sensitivity was strongly indicated in the category “emotionally responsive” (80). In Summer et al. (1990) it was noted that professional teams tend to separate the dual functions of formal and informal support systems by viewing emotionalism and professionalism as incongruent. Throughout the current study, the researcher noted indications that professionals were emotionally involved with students and student families. For example, an entry states that “There is a genuine sense of gentleness and accommodation here. It never lets up. When a student has a hard time, the gentleness and accommodation increases. Voice tone may become stern to intervene in a risk situation. That is the only time.”

Comeraderie among teachers and a parent was observed within effective information systems. Comeraderie was indicated in the observation entry that “A group of educators

is going to an international research conference this summer. A mom will be traveling and attending along with the teachers.”

Resources. On all 131 pages of observation notes, resources (552 items) were noted. Resource types cluster around three categories: high tech (157 items), low tech (322), and people (73). Table 11 shows categories and category definitions of resources available within effective information systems. It is important to note that within the observed effective information systems both low and high functioning students with autism used some combination of low and high tech resources and people resources. Some low functioning children who were not able to use a pencil were able to use a computer keyboard to engage in cause and effect activities. Others who were challenged to play a simple game of “toss the ball” with a group of 3-4 children were able to independently use a sophisticated software program to play a mathematics game. Through organized, structured intervention students were enabled to develop a combination of basic and technical skills. Students with autism were not required to achieve mastery of lower level skills before moving on to higher level skills. Uneven patterns of learning were expected and accepted.

### Key Themes

Given the exploratory nature of this study, it is necessary to avoid drawing conclusions from these results. However, some key themes emerge that are central to the data collected at both exemplar sites and are therefore worth pointing out. Key themes are summarized here and are discussed in terms of findings in Chapter 4.

Table 11

Resources Available Within Real Information Systems

<u>Category</u>	<u>Definition</u>
high tech (157 items)	published journals and books, computers, software, adaptive equipment, commercial developmental play things; teachers cars
low tech (322)	teacher-made teaching materials; multi-purpose items (e. g., baskets, tooth brushes, bottles, paper; tape, etc.)
people (73)	Siblings, parents, grandparents, teachers, related service providers, administrators

Participants' initial encounters with autism caused them to experience pivotal points in their lives. The problems associated with a child's inability to speak and/or to effectively communicate threatened the mental, physical and financial well-being of the children with autism as well as that of others within their environment. Information seeking was the first reaction of family members and professionals.

Although medical professionals were expected to have answers, educators and veteran parents of children with autism helped to interpret and to apply research-based publications to specific situations. While educators and parents reported initially using "learn-as-you-go" problem solving, educators found the most useful information in professional literature, observations of classrooms, university courses and workshops, research conferences, networking and consultation with others knowledgeable about autism. Despite in-depth searches, parents' access to autism specific information was obscure in comparison to that of educators.

To help children with autism, face-to-face, experiential information that was shared in discussion and demonstration was used in combination with theory-based, peer-reviewed publications. "People" sources of autism information were used weekly, more than twice as often as published resources. "People" in this case were those who had professional knowledge about autism and who knew and cared the most about the children.

Children with autism were helped through interventions that took place at school, at home and in other locations throughout their communities--in parks, grocery stores, libraries, churches and traveling in a bus or car. Structured interventions matched to the child's developmental levels and emotional abilities, that emphasized functional

communication, social and problem-solving skills and promoted protected independence were made available year-round except during holidays and other periodic breaks. Structured interventions included skill training during one-to-one discrete trials and during training in generalized settings.

Children with autism were helped by key people within the information system, including teachers, administrators, related-service providers (e.g., speech-language pathologist, school psychologist) and parents. Key people with professional roles functioned to share information with children with autism, with their family members and with other people within the child's environments.

Professionals engaged in student-centered activities and in teacher-centered practices. Student centered activities were those that included adapting and repackaging information for children. Teacher-centered practices were those that increased the teachers' knowledge of research, their understanding of individual children, and that served to disseminate autism specific information in the public.

Attributes including empathy, capability, knowledge and professionalism, interactions and relationships between parents and professionals, management styles, organizational structures and funding all functioned to minimize constraints that otherwise may have restricted the participation of children with autism within their homes, schools and communities. People with autism were considered to be culturally unique rather than "abnormal." Individually tailored programs that utilized low and high tech resources, and people resources served to maximize skills and to increase outcomes for people with autism. Autism intervention was accepted as a permanent life-style change rather than as



a temporary, therapeutic procedure to be completed.

## CHAPTER 4 DISCUSSION

From a review of the literature related to Greer's (1984) model for the information sciences, five theoretical elements of an effective information system were constructed for use as Weber (1904/1949) suggested to expose divergences between ideal and real cases and as Rorty (1989) suggested for edification. The results contained in Chapter 3 reveal elements that can be clearly located within the theoretical, multicriterion definition of an effective information system contained in Chapter 1 and, as such, suggest strong commonalities between the theoretical and the actual, effective information systems investigated in this study. These commonalities can be used to guide the practices of parents and professionals in providing a "technology of positive behavioral support" (Horner, Dunlap, Koegel, Carr, Sailor, Anderson, Albin, & O'Neill (1990, p. 127) to people with autism. Following a discussion of the limitations of this study, elements contained in the results will be named and discussed, exposing divergences between the theoretical, ideal type constructed from the literature and that of the studied sites. Implications of this study for future research and practice will follow.

### Limitations

Limitations of this study include (a) the tendency to make generalizations based on participant comments or frequencies reported, (b) regional partisanism and (c) possible researcher bias. It was not the purpose of this study to make sweeping statements about information systems or the perspectives of participants. Rather, the primary purposes were to attempt to better understand the elements of effective information systems that

enable parents, educators and service providers to help people with autism and to build new theory relevant to the fields of education and information studies. Although this researcher sought the assistance of an expert panel to select two exemplar sites for study, these sites may be located geographically too close, and therefore, uncharacteristic of information systems serving individuals with autism around the world. The selected sites may also reflect expert panel bias and unfairly characterize exemplar sites based on other informed points of view. Further, although a total of 18 tape recorded interviews, 18 questionnaires and 131 pages of field notes were analyzed, important elements may not have emerged or relationships between items may remain unclear. Given the qualitative and exploratory nature of this study, it is important to only view listing of frequently occurring items in Tables 1 - 11 as descriptive of participant experiences or perceptions regarding their local information system. Although the data were gathered using three separate investigation tools, member checks completed by each participant, and analysis of data reviewed and approved by the researcher's committee of three faculty members, it is possible that researcher bias could have mediated the identification of elements.

### Findings

The purpose of this study was to identify elements of effective information systems that enable parents, educators and providers to help individuals with autism and to extend knowledge of those elements to create new theory about effective information systems. Responses from interviews, questionnaires and observations contained 1299 distinct and meaningful items of information that formed 65 total categories (response types) and six unique elements of effective information systems. It should be noted that some overlap

exists among themes in questions asked of participants and participant responses and that mutual exclusivity was not a determining criterion for establishing themes. Instead, this research sought to “identify salient, grounded categories of meaning held by participants in the setting” (Marshall & Rossman, 1995, p. 114). Since this study is primarily a qualitative study with frequency data the only quantifying feature of the results, the findings are in the form of preliminary conclusions rather than empirically verified inferences. The remainder of this chapter is organized around the research question and sub-questions posed in Chapter 1.

#### Research Question 1: Elements of an Effective Information System

Six major elements that emerged from the analysis of results of the two, effective information systems investigated in this study were people and published resources, multiple formats of information, informational and experiential content of resources, multidisciplinary problem solving, shared environments, and extended family v. professional model of interactions. Figure 5 shows the elements found in this study in two categories: Human Elements and Environmental Elements. Separate elements are discussed in each of the following six sections.

People and published resources. The need for positive and practical information that will fill voids in understanding how to help children with autism to organize and make sense of their world emerged as a principle theme. All participants at both sites had

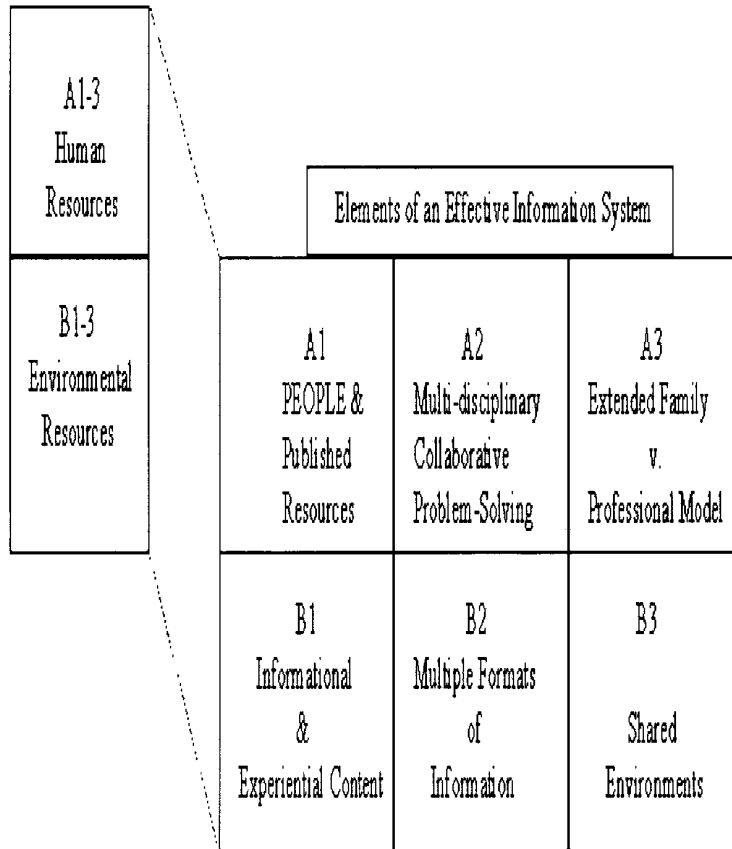


Figure 5. The elements of effective information systems.

comments about how difficult life was without an explanation for the child's challenging behavior. Parents recalled the constant fatigue and frustration that they endured while caring for a behaviorally-challenged child while attempting to locate and read books, or to locate and to talk to someone about how to help their challenged child. Teachers, administrators and service providers mentioned disruptions they experienced when attempting to keep behaviorally-challenged children at school without fully understanding the children or having meaningful activities for the children to be engaged in while attending school. The professionals also described the internal tension they had personally endured knowing that they were not adequately teaching or supporting students that appeared to have such common differences as deficits in language and communication, motor planning and social skills.

All participant groups at both sites expressed the need for access to easy-to-read publications about (a) neurobiological and medical interventions, (b) non-aversive instructional and support strategies, and (c) the lives of people with autism who are now living in communities. In addition, all participant groups expressed an extreme desire to have access to other people who "get it," and further, to the importance of having access to autism-resource specialists. Participants commented that while it is nice to have easy-to-read publications, publications must be supplemented with human resources. Participants wanted to be able to interact with someone who could "stand in their shoes." They indicated that survival depends on having knowledgeable people to talk to about individual manifestations of the disability.

All responses indicated access to an autism resource specialist was key to their current successes. In both studied locations, an autism resource specialist was highly accessible not only to teachers, administrators and service providers, but also to parents. At both sites, while the autism-resource specialist was observed directly teaching and supporting children, her primary responsibility was to organize and maintain other professionals in their full-time roles of teaching and supporting children. Although no one implied that the resource specialist had all the answers, the autism-resource specialists were available to address any and all issues related to the person with autism, to suggest adaptations to materials and/or alternative strategies, and to help information seekers to network with other people. While others' professional assignments remained constant over time, the autism resource specialist moved throughout the region over successive years of programming. In this way, children were never forced to start over with new professionals who were unfamiliar with the established, individualized communication systems.

Multiple formats of information. All participant groups indicated that a combination of formats of information was needed to assist them in helping individuals with autism. Of the 18 participants responding, 14 participants indicated that a combination of print, lecture, discussion, demonstration, and digital/electronic information was preferred. At both sites, a small yet complete, current autism collection comprised of books, journals, audio and video tapes was available to loan to seekers regardless of their role. The special collection was located in centralized location where materials were shared with seekers regardless of the seeker's role with a child. The policy for borrowing materials was

flexible, allowing users to exercise prudence in taking, keeping and returning materials. In addition, lectures, demonstrations and discussions were frequently offered. In many instances, parents reported attending sessions wherein topics of interest to professionals were presented. All participant groups described the benefit of information-sharing sessions organized by local professionals, which included social opportunities and information-sharing sessions such as Individualized Education Plan (IEP) meetings conducted in parents' homes. Members of all participant groups described face-to-face information sharing as a valued, positive, non-threatening learning experience.

According to all participants, having multiple formats of information available made it easier to "get through" the details. Some participants commented that printed journal or book articles were too difficult to read and understand. Participants indicated that using various formats of information made it possible to cover "heavy" details, sometimes more than once, without becoming overwhelmed by the complexity and sensitivity of the content.

Informational and experiential content. While participants wanted information containing research-based explanations for what autism is and what it is not, they were adamant about a need for handbooks or training manuals that provide step-by-step instructions on what to do and awareness publications. Participants wanted some experiential information to contain details on long-term issues such as how to teach and support youth and adults in vocational training, higher education or employment situations, and other experiential information to contain short-term details about what to do in particular situations such as during lunch time or during recess.



At both locations, autism-resource specialists had repackaged informational and experiential information for the benefit of all individuals with autism in their program and for their team members. The repackaged information was organized in three-ring notebooks that were easily accessible to those involved with the child. Those children/youth who were able to read and talk also utilized their own notebooks. Each individual notebook expanded published research about the disability in general to include details about the child in need of services. The notebook also contained and communicated details such as the child's strengths, current preferences and priorities, and behavioral and instructional plans. Of great importance to the parents and educators were charts revealing a combination of numerical and narrative data about the child's participation in certain tasks and activities. Details related to the necessary organization of physical space(s) where the child was expected to function either independently or semi-independently were also contained in the notebook. Members of all participant groups wrote in the notebook comments on established routines as they occurred.

It should also be noted that all participant groups were in strong support of the distribution of awareness information. Parents felt that their struggles were minimized when members of the public were accurately informed about their children's challenging behaviors. Administrators, teachers and service providers felt that securing of funds and building space were easier when interacting with program directors and policy makers who understand what it means to have autism. Moreover, all participant groups felt that people with autism and their family members were more likely to be valued by people who know about the neurological impairments experienced by people with autism.

Multidisciplinary-collaborative problem solving. In a deconstruction of the philosophical and political critiques of the professions, Skrtic (1991) identified eight disciplines of modern social knowledge: philosophy, inquiry, history, political science, sociology, economics, organization and psychology. Skrtic further asserted that for better or worse, given a conceptualization of knowledge as interpretation--a distinctively human process in which no single paradigmatic or disciplinary interpretation ever has enough cognitive authority to privilege it over another--choosing an interpretation becomes a political and moral act with implications for social justice (e. g., Derrida, 1972/1982; Feyerabend, 1975; Foucault, 1980).

A review of the participant demographics which included “role” information in addition to that of participants with children/youth with autism, it appeared that many, if not most, of the eight disciplines identified by Skrtic (1991) were represented. While the key people comprising the participant groups had been socialized into their own different academic discipline, the practices of parents and professionals reflected an attitude of mutual respect and trust, and this attitude seemed to exist without domination of one key person or participant group over another. It was as though all key people brought their intellectual knowledge to the discussion of life-critical issues to be used as “fuel” to guarantee positive outcomes for the individual with autism. The key people within the information system shared determination similar to that of people standing on a ship’s deck and throwing a life-line to a person about to drown. Questions that remain unanswered concerning problem-solving within effective information systems include “Do

people within a single discipline produce this level of problem solving?” and “Can effective information systems exist without the ‘fuel’ of academic knowledge?”

Shared environments. A high level of “openness” was central to the activities of key people within the effective information systems. As a part of developing strategies, configuring space, establishing patterns of interactions with children, parents entered classrooms to share and gather information from professionals, and professionals entered homes to share and gather information. On days when activities were scheduled at the school building, all parents and other family members or support providers accompanied the child into the classroom, talked with those in charge and observed the environment where things would take place. During this time, key people exchanged information about what had taken place since yesterday including activities, eating and sleeping or lack thereof; plans for session time and related activities; and/or how specific pieces of information would be used with the child. As a result of information exchanges on several different days, plans for how sessions would be conducted were altered or even changed to alternative plans. At the close the session, key people again shared details about what had transpired during session time.

During home sessions, all key people moved freely around the home environments involving the child. On one occasion, a home meeting including session time with the child was scheduled to begin when parents were able to be home from work. In this situation, the teacher interacted with the child until other members of the team including the child’s mom arrived. On other occasions, teachers accompanied children to community environments such as the library, grocery store, park, and swimming pool.

All participants commented on their improved understanding of the child and what works to improve communication, socialization and problem solving from observing the child. Sharing environments through *actual presence* was like having access to cognitive input from a sixth sense. The shared environment of sight, hearing, smelling, taste, and touch informed key participants and increased their capacity to overcome challenges and to create positive situations that otherwise could not exist for the people with or without autism. In all situations participants were encouraged by administrators to share settings with each other and with families, to build close relationships, to increase parental involvement, and to learn and use collaboration skills that would enlist overwhelmed and over stressed parents.

Extended family v. professional model of interactions. In regard to interactions between parents and professionals, the researcher found that while the professionals at both sites had access to current, research-based explanations of how to help individuals with autism, professionals seemed to avoid using their knowledge or credentials to be prescriptive with parents and others such as grandparents who were directly involved in decision making for the child. Instead, professionals used their knowledge of the disability and professional practices to offer help in a manner similar to that of an extended family member taking into account factors in the individuals and their families, schools and neighborhood. The help offered by professional participants within the studied sites required empathy and sensitivity to what the child and family were experiencing and an active commitment to improving the situation. The extended family model of services observed in this study is in sharp contrast to the model of professional services described

by Flexner, (1910), Greer (1984), and Skrtic (1991) as ordinarily used by educators and other social scientists, which was based on the physician's function to investigate, diagnose, and prescribe to the individual.

#### Sub-Question 1-A: Parameters of an Effective Information System

Identifying "parameters" in this study is affected by the researcher's choice of methodology. If using quantitative methods, results would likely have determined the "parameters" of an effective information system in terms of numerical meets and bounds stated in exact measurements such as those contained in a property abstract. Numerical meets and bounds would have marked the exact boundaries of the information system, making it possible to locate and to duplicate the effective information system in other locations if using those exact dimensions. That was not the case in this study.

Using qualitative methodology to locate the dimensions of an effective information system, the researcher was guided by the participants' conceptualization of their information system and the participants' explanations of how and why the social interventions they engage in helped to achieve certain, desired outcomes. Findings suggest that parameters of an effective information system are recognizable by two, co-existing components: a common purpose and theoretical discourse.

A common purpose. Key people within the effective information systems shared a common purpose: to control risk factors in children with autism and related developmental disorders that occur at an early age and are indicated in later outcomes of isolation, idle time, and frustration. This common purpose was a driving force that brought people together and propelled them forward. Although both sites operated within large public

systems, they were able to exist despite limited, traditional funding, accountability, governance and public perception. The question remains whether effective information systems of this kind that change lives and communities can be replicated in other locations.

Theoretical discourse. Within the effective information systems studied in this research, this researcher found continual movement between construction and deconstruction of practice. Participants designed teacher-made materials with specific interactions between teacher and student in mind. Instructional interventions were not considered to be therapeutic. Instruction, instead, focused on the context of the child's life. Once instructional materials were tried, participants began to talk about the design's completeness and/or incompleteness and contradictions. Participants' knowledge from peer-reviewed journals and texts about children with autism and interventions to help them gain communication, social and problem-solving skills was accepted or rejected on the basis of utility rather than whether knowledge about the disability and applied practices was true in a foundational sense. Further, each child's program utilized systematic instructional practices that incorporated the principles of data collection, prompt hierarchies, reinforcement procedures, and were provided in an intensive manner with many opportunities for generalization.

The theoretical discourse, or talk, among participants in this study revealed that their thinking about interventions for children with autism was located within both the functionalist and interpretivist paradigm of social science thought. In the role of instructor and/or provider, participants were concerned as are functionalists at a micro-level with how children with autism would fit into society and with documenting the extent and type

of disability and techniques and practices for “dealing with,” managing, and providing for them. Individualized Education Plans with goals and objectives and documentation of repetitious trials with students reflected participants’ desire for empirical support for their work. Statements by participants revealed the functionalist assumptions that educators and providers work in a benevolent and humanitarian manner for the good of children with autism. However interpretivist tendencies were reflected when conflicts between children with autism and others were explained. Challenging behaviors were seen as a consequence of the child’s neurology rather than as some form of deviance exhibited in the process of making choices when presented with a range of possibilities. This shift suggests that the narrow set of assumptions about disability and special education identified by Bogdan and Kugelmass (1984) are in fact widening to include a broader view of disability, education and what constitutes progress in the field.

Even while acting as functionalists, the interpretivist view of interventions was revealed in the participants’ spontaneous presentation of stories, as well as in communication and social skills curriculum, intervention strategies and evaluation. Participants explained the autistic individual’s deficits in communication, socialization and problem solving skills by relating stories and using metaphors to describe what the disability is like. Participants talked about the experience of the disability, rather than the nature of the disability, and devised instruction from the point of view of the child rather than basing instruction entirely on the “normals” of society. Through adequate conditions for telling and listening, the speaker and a listener became implicit collaborators in giving meaning to that which was told.

The tendency of functionalists to dislike the particularity of stories and to prefer controlling variables seemed to give way to the benefits realized in learning about individual manifestations of the disability from stories of how the child responded in certain situations. Teachers and parents made a practice of listening to each other and of asking open-ended questions leading to personalized versions of the intervention picture. Watching and listening to teachers and parents ask questions about their students, their work, and their professional growth revealed that much was known about how to help children with autism. By using theory, curriculum, instruction, assessment and research from more than one paradigm of social science thought, those operating within the observed information systems were able to reconcile the field's practices and discourses with the ethical ideal of serving the best educational and political interests of their students. Forming work groups comprised of all those who know and care about students with autism allowed participants to collectively express their need to be permitted to act, to create their own interpretation of change toward better practices that would lead the participants to satisfying actions and students to improved lifestyles.

While participants in this study did indicate movement away from the functionalist paradigm to include interpretivist methodology, there was no indication that participants in this society are engaged in humanist thinking or practices. Humanists believe that ideologies create a disjuncture between appearance and reality. For the humanist, ideologies are value schemata that emphasize the differences among people and allow injustices to be perpetrated self-righteously. Participants in this study did talk openly about believing that children with autism deserved services furnished by public schools and



agencies, and some commented that they worried that despite the strength of their local program that children with autism might not be receiving what they need or deserved.

Even though their comments indicated that participants were aware of a mismatch between need and services, participants did not engage in immanent critique of the government, did not compare the legal rights of children with disabilities with practice, nor at the individual level, compare their own standards or claims of conduct in Weber's sense with their own actions. There was no indication of the structuralist concern for the relationship of special education to other parts of the educational system and to other institutions or to the economy. For example, participants did not talk about what kind of preparation should be offered to a large social group such as all people with developmental disabilities who are likely to be partially or permanently unemployed and from a traditional industrial society perspective, not economically profitable to society. This lack of discussion suggests that key people within effective information systems are truly focused on individuals from a single perspective in the context of their own environments and not the needs of all people with disabilities within society.

#### Sub-Question 1-B: Functions of Participants Within Effective Information Systems

Observation notes revealed that key people within the two studied sites operated within five categories of individual and group dynamics: capable (teacher behavior with children, awareness of practice); management (planning, implementation of activities related to doing the work, filling the gaps); emotionally responsive (friendship building, caring, sadness, frustration, empathy); knowledge (scholarly awareness of autism, child development, curriculum); and professional (leadership, mannerisms with other adults).

With the addition of the “management” category, the remaining four categories are the same categories found by Summers et al. (1990) to be important to families and early intervention practitioners. The data in this study exposes the dynamic nature of the work with children with autism and serves to emphasize four functions of participants, which explains what is done within effective information systems to make the situation unique: (a) needs assessment, (b) systems design, (c) direct services, and (d) evaluation. Figure 6 illustrates the energy generated as a result of the functions of participants within parameters maintained by a common purpose and theoretical discourse.

Needs assessment. Central to the effectiveness of the system was the professionals’ abilities to devise interventions that matched the needs of the children and to develop responsiveness to match the individual needs, preferences, and cognitive styles of parents or other family members directly involved with the child. This two-part responsibility creates for the professional a dual function--as teacher and as information professional--that in a sense, simultaneously occurs as the professional interacts with the child and her/his family members.

The professional literature in library and information studies identifies the interdependency of the professional/client relationship that exists when attempting to satisfy information needs (Grover & Carabell, 1995). While it was once the practice of librarians to “give out” the “right” information, it is currently considered best practice of information professionals to facilitate learning and to change constructs through a diagnostic process used for examining individual problems from the client’s perspective.

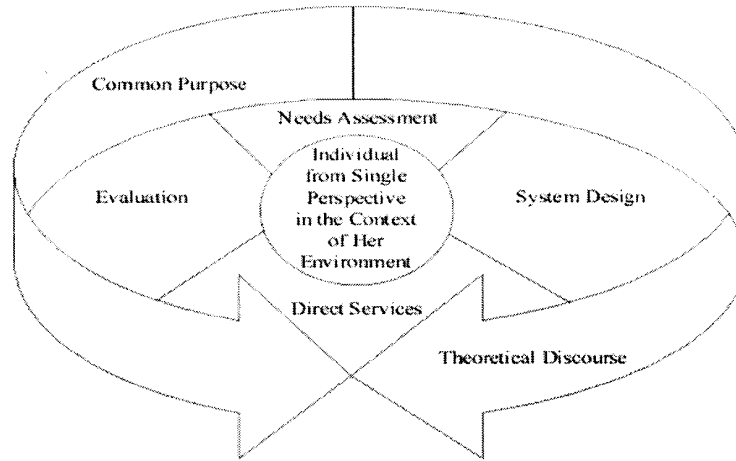


Figure 6. Functions of key people within effective information systems. At the center of the system is the individual in need of information. The boundaries of the system include the outside limits of the common person and theoretical discourse shared in the process of conducting needs assessment, systems design, direct services and evaluation.

The diagnostic process is “knowledge-based, continually evaluated, holistic and combines theory, skill and intuition” (p. 4).

Within the two effective information systems investigated in this study, administrators and autism-resource specialists began with a careful diagnosis of needs, both of the child and of the child’s primary care givers, while taking on a partnership role with the information seeker in order to arrive at a best match as perceived by the seeker of information. By taking on a partnership role with the seekers of information, who were in this case the parents, the professional was better able to accurately assess the needs and to sustain their role as a vital link in the information organization’s infrastructure.

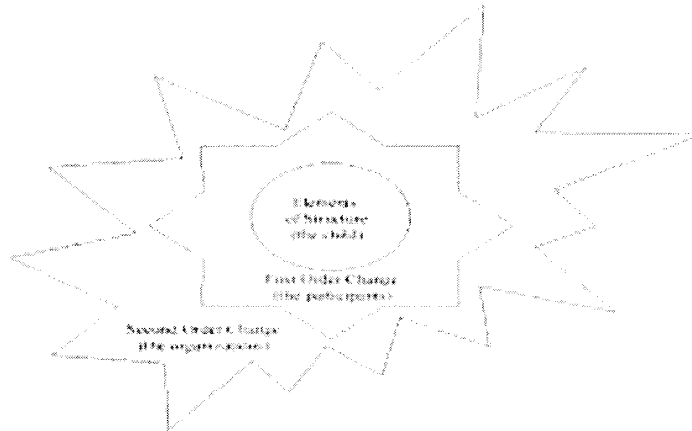
As the partnership evolved, the information seeker was offered numerous opportunities to answer “neutral questions” (Derwin & Dewdney, 1986, p. 509) that enabled the professional to assess the situation, the gaps in understanding, and the uses of information. According to Derwin and Dewdney (1986), “the neutral questions are open in form and structured in content terms that invite the user to talk about specific elements-situations, gaps, uses” (p. 509). The professional used neutral questioning as a systematic means of gathering information while avoiding the tendency to make premature judgments about the seeker’s needs based on the professional’s experiences, biases, or history with the information seeker. For example, a mom was asked, “If you could have exactly the help you want, what would it be?” Also the partnership that evolved enabled the professional to assess the environment or “culture” in which the child and family operated to better understand the manifestations of the disability in the context of the child’s setting and the family’s habits. Given the on-going, complex nature of the

disability and consequently the on-going nature of the needs assessment, the diagnostic process was periodically evaluated to determine the accuracy of the understanding of the information seeker's needs. The professional commonly asked the parent, "How are we doing?"

Systems design. The two sites selected for investigation in this study were considered to be exemplary programs where participants with various roles reported approval of how things were going for children with autism. In both locations, participants were, in contrast to replicating a model, perhaps unknowingly creating a new model of an effective information system in the process of serving the people with autism. Figure 7 shows the kaleidoscopic model of effective information systems participants appeared to create.

The studied information systems began and ended with elements of structure, those bits of behavioral sequences that characterized the child's day-to-day functioning. Evaluation of those elements changed according to the context of the evaluation. First order changes occurred through increments of adaptation and mastery made by participants within the information system. Second order changes occurred when the agencies and organizations adapted to the participants' changes, resulting in transformation of status and meaning within the system and the evolution of new elements of structure. Concepts intrinsic to this information systems model are interrelationships, interdependencies, and interlocking chains of being. These are concepts that can operate without hierarchy and without ascending and descending levels of power and value.

This model of an effective information system is similar to Terkelsen's (1980) family systems model except that in this case, the information system is comprised of participants



**Figure 7.** Kaleidoscopic model of an effective information system. The system begins with the structure of the individual. The illustration depicts the first order change in the shape of the system as the participants master skills and adapt the environment to match the needs of the individual, and the second order change in the shape of the system that results as various agencies and organizations absorb the first order changes.

in addition to, and other than, family members. In this information systems model, first order changes to accommodate the child with autism are made by administrators, educators, and related-service providers from more than one organization, and parents. Changes that occur within each individual and participant group effect second order changes that will in turn reverberate in the whole system producing a kaleidoscopic rearrangement of parts.

While both sites were a part of a larger organization, both could be viewed at the time of the investigation as being on the “fringes” of their larger organization. Despite the juxtaposition of the studied information system to the larger organization, the studied information systems were nevertheless valued and respected by policy makers within their respective organizations. This raises the questions of whether or not other people with and without disabilities could have benefited from the effective information systems serving children with autism, and if so, why weren’t they? This model of effective information systems may be useful in other human service situations. The success will hinge on the participants’ abilities to first share a common purpose, to engage in theoretical discourse, and to make the six elements of effective information systems become reality.

Direct services. As has been described in other sections of this paper, all participants (even those participants with managerial responsibilities) in the studied information systems during the course of a day engaged in direct services to children and their families. The critical elements of direct services were early intervention, parent training, education, communication skills training, social and leisure skills training, and vocational preparation.

Intervention focused on improving the adaptive functioning of the individual with autism while modifying the environment to accommodate the unique characteristics associated with autism. Educators and related-service providers were knowledgeable of and skilled in using a variety of best practice strategies that have been researched and/or reviewed in professional journals and, according to peer-reviewed publications, hold the most promise for helping children with autism. No single intervention was viewed as the only means for helping children with autism. Since the intervention process was viewed as multidimensional and rejected a singular orientation to treatment, ambiguity and frustration that otherwise might have interfered with progress was replaced with a sense of satisfaction that every non-aversive intervention appropriate to the individual needs of a given child was being exhausted. Tension created around issues of intensity and duration of treatment were replaced with the satisfaction that the entire, on-going program addressed the child's autism first and foremost through the provisions of direct services to the child.

Evaluation. Goals and objectives for instruction were written for each child with the intent to promote active engagement in instruction and to apply the skills that were learned in other locations. The purpose of evaluation was to determine whether or not predetermined outcomes were the result of instruction. Data were collected to form a "picture" contained in charts and tables of the children's performance and on which to base instructional and interventional decisions. The details of daily instruction contained in notebooks informed the participants with the child with autism in much the same way that up-to-the-minute notes kept by a medical staff inform medical professionals as to the



physical condition of a patient in a critical care unit of a hospital. The written evaluation process was particularly helpful given the limited language and communication skills of the children that prevented a child from answering questions such as “How did it go yesterday?” or “Which parts of this are too difficult or seem uninteresting to you?”

Just as evaluation functioned to ensure desirable child outcomes, so did evaluation function to ensure desirable instructor outcomes with children and families. At site two, a curriculum had been developed for new teachers which included specific competencies, or outcomes to be achieved. The curriculum outlined in lesson plan format included new information to cover and apply, and skills to accomplish when teaming with parents and other professionals, assessing needs and deciding what to teach children, instructing children, and when evaluating procedures. At site one, although evaluation was not tied to a specific training curriculum, evaluation was conducted in the form of regularly scheduled team meetings. In both situations, evaluation was the tool for determining whether to continue or to change intervention procedures. Changes in intervention procedures resulted in some further adaptation or accommodation within the environment that brought the child closer to “an equilibrium of interaction” (Piaget, 1980, p. 8) with their environment. In this way, the child never realized harmful effects from the environment, and the system was maintained through acts of assimilation and accommodation.

#### Sub-Question 1-C: Organizational-Managerial Style of Effective Information System

Circular formation propelling variable motion. As earlier described in findings from interview question 7 (Interactions) and interview question 8 (Relationships), 17 of 18

participants described their relationship with others within the information system in a circular shape that, when set in motion, moved around in various directions depending on the feed-back and feed-forward momentum of the group. In listening to the participants and in watching their interactions with each other, it was clear that the participants were not preoccupied with rules and regulations, nor were they tied to a centralized bureaucracy or hierarchical chain of command as one might expect to find in a public school or social service agency developed during the industrial era. One administrator commented on “intertwined” and “overlapping” responsibilities. The operations of the system were described as existing through “give and take,” close relationships. This suggests that the organizational structure of the investigated systems ignored traditional pyramid-shaped organizational structures and were attempting to create alternative forms of mutual adjustment.

Relationship-based services. John Dewey eloquently described democratic participation as “face-to-face relationships by means of direct give and take” (Dewey, 1927/1988, p. 371). If democracy is about equal participation by all in the dialogical discourse of humankind, as Dewey believed, then education is the means by which humans are prepared to enter the conversation (Dewey, 1899/1976, 1916/1980, 1927/1988, 1929-30/1988.) While Dewey was once described as “the first philosopher who tried to read democracy into the ultimate nature of things and social reform into the meaning of knowledge” (Feuer, 1959, p. 568), his exact image of “equality” is not known. It is questionable whether Dewey imagined humans in “face-to-face relationships” about how children should spend time in publicly-funded programming.

But there is much in the data confirming the existence of “face-to-face relationships” in a Deweyian sense among participants in effective information systems. The functions of participants within the studied systems, one a school and one a mental health agency, can be described as a democratic process in which professionals shared decision-making power with those who consumed their services. Parents and their children with autism were positioned as consumers with educators and providers as professionals. Actions of giving and taking among participants were similar whether in or outside school programming.

The data analysis showed that professionals with various educational backgrounds (e.g., special education, regular education, Human Development and Family Living, speech-language pathology) were able to engage in face-to-face relationships with each other resulting in acceptable interventions to children with autism. This raises the question of whether or not it is necessary for educators of children with autism to be credentialed as special education teachers to instruct children in schools. Perhaps the autism/Pervasive Developmental Disorder specialization is more important than the teacher certification. Of greatest importance to all participants in this study was having easy access to “people” knowledgeable about autism, as well as access to course work, workshops, conferences, and publications about autism and autism interventions. All degreed participants indicated that their autism-specific information was obtained over and above undergraduate program requirements. The challenge for educational institutions is to build multidisciplinary undergraduate and graduate degree plans that will prepare professionals to utilize theory from more than one discipline and to engage in relationship-based

services.

Skill in relationship development with children and adults, the ability to constructively give and take criticism, and the ability to cope with ambiguity and uncertainty were central to an effective information system. In some cases, people with autism were considered to be culturally different from their educators, providers and parents. Autism culture created an opportunity for the balance of society to interact with another sub-culture within society. Professional-consumer dialogue made interaction between people with and without autism possible.

#### Implications for Research and Practice

The results of this study reveal a number of implications that have the potential to positively effect the way we go about helping people with autism as well as to positively effect the people who seek to help individuals with autism make sense of their world. The following implications are intended to reflect the multidisciplinary orientation of this study, and consequently, professionals with a variety of disciplinary backgrounds. It seems most certainly reasonable to first “speak out” about implications this study has for people with autism, and in so doing, to set the tone for applying the indicated implications of this study for future research and practice.

A new research agenda. As the observation and interview data shows, life with autism is an example of profound information needs within our current society. The complex nature of autism creates for the individual effected first-hand, and those around them, frustration and ambiguity that has the potential to disrupt every aspect of human existence in much the same way that critical, chronic illness impacts lives. Even without the

presence of aggression, self-injury, mental retardation and other characteristics described by Turnbull and Ruef (1997) as “problem behavior” (p. 213), people who experience the spectrum of impairment described by Wing (1988) are likely to have a very difficult time assimilating the social nuances of industrial society such as motivation to learn and work, and to earn money to use in exchange for necessities, luxuries and person or professional influence in society. It is easy to imagine that in Lovaas’ earliest effort to “construct a person” (Chance, 1974, p. 76), that he was attempting to stop human behaviors that were in fact more dreaded and intolerable than the treatments he recommended.

Focusing on information needs of this extreme nature, which bring together people with and without autism, creates opportunities for educators and information professionals to formulate a clearer vision of how to articulate meaningful research questions and to design studies that will inform practices that have the potential to improve learning opportunities in general. It is hoped that this study will stimulate the curiosity of motivated and learned researchers, regardless of their disciplinary background, to continue to build on the grounded theory presented here about effective information systems and to gather data that further describes the functions of key people within those systems.

Revised certification and credentialing of professionals. Information that disseminates the most current knowledge from neuroscience and medicine, and behavioral and social sciences addressing education, family perspectives and person-centered practices were clearly the “keys” for participants in this study to be able to intervene and to sustain positive outcomes. Despite the complexities of the neurological condition of autism,

through a collection of interventions such as those identified by Heflin and Simpson (1998), children with autism in this study were able to live at home with their families, to attend school and to become contributing members of their society through direct, frequent interactions with peers, teachers, relatives and other members of their community. Central to the successes of the participants in this study were the abilities of parents, educators and other related service providers to share a common understanding of the disability and a common purpose that resulted in active individual and agency partnerships. What is not known is how to overcome the barriers that are created by education and social service policies and funding that separate children and families from the “people” resources that were strongly indicated as essential to the on-going process. Moreover, more information about curriculum that will prepare and qualify professionals from a variety of disciplinary backgrounds and interests to use scholarly knowledge in combination with relationship-based practices with children, youth and adults with autism and other related developmental disabilities.

Interdisciplinary training and research. The literature of library and information studies offers convincing evidence that information seeking is an intellectual process. Concentrating on cognitive aspects, Belkin, Brooks, and Oddy (1982) described the constructive process of information seeking in terms of the ASK (Anomalous State of Knowledge) hypothesis. An information search begins with the user’s problem. The gap between the user’s knowledge about the problem and what the user needs to know to solve the problem is the information need. Data from Kuhlthau’s (1993) year-long study of information needs of 25 academic students revealed five levels of intervention relevant

to reference services and instructional services. Kuhlthau's research redefined the role of the reference librarian as Organizer, Locator, Identifier, Advisor, and Counselor. The role of those involved in instruction was redefined as Organizer, Lecturer, Instructor, Tutor, and Counselor. According to the Kuhlthau model, at the lowest level (Organizer) and at the highest level (Counselor), the services of reference/mediation and instruction/education merge into one. Kuhlthau's findings and the data from this research indicate a clear need to perceive the information professional and educator as equally important to individuals with autism and other related developmental disabilities.

Participants in the current study provided many details indicating a need for the effective information system to be highly sensitive to individualized needs of information seekers and for participants with children with autism and their families to be organizers, lecturers, instructors, tutors, and counselors. However, there was seemingly no connection between best practices (those presented in peer-reviewed publications) of information professionals and best practices of educators and related service providers or school and agency administrators. The obvious question raised by this apparent gap between professional knowledge and practice was, "Why wasn't there any mention of best information practices?"

Kuhlthau's levels of intervention can be used in disability research and the training of teachers, administrators and other providers to improve their vision of what is actually needed to change the environment to better serve people who experience uncertainty like that experienced by students with such diverse learning needs as autism. Kuhlthau's levels of intervention could also be used to more clearly determine what is meant by a

“technology” of positive behavioral support.

Utilizing a theoretical multicriterion description of an effective information system.

When investigating the two actual effective information systems, it became clear from listening to and watching the participants that they were not aware of the unique aspects of the “system” in which they operated. Therefore, participants were only able to describe and explain their actions at the level of the child. The theoretical multicriterion description of an effective information system formed from Greer’s (1984) model for the discipline of information science and articulated in Chapter 1, can be used:

1. as a framework to structure discussions that will facilitate selection of a mutually agreeable process for making treatment and intervention decisions.
2. as an ideal-type from which to explore the social-political-cultural context of disability as an alternative to placing the cause of deviance within the child.
3. by participants in this study, as well as others similarly situated, as an “edifying philosophy” (Rorty, 1979, p. 389) or optional description of what they think and do. In using this optional description, the participants within the system will be forced to ignore traditional, futile questions by substituting new, potentially more interesting questions.

Conclusions

The contributions of this research study are at least three fold. First, the research contributes through the convergence of participant activities and perspectives to an understanding of what it means to “help people with autism.” This information can be used to help better understand what to do when confronted with the disability. Second, the research contributes to the literature on information transfer (Greer, 1984) by



formulating new, grounded theory about effective information systems from which to guide the practices of educators and information professionals. Third, the results relating to individuals with autism and effective information systems brings knowledge together from multiple disciplines and contributes new patterns of language (e.g., first person language), special vocabulary (e.g., challenging behavior v. abnormal behavior; repackaging information v. remediating subject matter; special population v. people with disabilities); significant people (e.g., parents, educators, information resource specialists), and uniquely important locations (homes, schools, resource centers).

While analyzing the perspectives of people with autism indirectly revealed within their Individualized Education Plans, their parents, administrators, teachers and related service providers, it was easy to become overwhelmed by the intensity, frequency and duration of many manifestations of the neurological disability of autism and to lose sight of the elements of the effective information system. It may be that the complexities of living and working with people with autism have interfered with conducting earlier studies of this kind. The study may stimulate and inform future investigations about what to do and what not to do to gain insights into special populations and their information needs.

It became clear in reading the data collected that participants had a good understanding of what they must do to repackage important details, to develop teaching and supporting strategies, and to reconstruct the environment of the individual with autism. They were not “bogged down” by the concept of “abnormal.” Clearly the participants within the studied systems were not operating under the assumption that people with autism were “abnormal” or that the practices of parents and professionals with

people with autism were “abnormal” as was suggested by Bogdan and Kugelmass (1984) and was contained in a summary of unconscious assumptions behind special education knowledge and practice. This acceptance of people with autism as another culture to be respected is perhaps one of the most important findings in the study.

The participants at both exemplar sites agreed that having and sharing autism-specific information was critical to the survival of individuals with autism and their family members and professionals and to other members of the support community. If having and sharing autism information within a system that uses creative collaboration to develop a circle of support and full participation of all members in making life-critical decisions is what is desirable, then the voices involved must be better understood by school and social service administrators, policy makers, teachers, information professionals, and parents. The challenge for the field of information studies is, as Greer (1984, 1987) suggested, to lead (rather than to follow and accommodate) in the development of effective information systems to better serve the needs of society.

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Appendix A

Interview Questions

1. Tell me about the circumstances that lead you to seeking information about autism.
2. How did you decide what to do?
3. Tell me about the formats of information.
4. What specific interventions are included in the student's program?
5. How do interventions look now compared to initial interventions?
6. Where does intervention take place?
7. Describe the interactions of the key people responsible for direct intervention?
8. Draw a picture of what you think your relationship is to the other key people? If the picture was set into motion, how would the picture look?
9. Tell me about local policies that effect your work with students with autism.
10. Who makes educational decisions about students with autism in your building? Who makes educational decisions about students with autism in your district?
11. Tell me about the mission, goals and objectives of your school. What do they have to do with your work with students with autism?
12. From your experiences, what attributes do you feel are necessary to being able to work with students with autism?
13. If you could create an ideal program to support children with autism, what would it look like?
14. Is there anything else that you would like to say?



## Appendix B

Consent Form

**Title of Project:** Toward a Technology of Behavioral Support for  
Individuals with Autism: An Ideal Information System

**Researcher:** Mirah Dow, Emporia State University

**Informed Consent**

The Division of Library and Information Management at Emporia State University supports the practice of protection of human subjects participating in research and related activities. The following information is provided so that you can decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time, and that if you do withdraw from the study, you will not be subject to reprimand or any other form of reproach.

This study seeks to answer the research question: What are the elements of an effective information system that will enable parents, professionals and care givers to help children with autism? An expert panel has identified \_\_\_\_\_ as an exemplary program in Kansas for children with Autism and other Pervasive Developmental Disorders. Through this researcher's observations, and your completion of one interview (1-3 hours in duration) and one questionnaire (ten questions), you will be helping others to learn important aspects of a human information system that makes life-critical decisions for individuals with autism. It is anticipated that a model for designing an information system can be extrapolated from the data collected in this investigation. This model containing definitive information about the elements of the information system can be used by educators, community providers and parents to improve collaboration that is likely to yield answers to the unavoidable question asked when a child is diagnosed with autism, "What do I do now?"

It should be noted that at no time during this study will the researcher attempt to involve or collect information from the children or youth being observed.

The identity of students and adults and the location of the research will be kept confidential. Interviews will be tape recorded to enable the researcher to have the exact responses of participants. Once the research is completed (before May, 1999), the tapes will be destroyed. To validate the researcher's recording of interviews, member checks will be conducted by summarizing the information collected and presenting it back to the providers and parents for verification.

"I have read the above statement and have been fully advised of the procedures to be used in this project. I have been given sufficient opportunity to ask any questions I had concerning the procedures and possible risks involved. I understand the potential risks involved and I assume them voluntarily. I likewise understand that I can withdraw from the study at any time without being subjected to reproach."

---

 Participant

---

 Date

Appendix C

Questionnaire

Respondent Code \_\_\_\_\_

**Return to Mirah Dow**

**Parent - Provider Questionnaire**

1. Do you have published information resources about autism available to you?  
\_\_\_\_ Yes \_\_\_\_ No

If Yes, how often do you refer to published sources of information about autism?  
\_\_\_\_ weekly \_\_\_\_ 3 - 5 times/nine week period \_\_\_\_ 3- 5 times/semester  
\_\_\_\_ 3 - 5 times/school year \_\_\_\_ other explain other \_\_\_\_\_

2. Do you have people information resources about autism available to you?  
\_\_\_\_ Yes \_\_\_\_ No

If Yes, how often do you refer to people sources of information about autism?  
\_\_\_\_ weekly \_\_\_\_ 3-5 times/nine week period \_\_\_\_ 3-5 times/semester  
\_\_\_\_ several times/school year \_\_\_\_ other explain other \_\_\_\_\_

3. Based on your personal experiences, please rank these sources of information about autism (1- most valued; 7 - least valued).

\_\_\_\_ journals/books \_\_\_\_ university faculty  
\_\_\_\_ classroom teachers/program specialists \_\_\_\_ T.V./Internet \_\_\_\_ medical professionals \_\_\_\_ parents \_\_\_\_ personal experience

4. What and/or who is your single most valued source of authority about autism? Be specific.

5. When you refer to information resources about autism, do you feel that you are better able to problem-solve? \_\_\_\_ Yes \_\_\_\_ No If no, why not?

6. In what format do you prefer to have information about autism?  
\_\_\_\_ print \_\_\_\_ lecture \_\_\_\_ discussion \_\_\_\_ digital/electronic  
\_\_\_\_ demonstration \_\_\_\_ combination of formats \_\_\_\_ other

7. What is the most important aspect of teaching and supporting a child with autism?

Does that aspect exist in your current situation? \_\_\_\_ Yes \_\_\_\_ No

\* If more space is needed, please write on the back of this document or attach additional pages.

## Appendix D

Children Demographics and Placement Information

Site	Child/Youth Observed	Racial/Ethnic Status	Sex	Program Level	School Placement	Organized Home Program
1	S1	E-A	M	elementary	regular-special	X
1	S2	E-A	F	pre-school	regular-special	X
1	S3	E-A	M	elementary	regular-special	X
1	S4	A-A	M	elementary	special	
1	S5	E-A	M	elementary	special	
1	S6	E-A	M	elementary	regular-special	
1	SS7	AS-A	M	pre-school	special	
1	S8	E-A	M	elementary	special	
1	S9	A-A	M	elementary	regular-special	
1	S10	A-A	M	elementary	regular-special	
1	S11	E-A	M	middle school	regular-special	
1	S12	E-A	M	middle school	regular-special	
2	S1	E-A	F	elementary	special	X
2	S2	E-A	M	preschool	special	X
2	S3	E-A	M	preschool	special	X
2	S4	E-A	M	preschool	special	X

16 total children with autism

Note. A-A = African American; AS-A = Asian American; E-A = Euro-American

## Appendix E

Participant Demographics

Number of Site	Respondent	Role	Children with Autism/PDD
1	certified teacher	elementary-special education	n/a
1	parent	father-graduate student-business	2
1	certified teacher	district autism consultant	n/a
1	administrator	coordinator of services	n/a
1	parent	mother-chemist	2
1	certified teacher	early childhood special education	n/a
1	related service provider	speech-language pathologist	n/a
1	support staff	paraeducator	n/a
1	parent	mother-school counselor	1
1	related service provider	school psychologist	n/a
2	uncertified teacher	teacher-administrative assistant	n/a
2	parent	mother-masters level nurse	1
2	administrator	program director	n/a
2	parent	mother	1
2	uncertified teacher	consultant	n/a
2	uncertified teacher	teacher-consultant	n/a
2	parent	mother-computer programmer	2
<u>2</u>	administrator	program director	n/a
18 total participants			

Appendix F

Observation Form

**Observation Protocol**

**Date:**

**Location:**

<b><u>Individual/Group Dynamics</u></b>	<b><u>Resources</u></b>
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Appendix G

Member Check Form

September 21, 1998

Dear

I finally have collected and transcribed all the interviews that will be included in my study! Your transcribed interview is attached. I would like for you to look at it, make changes if necessary, and return it to me as soon as possible in the postage-paid envelop that I have enclosed.

Please remember that this interview was an informal conversation. Trying very hard to listen carefully and type accurately, I have typed the words we used as they were recorded on the audio tape. You will see that we did not always speak to each other in perfect sentence form. That was expected and is OK. Please do not try to correct informal language or spelling errors unless you feel that the change(s) will impact the accuracy of your statement(s).

Again, thank you for allowing me to interview you and for now taking time to participate in this "member check." *It will be a great help to me if you will return this to me in tomorrow's mail.*

Thanks to each of you who have mailed completed questionnaires to me since we were last together.

If you have any questions, please do not hesitate to contact me.  
Sincerely,

Mirah Dow

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\_\_\_\_\_ I have read the attached transcript of my interview and find my answers to be acceptable as they appear.

\_\_\_\_\_ I have read the attached transcript and have marked changes that reflect my desired response.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Phone Number

**Please return both this signed statement and the transcript.**