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Deinstitutionalization Effects on Medication Use for People with Mental Retardation

Paul D. Kolstoe

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DEINSTITUTIONALIZATION EFFECTS ON
MEDICATION USE FOR PEOPLE WITH MENTAL RETARDATION

by

Paul D. Kolstoe
Bachelor of Arts, University of North Dakota, 1980
Master of Arts, University of Nebraska - Lincoln, 1985

A Dissertation
Submitted to the Graduate Faculty
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Doctor of Philosophy

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PERMISSION

Title Deinstitutionalization Effects on Medication Use
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ABSTRACT

Historically, patterns of psychoactive medication use in institutional settings for people with mental retardation were considered excessive. Service standards substantially reduced levels of such medication use. Similar research in community settings has been limited, but comparisons between the two settings are fraught with complicating variables. Rapid deinstitutionalization in North Dakota provided a unique opportunity to follow the medication use patterns of people who stayed and those who left the institution. Follow up time periods were selected for statewide accreditation (1989) and several years later through which those standards have been consistently met (1995). Psychoactive medication use decreased with the onset of standards for the entire population, and decreased for the people both within institution and community settings by 1989. Medication use was highly similar between institution and community settings at each time point, but medication use returned to near pre-standards institutional levels no matter where the individual resided by 1995, the important exception being neuroleptics. Neuroleptic use remained stable at the lower level established in 1989.

DEINSTITUTIONALIZATION EFFECTS ON
MEDICATION USE FOR PEOPLE WITH MENTAL RETARDATION

Paul D. Kolstoe, Ph.D.

The University of North Dakota, 1998

Faculty Advisor: Associate Professor Joseph J. Plaud

Historically, patterns of psychoactive medication use in institutional settings for people with mental retardation were considered excessive. Service standards substantially reduced levels of such medication use. Similar research in community settings has been limited, but comparisons between the two settings are fraught with complicating variables. Rapid deinstitutionalization in North Dakota provided a unique opportunity to follow the medication use patterns of people who stayed and those who left the institution. Follow up time periods were selected for statewide accreditation (1989) and several years later through which those standards have been consistently met (1995). Psychoactive medication use decreased with the onset of standards for the entire population, and decreased for the people both within institution and community settings by 1989. Medication use was highly similar between institution and community settings at each time point, but medication use returned to near pre-standards institutional levels no matter where the individual resided by 1995, the important exception being neuroleptics. Neuroleptic use remained stable at the lower level established in 1989.

CHAPTER I

LITERATURE REVIEW

Introductory Overview

People with mental retardation, or the more general term developmental disabilities, were viewed as displaying behavioral problems rather than as experiencing valid mental illness until the 1970's and 1980's (Menolascino, Wilson, Golden, & Ruedrich, 1986). Medications were widely used in the institutions to the point that substantial concerns were expressed about their overuse (Lipman, 1970; Rivinus, 1980).

As concern developed over the types and availability of services for people with mental retardation through the 1960's, standards for such services developed while new forms of services -- special education, large and small group community living, employment opportunity, and family supports -- were introduced (Scheerenberger, 1987). These new services are usually more effective at promoting independence while generally less expensive to operate, except for people with more complicated needs (Borthwick-Duffy & Eyman, 1990). These new service options, increasingly funded opportunities, and court/legislature mandated expansions produced a dramatic decrease in institutional populations following 1969 (Lakin, Braddock, & Smith, 1994a & b).

Inferences about community services based upon institutionally based research, especially in the area of medications, are difficult to make because so many variables differ between the two populations (Gowdy, Zarfas & Phipps, 1987; Burd, Fisher et al., 1991; Burd, Williams et al., 1997). The rapid deinstitutionalization which occurred in North Dakota as a result of the ARC v. Olson (1982) court order provides a rare opportunity to examine the change of residential context on a group of individuals with respect to the pattern of medication use.

Concept of Dual Diagnosis

People simultaneously evidencing conditions of mental retardation and another form of psychopathology are often referred to in the mental retardation literature as experiencing dual diagnoses (Sovner & Hurley, 1990). This same term is also used in other aspects of medical and psychological research (e.g., diabetes and seizure disorder, or chemical dependency and bipolar affective disorder), and so may be confusing to the reader with a perspective outside of mental retardation services; yet this sub-population is the most noticeable of people in the community and as a group require more extensive support services than the general population of people with mental retardation (Borthwick-Duffy & Eyman, 1990).

Other commonly used terms which may be used include psychopathology, psychiatric diagnosis (disorder, condition), mental disorders (illness, health needs), emotional disorder, maladaptive behavior, or behavioral disorder (Szymanski,

1980). The exact term used, and the definition of the term as used, often varies by author. Most authors will cite the Diagnostic and Statistical Manual (1980, 1987, 1994), published by the American Psychiatric Association, as the source of diagnoses considered as "dual". Which diagnoses are actually considered to be comorbid (e.g., caffeine addiction is not likely to be included, whereas schizophrenia is universally considered such) can vary widely between studies and may not always be clearly explained in the article (Reiss, 1990b).

Institutions, now often referred to as Public Residential Facilities (PRF's), formerly were a common residence for many people with mental retardation, especially those with noticeable behavior problems (Scheerenberger, 1987). However, over half of institutional residents in the United States have moved to the community (Lakin, Braddock, and Smith, 1994a & b). Of the 345 PRF's operating in 1960, 116 had been closed by 1995 (34%). The total population of people with mental retardation in PRF's in 1967 was 194,650, which was reduced to less than half that number by 1987 to 94,696, and these numbers were further reduced to 77,697 by 1991. This is a reduction of 17% from 1987, and over 60% from the 1967 population level. The movement of the population to the developing community services has produced a dramatic shift in the research from "behavior problems" in the PRF's to addressing the full range of "mental health" problems (Reiss, 1987) across the variety of new settings.

Efforts at Medication Comparisons

Many attempts have been made to establish the prevalence of dual diagnoses among people with mental retardation, but reliance on diagnostic labels alone presents several problems in understanding the needs for this population of people. Borthwick-Duffy and Eyman (1990) clearly identified many of these issues in their examination of labeling among the over 78,000 people served in the California mental retardation service system. They found that the presence of a second diagnostic label for a person is affected by such issues as questions about the accuracy of the mental retardation diagnosis itself, isolation of a psychiatric disorder from the effects of low intelligence, the level of cognitive ability, the particular topography of the behaviors displayed, and the base rates of the symptoms in each person's setting.

Although Menolascino's group (Menolascino et al., 1986) and many other leaders of the mental health movement within mental retardation services (Kastner, Friedman, O'Brien & Pond, 1990; Poindexter, 1989; Sovner & Hurley, 1987) urge increased efforts to obtain accuracy in diagnoses, the accuracy in medication use on people with mental retardation is not made any clearer. Bates, Smeltzer, and Arnoczky (1986) examined the relationship between the recommended uses of various psychotropic medications and the diagnostic labels applied to the individuals to whom they were given. Diagnoses were determined by evaluation teams that included fully trained psychiatrists and the medication regimens were

evaluated against the then most recent version of the American Psychiatric Association's Manual for Psychiatric Peer Review. A range of one-third to over one-half (39.1% to 54.6%) of the medications were rated as inappropriate for the conditions diagnosed.

The authors clearly stated a caveat that "it is certainly an oversimplification to evaluate individual psychotherapeutic regimens as appropriate or inappropriate solely on the basis of the types of drugs prescribed and the principal diagnoses" (p. 368). However, they went on to note that 14.5% of the subjects in the study who were receiving medications had no mental disorder other than mental retardation. They expressed disappointment in their findings, and concluded that "although acknowledging the difficulty of diagnosing functional disorders in retarded [sic] persons, we believe that most of the discrepancies reflect errors in treatment decisions" (p. 368). Thus, the pattern of medication use is not necessarily validated even in the presence of a diagnoses.

Institutional prevalence rates of medications have been carefully monitored in the literature since the early 1960's, but only recently has it been studied in the community living context (Gowdey, Zarfas, & Phipps, 1987). Medication use in institutions was often found to be in the 40 to 60% ranges even into the 1980's (Rivinus, 1980; Zaharia, 1986), although there are several examples of substantially lower levels into the range of 10% to 20% (Findholt & Emmett, 1990; Poindexter, 1989; Zaharia, 1986). Concerns remain about excessive use of

medication, as noted by Schaal and Hackenberg (1994) in their survey of the literature. In their extensive review, those authors point out that many physicians continue to prescribe medications to manage the topography of behavior (e.g., aggression, withdrawal) rather than the functional issues underlying that behavior (e.g., psychosis, depression, attention deficits), and this may be one of the most significant issues leading to excess use.

Rules, regulations, and standards governing medication use have been developed in response to concerns about over medication in PRF's (Rinck, Guidry, & Calkins, 1989). This has led many physicians to be concerned about loss of authority for medical decision-making (Kastner & Walsh, 1994) and in some places even turned this decision making over to the courts in review of the physicians' decisions (Poindexter, Antanitus, Green, Cullen, & Campanella, 1994). These rules have also been partially credited for prompting and guiding decreases in the prevalence rates within the large facilities (Briggs, 1989; Poindexter, 1989; Zaharia, 1986); however, these important lessons have not been consistently applied in community settings. In their survey of states' rules governing the use of psychotropic medication in the institution versus the community, Rinck et al. (1989) received responses from all 50 states and the District of Columbia as they addressed two basic issues. They found that responses were somewhat different between those rules applied within institutional settings versus those applied within community service providers. Institutions tended to have

more of the basic rules on implementation procedures in place (90 to 96% versus 52 to 62%) and more standard screening for side-effects (61% versus 18%) than did community programs. Rinck (1998) cited these and other studies recognizing differences in regulation and systematic control between the community and the more structured PRF settings.

A few researchers have examined medication prevalence in the community systems, but the methods vary somewhat from that used in PRF settings and the populations in each setting differ (Luchins, Dojka, & Hanrahan, 1993). Individuals residing in an institution tend to display 1) more socially undesirable behavior, 2) more serious or frequent aspects of undesirable behavior, and 3) more serious medical conditions as compared to their counterparts residing in community settings (Reiss, 1990a; Scheerenberger, 1983), the first two issues being directly related to increased psychotropic medication use (Jacobson, 1990).

Methods used to measure who is on medications has differed as well. Anti-epileptic medications were included in measures of community medication use in the few available studies (Gowdey, Zarfes, & Phipps, 1987; Burd, Fisher, et al., 1991; Burd, Williams, et al., 1997). These studies found rates of 40%, 37%, and 38% respectively with the antiepileptic medications, and approximately 23%, 18%, and 20% on psychotropic medications other than antiepileptics. Buck and Sprague (1989) used the more traditional approach without the antiepileptic medications, but their sample was strictly people in Medicaid funded residences in the

community in Illinois, and established a rate of 28.9%. They went on to compare this with a similar population of nursing home residents (without mental retardation) and found that neuroleptic medication use was somewhat higher for those with mental retardation (74% to 88% of those receiving psychotropic medications).

Diagnosis of Psychopathology

People with developmental disabilities have received psychotropic medications to change their behavior since they became readily available in the early 1950's (Scheerenberger, 1987). Initially, the medicated change in behavior was not even conceptualized as treatment for psychopathology, as people with mental retardation were considered primarily behaviorally disordered or organically impaired (Reiss, 1987).

Frank J. Menolascino, a psychiatrist who worked at the Nebraska Psychiatric Institute treating individuals served by the community agency ENCORE, Inc. in Omaha, has been credited with generating much of the recognition of formal psychopathology diagnoses for people with mental retardation. Since 1982 the Mental Health Aspects of Developmental Disabilities (previously named The Habilitative Mental Health Care Newsletter and Psychiatric Aspects of Mental Retardation Reviews) has provided an ongoing forum for discussing the mental health issues presented by people with mental retardation under the editorship of psychologist Anne DesNoyers Hurley and the late psychiatrist Robert Sovner.

Increasing interest in the needs of people with this form of multiple disabilities has led to the establishment of sub-groups and independent organizations whose sole purpose is to facilitate the development and exchange of information on services. NADD (previously known as the National Association for the Dually Diagnosed) holds annual international conferences and promotes literature focused on various specialized topics under the combined mental retardation and mental health banner. Within the American Association on Mental Retardation (AAMR), a Special Interest Group was approved to form as an official body in its executive board meeting in December, 1992, although disagreement about a politically acceptable name delayed the public announcement and full recognition until June, 1994. At that time, the Mental Health Services Special Interest Group (MHS-SIG) was named and attracted over 10 percent of the AAMR membership within two years, becoming the fastest growing and largest special interest group in the associations history (A. Poindexter, MHS-SIG co-founder, personal communication, June, 1996).

Much of the interest comes from the enduring lack of information available about how to meet the needs of such people now that there is professional acceptance of its very existence (Sovner & Hurley, 1983). Despite widespread support to make use of a diagnostic system (i.e., the Diagnostic and Statistical Manual), the currently available system suffers from a high degree of inconsistency for people with mental retardation (Crew, Bonaventura, & Rowe, 1994).

Borthwick-Duffy and Eyman (1990) examined the labeling practices used on the over 78,000 people in the California system and found specific patterns to the application of mental health diagnoses. The presence or absence of such a diagnosis is affected by such issues as the accuracy of the mental retardation diagnosis itself, isolation of psychiatric disorder symptoms from the effects of low intelligence, the level of cognitive ability, the particular topography of the behaviors displayed, and the base rates of the symptoms in each person's setting.

Borthwick-Duffy and Eyman noted that the accuracy of the mental retardation diagnosis itself is more difficult around the borderline and mild ranges of intellectual functioning. It is often not clear to what degree the psychiatric disorder may be imposing substantial impairment on the cognitive abilities of the individual when attempting to accurately assess the innate capabilities which the person may possess. This effect is well documented in the general population among people for whom the intellectual level was well established before the onset of symptoms (Menolascino et al., 1986; Pawlarczyk & Beckwith, 1987). Macmann and Barnett (1993) further examined this issue and found an overall proportion of agreement of only .55 between psychiatrists and psychologists in reviewing actual records of individuals with dual diagnoses at the "cutoff" level of intellectual performance (i.e., differential diagnosis between borderline intellectual functioning versus mild mental retardation).

The researchers next point, isolating a psychiatric disorder from the effects of low intelligence, is also one that has been extensively discussed in the literature (Jacobson, 1990; Pawlarczyk & Beckwith, 1987; Sovner & Hurley, 1986; Sturmey & Bertman, 1994). Reiss (1990a) argued that there is an overshadowing effect on perception by inexperienced mental health professionals. These mental health professionals assume that the low intelligence accounts for behaviors that, in someone else, would be viewed as symptomatic of a psychopathology different than mental retardation.

A different aspect of the same unreliable diagnostic patterns is also related to the level of cognitive ability as in the previous point, resulting in an over-representation of people with higher ability being given diagnoses as compared to the general distribution of people with mental retardation (Borthwick-Duffy & Eyman, 1990). Essentially, the authors conclude that it is the otherwise capable person who can access more of their environment and surrounding community, therefore the more capable people have more opportunity to display noticeable and undesirable social behaviors. This increased visibility results in increased referral to mental health services for assessment and treatment (Borthwick-Duffy & Eyman, 1990; Jacobson, 1990; Reiss, 1990b).

Referral to mental health evaluators is also dependent upon the particular topography of the behaviors displayed (e.g., aggression versus crying). Psychotic behaviors, for example, were found by Jacobson (1990) to be reported to

mental health providers significantly more often in people with mental retardation than non psychotic maladaptive behaviors. He concluded that this appears to lead to an over-diagnosis of psychotic disorders compared to those expected for non-mentally retarded people with organic brain syndrome, neurosis, and personality disorders (other groups with mental disorders), and an under diagnosis of depression when compared to the general population rates.

The last point in Borthwick-Duffy and Eyman's (1990) conclusion was that the base rates of symptoms in each person's setting also impact the rate of referral to mental health services. Symptoms displayed in settings in which similar symptoms are displayed by everyone may become less noticeable because it may be more acceptable in the context of caregiver observation. It becomes commonplace that the behavior occurs and the novelty wears off for the staff, who are making judgments about whether it is a problem or not. Another aspect of this same point is referred to as the more "extrapunitive" behavior (e.g., aggression and destruction of property) which is linked with increased referrals, whereas the "intrapunitive" behaviors (e.g. sadness, regression, sleep problem, low energy, inattentiveness) may be under referred. The distinction is that the former behavior tends to place more demands on caregivers than does the latter.

Leading authors in the field (Sovner & Hurley, 1986; Reiss, 1987; Kastner, Friedman, O'Brien, & Pond, 1990) have reflected on the difficulty involved in sorting out conflicting information about psychopathology symptoms to

arrive at a diagnosis for people with mental retardation. Whereas Borthwick-Duffy and Eyman (1990) addressed systemic issues influencing diagnostics, Sovner and Hurley (1986) list four broad presentation issues which make the process difficult for the individual diagnostician: 1) intellectual distortion, 2) psychosocial masking, 3) cognitive disintegration, and 4) baseline exaggeration.

Intellectual distortion refers to diminished ability to think abstractly and communicate intelligibly. This can include deficits in ability to describe one's own behavior and feelings, therefore impairing accurate delivery of basic information about symptoms. In the effort to demonstrate competence and acceptance people with intellectual deficits encounter numerous situations where the individual may not understand what is being asked, yet simply agree to whatever is asked (Baroff, 1986). Despite not understanding or being unclear about the question posed, people with mental retardation often overtly agree with the authority figure even when they do not believe that they agree with what they are saying. In the extreme cases -- although surprisingly frequent, according to Baroff -- this has resulted in criminal cases where an objectively innocent individual has been placed on death row (Perske, 1991) resulting from a desire to please the police and judge. Baroff, in his research on people with mental retardation understanding Miranda Rights, has demonstrated that questioning of individuals with such limited powers of abstraction must be done in a manner where the individual is able to report the

answers in his/her own words, rather than simple parroting or giving yes/no answers.

Psychosocial masking, another variable making diagnostics difficult when applied to people with mental retardation (Sovner & Hurley, 1986), refers to the likelihood that people with mental retardation have so much narrower a range of life experiences than their non-handicapped peers. In describing their activity patterns, the individual may relate very few and/or simple social behaviors and they literally do not have the experiential resources to draw upon to explain themselves and their symptoms. For that matter, without a rich background of experience, delusions of people with mental retardation tend to resemble the fears of young children as opposed to the generally imaginative belief systems commonly associated with schizophrenia and mania. Where the individual may talk of "angels" and "badmen" trying to do something to him, the diagnostician must distinguish between loss of reality contact versus a highly concrete and immature -- though well grounded -- understanding of life events.

Cognitive disintegration occurs in the general population as a result of stress (Sovner & Hurley, 1986). This refers to stress-induced deterioration in intellectual functioning and can also result in adaptive behavior regression, similar to pseudodementia. This generally reflects being overwhelmed by the events going on around the person. For people with mental retardation, the arsenal of coping skills is already limited (Hurley & Sovner, 1991),

thus when a significant environmental stressor occurs the person can quickly lose the ability to perform even simple tasks previously mastered under more stable conditions.

Finally, the exacerbation of preexisting cognitive deficits is referred to as baseline exaggeration (Sovner & Hurley, 1986). This can be displayed as increased distractibility, poor judgment, self-injury, or other changes in already existing behavioral patterns which may appear to be like, or mix with, symptoms of psychopathology. From a diagnostic standpoint, the change in rate or quality of a behavior may be all that is indicative of an active psychopathology process, rather than the onset of such symptoms.

Kastner et al. (1990) also described medical conditions which can further confuse the situation. They advocated a thorough medical examination and encourage the physician to carefully consider factors in addition to those raised by Borthwick-Duffy and Eyman (1990) and Sovner and Hurley (1986). They point out that what appears to be maladaptive behavior can often be the result of other issues around the person. Drug-induced effects can occur, such as paradoxical hyperactivity from benzodiazepines and other tranquilizers; dystonia, tardive dyskinesia, akathisia, and akinesia from antipsychotic drugs; and tricyclic agents and carbamazepine (Tegretol) have been shown to induce mania.

Even methods used in the work-up must be scrutinized, according to Kastner et al. (1990). For example, wearing medical clothing may cause a fear reaction in the individual

and result in atypical behavior during the contact time with the physician. This can grossly change the impression of the individual's presenting problem, result in treatment for conditions unrelated to the problems encountered in daily life, or interfere with other aspects of service.

Kastner et al. (1990) discussed common medical problems associated with specific syndromes that are seldom readily obvious to many physicians. For example, they describe various behavioral presentations which are consistent with depression (appetite disturbance, sleep disturbance, loss of energy, etc.) and note that these are also consistent with such physical conditions as pneumonia, hyper/hypothyroidism, dementia of the Alzheimer type, and congestive heart failure as well as causes of mental retardation such as congenital rubella, Down, Noonan, Turner, and fetal alcohol syndromes, and arrested hydrocephalus. Kastner et al. point out that each of these are areas with which the general physician, and often the community psychiatrist, may have little knowledge or experience unless provided with additional resources upon which to rely.

Even when the diagnostic category is thought to have well-defined criteria, such as level of mental retardation, there is significant inconsistency in actual practice.

Macmann and Barnett (1993) summarized findings that "in general, diagnoses of mental retardation have fared well in DSM 'field trials' and related research, with estimates of chance-corrected inter-rater agreement [that are] usually greater than .80.", but they pointed out that this is an

"...upperbound [sic] for estimates of inter-rater agreement..." (both p. 559) where all diagnostic conditions are perfect.

McMann and Barnett (1993) examined interrater agreement in a natural setting where the individuals also had a secondary psychopathology diagnosis. Psychologists and psychiatrists independently completed evaluations on the individuals residing at the facility in the normal course of their duties. Comparisons were made between the psychiatrists' and psychologists' diagnoses of mental retardation, and the specific level of impairment. They found that the overall chance-corrected agreement (kappa) was .47 under these naturally occurring situations. The authors characterize this as displaying "very little agreement" (p. 564) between psychiatric and psychological reports contained in client records. Further, this illustrates that even the most specific diagnostic criteria in the DSM still result in poor inter-rater reliability, and therefore bring to question validity and utility of diagnoses in this population when making treatment decisions.

Based upon these issues the debate has been extensive over continued use of the levels of mental retardation in the diagnostic determination process. The recent Definition of Mental Retardation: Terminology, Classification, and Systems of Support (Lukkason et al., 1992) eliminated the levels altogether, while the Diagnostic and Statistical Manual (4th Edition, APA, 1994) adopted cutoff guidelines from the AAMR publication, but did not eliminate the levels.

Standardized assessments do not resolve the issue of accuracy in diagnoses. As an example, Sturmey and Bertman (1994) validated the REISS Screen against the Psychopathology Inventory for Mentally Retarded Adults [Psychopathology Inventory], the Aberrant Behavior Checklist, the assigned diagnoses of psychopathology, actual medication use, implementation of a behavior therapy program, and residence on a specialized behavior modification unit. Although several were statistically significant ($p < .01$), the correlations between the devices on subscales and total scores were not a remarkable improvement from a clinical utility perspective (e.g., $r = .605$) in that barely a third of the variance ($r^2 = .366$) is accounted for by measurement with the instruments.

The REISS Screen is a behavioral symptom checklist based upon criteria in the Diagnostic and Statistical Manual (APA, 1980, 1987, 1994), which provides a total score and subscales that are labeled consistent to specific diagnostic categories. As noted above, Sturmey and Bertman (1994) also made comparisons to clinically relevant indices of psychopathology such as use of psychotropic medications, presence of a psychiatric diagnosis, implementation of a behavior therapy program, and residence on a "dual diagnosis" unit. The largest obtained correlations were between each indicator variable and the total score, with only two of these four correlations statistically significant. Even the statistically significant correlations were rather small (REISS total score to psychiatric diagnosis, $r = .326$, $p < .01$;

REISS total score to behavior therapy program, $r = .426$, $p < .01$) suggesting poor predictive utility.

Relationship of Diagnosis and Medication

Many authors have argued that more emphasis on diagnostic accuracy will come more precise treatment using medications. Szymanski and Grossman (1984) assert that the whole concept of "dual diagnosis" should be eliminated because it encourages the development of a new area rather than applying service systems which already exist. They urge use of the general system for classifying mental disorders (i.e., DSM), but call for an intensive program for training mental health professionals to provide a full range of services to all persons. In this way, the mental health system would integrate services to people with mental retardation rather than segregate and discriminate against them.

Their theme is echoed by others (Poindexter, 1989; Sovner & Hurley, 1983), who express the opinion that with greater education of mental health professionals about mental retardation will come greater precision in diagnostics, and therefore an increased accuracy in the application of treatments such as medication. They infer that the problem is our systems' current inadequacy to assign a diagnosis, but that once we have a diagnosis the appropriate treatment is known.

This call for diagnostic accuracy as a means to achieve greater treatment efficacy was not well-supported in findings by Bates, Smeltzer, and Arnoczky (1986), when they examined

the concordance between diagnoses and prescribed medications. They examined records of individuals living in a PRF for people with mental retardation receiving psychotropic medications in comparison to the mental health diagnoses that were assigned them. Multidisciplinary teams, incorporating fully trained psychiatrists, identified individuals upon whom there was unanimous agreement on the diagnosis which resulted in selecting 62.9% of the original pool of people considered, and ranged in level of mental retardation from mild to profound.

The diagnoses were collapsed into the major categories of the Diagnostic and Statistical Manual, 3rd Edition [DSM-III] (APA, 1980) and medications were grouped by their standard classificatory category (e.g., antipsychotics, antidepressants, etc.) using published standards. They rated medication regimens for each diagnostic group to medication class by rating them as "probably appropriate, uncertain, or probably inappropriate (Bates et al., 1986; p. 365)" for each individual in the study. In addition, they evaluated use of multiple medications by distinguishing between coparmacy and polypharmacy as follows: coparmacy is the "nonredundant combinations of drugs and is not necessarily inappropriate", whereas "polypharmacy is the simultaneous use of two or more drugs of the same basic types and is always inappropriate because it involves increased risk without likelihood of increased benefit" (p. 365).

Percentages of the total number of people were calculated and they found that there was almost the same

proportion of appropriate as inappropriate ratings. Results indicated that 15.5% of the individuals were rated as in the Uncertain Category, 45.4% were rated as Probably Appropriate as compared to 39.1% rated as Probably Inappropriate. They then used the 15.5% Uncertain Category figure to calculate the categories potential extreme range by combining those individuals with each category. Thus, the authors estimate the proportion of individuals potentially Receiving Medications Appropriately was between 45.4% and 60.9% , versus 39.1% to 56.4% potentially Receiving Medications Inappropriately. Of those on multiple medications, the authors found that at least 50% were judged as Probably Inappropriate, and that it could range up to 95.6% when considering the Uncertain Category, despite their differentiation for appropriateness between coparmacy and polypharmacy.

Most striking were the conclusions expressed by the authors (Bates et al., 1986). They explicitly understood that their judgments of the drug regimens were lenient. Even regimens often regarded as inferior to others were rated in the Appropriate Category or Uncertain Category if there were modern references describing them as acceptable under certain circumstances for a given diagnostic group. Despite these accommodations, they reflect that their findings were "extremely disappointing" (p. 368) and state that "we are dismayed not only because many patients receive inappropriate medication but also because many do not receive treatment that can be immensely beneficial" (p. 369). While noting

that successful use of the medical model requires rigorously determined primary diagnoses, their finding illustrates the poor relationship between the assigned diagnosis and prescribed medication - even when the diagnoses are unanimously agreed upon.

Rates of Medication Use

As noted previously, prevalence data on medication use in institutions has historically been well documented at excessive levels. Rivinus (1980) conducted a systematic search of the literature, reviewing 166 studies from the 1960's through the 1980's regarding the use of medications on people with mental retardation. He noted a series of studies which were completed on medication use rates in public facilities across the United States. These surveys reported institutional psychotropic drug use rates to generally be between 51% and 64%. Lipman (1970) surveyed 109 facilities on medication use and found that they averaged 51%.

Rivinus noted one state where one facility was large and the other was small, each had a highly similar rate of 50% of the population receiving psychotropic medications. In another case, a relatively stable average of 47% of the people served across five facilities in eastern Canada were receiving neuroleptic medications. As a further example in a state with two facilities, with an important twist, 53% of the people received psychotropic drugs in one and 25% in the other, despite being of comparable size and population type.

Rivinus also reported a survey of the facility in which he was working and noted the incidence of neuroleptics use --

alone -- to be 57% prior to the availability of regular psychiatric consultation. Further, a rate of polypharmacy was noted in 27% of the people. After four years of regular psychiatric consultation the neuroleptic drug use was reduced to 23% and polypharmacy was eliminated completely. Four conclusions from these surveys were identified (1980, p. 198):

1. Psychotropic agents have come into widespread, poorly controlled, and poorly reviewed use in institutions for mentally retarded persons.
2. Polypharmacy is practiced widely in institutions.
3. The use of drugs is often the measure of the lack of alternative approaches to unacceptable behavior and programmatic shortcomings in most institutions for retarded persons.
4. Psychotropic agents can effectively be part of the responsible treatment and habilitative programs for some institutionalized retarded persons.

He went on to point out that by 1980 "studies of the effect of psychotropic agents on the functioning of noninstitutionalized retarded [sic] patients are rare or inconclusive; there is a need for such studies" (p. 199).

Aman and Singh (1986), following up on Rivinus' article, reviewed nine new research reports on medication use rates in institutions. They observed no real change in psychotropic drug use rates among public residential facilities. While finding that between 40 and 50% of institutional residents could be expected to be receiving psychotropic medication at

any given time, they conclude that the mentally retarded are probably among the most medicated people in society.

Standards Effect on Medication Use

Concerns about medication overuse contributed to the development of standards of services. In his book detailing the changes in the latter half of the 20th century, Scheerenberger (1987) points out that the American Association on Mental Deficiency ([AAMD], now American Association on Mental Retardation [AAMR]), began to establish standards for institutions as early as 1944. Their initial concerns were over the optimal size of facilities, and did little to address medical or program services. By 1971 AAMD joined with the American Psychological Association and several other professional associations to establish the Accreditation Council for Facilities for the Mentally Retarded, more recently known as the Accreditation Council on Services for People with Disabilities [Accreditation Council]. They are now known as the Council on Leadership and Quality in Services for People with Disabilities [The Council].

In 1974, the standards in use by The Council were made into the Federal Administrative Law for the Health Care Financing Administration's [HCFA] certification standards on Intermediate Care Facilities for the Mentally Retarded [ICF/MR] (Scheerenberger, 1987). These standards became the criteria for states to receive federal Medicaid and Medicare dollars in reimbursement for services of institutionalized people with mental retardation or other developmental

disability. Procedural and programming requirements were spelled out in detail.

Studies have demonstrated that the implementation of procedural safeguards and programmatic supports mandated by standards could reduce the rate of psychotropic medication use substantially. Zaharia (1986) reported how the Caswell Center in Kingston, North Carolina, was able to reduce its overall use of major and minor tranquilizers from 19.3 to 10.0% over a five year period. The agency began the process as a concerted reduction effort to meet the standards of HCFA (sometimes also referred to as ICF/MR or Title XIX) and The Council.

Zaharia credited a four-point approach to the medication use in his facility with the success of the reductions. The first was an individualized written program for each person regarding their drug therapy. This involved a team effort to develop alternatives and implement focused training by the various disciplines. Agency administrators increased staffing, developed day programs, and initiated the development of interdisciplinary teams to design individualized services. Second, guardian or individual consent was obtained prior to the initiation of a psychotropic drug. No medication was started without the consent of the individual, or in the case of a guardianship, the individual (where possible) and their guardian.

Third, the quality of the behavior therapy plans were improved through a mandatory review by the Behavior Management Committee. This committee was comprised of an

interdisciplinary mix of professionals with the responsibility to ensure that the most effective learning principles were employed in coordinated manner. Review of each plan before implementation also acted to ensure that human rights were respected (i.e., review was completed by the individual/guardian and their access to appeal was guaranteed). The fourth point Zaharia (1986) credited was a screening program for tardive dyskinesia. This placed a systematic review process into the decision making regarding the costs of using neuroleptic medications. With this reduction firmly in place, Zaharia commented that ". . . control and review of drug programs were returned to medical personnel" (p. 12) at the end of the period under study, and concluded with the notation that ". . . there have been no perceptible increases in drug usage" (p.12) a year later.

Although Zaharia's article was in a newsletter, Poindexter (1989) published similar data for an Intermediate Care Facility/Mental Retardation [ICF/MR] facility in Conway, Arkansas in one of the most respected peer-review journals focusing on mental retardation. The Conway Human Development Center was ICF/MR Certified through the time of the study and later received accreditation by The Council. She continuously monitored the same people over a ten year period and recorded a decrease in psychiatric drug usage from 32.1% in 1978 to 12.2% in 1987, almost a two-thirds reduction. Although not a cohort study as in Poindexter's Arkansas research, Hancock, Weber, Kaza, and Her (1991) recorded a similar pattern in another facility where the medication

prevalence dropped from 30% to 12% over a ten year period, again attributed to interdisciplinary team review processes.

Standards are sometimes criticized for infringing upon the physician's capacity to perform effectively (Poindexter, Antanitas et al., 1994) as was the case in the Caswell Center experience described in Zaharia's quotation. In contrast to taking such controls away from the physician, Poindexter (1989) pointed out physician autonomy was assured:

At no time during the 10-year period surveyed was any attempt made by the administrators of the facility to dictate to prescribing physicians rules or regulations outlining drugs that could or could not be prescribed. No legal actions were brought during this period to force regulation of medications. Decisions concerning drug regimens were made individually by each physician for his or her own patients (p. 625).

She credited the success of the reduction to a substantially increased involvement of the physician with the overall planning for the individual, an increase in the amount and frequency of information available to the physician, improved behavior modification techniques including increased input from all team members, increased information to the physician about neuroleptic drug side-effects, and greater precision in psychodiagnostics for people with mental retardation.

Stone, Alvarez, Ellman, Hom, and White (1989) examined the medication rates across the eight PRF's in California and made comparisons with previous findings. Medication rates ranged from 13.7% to 63.8% in the facilities, with the higher

rates in the two facilities that combined services for people with mental illness with those with mental retardation. Overall, the rates for PRF settings in California were 35.4% and the authors concluded that rates of medication use were dropping in comparison with earlier averages estimated around 51% by Lipman (1970).

The interdisciplinary review process has been described earlier as receiving part of the credit for positively affecting medication use patterns (Briggs, 1989; Findholt & Emmett, 1990; Glaser & Morreau, 1986; Lepler, Hodas, & Cotter-Mack, 1993). Whereas Findholt and Emmett reported results consistent with Glaser and Morreau of substantial decreases in rate of institutional medication use, Lepler et al. did not report similar findings in the community sample.

Glaser and Morreau (1986) compared the interdisciplinary process in a large public residential facility to a physician-only service program. They selected 28 individuals receiving neuroleptic medications and investigated the monthly prescribing pattern of physicians over a six month period. This included a six-month period of monthly interdisciplinary review meetings, attended by the physician, clinical nurse, pharmacist, psychologist, social worker, mental health technician (i.e., primary caregiver), and administrator.

The group collectively reviewed services utilizing a four-step process. First, the reason for the medication use was established by the team to be either psychiatric or behavioral control, with the specification of the target

behavior for the behavioral control as the second step. Third, the team reviewed the existing behavior management program to ensure that it was current and functional and determined the current levels of the target behaviors. The last step consisted of revisions of the behavior management plan and medical regimen. This process continued for the following six-month period. The differences between the two methods of decision making resulted in elimination of the medication for 17.9% (5 people) of the group in the six months, and an overall decrease across all individuals of 42.5% in daily dosage. This was calculated through what the authors call "oral dose equivalents" (Glaser & Morreau, 1986, p. 373), which was used to compare total daily doses of a specific group of medications in a standardized manner.

Reflecting upon the mission of a formal review committee, Findholt and Emmett (1990) explicitly noted that their facility did not establish the Behavior and Medication Review Committee [BMRC] to eliminate psychotropic drug use at the institution. Instead, it was "...formed to evaluate the effectiveness of these medications and reduce dosages whenever possible" (p. 44). Members of the committee were the attending physician, a registered nurse, two registered pharmacists, a psychologist, the supervisor of education, the director of the residential living department, and the supervisor for the resident's living area. Although team members were encouraged to ask questions, votes were not taken out of respect for the physician holding the ultimate responsibility for prescribing medications. The committee

reviewed each individual's treatment every 6 months through a review of medication, diagnosis, and a graphic display of the target behavior data. As can be seen in Table 1, generated from data within the article, every category of medication decreased substantially.

Table 1. Percentage Change Due to BMRC Review

Medication Category	Years	
	1979	1987
Antipsychotics	41%	12%
Antidepressants	14%	2%
Anxiolytics	13%	3%
Polypharmacy	9%	0.7%

The authors (Findholt & Emmett, 1990) found it interesting that the agency employed 14 different physicians during this time period with an average length of stay of 22 months. They concluded that the beneficial effect of the committee was clearly demonstrated, even given the pattern of physician changes.

In a follow-up to data collected earlier, Briggs (1989) examined the medication use pattern in the Walter E. Fernald State School (FSS) in Massachusetts, one of the nation's oldest public institutions for people with mental retardation. The FSS instituted interdisciplinary review procedures in 1980. By 1983 the medication rate had been brought down to approximately 20% of the population. Briggs examined the follow up services to these individuals to

determine what happened to them in the intervening years (to 1987). The overall prevalence rate of psychiatric medication use was reduced from approximately 44% to and maintained around 20% for four years, and of the 130 people who were withdrawn from the medications by 1983, 69% remained medication free an additional four years later in 1987. Further, of the people who had continued on medications from 1982, 91% had received dose reductions even though discontinuation was not attempted. Of people on medications, 99% received a behavior intervention plan detailing the target behaviors selected for the effects of the medication.

As stated earlier, however, not all reported interdisciplinary team review process have resulted in decreases in the use or doses of medications. Lepler, Hodas, and Cotter-Mack (1993) reported on a similar process of review instituted in a community program setting. They cited problems with poor communication and cooperation between the day and residential programs, subjective reports given by direct contact staff as the only source of psychiatric consultation information, and lack of coordination of treatment strategies as some of the needs for the review process. However, they refer to reductions in the rate of medication use from 21% to 19%, figures representing questionable statistical significance (Kastner & Walsh, 1994).

Kastner and Walsh (1994) point out that such a difference in percentages cannot be taken to construe a true difference, especially considering the fact that almost a

third of the individuals about whom Lepler et al. (1993) reported were not even seen by the review team. In their response, Lepler et al. (1994) agree with Kastner and Walsh that there was no significant reduction as has been consistently reported in the literature on institutional interdisciplinary review teams. Instead, they restate the intent of the publication of their first article not as an example of effective change in medication rates, but as a model for community programs to evaluate for potential use in their own setting.

Over medication in institutions promoted development of several rules, regulations, and standards governing drug use (Rinck, Guidry, & Calkins, 1989). These rules have been partially credited with prompting and guiding decreases in the prevalence rates within PRF's (Briggs, 1989; Poindexter et al., 1994; Zaharia, 1986). In their survey of states' rules governing the use of psychotropic medication in PRF's versus communities, Rinck et al. received responses from all 50 states and the District of Columbia. They found that responses were somewhat different between those rules applied to PRF settings versus those applied to community service providers. Institutions tended to have more of the basic rules on implementation procedures in place (90 to 96% versus 52 to 62%) and more standard screening for side-effects (61% compared to 18%) than did community programs.

The first question raised by Rinck et al. (1989) concerned drug evaluations. They found that almost all of the states' PRF settings were required to explicitly state

the behaviors the medications were intended to modify (approximately 90% of states), include methods for evaluating the effects in the individual's treatment plan (96%), and maintain documentation of these data in the individual's record (90%). However, the same was less true for documentation of the behavioral effects of drugs for community service providers. When these same issues are applied to community services, the proportion of states requiring that community service providers explicitly state the behavior targeted for the medication was only 58%, methods describing the evaluation of the medication effects having to be included in treatment plans was 62%, and requiring the maintenance of behavioral change data in the individuals' records was present in the rules of only 52% of the states.

The second issue examined by Rinck et al. (1989) was the requirement for evaluation for potential side-effects, specifically referring to tardive dyskinesia. Tardive dyskinesia is a potentially permanent side effect which can involve serious movement disorders of the arms, legs, and torso, facial tics, and which can even result in death (Slaw & Kalachnik, 1985). The monitoring for such side-effects was required in 61% of states for PRF settings by 1987, and only 9 states (18%) for community service providers by that same year.

The rules for the respective service settings continue to not be consistent. In a more recent review, Rinck (1998) repeated the conclusion that there is a substantial effect of

review committees demonstrated in research in PRF settings, while finding no similar community-based studies to cite.

Medication Use in Community Settings

Only in recent years has any information been available about medication use rates in people with mental retardation living in the community. In general, these rates are being found to be similar to or even higher than the rates found in institutions after the implementation of standards on services (Luchins, Dojka, & Hanrahan, 1993; Rinck, 1998).

Thomas (1994) expresses deep concern for the arrangement of services in the community setting, and contrasts it with services in PRF contexts. Noting that psychologists, psychiatrists, general physicians, and other mental health/retardation professionals have direct ethical responsibility and authority over services for people in institutions, Thomas raises the concern that inadequate services may result from the community arrangement of an administrator in the seat of responsibility. Despite the similarity between the ethical principles of the American Psychological Association and the National Rehabilitation Administration Association codes of ethics outlining specific responsibilities, he contends that administrators and staff supervisors tend to be unaware of this ethical responsibility. He asserts that they may accept minimally adequate services as sufficient for people with dual diagnoses. He makes it clear that there is no specific such accusation, only that the likelihood appears significantly higher.

Medication in the community context was first addressed by Gowdey, Zarfas, and Phipps (1987), but they included all psychoactive medications in their study (i.e., antiepileptic in addition to neuroleptics, anxiolytic, antidepressant, etc.) to arrive at the overall medication rate of 40% for people with mental retardation who lived in community group homes. This is inconsistent with the usual reporting methods; where seizure medications were not typically counted together with other psychoactives (Poindexter, 1989; Rivinus, 1980). However, Gowdy et al. did report rates on the use of the individual classes of medications: 14%, neuroleptics; 5%, sedative/hypnotics; 3%, antidepressants; and 1%, antimanic. This reflected an overall rate of approximately 23% of people on psychotropic medications other than seizure medications.

Buck and Sprague (1989) used a slightly different methodology to measure psychotropic medications by examining the Medicaid billing patterns for community Medicaid funded facilities in the communities of Illinois. They used pharmacy billing information to determine medications given to individuals included in the study, although they cautioned that it did not represent all individuals with mental retardation living in the community. Their findings were specific to traditional psychoactive medications, as they did not count any antiepileptic medications, establishing the rate of 28.9% of the target population receiving such medications. Although the authors found this rate to be comparable with nursing home patients without mental

retardation in facilities funded in the same manner, the use of neuroleptic medications was somewhat higher; 88% of people with mental retardation on psychotropic medications received neuroleptics as opposed to 74% of nursing home patients.

It is important to note that the names of these different classes of medications have reflected, to a large extent, the intended condition for which they are commonly used (e.g., anti-depressant for depression, anxiolytic for anxiety); however, the use is not restricted by such classification (Bates, Smeltzer, & Arnoczky, 1986). In recent years there has been increasing use of medication with disorders outside of the traditional class for which it is named, such as the relatively common practice to use antiepileptic medications for mood disorders (Burd, Fisher, Vesely, Williams, Kerbeshian, & Leech, 1991).

Burd, Fisher et al. (1991) conducted their survey of all group homes in North Dakota in 1988 and again in 1993 (Burd, Williams et al., 1997) in order to comprehensively establish the rate of medication use. They received a 97% and 100%, return rate, respectively, that revealed a psychotropic medication prevalence rate of 37% in 1988 and 38% in 1993. The North Dakota researchers (Burd, Fisher et al., 1991; Burd, Williams et al., 1997) used the same procedures as Gowdey et al. (1987) in that their methodology included antiepileptic medications in the data collection. As noted earlier, however, in both of the North Dakota studies the research teams were attempting to incorporate the fact that antiepileptic medications were increasingly being used to

treat non-seizure related disorders such as behavioral problems and some psychiatric symptoms. They also wanted to reflect on concerns they noted in the literature about cognitive side-effects of these medications. When eliminating anti-epileptic medications (note, however, not based on presence/absence of a seizure disorder), the prevalence rate of medication use drops to 18% in 1988 and 20% in 1993. These rates (37%:18% and 38%:20%) are relatively similar to that found by Gowdey et al. (40%:23%).

Community rates of medication use, from what little information is available, appear to be in the range of 18% to 40% depending upon the medications examined and the population sampled. In contrast, PRF levels were historically described as between 25% and 64% depending upon when data were collected, contemporaneous standards, and medications chosen for review. In several more recent reports (Briggs, 1989; Findholt & Emmett, 1990; Poindexter, 1989; Rinck, 1998; Stone et al., 1989; Zaharia, 1986) investigators report rates in the 10% to 24% range which is somewhat lower than previous PRF rates and available community rates.

Changes in Service Delivery in North Dakota

North Dakota established the Institution for the Feeble Minded at Grafton, North Dakota, for the stated purpose of training and education in productive work such that the individual might return to his or her community as a productive member. This mission was a common one for institutions when they first opened (Scheerenberger, 1983)

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and was reflected in much of the self-sufficiency of the facilities. A 1907 letter from superintendent refused admission for an individual whose handicap was so severe that "he would not receive benefit" the training. The capabilities of many people were developed to the point that a superintendent in the 1930's established a brass band which was admired by many of the people in the communities around Grafton (personal communication/photograph in class "History of the Developmental Center" by Ken Weisen, Director of Personnel, North Dakota Developmental Center, October, 1996).

The mission of educating the residents was reflected in the name change in 1933 to the Grafton State School. Throughout the years, individuals were placed out of the facility into homes, factories, cafes/restaurants and other settings where the supervising family was expected to provide a job, supervision, a residence and personal time in exchange for their labor. The term "Job Training/Placement" was used in records as early as 1907 and continues to be the official term used by the records staff to denote the individual moving to a work/residential setting in the community.

The population of the Grafton State School continued to grow through the century. The additional site of the San Haven Tuberculosis Sanitorium came under the authority of the Grafton State School Superintendent during the 1960's and appears to have become almost exclusively populated by people with mental retardation. As is true of the institutionalized population of the United States (Lakin, Braddock & Smith, 1994b), the institutionalized population at Grafton/San Haven

began to decrease after 1969 (see Figure 1). This is likely due to the emerging availability of special education programs and some community opportunities following President Kennedy's administration (Scheerenberger, 1987).

Events affecting the delivery of services and the living conditions for people with mental retardation in North Dakota began a radical change in the early 1980's. The North Dakota Association for Retarded Citizens (ARC) and six citizens with mental retardation filed suit in the Federal District Court of North Dakota seeking declaratory and injunctive relief under the First, Fourth, Fifth, Eighth, Ninth, and Fourteenth Amendments to the United States Constitution, as well as several federal Acts and North Dakota state laws (ARC v. Olson, 1982).

When the ARC filed its complaint in September, 1980, the district court granted class certification consisting of the ARC and all persons who, as of September 26, 1980, and at any time thereafter, have been or may become residents of the state's institutions for the mentally retarded. Although the complaint was filed and certified, the court granted a stay to permit the North Dakota legislature to resolve the issues raised during its sessions, which began in January, 1981. Immediately after the legislature concluded business in May, 1981 the court lifted the stay and interceded in the state's operation of the services by appointing a court monitor to report to the court on activities of the state. Plaintiffs had not been satisfied with the legislature's attempt to rectify the conditions at the facility and in the state.

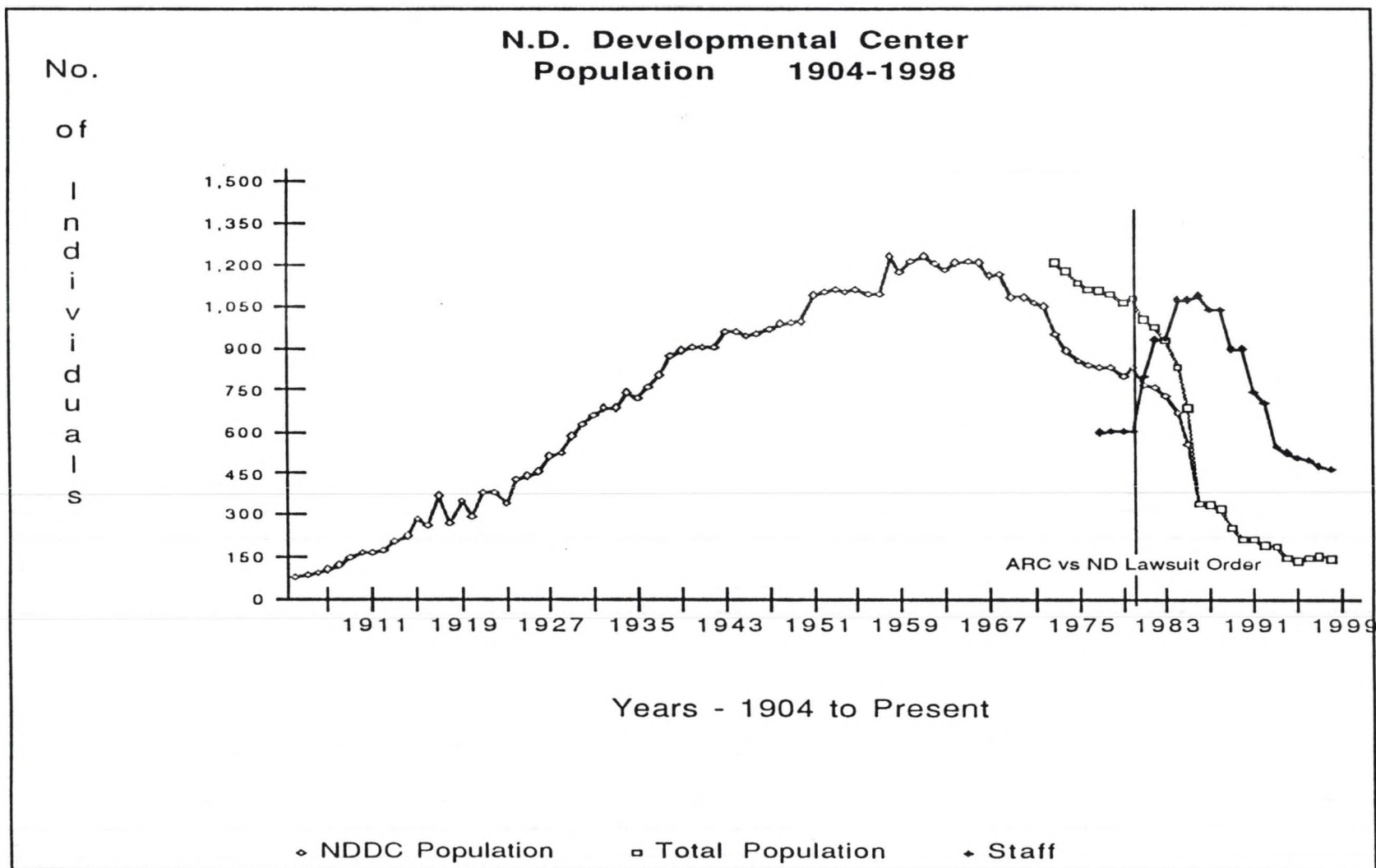


Figure 1. N.D. Developmental Center (1904-present) population with available San Haven and total staff levels

Trial commenced in January, 1982 and the order was handed down the following May which required, among other issues, that the state permanently comply with all Title XIX regulations of the Social Security Act (Title XIX - Health Care Finance Administration [HCFA]) by July, 1985 and to comply with all ACMR/DD (The Council) standards by July, 1987 at all facilities where any class member resided (ARC v. Olson, 1982). The standards which were required to be implemented include management systems for medication use. The court further required the state to develop community based residential services sufficient to reduce the combined institutional population to 450 by July, 1987 and to 250 by July, 1989. The state has since met these requirements and the court's involvement ended in May, 1995.

These changes have resulted in the movement of nearly 700 people from the institution to the community, the closure of the San Haven facility, and all agencies -- as required by the court -- have met Title XIX and The Council standards since the Developmental Center achieved that status in April, 1989 (two years later than was ordered by the court).

Under these standards, all psychotropic medications used to modify behaviors, other than seizure-related conditions, must have plans for their use outlined in a plan written by the team and reviewed by behavior intervention review and human rights committees (Gardner, 1990). Thus, all individuals with mental retardation in North Dakota receiving psychotropic medications were receiving planning, review, and oversight that have been reported as reducing medication use

levels in institutions (Kastner & Walsh, 1994; Rinck, 1998). As of the time of this dissertation (1998) all services in North Dakota had maintained certification and/or accreditation as had been ordered.

Statement of the Problem

It is difficult to make comparisons between medication rates for institution and community populations of people with mental retardation. Those who remain living in the institution tend to display more severe psychopathology than the individuals living in the community (Luchin et al., 1993) so such comparisons have become less meaningful as people have moved to the community (i.e., deinstitutionalization) and others in the community have been referred to mental health services (Jacobson, 1990). The people who are admitted to such facilities, or remain institutionalized, are more likely to display severe maladaptive behavior, often being assigned a mental health diagnosis, thus increasing the base rate of problems likely to generate treatment with medications (Borthwick-Duffy & Eyman, 1990).

Medication use rates on individuals for whom both institutional and community living have been a part of their lives are examined. By following such individuals over time, conclusions can be derived about effects of the different settings and the impact of standards. This is accomplished by examining the individuals who were living in the institution as it was, and are now living in the institution and community under current standards. As outlined from the literature, medication use has been more closely monitored in

the PRF setting and community dual diagnosis services have been characterized as more loosely developed and organized. Three basic issues are examined.

First, it is clear from previous studies conducted within institutions that the initiation of standards and development of a systematic review processes has resulted in a decrease in medication use for those continuing to reside in that setting (Rinck, 1998). Thus, the assertion that medication rates have been reduced among the individuals remaining in the institutional setting given the introduction of regulations will be examined.

Second, there is very little research available on medication use for people that have moved from institutions to communities; however, use of the planning and review systems appears to have a significant impact at reducing the rate of medication use in the institution. Where rates have been measured in the community, they appear to be in a similar range as rates historically measured in institutional settings. In fact, there are more recent reports where institutional rates have been found to be lower than those found in the community (Rinck, 1998). From this difference in service settings it is hypothesized that medication rates for the group of individuals that moved into the community from the institution are higher than those who did not move.

Third, it is the widely held that people were admitted to the institutions due to problems they encountered while living in the community for which there were inadequate supports (Scheerenberger, 1983). The supports that have been

created have allowed many of these individuals to return to the community, but there are now greater opportunities to be recognized for deviant behavior and therefore to be referred to mental health services (Reiss, 1990a). To examine the accuracy of this assertion it would be appropriate to test the statement that medication rates on individuals currently in the community are greater than their proportion under pre-standards institutional living. For this to be accurate, a greater proportion of people would be on psychotropic medications now that they are living in the community than when the same group was living in the institution.

CHAPTER II

METHOD

Subjects

The records of 1,077 individuals recorded as living at the Grafton State School (now known as the North Dakota Developmental Center) and the San Haven facility on January 1, 1980 were followed on two later dates, January 1, 1989 and January 1, 1995. Of the 1,012 (94%) people with records found, 539 (53.3%) are male and 473 (46.7%) are female, with the age range from 1 year, 4.5 months to 90 years, 10 months in 1980. Although the July 1, 1980 census for the Grafton facility showed 829 people on the records, this project identified 867 people estimated to be at the Grafton facility by the data collected around the January 1, 1980 date. The excess is related to the movement of people between the two facilities with records that are unclear as to the person's exact location on the target date. Of the 867 identified at Grafton, the gender proportions were the same as the total population, 52.9% (459) were males and 47.1% (408) were females.

A distinction between the total population (both Grafton and San Haven residents) and the Grafton facility residents is made in several instances. Historical administrative statistics are available for the Grafton facility alone for

which comparisons of reliability and validity are based. At the outset of the study, only Grafton individuals were going to be considered as the records were known to be in relatively good condition. As the San Haven facility was closed, the records received at the Grafton facility arrived disorganized with several records of people appearing to have been lost. Given this pattern, the people at San Haven were not going to be included out of concern for a lack of accessibility. As data collection began, it was necessary that records from both facilities be examined as people were moved between them on a regular basis. As well, those records from the San Haven facility that could be found had appropriate data in most cases and findings about all of the people "institutionalized" in North Dakota would be more complete if they were included.

The age of individuals averaged 37.09 (SD = 17.11) years at the 1980 study date and averaged 12.82 (SD = 10.93) years old when they were admitted to the institutional system.

Study Variables

A number of variables were defined for data collection about this population of institutionalized people. As mentioned earlier, the definition of Institutionalized was required to be revised almost immediately upon initiation of data collection due to confusion in the records. However, the final result is a more complete assessment of the experiences of institutionalization during years of such phenomenal changes in public policy.

The dates of the study (Study Dates of January 1 of 1980, 1989, 1995) represent three stages. The 1980 time period represents those experiences prior to systematic use of externally evaluated professional standards and prior to the court-ordered deinstitutionalization. The second point, 1989, represents the point at which the newly developing system has met all standards required by the court for the first time and a substantial number of people have moved from the institution to live in services covered by the same standards in the community. Change is seldom permanent, but without a measure of the stability of change following such sweeping public policy shifts, outcomes fail to be meaningfully evaluated for endurance. The conclusion of the lawsuit (ARC vs. Olson, 1982) in 1995 reflects a time at which the public policy change agents have concluded the system is adequately stable such that further mandates were not required.

Each time variable was also selected because of proximity to other time variables available for comparison. In association with efforts of the lawsuit, medication use patterns in the North Dakota community-based developmental disabilities system first occurred in 1988 (Burd, Fisher et al. 1991) and was repeated in 1993 (Burd, Williams et al. 1997). The dates, although not precisely overlapping, provide a comparison within the same geographic region at similar time points and an overlapping of people.

The total cohort of people during this period of institutional and community living conditions permit

comparisons between medication use rates in both sites, while following the same cohort of individuals through time and settings/events.

Although the total institutionalized population is examined, each individual's residence as indicated in the record is maintained in the database so that in some instances the Grafton group can be separated from the San Haven facility. The separation enables an evaluation of differences, noting similarities, and relating reliability/validity measures taken just at Grafton to the appropriate sub-populations.

Diagnoses are coded by the major categories of the Diagnostic and Statistical Manual, 4th Edition (APA, 1994) and examined at each point in time. The broad diagnostic categories were used rather than specific diagnoses both because of the changing diagnostic concepts over time, but also for categorization at a level of data aggregation that permitted comparisons to be made. This method has been used by other authors (Bates, Smeltzer & Arnoczky, 1986; Burd, Fisher et al, 1991; Burd, Williams et al., 1997).

Medication categories based upon classifications in the Physician's Desk Reference (Medical Economics Company, 1997) were also selected based upon similar procedures by other authors and for the same basic purposes of data management as diagnostics (Bates, Smeltzer & Arnoczky, 1986; Burd, Fisher et al, 1991; Burd, Williams et al., 1997). Medication dose comparisons are difficult to be made directly with one another because there are few commonalities between them.

Only the Neuroleptics (e.g., haloperidol, thioridazine, etc.) have a relative potency table which permits a measure of comparison (Maxmen, 1991). Data on doses were collected on all individuals where available. No data recorders were asked to codify the diagnoses, medications, or doses as each recorder simply recorded verbatim the actual diagnoses, medications and doses by the names, codes, and measurements available in the record. The Psychoactive variable consists of both medications used for seizure management and medications used for psychiatric/behavioral change in the individual, with the addition of the Beta blocker Inderal, which was found to have frequent psychiatric/behavioral change uses. Psychiatric use medications are those identified for use in the records for the change of psychopathological symptoms or behavior, whether a specific diagnosis is provided or not. The Seizure medication variable consists of medications used for epilepsy as indicated in the record. Finally, the Neuroleptic variable consists of those antipsychotic medications for which there is a potency equivalence formula enabling the comparison of doses (Maxmen, 1991).

Level of mental retardation was taken from psychological evaluations nearest to 1980. Presence of a seizure disorder was determined if there was a medical diagnosis of the seizure disorder in each of the years of the study. Date of birth was taken from birth certificates where possible, or from the most reliable document available in the record based upon the professional experience of the data collector. In a

few cases, no actual birth date is available because birth records in North Dakota -- and some other states -- in the late 1800's and early 1900's were not highly systematized. In those cases, the birth date accepted as the best approximation by the facility was used. Date of admission is the date admitted to the institution without placement until after 1980. Placement date was the last date of placement prior to either Study Date. Of the 115 people remaining in the institution in 1995, only two (1.7%) had been on placement on the Study Date in 1989. Discharge dates were also collected as a means of assisting in tracking people. The Placement Date is when the individual moves out of the facility to reside elsewhere, whereas the Discharge Date is that date at which the individual is removed from the Roster of the Developmental Center. The exact meaning and purpose of the Roster goes back to ease of returning a person to the institution, a distinction which became virtually meaningless over time. However, mail was sent to people on the Roster which sometimes provided evidence of residence, survival, and death.

Date of death reflects the date recorded as the person having died; however, sources of information on death did not always provide exact dates. Sources of death included death certificates on file in the archive, letters announcing the individual's death in the archive, a search by the North Dakota Department of Vital Statistics, human service center file entries, and the Social Service Death Index (SSDI). The SSDI is an electronic website (www.ssdi.archive.com) at which

a database of death information taken from the Social Security Administration death files can be searched by social security number, name, residence, or even dates of birth or death. In several cases the date of death is limited to the month and year. In those cases, the first of the month was arbitrarily selected to represent the specific date of death.

Etiology of mental retardation was taken from records indicating a professional opinion about the cause of the mental retardation. It should be noted, however, that the basis for such professional opinion varied and were often reflective of theories active at different points in history. A common example is an etiology of cultural-familial cause which could range from genetically influenced (e.g., a "slow" family as one social history noted) to situational (e.g. one individual that only spoke Norwegian was admitted in the 1930's for having attempted to harvest his neighbor's land and the sheriff could not understand him). Most etiological classifications of Down Syndrome did have support of genotyping, as did several other genetic disorders.

The diagnosis of Autism or Pervasive Developmental Disorder was not included in the Diagnosis category because of the etiological implications and as a means of keeping it separated from the already-broad category of Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence. These diagnoses can range from learning disabilities to conduct disorder, movement disorders, and genetic abnormalities (e.g., Rett Syndrome).

Materials

The investigator, research assistant, and Human Service Center Developmental Disabilities Casemanagers (DDCMs) used the same data collection forms to search the current and archived records of each individual. There was a section of the form for each time period on which the individual's code number was identified on each page. The individual's name, for use by those authorized to review the records during the collection phase, was identified with the code on a label pasted to the forms. The label included the individual name, Social Security Number, date of birth, date of placement, region placed to, agency placed to, and gender.

The archived Developmental Center data was collected first in order to: 1) base identification on original records (including birth certificate, Social Security card); 2) minimize the volume of data for the DDCMs in the community to complete; and 3) clarify the individual's qualifications for participation to minimize excess effort. The records clerk maintains a master list of identification codes to permit follow-up studies by qualified investigators.

The data collection form for each follow up survey date (i.e., 1989, 1995) was color coded to promote accuracy, with only the 1995 form prepared for those placed after January 1, 1989. For those forms disseminated to Developmental Disabilities Program Administrators (DDPA) there were instruction sheets. They were for the DDPA's to help answer questions DDCMs might have, in addition to the individual instruction sheet for the DDCM to use.

The community based data collector (DDCM) could indicate information about the individual's death whether prior to or after the study date, if it applied. Type of residence and vocational activity were circled from among the choices, which were supplied by the Division of Disability Services (the central state agency which determines services available).

Data spaces are provided for up to eight diagnoses of medical conditions and/or psychopathology as identified in sources of information with which the DDCM is highly familiar as a central part of the job description. These sources were the same as those examined in the institution's archive for the 1980 data collection and could be from a variety of sources including the individual's program planning document, psychological evaluation, physician record, or psychiatric consultation note. Similarly, nine spaces are provided to list all medications prescribed as of that date and the dose per day. For each, the diagnoses and the medications, a "Date of Data Source" by month and year of the document is collected in order to permit an estimate of how consistent the time point of information was available across individuals. For example, one individual may have seen a physician on the exact date with diagnoses and medications prescribed noted on that day (a highly unlikely event, given the day was a national holiday in each case), yet another individual may have last been seen in the DDCMs records in the previous July and another not have had a psychological evaluation or psychiatric visit for four years (because he or

she did not display a need for those services). In this last case, the most recent review of the diagnosis may be up to several YEARS prior to the study date. Instructions were to identify two points of information around the Study Date, and use that to interpolate the specific medication dose.

Additional data, although not directly involved in the analysis of the hypotheses, is collected to provide further characteristics of the population. Such variables include: type of residence, closest adaptive behavior measure, intellectual and/or mental age measure, original date of institutionalization, length of stay, years in the community, and county/region of admission.

Procedure

The procedure of the study is straightforward as an archival project. The subjects at the Center on January 1, 1980 were identified through a systematic review of admission, discharge, and transfer records. Each individual's file was examined in the archive of the Center for the relevant variables as of 1980. Forms for individuals found and thought to be surviving to 1989 and 1995 were created and disseminated to the regional human service centers. People moving across regions or unfamiliar to the region were referred back to the investigator. For those people remaining at the Center, each person's archive file was further examined for the 1989 and 1995 data points.

Although some DDCM's completed the community data forms, most of them were completed by the principal investigator traveling to each human service center, except for one, and

examining the records on each person that were available. Closed records older than three years were often not available and are considered missing data points for that Study Date.

Individuals were tracked through the Central Records Department of the Developmental Center, the computerized files of the Division on Developmental Disabilities of the Department of Human Services, and by case managers in each of the eight Human Service Centers throughout North Dakota. Consent for involvement in the study was not relevant as this is a review of existing records of treatment, does not involve any manipulation, and confidentiality of individuals is maintained. Although provisions were being made to contact those people leaving the state, the small numbers of people (13 people or 1.2% of the original census) made for a negligible impact which, when compounded with years of lost contact, made this impractical and meaningless.

Each individual is identified by name and social security number within the North Dakota Department of Human Services (DHS) and were additionally assigned individual subject codes for data handling. The codes and names for each person, both those currently living in the Developmental Center and those living in the community, will continue to be maintained by the Records Clerk of the Developmental Center for cross-referencing purposes and further research on this population. Such responsibilities are consistent with the job position relative to the maintenance of information on people with developmental disabilities in North Dakota.

Approval for the research was obtained from the Institutional Review Board of the University of North Dakota, the Research Services Committee, Human Rights Committee, and Superintendent of the North Dakota Developmental Center, and Director of Management Services (Chief Financial Officer) in the Department of Human Services prior to the formal data collection. In preparation for proposing the project, data relevant to the operation of the Developmental Center and consistent with employment responsibilities of the principal investigator was examined to estimate the logistical viability of the project. Records based in the regional mental health centers had not been systematically examined prior to the study, except through individual cases referred to the Developmental Center, prior to the project beginning.

A single research assistant was involved with the investigator in extracting the data from the archive records of the Center to complete the forms. Of the possible maximum of 25 items on each archival form that could be completed, ten records were examined by both workers with three coding items different (1.2%) between them, none of which in this instance would impact the final coding of the data (i.e., a mistaken Social Security digit, misspelled county name, and a placement and discharge date interchanged).

Both the investigator and DDCMs collected data in the community settings. Developmental Disabilities Casemanagers' (DDCM) job responsibilities include the facilitation of all services for people identified as being entitled to services, which specifically includes all individuals residing at the

San Haven and Grafton facilities as of January 1, 1980. They are trained in record keeping and in obtaining all services for the individual including residential, vocational, medical, and other need areas. Many individuals are likely served by private residential and vocational services, whose records on the individual are considered open for review by casemanagers and from whom assistance in obtaining information is regularly obtained by the DDCM.

The current location of each individual, or their location at the time of death, was ascertained through Developmental Center records, Division of Developmental Disabilities computerized records, and the assistance of each of the eight regional human service centers' DDPA. A preliminary list was sent to each DDPA for them to check against the records in their region prior to disseminating forms. With agency support from a few of the DDPA's, casemanagers were provided information about the study and the nature of the information to collect. They were provided forms for the individuals on their caseload as well as those on their caseload upon the individual's death. In one region, all forms (40) were completed by the DDCMs, in another region about one-third of the forms were done by DDCMs (40), and in a third region there were a few completed by the DDCMs (25). In all other cases, the principal investigator completed the community forms from records at each human service center.

Data was accumulated from files of the Developmental Center from documents most closely related to the target

information; for example, diagnoses were taken primarily from psychological evaluations as they were a consistent source of diagnosis listing. Medical diagnoses were reviewed in those evaluations and in medical evaluation forms which began in 1981. Full time physicians were consistently employed at the Developmental Center since the facility had opened, and all prescriptions were being recorded in the Medical Running Record document at that time. The psychological evaluations also provided level of mental retardation, intellectual testing, adaptive testing, and etiological information. Birth certificates and social security cards were maintained on everyone that was at the facility after approximately 1981, unless their record was damaged.

Later information (medications and diagnoses) for people residing in the Center were available from the computer database as a result of real-time data entry. All Center data was considered to be accurate for the study dates (month/year zero) because it was taken directly from the specifically active database coded to be relevant to the person at the time. The same way with medications, as the prescription for that date and would show canceled or changed if there had been any changes.

For the community data collection sheets, the diagnoses were taken from any psychological evaluation, team planning document, medical evaluation, or psychiatric chart note which was the closest to yet still preceded the Study Date of data collection. For example, if there were a psychological evaluation dated 10/15/1987 and another 3/12/1993, the

date/month would be 10/87 for the 1989 study date and 3/93 for the 1995 study date.

In coding, this would be considered 12/88 minus 10/87 (scored -14 months) and 12/94 minus 3/93 (scored -21 months). In each calculation the sign was preserved with items found in documents after the study date considered positive months. In each situation, however, there were occasions where the only data available had to be found on the "wrong" side of January 1 of the study target date as the best estimate of their status at the time.

Information on some individuals did not survive in the service system. This may have occurred for a variety of reasons, such as loss of records at the San Haven facility (estimated at $N=52$, 4.8% of census), misfiling of materials, moving out of the state ($N=13$, 1.2% of census), discharge from the developmental disabilities services, or expiration of the storage period (minimum of three years) after any of these events or death, the latter of which are accounted for in the results as missing data. The exact location of 69 people (6.4% of 1,077 Census) whose 1980 records were found is yet beyond the resources of this investigator to find. The number of "lost" people was anticipated to be limited due to the state's general practice to maintain periodic contact with all individuals receiving services.

January 1, 1989, reflects the earliest moment in which all individuals with developmental disabilities received services certified under the Health Care Financing Administration (HCFA) standards and a point at which all

services were at a level which the The Council grants Accreditation status for compliance to their standards. January 1, 1995, represents a point in which all services have met or exceeded the HCFA and Council standards for more than five years, thus demonstrating a consistent pattern of meeting those standards with a maturing service delivery system. Furthermore, the data was anticipated to be collected in 1996-97 in which records would have sustained the 1995 data more effectively than when it was collected in 1998.

The data was unable to be collected due to unforeseen and insurmountable obstacles in 1996-97. At the initiation of the data collection in 1998, the 1995 date was maintained because: 1) a substantial proportion of data was estimated to still be collectible for meaningful analysis (as had been estimated of the 1989 data in the original design); 2) concern over the likely mounting mortality loss of the population; 3) comparative power with the Burd, Williams et al. (1997) 1993 North Dakota data; and 4) to permit future follow-up studies a larger time span in which to examine system and population change against data collected at the point the lawsuit was closed. Data on deaths and residence was collected for the time period after 1995 for future researcher use.

Support and cooperation for the research was obtained from the Chief Financial Officer of the Department of Human Services, who is the legal authority to approve research conducted in the records of state agencies. The Director of

Disability Services, each Regional DDPA, and initially the Director of Human Services (the Director at the beginning of the project resigned in 1995) were included in meetings in advance to foster their support. In addition, an informational telephone number and e-mail address was offered to regional case managers to use to answer questions, assist in solving problems, or coordinate finding information which may have proven to be elusive. No such requests for further information was received and interviews of those completing the forms revealed they were clear and understandable. No forms completed by the DDCMs required follow up for more information or clarification, even of their handwriting.

Reliability/validity is best determined by comparison with administrative reports from 1980 and 1989 for the institutional context. This was determined to provide a more efficient, empirically valid, and reliable estimate of accuracy than individual form calculation.

Once data was collected and recorded, the data is boxed for storage. If additional information is necessary to be further examined the Record Clerk of the Developmental Center will match the forms to support confidentiality.

The study results will be shared with the Department of Human Services, which includes the Developmental Center, the Developmental Disabilities Division, and the regional centers in exchange for the support, assistance, and permissions. In addition, a gift certificate drawing provided incentive for DDCM assistance. Since research funds were not available to provide a gift certificate for each participating DDCM,

subject numbers are randomly selected until eight of the contributing DDCMs are identified to receive the gift. All assisting DDCMs are receiving a note of thanks.

Data manipulation has been continuously updated with subject information in a database file. The data was converted to SPSS for Windows statistical software package (Version 7.5.1, 1996) for analysis and all entry and coding was done by the principal investigator.

Coding of each set of variables was based upon existing categories. Each individual was coded to home region (region of the admission county) and each study date location by region of residence. Gender, dates and Grafton/San Haven facility residence are self-explanatory.

CHAPTER III

RESULTS

Data Collection Time Characteristics

In contrast to one another, diagnostic information was found to be more accurate from documents before the study date, but medication dose information was generally found in documents after the study dates to be most accurate (see Table 2). A physician's appointment in 2/95 that indicated the dose of depakote would increase from 600 to 700 milligrams was generally a better source of information than one from the previous July, as the records were not clear enough about whether further appointments occurred after July. Thus, the months of Diagnostic Information reflect a negative average near zero and the month of medications and their dose information reflect a positive average near zero.

Table 2. Months of document before/after target Study Date for Diagnostic Information and Medication Information.

Data Category	N	Mean Months	Std. Deviation	Skewness
Diagnostic 1989	710	-.85	9.95	-.575
Diagnostic 1995	711	-2.59	13.68	-1.791
Medication 1989	661	.58	7.45	.562
Medication 1995	663	1.30	7.12	-.175

The diagnostic information has a much broader distribution skewed heavily towards earlier months (Table 2), which reflects the large number of individuals whose only diagnosis of psychopathology is mental retardation, testing for which is not repeated frequently once clearly established. People without significant problems often had an evaluation even as early as 1988 and may never have had another since (thus, the same evaluation serving both 1989 and 1995 study dates). The distribution of medication information tended to reflect specific physician appointments held during that year, even an annual physical for those on no medications.

Demographics of the Population

Descriptive characteristics of people institutionalized in North Dakota as of January 1, 1980, are developed for the variables of the study and used in the comparisons. An alpha level of .01 was used in all statistical tests.

Because the two facilities' populations were originally intended to be separated, unique characteristics of the records of those people found at each facility are presented. Similarities and differences existed between the two as unique, but interrelated, organizations and these are of historical interest of themselves. As record keeping was both somewhat more confused (as to exactly who was at each facility on a given date) and more intact than originally expected, the opportunity to consider all institutionalized people in North Dakota on January 1, 1980 was capitalized upon.

The age of all individuals averaged 37.09 (SD = 17.11) years at the time of the 1980 Study Date and had averaged 12.82 (SD = 10.93) years old at the time they were admitted to the institutional system. As of the initial Study Date,

Table 3. Time variable comparisons by setting.

Time Variable	Facility	N	Mean Years	Std. Dev.
Admit Age	GSS	864	12.50	10.65
	SH	145	14.75	12.34
1980 Age	GSS	866	35.39	16.15
	SH	145	47.28	19.15
Years in Institutions	GSS	864	22.97	13.62
	SH	145	32.53	14.48
Placement Age	GSS	866	35.38	16.15
	SH	145	47.28	19.15

Facility Comparisons	t	df	Sig.
Age at Admission	2.303	1007	p>.01
Study Age	7.751	1009	p<.01
Years Institutionalized 1980	7.985	1009	p<.01
Placement Age	10.141	793	p<.01

average years of institutionalization was 24.35 years (SD = 14.14) with the range of .02 years to 66.58 years. Table 3 displays the time-related demographics for each of the

facilities, with each facility identified by the name as it was known in 1980 (i.e., Grafton State School is GSS, San Haven is SH). A series of comparisons between the people in the two facilities is displayed at the bottom of the table.

Although age of life events are an important way to examine the two populations, level of mental retardation provides a more direct examination of the characteristics of the population institutionalized. This variable reflects the ability level related to the condition. These data are reflected in Tables 4 and 5.

Table 4. Mental retardation level by gender, and setting of the people with surviving archival records.

	Grafton St. School (N=867)		San Haven (N=145)		Total (N=1,012)	
Level of MR	Female	Male	Female	Male	Female	Male
Normal	3	20			3	20
Mild MR	67	74		7	67	81
Moderate MR	79	98	11	10	90	108
Severe MR	102	105	16	23	118	128
Profound MR	148	150	32	34	180	184
Unspecified MR	2	2			2	2
Missing	7	10	6	6	13	16
Totals	408	459	65	80	473	539
Facility Percent	(47.0)	(53.0)	(44.9)	(55.1)	(46.7)	(53.3)

To put these numbers in a larger context, prevalence estimates of mental retardation in the general population range from 2% to 3% (APA, 1994), which would equate to approximately 13,000 to 19,500 people of the approximately

650,000 citizens of North Dakota. At the peak, there were under 1,300 people (0.2%) of the state's population, or between 6 to 10 percent of the estimated total number of people with mental retardation, who were institutionalized.

As a distribution across levels of mental retardation at each facility, the characteristics of the two are compared on a series of variables to examine differences which might make a difference when making comparison to the Grafton State School administrative records on medication use. These facility functioning level profiles can be found in Table 5 and medication profiles in Table 6. The pattern of functioning was different between the two facilities (Pearson Chi-Square = 23.193, $df = 5$, $p < .01$) with San Haven serving predominately less capable people.

Table 5. Proportion of people at each facility by level of mental retardation.

Level of MR	Grafton St. School (N=867)		San Haven (N=145)		Total (N=1,012)	
	Count	Percent	Count	Percent	Count	Percent
Normal	23	2.7%			23	2.3%
Mild MR	141	16.6%	7	5.3%	148	15.1%
Moderate MR	177	20.8%	21	15.8%	198	20.1%
Severe MR	207	24.4%	39	29.3%	246	25.0%
Profound MR	298	35.1%	66	49.6%	364	37.0%
Unspecified MR	4	.5%			2	.4%
Totals	850		133		983	
Missing of N	17	2.0%	12	8.3%	29	2.9%

Medication use patterns, the central issue, is examined to consider what differences may be contributed by combining the two populations. An examination of the two groups by psychoactive medications (psychiatric and seizure combined), and separate categories of psychiatric and seizure medications is provided in Table 6. Given that most of the

Table 6. Proportions of people at each facility by type of medication, with Pearson Chi-Square comparison on each setting.

	Grafton St. School (N=867)		San Haven (N=145)		Total (N=1,012)	
Medication	Count	Percent	Count	Percent	Count	Percent
Psychoactive-Y	454	54.8%	76	59.4%	530	55.4%
Psychoactive-N	375	45.2%	52	40.6%	427	44.6%
Psych. Use-Y	249	30.0%	31	24.2%	280	29.2%
Psych. Use-N	581	70.0%	39	75.8%	678	70.8%
Seizure Med-Y	276	33.3%	48	37.5%	324	33.8%
Seizure Med-N	554	66.7%	80	62.5%	634	66.2%
<hr/>						
SH/GSS Comparisons	Pearson Chi-Square		df	Sig.		
Psychoactive Med Use	0.954		1	p=.329		
Psychiatric Use	1.792		1	p=.181		
Seizure Medication Use	0.894		1	p=.344		

people had data available for analysis (psychoactive medications = 957, psychiatric use medications = 958, and seizure medications = 958) the facilities were similar.

The psychiatric medication use pattern reported by the administrative recording system in 1980 and 1989 is provided for comparative purposes to estimate the capacity of this data collection method to reflect the population's experiences. Data collection was initiated by Dr. Kenneth Yearwood in December, 1980 on the use of medications (memorandum to the Superintendent from Dr. Yearwood, January 14, 1987) with 30.1% on psychiatrically used medications compared to the study results of 30% without the known San Haven people, and 29.2% explicitly including San Haven residents. The data was administratively summarized again from a computer printout completed on January 12, 1989 (after San Haven closed) using all 281 of the individuals then at the Developmental Center (AIMS printout, 1/12/89). Of those 281, 256 are study participants. Psychiatrically used medications total 20.3 percent of the 281 residents, and the archives review of this study produced 20.9% of those from 1980 remaining in the institution at the same time period.

Meanwhile, the Burd Studies (Burd, Fisher et al., 1991; Burd, Williams et al., 1997) provide proportions of similar variables for people throughout the community in 1988 and 1993. Their results of 18% in data collected in 1988 is very similar to this study (19.2%) of psychiatrically used medications. On the dimension of overall psychoactive medication, the community data reflected a stable 37% (1988) and 38% (1993), and the previously institutionalized group now in the community displays a 40% (1989) and then 51% (1995) in overall medication use.

Psychotropic Medication Use with Standards

Psychotropic medication use in the institution following the implementation of standards is evaluated through the McNemar Test in comparing the proportions in 1980 and 1989 for those remaining in the institution. Another McNemar Test series is used to evaluate any proportional change from 1989 in the 1995 data (examining stability of any effect), as well as a comparison of proportions from 1980 to 1995. Data is provided in Table 7 which describes available data used in each analysis.

Table 7. Types of data points available for analysis.

Medication Type	Individuals Available for Analysis		
	1980	1989	1995
Surviving Individuals	1,012	898	793
Psychoactive	957	722	664
Psychiatric Use	958	721	664
Seizure Use	958	722	659

A series of cross-tabulations were computed from the above available data for use in the McNemar Test to evaluate differences in psychoactive, psychiatric and seizure use medications. The comparative data for 1995 is provided in the same table for each of the medication conditions as the data for 1989. The series of McNemar Tests for the 1980-89 institutional patterns are provided in Table 8 for each medication condition, with the 1980-95 comparisons provided in Table 9. Comparison tables for 1989-95 are in Table 10.

Table 8. Cross tabulations used to calculate McNemar Test for those remaining institutionalized.

Psychoactive 1980		Psychoactive 1989		Psychoactive 1995	
		No Med	Med	No Med	Med
No Med		49	13	14	10
Med		48	121	9	68

Psychiatric 1980		Psychiatric 1989		Psychiatric 1995	
		No Med	Med	No Med	Med
No Med		129	17	52	15
Med		47	38	11	23

Seizure Med 1980		Seizure Med 1989		Seizure Med 1995	
		No Med	Med	No Med	Med
No Med		104	15	32	16
Med		33	79	9	42

Table 9. Cross tabulations used to calculate McNemar Test for 1989 and 1995 medication patterns.

Psychoactive 1989		Psychoactive 1995		Psychiatric 1989		Psychiatric 1995	
		No Med	Med			No Med	Med
No Med		20	13	No Med		40	9
Med		3	66	Med		1	50

Seizure 1989		Seizure Meds 1995	
		No Med	Med
No Med		129	17
Med		47	38

Table 10. McNemar Test series regarding related pair-wise comparisons.

McNemar Tests			
	Psychoactive 1980 & 1989	Psychiatric 1980 & 1989	Seizure 1980 & 1989
N	231	231	231
Chi-Square ^a	18.951	13.141	6.021
Sig.	p<.01	p<.01	p>.01
<hr/>			
	Psychoactive 1980 & 1995	Psychiatric 1980 & 1995	Seizure 1980 & 1995
N	101	101	99
Sig.	p>.01	p>.01	p>.01
<hr/>			
	Psychoactive 1989 & 1995	Psychiatric 1989 & 1995	Seizure 1989 & 1995
N	102	102	100
Chi-Square ^a		0.346	
Sig.	p>.01 ^b	p<.01 ^b	p>.01 ^b
<hr/>			
a. Continuity Correction			
b. Binomial distribution used			

The pattern of differences and obvious decrease in the use of psychiatric purpose medications is also seen in the decrease of the combination variable, Psychoactives. The decrease in Psychoactive and Psychiatric medications reverses by 1995, to disappear in contrast to the 1980 levels. Seizure medication patterns, although displaying a moderate

decrease, does not reach a significant level at any time point for those living in the institution.

Institution and Community Comparison

Examination of later patterns must be done in the context of factors occurring in 1980 (Table 11). Finding a good way to provide information about previous medication status is complicated given the various ways of examining the issue. Table 11 provides a sense of where everyone went in the follow up study years as a function of their 1980 medication status.

Table 11. Proportion of each setting with 1980 medication group members, as a proportion of the later setting in 1989 and 1995.

		1980 Medication Prescribed			
		Institution		Community	
<u>Variable</u>	<u>1980</u>	<u>1989</u>	<u>1995</u>	<u>1989</u>	<u>1995</u>
Psychoactives	55.4	73.5	76.9	49.5	52.8
Psychiatric	29.2	36.8	33.7	26.8	28.7
Seizure Med	33.8	48.7	51.9	29.0	31.6
Neuroleptic	15.1	22.6	23.1	12.7	14.2

In order to understand the impact on the population of medication use in 1989 and 1995 in the two settings, it is important to understand the base rate occurring in 1980. Table 11 provides a tremendous amount of information in a concise fashion; however, it must be reviewed carefully to avoid misinterpretation. The data from 1980 is the actual percentages, where the 1989 and 1995 data for institution and

community is the percentage in each setting at each date of the people who were receiving those medications in 1980.

The medication use patterns between those who moved to the community as compared to those remaining in the institution is compared through the Mann-Whitney U Test with the data displayed in Table 12.

Table 12. Mann-Whitney U test of independent cells of each type of medication use for 1989.

	Residence	N	Mean Rank	Sum of Ranks
Psychoactives	NDDC	233	407.21	94880.50
	Community	489	339.72	166122.5
Psychiatric	NDDC	233	375.64	87525.00
	Community	488	354.01	172756.0
Seizure Meds	NDDC	233	398.19	92778.00
	Community	489	344.02	168225.0
Neuroleptics	NDDC	233	365.38	85134.00
	Community	489	359.65	175869.0
Mann-Whitney U Test				
	Psychoactive	Psych.	Seizure	Neuroleptics
Mann-Whitney U	46317.5	53440.0	48420.0	56064.0
Sig.	p<.01	p>.01	p<.01	p>.01

The combined variable of Psychoactive medications and the specific category of Seizure medications demonstrate a difference between the two settings, with the smaller proportion in the community settings in each case.

Community Rates Post-Institutionalization

Evaluation of the third hypothesis requires the examination of those individuals residing in the community and an examination of the proportionate changes in medication use patterns. The proportions for that cohort is provided in Table 13. The hypothesis prediction would be supported if the percentage of psychiatric use medications increased in the 1989 or 1995 time periods.

Table 13. History of medication use patterns for residents now in the community setting.

Medication	1980	1989	1995
Psychoactive	57.5%	45.2%	55.0%
Psychiatric	31.1%	19.6%	28.3%
Seizure	35.1%	30.4%	35.3%
Neuroleptics	17.0%	11.0%	10.9%

Cross tabulations for each medication variable between Study Dates is provided in Table 14. This allows an examination of the treatment individuals received through movement between use and non-use of each medication variable. For convenience of reading, the 1980 rows continue across the table to allow the same variable to be examined at both times. Because the comparisons between the 1989 and 1995 would require a third dimension to the table which is not possible on two dimensional paper, these cross tabulations are provided in Table 15.

Table 14. Cross tabulations used to calculate McNemar Test for those moving to the community.

		<u>Psychoactive 1989</u>		<u>Psychoactive 1995</u>	
Psychoactive 1980	No Med	243	39	14	10
	Med	120	261	9	68
		<u>Psychiatric 1989</u>		<u>Psychiatric 1995</u>	
Psychiatric 1980	No Med	410	47	52	15
	Med	123	83	11	23
		<u>Seizure Med 1989</u>		<u>Seizure Med 1995</u>	
Seizure Med 1980	No Med	401	30	32	16
	Med	61	172	9	42
		<u>Neuroleptics 1989</u>		<u>Neuroleptics 1995</u>	
Neuroleptics 1980	No Med	524	28	506	35
	Med	68	45	76	36

Table 15. Cross tabulations used to calculate McNemar Test for 1989 and 1995 medication patterns for those moving to the community

<u>Psychoactive 1995</u>			<u>Psychiatric 1995</u>		
Psychoactive 1989	No Med	Med	Psychiatric 1989	No Med	Med
	No Med	279	80	442	84
	Med	17	280	26	103
<u>Seizure Med 1995</u>			<u>Neuroleptic 1995</u>		
Seizure Med 1989	No Med	Med	Neuroleptic 1989	No Med	Med
	No Med	413	40	562	20
	Med	9	189	19	53

Table 16. McNemar Test series regarding related pair-wise comparisons for individuals who moved to the community.

McNemar Tests			
Comparison Variable	N	Chi-Square ^a	Significance
Psychoactive 80/89	663	40.252	p<.01
Psychoactive 89/95	656	39.629	p<.01
Psychiatric 80/89	663	33.088	p<.01
Psychiatric 89/95	655	29.536	p<.01
Seizure Meds 80/89	664	9.890	p<.01
Seizure Meds 89/95	651	18.367	p<.01
Neuroleptics 80/89	665	15.844	p<.01
Neuroleptics 80/95	653	14.414	p<.01

^a.Continuity Corrected

Table 16 provides the analyses of comparisons for just those people who moved to the community. The overall rates of 1980, again, need to be considered in terms of their original treatment status, which is accounted for here in the McNemar Test for related groups. All other comparisons were also completed in an examination of these variables, but non-significant findings were not included in the table in order to increase clarity. Simply, medication rates decreased from 1980 to 1989 across all medication areas, and increased again in all areas except Neuroleptics by 1995. Differences were only found for Neuroleptics between the 1980 and 1995 dates.

To illustrate the pattern of medication changes across the years, Table 17 provides an overview of each variable by

each setting, across each of the years of the study. The basic pattern is repeated in each setting, with a decrease in 1989, followed by a return to near previous levels by 1995 with the exception of the neuroleptics.

Table 17. Medication use proportions of each setting at each time point.

Medication	1980		1989		1995	
	Inst.	Comm	Inst	Comm	Inst	Comm
Psychoactive	76.9%	57.5%	58.4%	39.7%	77.5%	51.2%
Total	55.4%		45.7%		55.3%	
Psychiatric	33.7%	31.1%	24.0%	18.0%	38.2%	26.9%
Total	29.2%		20.0%		28.6%	
Seizure	51.9%	35.1%	40.8%	25.8%	59.0%	31.1%
Total	33.8%		30.6%		35.4%	
Neuroleptics	23.1%	17.0%	11.8%	10.4%	10.8%	11.3%
Total	15.1%		10.9%		11.2%	

CHAPTER IV

DISCUSSION

From the changes measured in this population's characteristics over the 15 year time period encompassed in this study the improvement in service opportunity is dramatic. Although it is clear those people remaining in the institution experienced an overall decrease in medication use across all categories, the same was true of the general population of people from the institution. However, the fact that proportions of every group returned to near base-line levels is a rather astonishing finding. The important exception to this rebound is the Neuroleptic class of medications, which dropped by about one-third in their use (15.1% to 10.1%) and remained there in 1995 (11.2%).

Population Characteristics

Although the age of the individuals at the San Haven facility averaged over ten years than the people at the Grafton facility in 1980 (47.28 years vs. 35.38 years), average years of admission at the time of the initial Study Date (32.53 vs. 22.97 years), and the same was true of the average age of placement (57.78 years vs. 41.59 years), the average age for admission of the individuals was relatively similar (14.75 years vs. 12.50 years). This would indicate that a significant characteristic at the time of

institutionalization (age) was similar to the overall population, but the San Haven individuals were an older subset of the institutionalized population. There are a variety of dimensions that can be examined for differences in the population, however all of these individuals were institutionalized whether they were served at the same time in one facility. In fact, as placements began to make maintenance of a second facility untenable, those remaining in San Haven were transferred to space at the Grafton facility by the time of closure.

The functioning level, medication use pattern, and the level of mental retardation at the San Haven facility is proportionately lower than the Grafton facility (Table 3) in 1980. The San Haven facility had been described by Assistant Superintendent Paul Witucki (personal communication, 1983) as a location for people with few ties to the Grafton site, either by not having family concerned about location, or by family seeking placement at San Haven to be closer for themselves to visit. Mr. Witucki worked in various staff positions at the Grafton State School for over 35 years when he retired in 1996 and served as Assistant Superintendent for the last 20 years.

The original intent to avoid what was considered the lack of records from San Haven. Instead, it was found to be fortuitous that the records which were recoverable enabled the inclusion of a greater proportion of North Dakota's institutionalized population.

Institutional Medication Use Pattern

Administrative records at the then Grafton State School, now North Dakota Developmental Center, provided clear evidence of a decrease in psychiatric medication use in the early years of the 1980's. The data supports the hypothesis that standards do decrease medication use, however that decrease did not remain stable except for the Neuroleptics.

Initially, there had been some confusion over whether to discriminate between those with diagnoses and those without diagnoses (i.e., for "behavioral" reasons). Standards and policies in the late-1980's established the need for formalized plans if any psychoactive, non-seizure use medication were prescribed. This obviated even the need for diagnoses, although it also permitted a more intellectually honest approach to diagnostic evaluation.

When distinctions existed between receiving medications with or without a diagnostic label, significant pressure existed for the psychologists and physicians. The teams were often faced with the need to develop a thoroughly detailed, formal intervention plan requiring much time and other resources. The psychologist was generally responsible for doing the diagnostic evaluations. Political pressures were even brought by staff approaching the consulting psychiatrist to obtain a diagnosis and thereby professionally "outflanking" the psychologist. These diagnostically related games were eliminated by requiring plans to be in place even if a diagnosis is provided.

In most respects then, there was some pressure through administrative hassle to minimize the use of medications as a way of avoiding the work involved in developing such plans.

Further, as the agencies were first attempting to meet standards with which they were unfamiliar there were extreme interpretations in some situations, and an overall resistance to enter into anything that was complicated to do -- such as medication use. This may help to explain the accompanying decreases in seizure medications, which should have been less subject to these effects as their use is based upon periodic objective testing and physiological reactions. Seizure medications, also, were being examined closely during this time period as the records on many people were poor as to how well the symptoms were documented. Monotherapy, or single drug treatment, was also an important concept being implemented at that time. Lastly, there was a time in this period where literal drug holidays were being recommended (Rinck, 1998), at which point problems that had been prompting medication use may have remained dormant or minimal for some time after discontinuation, but which would not last forever.

By 1995 the decreases in medication use disappeared, again with the important exception of the Neuroleptic which remained decreased. Whether these politically arranged and maintained pressures decreased as the system matured, or the technology and accuracy of medication use increased, or there new developments in pharmacology made more conditions treatable through medications, none of these can be

determined as is beyond the scope of this study. The effects were supposed to be maintained over time.

Community/Institution Comparisons

Right from the beginning the population of this study could have been changing. People continued to be admitted to the Developmental Center after January 1, 1980 and will do so into the future. The characteristics of the institution are even changing towards that of simply a state-operated community residential, vocational, and social services agency. One characteristic that appears to remain constant in the North Dakota developmental disabilities system is the need for a zero-rejection service option. When the complexity an individual presents is more than the resources of the private service agency, or other state or public school agency, the Center is a place of last recourse.

Over 15 of those institutionalized in 1995 were known to have been placed into the community and returned to the Center, in some cases with several attempts. Of very positive note, only two of those people were returned during the 1989 to 1995 time period. The remaining individuals at the Center in the late 1990's, about one-third of the population current population, had never been admitted to the Center until this admission. Efforts to curb admissions to the Center have not been highly successful, as the 1993 Developmental Center budget projection was designed to serve an average daily population of 127 which has never been achieved (current population is approximately 140).

Despite this, and in contrast to successful decreases in medication use in the institution in the first hypothesis, the community residing individuals do not require a higher use of medications in comparison with those "left behind" in the institution. To the contrary, individuals in the institution are given psychoactive medications at a higher rate than the community counterparts (58.4% to 39.7%) but primarily in the area of medications for seizure management (40.8% to 25.6%) to a significant degree (Table 12). This was not the case for either Psychiatric Use medications or the specific subset of Neuroleptics. Both groups sustain their decrease in Neuroleptics through 1995, but the general return towards 1980 proportions in medications use is pervasive across all other categories (Table 13) despite setting.

Community Medication Use Patterns

It is not entirely clear if the features of the increase in Psychoactive medication use was noticeable in general ways in this investigators clinical practice and therefore contributed to the errant third hypothesis. It is now apparent that people in the community would be receiving as high a rate of medication use as they were receiving in the institution, but not until after a significant decrease by 1989 that was a matched characteristic of the entire population of study. The increase in medication use simply returned them to near the 1980 level that had been experienced in the institution. Perhaps that was an appropriate rate of medication use for the population.

It is striking that the 1989 data was so similar to the Burd, Fisher et al. (1991) data collected in North Dakota group homes in 1988 (Psychoactives = 37% in the Burd Study, 39.7% in this study; Psychiatric Use = 18.0% Burd Study, 18.0% in this study). Whereas the later study conducted in 1993 (Burd, Williams et al., 1997) displayed a minor increase (e.g., 37% to 38% in Psychoactive medications; 18% to 20% in Psychiatric Use medications), such minor changes are negligible -- unless, as a total population measure (97% return rate) it was indicative of a rise in overall use (besides just with the deinstitutionalized population). Between 1989 and 1995 the people that had been institutionalized, which were now living in the community, showed a dramatic increase back to the range that had been characterized as "excessive" by the plaintiffs and recognized as such by the federal court (ARC v. Olson, 1982) in 1980.

Summary and Conclusions

It remains to be further studied as to the ramifications of standards, policies, and procedures that are state-of-the-art in medication use, and what role this has on changing medication use rates over time. As discussed in the introduction, the movement towards recognizing people with mental retardation as capable of having mental illness has been dramatic. Several scales towards objectivity have been or continue to be in development, entire organizations have been founded or subgroups formed, and fewer people than ever are being segregated in institutions.

The process of collecting information about the course each life has taken after such a dramatic shift of events as occurred in North Dakota has been a fascinating one. Embedded within the immense database that has been developed as part of this project, there are several more answers to the question "What happened to the Class (-action lawsuit) of ARC vs. Olson", and -- possibly more important -- questions that will arise from the patterns of life events. This is beyond the scope of a dissertation, but promises to be a fascinating adventure for the next few years. Through this project, support has been generated for an annual review of the status of those individuals remaining. Thus, the story is not over!

Questions already being asked about the deinstitutionalization process have to do with quality of life, mortality patterns, cost of services, protection of the individual and society, and similar issues. As is always the case with scientific endeavor, the answering of the questions posed in this study have only prompted further questions to investigate.

REFERENCES

American Psychiatric Association. (1980). Diagnostic and statistical manual of mental disorder (3rd ed.).

Washington, DC: Author.

American Psychiatric Association. (1987). Diagnostic and statistical manual of mental disorder (3rd edition, revised). Washington, DC: Author.

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorder (4th edition).

Washington, DC: Author.

ARC v. Olson, 713 F. 2d 1384 (D.C.N.D. 1982).

Baroff, G. S. (1986). Mental retardation: Nature, cause, and management, (2nd edition). Washington, DC: Hemisphere Publishing Corp.

Bates, W.J., Smeltzer, D.J., & Arnoczky, S.M. (1986). Appropriate and inappropriate use of psychotherapeutic medications for institutionalized mentally retarded persons. American Journal of Mental Deficiency, 90, 363-370.

Borthwick-Duffy, S.A. & Eyman, R.K. (1990). Who are the dually diagnosed? American Journal on Mental Retardation, 94, 586-595.

Briggs, R. (1989). Monitoring and evaluating psychotropic drug use for persons with mental retardation: A

follow-up report. American Journal on Mental Retardation, 93, 633-639.

Buck, J.A., & Sprague, R.L. (1989). Psychotropic medication of mentally retarded residents in community long-term care facilities. American Journal on Mental Retardation, 93, 618-623.

Burd, L., Fisher, W., Vesely, B.N., Williams, M., Kerbeshian, J. & Leech, C. (1991). Prevalence of psychoactive drug use among North Dakota group home residents. American Journal on Mental Retardation, 96, 119-126.

Burd, L., Williams, M., Klug, M.G., Fjelstad, K., Schimke, A. & Kerbeshian, J. (1997). Prevalence of psychotropic and anticonvulsant drug use among North Dakota group home residents. Journal of Intellectual Disability Research, 41, 488-494.

Chadsey-Rusch, J., & Sprague, R. (1989). Maladaptive behaviors associated with neuroleptic drug use. American Journal on Mental Retardation, 93, 607-617.

Crew, W. D., Jr., Bonaventura, S. & Rowe, F. (1994). Dual diagnosis: Prevalence of psychiatric disorders in a large state residential facility for individuals with mental retardation. American Journal on Mental Retardation, 98, 688-731.

Eyman, R.K., Chaney, R.H., Givens, C.A., Lopez, E.G., & Lee, C.K.E. (1986). Medical conditions underlying

increasing mortality of institutionalized persons with mental retardation. Mental Retardation, 24, 301-306.

Findholt, N.E. & Emmett, C.G. (1990). Impact of interdisciplinary team review on psychotropic drug use with persons who have mental retardation. Mental Retardation, 28, 41-46.

Gardner, J.F. (1990) Application of behavior intervention standards for individual with a developmental disability and a mental health diagnosis. ACDD Accreditation Update Newsletter, 7 (2), 4.

Glaser, B.A., & Morreau, L.E. (1986). Effects of interdisciplinary team review on the use of antipsychotic agents with severely and profoundly mentally retarded persons. American Journal of Mental Deficiency, 90, 371-379

Gowdey, C.W., Zarfes, D.E., & Phipps, S. (1987). Audit of psychoactive drug prescriptions in group homes. Mental Retardation, 25, 331-334.

Hancock, R.D., Weber, S.L., Kaza, R. & Her, K.S. (1991). Changes in psychotropic drug use in long-term residents of an ICF/MR facility. American Journal on Mental Retardation, 96, 178-141.

Hurley, A.D. & Sovner, R. (1991). Cognitive behavioral therapy for depression in individuals with developmental disabilities. The Habilitative Mental Healthcare Newsletter (formerly the Psychiatric Aspects of Mental Retardation Reviews), 10, 41-47.

Jacobson, J.W. (1990). Do some mental disorders occur less frequently among persons with mental retardation? American Journal on Mental Retardation, 94, 596-602.

Kastner, T., Friedman, D.L., O'Brien, D.R., & Pond, W.S. (1990). Health care and mental illness in persons with mental retardation. The Habilitative Mental Healthcare Newsletter (formerly the Psychiatric Aspects of Mental Retardation Reviews), 9, 17-24.

Kastner, T.A. & Walsh, K. (1994). Exchange of views on psychotropic drug review: Interdisciplinary team review of psychotropic drug use in community settings. Mental Retardation, 32, 243-245.

King, B.H., DeAntonio, C., McCracken, J.T., Forness, S.R., & Ackerland, V. (1994). Psychiatric consultation in severe and profound mental retardation. American Journal of Psychiatry, 151, 1802-1808.

Kolstoe, R.H. (1973). Introduction to statistics for the behavioral sciences, revised. Homewood, IL: Dorsey Press.

Lakin, K.C., Braddock, D. & Smith, G. (1994a). Trends and milestones: State institution closures. Mental Retardation, 32, 77.

Lakin, K.C., Braddock, D. & Smith, G. (1994b). Trends and milestones: Changes in residential setting size. Mental Retardation, 32, 248.

Lepler, S., Hodas, A. & Cotter-Mack, A. (1994). Exchange of views on psychotropic drug review: What input do

community-based psychiatrists need from staff and families of our consumers? Mental Retardation, 32, 245-247.

Lepler, S., Hodas, A. & Cotter-Mack, A. (1993). Implementation of an interdisciplinary psychotropic drug review process for community-based facilities. Mental Retardation, 31, 307-315.

Lipman, R.S. (1970). The use of pharmacological agents in residential facilities for the retarded. In F.J. Menolascino (Ed.) Psychiatric Approaches to Mental Retardation. (pp. 387-398). New York: Basic Books.

Luchins, D.J., Dojka, D.M., & Hanrahan, P. (1993). Factors associated with reduction in antipsychotic medication dosage in adults with mental retardation. American Journal on Mental Retardation, 98, 165-172.

Lukkasson, R., Coulter, D.L., Polloway, E.A., Reiss, S., Schalock, R.L., Snell, M.E., Spitalnik, D.M., & Stark, J.A. (1992). Mental retardation: Definition, classification, and systems of supports, 9th Edition. Washington, DC: American Association on Mental Retardation.

Macmann, G. M. & Barnett, D.W. (1993). Reliability of psychiatric and psychological diagnoses of mental retardation severity: Judgements under naturally occurring conditions. American Journal on Mental Retardation, 97, 559-567.

Maxmen, J.S. (1991). Psychotropic drugs: Fast facts. New York, NY: W.W. Norton & Company.

Menolascino, F.J., Wilson, J., Golden, C.J., & Ruedrich, S.L. (1986). Medication and treatment of schizophrenia in

persons with mental retardation. Mental Retardation, 24, 277-283.

Pawlarczyk, D. & Beckwith, B.E. (1987). Depressive symptoms displayed by persons with mental retardation: A review. Mental Retardation, 26, 325-330.

Perske, R. (1991). A sudden change in the life of Johnny Lee Wilson. In Unequal Justice?, (pp. 43-50). Nashville, TN: Abington Press.

Poindexter, A.R. (1989). Psychotropic drug patterns in a large ICF/MR facility: A ten-year experience. American Journal on Mental Retardation, 93, 624-626.

Poindexter, A.R., Antanitus, D., Green, D. Cullen, E. & Campanella, T. (1994, May). Perspectives of institutional psychiatrists on the imposition of standards, in the panel Integration of physicians in the interdisciplinary team process. Paper presented at the meeting of the American Association on Mental Retardation, Boston, MA.

Reiss, S. (1987). Symposium overview: Mental health and mental retardation. Mental Retardation, 25, 323-324.

Reiss, S. (1990a). Special section on dual diagnosis: Introduction. American Journal on Mental Retardation, 94, 577.

Reiss, S. (1990b). Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. American Journal on Mental Retardation, 94, 578-585.

Rinck, C. (1998). Epidemiology and psychoactive medication. In S. Reiss & M.G. Aman (Eds.), Psychotropic

medications and developmental disabilities: The international consensus handbook (pp. 31-44). Toledo, OH: The Ohio State University Nisonger Center.

Rinck, C., Guidry, J., & Calkins, C.F. (1989). Review of states' practices on the use of psychotropic medication. American Journal on Mental Retardation, 93, 657-668.

Rivinus, T. (1980). Psychopharmacology and the mentally retarded patient. In L.S. Szymanski & P.E. Tanguay (Eds.), Emotional disorders of mentally retarded persons: Assessment, treatment, and consultation (pp. 195-221). Baltimore, MA: University Park Press.

Schaal, D.W. & Hackenberg, T. (1994). Toward a functional analysis of drug treatment for behavior problems of people with developmental disabilities. American Journal on Mental Retardation, 99, 123-140.

Scheerenberger, R.C. (1983). A History of Mental Retardation. Baltimore, MA: Paul H. Brookes Publishing Co.

Scheerenberger, R.C. (1987). A History of Mental Retardation: A Quarter Century of Promise. Baltimore, MA: Paul H. Brookes Publishing Co.

Slaw, K.M. & Kalachnik, J.E. (1985). Tardive dyskinesia: Facts the mental health administrator may not know. Journal of Mental Health Administration, 12, 22-27.

Sovner, R. & Hurley, A.D. (1983). Do the mentally retarded suffer from affective illness?. Archives of General Psychiatry, 40, 61-67.

Sovner, R. & Hurley, A.D. (1986). Four factors affecting the diagnosis of psychiatric disorders in mentally retarded persons. Psychiatric Aspects of Mental Retardation Reviews, 5, 46-48.

Sovner, R. & Hurley, A.D. (1987). Guidelines for the treatment of mentally retarded persons on psychiatric inpatient units. Psychiatric Aspects of Mental Retardation Reviews, 6, 7-14.

Sovner, R. & Hurley, A.D. (1988). The community residence psychiatric interface. Psychiatric Aspects of Mental Retardation Reviews, 7, 52-59.

Sovner, R. & Hurley, A.D. (1990). Assessment tools which facilitate psychiatric evaluations and treatment. The Habilitative Mental Healthcare Newsletter (formerly the Psychiatric Aspects of Mental Retardation Reviews), 9, 91-97.

Sovner, R. & Hurley, A.D. (1991). Seven questions to ask when considering an acute psychiatric inpatient admission of a developmentally disabled adult. The Habilitative Mental Healthcare Newsletter (formerly the Psychiatric Aspects of Mental Retardation Reviews), 10, 27-30.

Stone, R.K., Alvarez, W.F., Ellman, G., Hom, A.C., & White, J.F. (1989). Prevalence and prediction of psychotropic drug use in California developmental centers. American Journal on Mental Retardation, 93, 627-632.

Sturmey, P. & Bertman, L.J. (1994). Validity of the Reiss Screen for maladaptive behavior. American Journal on Mental Retardation, 99, 201-206.

Szymanski, L.S. (1980). Psychiatric diagnosis of retarded persons. In L.S. Szymanski & P.E. Tanguay (Eds.), Emotional disorders of mentally retarded persons: Assessment, treatment, and consultation (pp. 61-81). Baltimore, MA: University Park Press.

Szymanski, L. & Grossman, H. (1984). Dual implications of "Dual Diagnosis". Mental Retardation, 22, 155-156.

Thomas, J.R. (1994). Quality care for individuals with dual diagnosis: The legal and ethical imperative to provide qualified staff. Mental Retardation, 32, 356-361.

Zaharia, E.S. (1986). Reducing reliance on psychotropic drugs. Superintendents' Digest - NASPRFMR, 5, 11-13. (National Association of Superintendents of Public Residential Facilities for Mental Retardation).