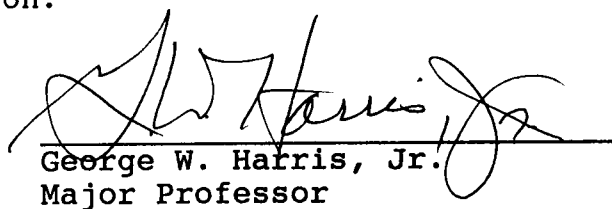


To the Graduate Council:

I am submitting herewith a dissertation written by Terry Allen Wallace entitled "The Relationship of Health and Safety of Individuals with Mental Retardation and Developmental Disabilities and the Size of Their Residential Facilities in Ohio." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Education, with a major in Educational Administration and Supervision.


George W. Harris, Jr.
Major Professor

We have read this dissertation
and recommend its acceptance:

Mary Jane Connelly

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Accepted for the Council:


Associate Vice Chancellor and
Dean of The Graduate School

THE RELATIONSHIP OF HEALTH AND SAFETY OF INDIVIDUALS WITH
MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES
AND THE SIZE OF THEIR RESIDENTIAL FACILITIES
IN OHIO

A Dissertation
Presented for the
Doctor of Education
Degree
The University of Tennessee, Knoxville

Terry Allen Wallace

December 1993

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DEDICATION

This study is dedicated to the millions of men, women and children with mental retardation and developmental disabilities and their families.

ABSTRACT

Individuals with mental retardation and developmental disabilities and their families have chosen living arrangements in small, community-based settings rather than larger traditional facilities in increased numbers in recent years. The purpose of this study was to obtain and analyze previously unexamined information concerning the health and safety factors of those individuals related to the size of the residential facilities in which they lived. A secondary purpose was to identify recommendations for public policy related to facility size and individual health and safety.

Statutorily mandated public domain information reported on Major Unusual Incidents (MUI) occurrences involving individuals with mental retardation and developmental disabilities during a four-year period in Ohio was gathered and analyzed. From examination of these data, it was found that MUI occurred with greater than expected frequency in small facilities and with less than expected frequency in large facilities. Certain types of MUI also occurred more frequently than expected.

The researcher concluded that public policy should increasingly address health and safety issues regardless of the size of individual living arrangements, particularly in light of the acceleration in the rate of movement of individuals to smaller living settings.

PREFACE

The number of Americans with mental retardation and developmental disabilities is continuing to grow and is outstripping the traditional systems and resources available to adequately serve them. The changing family structure, longer life spans and greater competition for resources are interacting with increased individual freedoms and civil rights to force new options for individuals.

As decisions are made involving an increasing array of choices and options, the need for empirical information to better inform public policy makers, families and individuals has never been greater. The recommendations in this study are founded on current information. Consumers and others making life choices involving residential settings should seek all available information from government, local and national support organizations, service providers and other consumers in order to secure the latest information to meet their needs.

TABLE OF CONTENTS

CHAPTER	PAGE
I. INTRODUCTION	1
Background	1
Alternative Living Arrangements	3
Size of the Facilities	5
Lack of Research on Facility Size	8
Need for an Empirical Basis for Public Policy	13
Statement of the Problem	16
Purpose of the Study	17
Research Questions	18
Importance of the Study	18
Assumptions of the Study	21
Limitations of the Study	21
Delimitations of the Study	22
Definition of Terms	22
Organization of the Study	27
II. REVIEW OF THE LITERATURE	28
Historic Overview	28
Mid-Twentieth Century Changes in Public Policy	35
Late Twentieth Century Changes in Public Policy	38
Social Interactions and Life Conditions	41
Safety and Health in Institutional and Community Settings	44
Quality of Care	47
Changes in Adaptive Behavior	50
Community Supports	52
Possible Research Bias	54
Community and Family Opinion	55
Summary	56
III. METHODS AND PROCEDURES	58
MUI Report System	58
Source of Data	59
The Sample	60
Research Design and Data Analysis	62
IV. FINDINGS, ANALYSIS AND INTERPRETATION OF THE DATA	64
Findings	64
Summary of Significant Findings	74
V. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	75
Summary	75
Conclusions	77

CHAPTER	PAGE
Recommendations	82
BIBLIOGRAPHY	86
APPENDICES	96
A. Outline for Major Unusual Incident Reporting	97
B. Initial Major Unusual Incident Report for <u>Counties</u>	111
C. Follow-up Major Unusual Incident Report for <u>Counties</u>	113
D. Flow Chart--County Board Major Unusual Incident Notification	114
E. Major Unusual Incident Tracking System	115
F. Suggested Guidelines for Reporting Major Unusual Incidents	116
G. ODMR/DD Letter of Authorization	121
VITA	122

LIST OF TABLES

TABLE	PAGE
1. Sample of 1000 Major Unusual Incidents Selected for State Fiscal Years 1987-1990	65
2. Calculation of Chi-square Comparing Observed and Expected Frequencies of MUI by Facility Size	67
3. Analysis of Variance Test of Significance of the Relative Frequency of Occurrence of MUI in Small and Large Facilities for the Period of the Study	68
4. Chi-square Analysis of Types of MUI Incidents Occurring in Small and Large Facilities for the Period of the Study, 1987-90	70
5. Difference in the Occurrence of MUI in Small and Large Facilities Using a Chi-square Analysis of a Random Sample with 250 Incidents for Each State Fiscal Year	72
6. The Relationship between Facility Size and the Mean Number of MUI Using Pearson Correlation Coefficients for Sample with 250 Incidents Per State Fiscal Year	73

CHAPTER I

INTRODUCTION

Background

It's hard to describe to you the sacrifices that the parents of handicapped children have to make The simple pleasures of going to a movie or out to dinner takes a lot of planning. Due to a lack of trained (people in the community) . . . we must take Nicci with us almost everywhere we go. As Nicci gets older, we become more and more concerned about her future. Eventually, Nicci will have to rely on others to care for her as her mother and I cannot be sure we will always be well enough to care for her.

Jack Starr, parent
Defiance, Ohio (Bruney, 1990)

The provision of appropriate residential and necessary related services to individuals with mental retardation and developmental disabilities (MR/DD) is a major and growing concern in America today. The lives and futures of millions of men, women, and children are directly affected. They and their families are faced with few options, long waiting lists for services and little or no reliable information for making informed decisions. Aging parents are increasingly concerned with finding appropriate living settings for their adult children; settings that will be safe, healthy and stable. Since many parents fear they will die and leave their sons or daughters unattended, they often accept placements as they

become available through waiting lists in a "take-it-or-leave-it" atmosphere. When options do exist, little information is available to aid families in making informed choices concerning health and safety issues surrounding residential settings. It is ironic that families have more government mandated health and safety information available to them when shopping for a new automobile than when choosing a residential setting for a family member.

Decision makers in government are facing much the same problem as families when they attempt to allocate scarce resources to growing and competing groups. The imperative to balance healthy and safe environments with greater efficiency and cost controls while simultaneously attempting to reduce burgeoning waiting lists is growing daily. Yet, basic empirical information concerning individuals' health and safety within residential facilities presented in an easily understood context, such as the relationship to facility size, is currently unavailable. The need for this information will not diminish in the foreseeable future and is, in fact, growing.

The number of individuals identified as having mental retardation (MR) and/or a developmental disability (DD) has grown faster than increases in the general population of the United States during the past fifty years. Better and more available medical treatment technology, improved infection control, improved nutrition and living conditions, growing

infant survival rates, extraordinary trauma recovery and an increasing incidence of children exhibiting the effects of family dysfunction, parental substance abuse, physical abuse and neglect have all contributed to growing prevalence numbers and increased pressures on current service systems.

Further, as assessment and reporting procedures have become more efficient, a greater percentage of individuals has been identified as needing services. By 1990, the number of people with MR/DD on waiting lists for community homes in Ohio, the focus of this study, was well over 7,000 and increasing (Bruney, 1990). By 1992, the number had grown to 8,000 (ODMR/DD Survey, 1992).

Community living for vulnerable individuals of all ages, particularly those least able to speak for or represent themselves, has been a topic of growing public policy and debate. Resources, nationwide, have been inadequate to meet present needs given the high cost of the current system of residential service delivery. Questions have arisen concerning the most appropriate and most cost effective ways to provide homes for children and adults with MR/DD who no longer live with their families.

Alternative Living Arrangements

Today's families, by orientation, structure and need have been searching increasingly for more community assistance and

better supervision of appropriate and safe living alternatives for their sons and daughters who have disabilities. They no longer attempt life-long care responsibilities without such supports, particularly when disabling conditions are severe and place considerable stress on their families and resources. Many older parents who previously maintained their sons and daughters at home now find themselves increasingly frail and unable to adequately care for their middle-aged, disabled offspring. Parents are concerned, too, about the fate of their adult disabled sons and daughters after their own deaths. Parents expect more assistance from the community for their disabled family member to fill each day with appropriate daily living activities. They also support the development of facilities closer to their own homes and in their own neighborhoods. They also expect ongoing vocational and social training to be provided by such facilities and for lifestyles to more nearly approximate their own family's standard of living. Less tolerance exists for living conditions that are perceived as substandard. Above all, families expect alternative living arrangements to be publicly monitored and supervised and for living arrangements to be homelike, safe and very secure for their family members.

Size of the Facilities

Differing opinions currently exist in the MR/DD service field over whether smaller facilities are "better" than larger facilities in providing the best environment for persons with MR/DD. Notwithstanding the ongoing strong differences of opinion concerning the optimum capacity for a facility, size of a facility (the number of residents who live there) as a variable, has become a significant criterion of choice that has affected the flow of funds and the promulgation of laws and regulations in services for persons with MR/DD (Heal and Chadsey-Rusch, 1985). Traditionally, greater funding has been assigned to larger facilities. However, smaller foster homes and group homes have recently begun to receive favorable public support as alternative settings to house persons with MR/DD. While this national trend toward smaller facilities has grown, small facilities have not eliminated or replaced all large facilities and public institutions as providers of residential services. Tens of thousands of individuals have continued to be housed in large public institutions, nursing homes and private institutions in which they receive services highly acceptable to themselves and their families.

Size of a facility as a selection variable has been very effective as it is discrete, reliable and easily agreed upon by interested parties, (White, Lakin, Hill, Wright and Bruininks, 1988). Size of a community residential facility

has usually been measured in terms of the number of people or residents living in the facility on a full-time permanent basis. Size of a facility is not usually measured by the number of staff who live or work in a facility, as this number can vary. In small facilities, such as foster family or group home settings, staff providing supervision and support services often live in the same facility and are on call on a twenty-four hour basis. Staff, in larger institutional settings, on the other hand, tend to live in the community and to work on a shift basis at the facility.

By administrative rule in Ohio, a facility that was a foster home or a group home has been, by definition, small; although it might vary in size from one resident through ten residents. Other residential facilities, such as Intermediate Care Facilities for the Mentally Retarded (ICF/MR), are also referred to as small if they serve less than sixteen residents. In Ohio, community residential facilities for persons with MR/DD are considered large if they house sixteen residents or more. Such large facilities have been discouraged in Ohio through a building moratorium in place since the early nineteen eighties. Large facilities are generally not approved for development or construction without special dispensation or circumstances. Such size restrictions are designed to affirm the belief appearing recently in the literature in the field that persons with MR/DD are better served in smaller facilities. Such restrictions have been

strictly enforced as they are also designed to offset what is considered to be an already existing overabundance of larger facilities. Thus, facility size designation of small or large has generally become associated with fewer or more than sixteen residents living in a facility. Similar definitions of small or large are found in other states and are representative of current national thinking in the United States.

The distinction of fifteen or fewer and sixteen or more residents as a criterion delineating whether a facility is "small" or "large" has also been incorporated into a variety of national public policies, legislation and programs at the federal government level. This was typified in Senate Bill 384 of the 101st Congress (1989-1990), the "Medicaid Home and Community Quality Services Act" introduced by Senator John Chaffee (R-RI). Among the key provisions of the bill was a freeze on Medicaid payments to large facilities at the level in effect during the federal fiscal year in which the legislation was to be enacted. This proposed freeze of federal funds flowing to large facilities was intended to remove long-time financial incentives for the operation of facilities of sixteen residents or larger in favor of living arrangements involving some smaller number and to reverse a perceived trend which favored funds flowing to larger facilities that had existed for many years. Similar legislation has continued to appear on a regular basis in

Congress each year since 1989 as the entire financing mechanism for health care in the United States has come under intense examination.

Lack of Research on Facility Size

Despite the application of the size criterion as a means of shifting funds and other resources to a greater number of smaller facilities as seen in recent public policy decisions, powerful pressures still exist in communities to resist movement toward smaller living arrangements and to support the widely-held alternative opinion that large facilities can provide safer and more effective services for persons with MR/DD. These older and more traditional beliefs are held by a variety of groups including families and communities, organized labor and providers of large facility services. Over an extended period of time, concerns expressed by such groups include the need to protect and keep disabled individuals from harm, to provide highly specialized and often very costly services on an efficient basis, to maintain union jobs, to continue the use of long-term, experienced staff in well established facilities and exercise the cost advantages associated with economies of scale in using professional services across units in large facilities (Zautra and Goodhart, 1979). Many people with a family member living in a large facility did not want a change of environment and

wished to retain the option of a large facility living arrangement administered by a state agency or well established organization. Daily involvement of a state agency or a long term administration overseeing individuals' lives indicated to many families a strong sense of permanency in such living arrangements. Parents and/or citizen groups associated with large facilities affirmed the expectation that services in state operated facilities will continue throughout the foreseeable future, even though individual staff members might change from year to year.

Foster families or group home settings are viewed by many parents as being much shorter-lived, existing only as long as the individual foster parents or group home operators continued in business. The perception that foster homes or groups homes were time limited and less stable added an element of uncertainty to the lives of their family members. Parents and family members of persons living in large facilities are often cognizant of individuals who have been released from large public institutions and have since been housed in private institutions and smaller residential settings, including group homes, without appropriate training, opportunities for increased community participation in social or recreational events or acceptance by neighbors as was expected when movement to the smaller facility took place. While smaller has become a more acceptable philosophical tenet when describing living arrangements, smaller has not

necessarily led to a less restrictive or a more appropriate place to live simply by reason of the smaller size, despite early expectations that better conditions would follow and community acceptance would occur once a transfer to a smaller site took place.

There are also serious concerns regarding levels of health and safety of individuals in smaller facilities and whether small facilities are as safe as larger ones. Some families prefer the apparent comprehensive array of services available on-site in large facilities and the obvious daily involvement of a state agency in their loved ones' lives. To many families, the bureaucracy of larger sized facilities, extensive supervision, detailed rules, set procedures and a complex array of services generate a greater sense of safety, security and organization and is central to their selection of a particular facility for alternative residential care or to a change in a living plan.

As Maslow (1970) described in his theory of motivation and personality, physiological needs were met first and a new set of safety related needs emerged in individuals that centered upon security, stability in life styles, dependency on routines, protection from danger, freedom from fear, anxiety and chaos. Such needs were fulfilled through structure, order and law. Until such needs were met they dominated behavior and opinions. Maslow's concept is highly applicable to parental attitudes as they search for acceptable

alternative care for their family member. Parental emphasis on safety, stability and smoothly operating facilities has been consistent and predictable in light of parental and familial efforts to fulfill such basic safety needs for their loved ones with disabilities. As Maslow's construct predicted, parents expressed growing concerns as increases in community based activities reduced direct supervision provided to their family members activities. The encouragement of independence of action characteristic of smaller facility environments led parents to react anxiously to the possibility of increased vulnerability to injury or mishap for individuals with disabilities. They often perceived such freedoms as a reduction in safety levels for their loved ones. Further, many communities are fearful of the impact on their limited resources if all their people with MR/DD return from state and federally funded facilities to their original homes or to new communities of choice in the immediate future. Individuals with disabilities often need costly services that place a heavy burden on local resources already stretched to the limit. In Ohio, as in many other states, funds rarely follow the individual from a large facility to a smaller community setting. Funding for large facilities tends to be a mixture of state and federal dollars. Except through limited federally funded waiver programs that allow dispensation from specified stringent regulations, funds are difficult to reassign to new community settings and few states have had

sufficient local funds to underwrite community alternative living programs through state or local funds alone.

In view of mixed experiences, differing beliefs, deep seated fears and concerns held by many people about their family and their community's future well being as well as the ongoing investment of massive social and financial resources over a period of many years at the federal and state levels in well established larger facilities, it was surprising that there was no conclusive research based on empirical data to which decision-makers could turn for information. Empirical data was lacking that could support or oppose the newer trend toward smaller community alternatives or to indicate whether smaller facilities were or were not inherently better or safer providers of residential services because of their size. The assumption that small facilities were better than large facilities that underlays the current trend in thinking was simply that: an assumption. Despite the lack of definitive research that would give a clear indication whether small facilities or large facilities provided safer conditions, the application of size as a significant variable has continued to be fundamental to public policy and public decision making and seems to be here to stay.

Need for an Empirical Basis for Public Policy

Policy makers are faced with making changes in traditional residential patterns to include increased alternatives for families and communities and, at the same time, make fiscally sound and morally responsible decisions regarding the health and safety of persons with disabilities.

Yet, such decisions are often based on fragmented or conflicting information. As described by Landesman-Dwyer, in 1981:

The mental retardation field may be characterized by increased activism, polarization and disillusionment among many parents, professionals, service providers and advocates. The legislative and legal systems, as well as the media, have become more powerful than ever in deciding the future for retarded individuals. People who once worked together to achieve reasonable goals now are at odds. Anti-institution, pro-normalization forces fight head-on with groups that represent traditional institutions and that criticize many community programs. Heated debates about the merits of private versus. public services, specialized versus. generic programs, intensive versus. tender-loving-care treatment, and local versus. state or federal control of planning and service delivery" . . . were widespread. (p. 228)

Decisions to change to new residential alternatives were often made by policy makers with data provided by those most vocal groups or those most able to gain access at the time. New data were often a mixture of limited information and unsubstantiated beliefs, generally expressed by enthusiastic, well-meaning individuals and groups. Schopler (1989) noted that a preponderance of idealogues existed compared to

empiricists in the field of disabilities and that their opinions showed clearly the divergence in their beliefs. He spoke of idealogues who propounded such concepts as "mainstreaming individuals" or "normalizing services" and:

1. Insisted that their philosophies were grounded in ethical imperatives or religious revelations not accountable to empirical rules of evidence.

2. Advocated the use of their favorite concepts in treatment decisions rather than individualizing programs for the needs of the person.

3. As a result of their zeal for deinstitutionalization, their actions resulted in increasing numbers of street people, yet the narrowness of their vision did not permit an equal interest in the fate of those unable to cope with the normal scene but who were unable to return to the institution.

4. Further, the priorities of their positions prevented them from recognizing the need for compassion in understanding individual handicapping conditions and the need for each individual's need for services.

Zigler, Hodapp, and Edison (1990) expressed their concerns associated with the minimal levels of empirical data in the field and suggested that more effort was needed to develop an appropriate role of science and applied technology in the mental retardation field in order to establish basic program policy rather than the formulation of policy through

what was referred to as political expediency or panacea. Heal (1990) also lamented the lack of empirically proven methods in the field and pointed out that we already possessed advanced methodologies more than adequate for today's data gathering, analysis and management decision making. Yet such technology has rarely been applied in pragmatic policy decisions in the disability field.

Menolascino and Stark (1990) also emphasized that the missing element between researchers and advocates was the actual utilization of research findings in the field in program, policy and procedures. Mineo (1985), reported a very large gap between the potential and the actual application of technology in policy development, particularly for people with severe and profound mental retardation and/or severe physical impairments. The time has come, according to Landesman-Dwyer (1981), for public policy to take on directions more strongly grounded in research and objective evaluation of actual service delivery settings to help define benefits and program options more appropriately throughout individuals' lives.

This study was designed to provide unique empirical information about persons with mental retardation and developmental disabilities living in residential facilities in Ohio; to assist in formulating public policy recommendations regarding residential care of those individuals; and to examine the relationships of health and safety of individuals relating to the size of the facility in which they live.

Statement of the Problem

While the literature is rich in history and information concerning most aspects of community living for individuals with MR/DD, review of the literature reveals no articles directly relating the size of facilities to reported health and safety of the individuals living there. To date there have been no major studies which empirically compared health and safety of individuals to the size aspect of the residential setting. No definitive researched-based relationships between health and safety variables and the size of a facility have been established. Therefore, decisions have been made and resources have been historically allocated preferentially to larger facilities and, more recently, to smaller facilities without the most basic information: the relative safety of large residential facilities versus small facilities in providing appropriate living arrangements for individuals with developmental disabilities including mental retardation.

The problem investigated in this study concerned the relationship between the health and safety of individuals with mental retardation and developmental disabilities and the size of the residential facilities in which they lived. Is there a relationship between the size of the facilities in which these individuals live and their reported health and safety?

Purpose of the Study

The purpose of this study was: to attempt to discover whether the bed capacity of a residential facility is a valid criterion for consideration when living arrangements for individuals with mental retardation and developmental disabilities are being evaluated; and, to provide individuals, families, and public policy makers with additional empirical information and recommendations for decision making related to residential facilities.

A comparison of Major Unusual Incident records of large and small facilities in Ohio was designed to give an indication of the relative safety of large facilities compared to small facilities. A review of the safety levels was made by studying the differences in the number of major unusual incidents (MUI) that occurred involving individuals living in large and small facilities across Ohio over the period of the study. Major unusual incidents were reported in Ohio to state agencies as required by law (Appendix A). A review of the reported incidents over a four-year period provided a cross section of safety conditions in facilities in Ohio.

To meet the purpose of this study, the relative safety of small facilities versus large facilities as indicated by the occurrence of Major Unusual Incident (MUI) reports in residential settings for people with MR/DD in the state of Ohio for the state fiscal years, July 1986-June 1990, was

examined (Appendix B). The relative frequency of types of MUI was also studied, as was the year-to-year variation of MUI by facility.

Research Questions

The research questions investigated in the study were designed to examine the relationships between safety and facility size. Specifically:

1. Was there a relationship between facility size and reported frequency of Major Unusual Incidents.
2. Was there a relationship between facility size and reported type of Major Unusual Incidents?
3. Was there a year-to-year variation in the reported frequency of Major Unusual Incidents by facility size?

Importance of the Study

The health and safety of vulnerable individuals of all ages, particularly those least able to speak for or represent themselves, is a topic of growing national concern. The number of individuals with mental retardation and developmental disabilities now needing services is expanding faster than traditionally predicted. The assumption that only about one percent of the population should need services no longer holds true. Infants and children with severe and

multiple disabilities who would have died only a few years ago are now surviving because of the availability of better and more accessible medical treatment and technology. Children who have faced extraordinary trauma are living longer and doing so in greater numbers. Added to these are children exhibiting the effects of parental substance abuse who may also need life-long treatment and services.

Older parents who previously maintained their sons and daughters at home at their own expense now find themselves unable to adequately care for their middle-age offspring who have no place to live when the parents die. Many families who, in the past, accepted care in large institutions as the only alternative to home care, now expect and seek what they consider more socially appropriate, safe and secure options.

These additional numbers are combining to increase pressures on the current system of service at a time when available resources are inadequate to meet even present levels of need given the continuation of today's systems of residential service delivery. As a result, the number of unserved people is growing and waiting lists have become common for most community residential services.

As the amount of money needed to provide special services for vulnerable individuals continues to escalate, competition from other government funded programs has also been increasing. To illustrate, Ohio recently spent 56 percent of the State's \$4 billion annual Medicaid budget to serve

6 percent of the Medicaid population comprising one category-- aged, blind and disabled. Public policy makers everywhere need more and better information if they are to make the best possible application of resources on behalf of those they serve. Individuals and family members require clear and valid information as a basis for planning their futures. Families and others are being forced to make residential decisions for individuals with MR/DD without adequate empirical information regarding health and safety factors of various size facilities. The literature, though replete with historical and program information, provides little or no health and safety information.

The MUI data available in Ohio relating to the health and safety of Ohioans in MR/DD facilities is not available elsewhere and has not been previously analyzed. Ohio, in addition to being a large state, is a nearly perfect demographic microcosm of the United States and results of this study may have broad application elsewhere. This study, therefore, will be important in several ways:

1. Data will provide a picture of possible qualitative living differences among individuals residing in facilities of various sizes which may or may not support current practices in Ohio and elsewhere;

2. Dissemination of analysis and conclusions drawn from these data could have ramifications for public policy regarding the provision of residential services for

individuals with mental retardation and developmental disabilities in Ohio and elsewhere; and

3. Since Ohio is a large state and is a demographic microcosm of the United States, results obtained may be of broad interest and value.

Assumptions of the Study

This study assumes that:

1. Health and safety differences between large and small facilities can be compared and that both employ the same reporting procedures and rules as mandated.

2. Conditions in facilities for the period of the study can be generalized to current and future settings providing residential services to individuals.

Limitations of the Study

The factors in the design and makeup of the study that will inherently limit the scope include the following:

1. This study was affected by the level of compliance by staff and others in meeting the purpose and intent of Ohio laws for reporting major unusual incidents.

2. This study was affected by the statewide application of definitions of major unusual incidents. Even though training was ongoing, large numbers of individuals were

required to exercise their professional judgement concerning reporting and categorization.

3. This study began with the inception of mandated data reporting in Ohio in July, 1986 and ends June, 30, 1990.

4. This study did not account for all Ohioans with mental retardation and developmental disabilities living in private or otherwise unlicensed or unregulated settings in the state.

Delimitations of the Study

1. The study was focused on major unusual incidents concerning Ohioans in residential facilities and which had been reported and entered into the state reporting system in the specified period of the study.

2. The study reviewed all major unusual incident reports in the sample and treated each separately. No indication exists of multiple or duplicate reports.

3. The study included only those residential facilities that generated a major unusual incident report within the period of the study.

Definition of Terms

Several important terms are defined below for the purpose of this study.

AAMD Adaptive Behavior Scale: refers to a scale for reporting measurements of adaptive behavior originated by the American Association for Mental Deficiency.

Adaptive behavior: means the effectiveness or degree with which an individual meets standards of personal independence and social responsibility expected of his age and culture.

DD: means developmental disability or developmental disabilities.

Developmental disabilities (in Ohio)(Appendix A): means having a disability that originates before age eighteen, has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the individual's ability to function normally in society and can be attributed to one of the following:

1. Mental retardation, cerebral palsy, the epilepsies, or autism;
2. Any other condition found to be closely related to mental retardation because it results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons or requires treatment or services similar to those required for such persons.
3. Dyslexia resulting from a disability described in this definition.

Eugenics: refers to the movement devoted to improving the human species through the control of hereditary factors in mating.

Facility size: refers to the number of individuals with mental retardation and developmental disabilities living in a home or residential facility. Large facilities are those with sixteen or more residents. Small facilities are those with fifteen or fewer residents.

Integration: refers to the level of assimilation of an individual into his community as evidenced by shared interactions and activities, personal contacts and relationships, proximity to community activities and exercise of personal autonomy.

ICF/MR: means intermediate care facility for the mentally retarded.

Major Unusual Incident (MUI): refers to any one of areas defined by Ohio statute including such things as abuse, neglect, death, attempted suicide, serious injury, adverse drug reaction, medication error, extended unauthorized absence and inappropriate removal. Major unusual incidents were defined by Ohio law and rule as follows:

1. Abuse means an act, or absence of action inconsistent with human rights which result or could result in physical injury to an individual, except if the act is done in self-defense or occurs by accident; an act that constituted sexual activity as defined under Chapter 2907. of the Ohio Revised Code where such activity would constitute an offense against an individual under the Chapter; insulting or coarse language or gestures directed toward an individual

which subjects the person to humiliation or degradation; or depriving a person of real or personal property by fraudulent or illegal means (Appendix A).

2. Neglect means a purposeful or negligent disregard of duty imposed on an employee by statute, rule, or professional standard and owed to a client by that employee (Appendix A).

3. Death, including natural death, accidental death suicide and homicide.

4. Attempted suicide.

5. Behavior shown by an individual that might have led to serious/adverse injury or significant property destruction.

6. Fire resulting in an injury to the individual, relocation of the individual or an interruption of service.

7. Any major involvement of the individual with law enforcement authorities.

8. Serious injury to an individual which required hospitalization or resulted in permanent physical damage as a result of the injury.

9. Adverse reaction to a life-threatening degree because of an administered drug or dietary food item.

10. A medication error resulting in serious consequences for an individual, which was an apparent administration of an unprescribed drug or a prescribed drug at an incorrect frequency or dosage or a dietary error resulting in an ingestion of a contraindicated food item.

11. An extended unauthorized absence of an individual that exceeded the individual's program plan identification for community access.

12. Removal of an individual from either residential or program services without the consent of the individual, guardian or appropriate authorities.

13. Any violation for rights pursuant to Section 5123.63 of the Revised Code, which was determined as a pattern or repetition and/or which was considered serious in nature (Ohio Revised Code, Annotated, 1986, Chapter 2907).

MR: means mental retardation

MR/DD: means mental retardation and developmental disabilities

Mental retardation: means having significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period.

ODMR/DD: means the Ohio Department of Mental Retardation and Developmental Disabilities.

ODMR/DD Survey: refers to an informational survey conducted by the Ohio Department of Mental Retardation and Developmental Disabilities.

Public policy: refers to a principle, plan or course of action that directs a governmental agency and other bodies in their management of public affairs.

Year: means a state fiscal year (July 1 through June 30) unless otherwise indicated.

Organization of the Study

This study is organized in the following manner:

Chapter I presents an introduction consisting of background, statement of the problem, purpose, and significance of the study. It includes research assumptions, limitations, delimitations and definitions applicable to the study.

Chapter II reviews literature pertaining to various aspects of community living for individuals with mental retardation and developmental disabilities, the relationship to facility size and current public policy.

Chapter III describes sample selection, data gathering and statistical analysis of the data.

Chapter IV contains the presentation of the data, findings of the study and interpretation of the data.

Chapter V summarizes the research and findings, draws conclusions from the findings and provides recommendations regarding public policy issues and future research.

CHAPTER II

REVIEW OF THE LITERATURE

Historic Overview

Historical social policy in the United States has resulted in very different living conditions for individuals with mental retardation and developmental disabilities than for most other citizens in this country. In early America, disabled children were often left to die and those with seizures were thought to be witches or possessed by the devil (Sheerenberger, 1983). Blatt (1970) reported that individuals with mental retardation and mental illness were treated very inhumanely. He documented reports of persons with mental retardation being caged, locked in closets, chained naked, beaten and lashed into obedience were found throughout literature.

Community residential services for persons with mental retardation began in this country with the opening of the first private facility in Barre, Massachusetts, in 1848, and with the opening of the first public facility known as the Walter E. Fernald State School, in Boston in 1850 (Dunn, 1956; Zigler, Hodapp and Edison, 1990). The first State School in Ohio was opened in Columbus in 1857 as one of 10 facilities

especially designed for persons with mental retardation in the United States. Edouard Seguin had moved from France in 1850 and assisted in the organization of such facilities in five northeastern states. As first president of the association that is currently known as the American Association on Mental Retardation, Seguin was instrumental in the development of residential schools and educational programs in this country as humanitarian efforts to care for mentally disabled individuals. Seguin disavowed what he deemed inhumane therapies and overly harsh discipline. He proposed a moral education and a form of sensory-motor training designed to reawaken persons with mental disabilities into normal human existence. Seguin believed that mental retardation was a weakness of the nervous system that could be overcome through concerted training. The original purpose of 19th century residential schools was the application of Seguin's methods to bring dormant faculties of individuals into development and effect a cure for the condition of mental retardation. While early institutions were operated as training programs to improve skills and to return individuals to their homes and communities to live useful lives, the "state schools" that were built did not fulfill such early promises as intended. Despite the efforts of physicians and teachers to provide skill training, individuals continued to exhibit those behaviors that caused them to be labeled mentally retarded; few were actually returned to their homes. Instead, many were

maintained for the duration of their lives in residential schools.

Such schools had, by the turn of the 20th century, assumed indefinite custodial care of individuals with mental retardation (Davies, 1930) as part of an acceptance of a social obligation to help resolve the problem of mental deficiency in society. This continuation of the institutionalization and isolation of unwanted individuals has been a feature of the field of mental retardation as individuals' behavioral, physical or medical differences continued to make other people uncomfortable (Macmillan, 1982; Scott, 1969; Sheerenberger, 1983; Wolfensberger, 1977). The use of residential facilities in this manner still occurs as an expedient solution, even today.

Throughout the latter 19th century and extending well into the 1930's, there was strong support of Sir Francis Galton's belief that efforts should be made to improve the human stock by checking the birth rate of unfit persons and furthering the productivity of the most fit. Galton coined the word eugenic in 1883, as meaning wellborn. After the publication of Galton's work in 1901, the eugenics movement flourished as a science intended to improve inborn qualities of the human race. The application of Mendelian principles of heredity was advocated in a number of well publicized family studies including examinations of the Jukes family, the Kallikak family, the Zero family and the Hill folk between

1880 and 1920 (Davis, 1987). Discussions continued through the early part of the century on ways to handle human conditions such as retardation. At a meeting of the Research Committee on Eugenics held in May, 1911, ten remedies were suggested whose purpose was described as "purging from the blood of the race innately defective strains". Of these, segregation and sterilization were considered to have the greatest potential. (Davies, 1930, p. 50). Sweeping generalities were drawn that persons with mental deficiencies were increasing in number and the answer was to isolate them from society in institutions or to sterilize them so that reproduction of an inherited mental condition could be avoided or that various social ills could be controlled. As Davies stated, "To no other form of human inadequacy have so many social blights been attributed: crime, delinquency, degeneracy, poverty, vagrancy, immorality, and their train." (Davies, 1930, p. 3)

Fernald, a well known writer and pioneer in the field of mental retardation during the 19th century, expressed a belief strongly held by many parents and professionals that individuals with mental retardation were:

a parasitic, predatory class, never capable of self-support or of managing their own affairs. . . . They cause unutterable sorrow at home and are a menace to the community . . . every feeble-minded person . . . is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies (reported in Davies, 1930)

By 1924, Fernald had softened his opinion to some extent but retained a point of view essentially the same. Such beliefs, often untested but supported by many, encouraged the continued assignment of disabled individuals to institutions, ostensibly to improve their abilities to adhere to societal demands through planned skill training. Fernald said, " we honestly believed that nearly all these people should remain in the institution indefinitely . . . but the (1924) survey shows that . . . a few . . . do not need or deserve life-long segregation . . ." (Fernald quoted in Davies, 1930, p. 200-201)

Following the appearance of statements such as these in early literature, efforts to validate them was the subject of many research projects with considerable lack of success. Despite lack of empirical verification, application of such negative attitudes toward individuals with handicapping conditions continued.

The first sterilization law in the United States went into effect in 1907 in Illinois (Davies, 1930). By the 1930's, standard treatment for mental retardation mandated in legislation in twenty-five states routinely included sterilization, the object of which was eugenics. By 1958, 29 states had performed more than 31,000 documented sterilizations of persons deemed mentally deficient. (Lusthaus, 1985; Wertham, 1973).

Most public institutions in the early twentieth-century were prison-like farms designed to contain the largest number

of people at the lowest possible cost to the state. Institutional names of the period often reflected the prevalent negative and limited public perceptions. One 1935 survey of institutions in a large northern state was entitled Documents, Reports and Data Concerning Institutions for Insane, Feeble-Minded and Epileptic (Ach, Corwin, and Reed, 1936). It indicated admissions to state institutions occurred as a result of promiscuity and unruliness, as well as the other reasons one might infer from the title. There were virtually no opportunities for true community living, nor were families encouraged to keep their sons and daughters in their own homes. Doctors typically advised families to plan to send their children with disabilities to institutions as soon after birth as possible to avoid any attachment or bonding. Civil rights protections were almost entirely absent. Most public schools either excluded or sharply segregated children with handicaps, if they took any note of their existence at all. Blacher and Bromley (1990) acknowledged that a few positive therapeutic programs existed but their contributions paled by comparison with vast institutional facilities that existed at that time.

Thus, by the 1930's, the custodial aspect of institutional life had become very entrenched. The system was characterized by increased numbers of individuals in need of shelter, a shortage of funding, and the belief that such placements were in the best interests of individuals and

families. Societal indifference and reluctance of communities to create other alternatives led to overcrowding, a lowering of the quality of life in large self-contained institutions and to segregation and isolation of individuals from other community activities. Most facilities could afford little beyond ongoing custodial care as residential numbers increased by the thousands. Overcrowded conditions persisted and the concepts of large facility services and custodial care remained almost synonymous in their meaning.

The perpetuation and ultimate rejection of such negative conditions by mid-century has been instrumental in the evolution of more recent trends to monitor, regulate and certify facilities as a condition of ongoing funding and to consider the value of smaller more home-like settings as more acceptable places for persons with handicapping conditions to live. From 1900 to 1963 numbers of persons in large institutions increased from 14,000 to 125,000. (Blacher and Bromley, 1990). The increase slowed after 1963 as community day program alternatives became more wide spread and provided parents with a second alternative in which their children could be maintained in their homes and still receive services. Despite trends to deinstitutionalize people, avoid institutional placement in the first place or provide smaller more homelike settings, there were still over 100,000 individuals living in institutions in this country, both by preference or by necessity, in 1992.

Mid-Twentieth Century Changes in Public Policy

Facilities in the second half of this century were substantially different from the overcrowded custodial care centers of the first half of the twentieth century, although many institutions retained the stigma attached to their earlier years. Today, persons who live in institutions have been through thorough assessment and found to be mentally retarded and in need of institutional care. They generally have multiple handicaps or other serious social problems concomitant with a mental retardation, although many persons with similar levels of disabilities also live in community residential alternatives. Great emphasis has been placed on health, safety and training and virtually all of today's facilities are highly structured environments certified by federal or state agencies.

Higher functioning individuals with MR/DD are usually provided with other alternatives and have been served more often in community settings, including day-school programs, than in institutions. By 1960, approximately 220,000 persons attended day programs while continuing to live at home. In 1990, in the United States, persons with MR/DD receiving services and living at home numbered in the millions. This expansion of community residential alternatives has been sporadic as areas of strong community opposition resulted in the rejection of many individuals with mental retardation

continuing to live in their communities. Public awareness and understanding of mental retardation, mental illness and most other related institutional diagnoses has been generally negative and based on limited understanding of handicapping conditions as well as inaccurate stereotypes of individuals with disabilities. Expansion of community residential alternatives in the past 30 years, while unevenly developed across the nation, generally included a marked increase in smaller, community situated residential homes and apartments based on a relatively new belief that smaller facilities are better alternatives and more closely approximate normal family homes (National Institute on Disability and Rehabilitation Research, 1988).

Progress in changing social policy also accelerated with the rise to prominence of John F. Kennedy and Hubert H. Humphrey in the 1960's. Their experiences in coping with mental retardation in their own families, coupled with the tremendous power and influence at their disposal, launched a new wave of research, training, and public debate on ways to improve the lives of persons with disabilities.

The development of a national network of John F. Kennedy Centers for Human Development, university affiliated programs and the concomitant funding helped to shape today's service delivery systems and channel newly allocated funds into the field for the first time. Nirje (1969) verbalized the new social thinking by advocating that persons with mental

retardation should live in conditions "as close as possible to the norms and patterns of mainstream society" (Nirje, 1969, p. 181). This was a direct challenge to the more traditional view that persons with severe disabilities should be institutionalized. Exposés such as Blatt and Kaplan's (1966) "Christmas in Purgatory" were heralded nationally. By graphically highlighting squalid and inhumane conditions in an institution on a Christmas Day, these authors shocked and horrified many citizens and raised a strong reaction to the idea of persons living in large custodial care facilities with little hope of discharge or appropriate treatment.

The Rehabilitation Act of 1973 and the Education For All Handicapped Children Act (Public Law 94-142) of 1975, now known as The Individuals with Disabilities Education Act, brought civil rights to individuals with handicapping conditions. The doors to education opened for thousands of individuals who were formerly excluded, changing the face of public education dramatically. Massive federal Medicaid funding was applied to state institutions during the middle and late 1970's in a largely successful effort to provide active treatment rather than mere custodial care. Growing access to public education, jobs, housing and community living allowed many individuals to leave institutions for better lives of their choosing (Landesman, 1986; O'Connor, 1976). The terms normalization, least restrictive environment and mainstreaming were heard in every facet of public service and

education. The practice of "warehousing" individuals in institutions virtually came to an end.

Late Twentieth Century Changes in Public Policy

By the 1980's, substantial shifts in social policy lead to a complex array of residential services for individuals with mental retardation and developmental disabilities in the United States. Populations declined in state mental retardation institutions from an all-time high of 194,650 residents in 1967 to 100,000 residents in 1988 (White, Lakin, Hill, Wright and Bruininks, 1988). Professional opinions generally favored the view that families should raise children with handicaps in natural homes with community supports or in small community group homes (Cole and Meyer, 1989). Many parents and service providers, however, continued to support larger facilities that they believed were safer and more secure. Such growing advocacy for individuals with mental retardation and developmental disabilities had mixed effects. Studies and reports exposed unsatisfactory institutional conditions in targeted large facilities. Publication of these reports, usually lead to widespread and rapid improvements in services. At the same time, in other research, the safety and training capability of many smaller community living programs were questioned. Other studies reviewing smaller facilities highlighted the ability of small facilities to provide

integration opportunities for individuals in school, work and social life (Lakin and Bruininks, 1985; Lakin, Hill and Bruininks, 1985).

In 1985, United States Senate hearings were held that led to the passage of the Protection and Advocacy for the Mentally Ill Individual's Act as PL 99-319. Senator Lowell Weicker reported striking contradictions in state institutional conditions for mentally disabled people. Facilities were often set in tranquil, rural settings, certified to provide active treatment and subject to ongoing review by federal officials. Many institutions fulfilled these responsibilities. Some however, "masked interiors filled with abuse, neglect and tragedy . . . routinely understaffed . . . with a focus on paperwork rather than people" (Weicker, 1987, p. 1027). As a result of ongoing public debate, social policy changes began to dictate ongoing and stringent monitoring of facilities and, at the same time, the encouragement of a variety of residential alternatives. The enactment of PL 99-319 triggered investigations of abuse and neglect and the pursuit of legal and administrative remedies essential to the protection of fundamental civil rights of some of the most severely disabled people in the nation. Additional civil rights protections were extended through enactment of the Americans with Disabilities Act (ADA) in 1990.

Today, in most states, institutions for persons with mental retardation are usually referred to as Intermediate

Care Facilities for the Mentally Retarded (ICF-MR), primarily due to the funding source. They provide greatly improved living conditions with an emphasis on health care, home-like and comfortable living arrangements. Regulations require sufficient certified staff to provide twenty-four hour assistance and training to residents regardless of the size of the ICF-MR facility.

If Burton Blatt, . . . (an author of Christmas in Purgatory) . . . could spend a day in an ICF-MR today, he would likely see a smaller, more livable residence. It would be clean, well-appointed, even home-like. The people who live there would be appropriately dressed and a few might be interacting with direct-care staff members (Holburn, 1990, p. 65)

Pierce (1990), reported that today, in ICF-MR homes, residents spend more time in the community accompanied by staff and have fewer periods of unstructured time. As conditions improved in large facilities the debate continued as to whether community alternatives, especially small homes, were necessarily the best alternatives for persons with mental retardation and developmental disabilities.

Size of residential settings as a way to describe facilities was discrete, reliable and easily agreed upon as a variable. This fact was evident at all levels of program planning and description (White, Lakin, Hill, Wright and Bruininks, 1988). Whether a facility was small or large affected its funding level, its acceptance in the community and whether it was perceived as safe or secure. However, research focusing on the size of a residential setting and the

relationship the size of the facility may have on health and safety of people with mental retardation and developmental disabilities is surprisingly sparse. There was substantially more information available in research literature regarding outcomes for residents and how they were affected relative to such things as family satisfaction, social interactions, changes in adaptive behavior and community interactions. Christiansen (1980), for example, reported a large number of factors related to abuse of children in community facilities, but size as a variable was notably absent from discussion.

Despite the absence of research relating facility size as a health and safety consideration in residential facilities, it has continued to be used as a criterion to flow funds for operating and developing facilities and as a way to control the expansion of various types of residential facilities. Conclusions concerning health and safety were rare and mixed. Research linking size and health and safety was not found.

Social Interactions and Life Conditions

A number of researchers indicated positive relationships between life conditions of individuals and community activities, attributing these not only to the closeness of the available community activities, but often to the small size of the facility in which the person lived. The underlying assumption was that smaller facilities were presumed to be

located closer to community activities than larger facilities. A more positive lifestyle, defined as enhanced access to recreation, restaurants, stores, churches and friends, was identified and assumed to be a product of smaller community living settings by Crapps and Stonemen (1989), and Stonemen and Crapps (1990). Although O'Connor (1976) did not identify an optimum size, it was concluded that the ideal living arrangement for normalization was more likely to occur in facilities with fewer than twenty people rather than in larger ones. The presumption was a facility with fewer people would more closely resemble a typical family setting more so than a large facility. The relationship between the size of the residential setting and social interaction by residents led to a range of sometimes conflicting conclusions.

O'Connor (1976) pointed out that in some instances people in units with less than six residents actually had decreased opportunity for social interaction, contrary to what one might anticipate. Supervised living, in itself, may block community integration. Lutfiyya (1988) reported that the very presence of human services workers served as a negative barrier between individuals and the development of desired relationships, even when their presence was intended to be encouraging and supportive of such relationships. In evaluating the impact of enriched staff-to-resident ratios in small homes, the amount of staff-resident interaction was not related to size. Staff behavior, however, was considered a critical variable in all

settings (Landesman-Dwyer, Sackett and Kleinman, 1980). Baker and Salon (1986) reported dramatic positive changes in behavior of individuals vacationing away from state institutions in popular resorts. Their successful community integration in these instances was attributed to the institutional staff's positive, growth-promoting expectations and their attention to the needs of each individual. This community interaction took place regardless of the fact that the individuals called a large facility their home. It was also noted that residents in larger facilities also engaged in more social behavior with other residents and were more likely to have intense reciprocal friendships with other residents compared to individuals living in smaller facilities. Deprivation of social interactions in large facilities was not substantiated in this research, nor was it concluded that more social interaction took place in smaller rather than larger facilities.

Burchard, Hasazi, Gordon, and Yoe (1991) reported that examination of the lifestyles of 133 adults with mild and moderate levels of mental retardation indicated little or no integration. Individuals living in group homes, supervised apartments and natural families did not achieve social integration in any of the living settings. Although access to integrated activities was available, very little actually occurred.

Safety and Health in Institution and Community Settings

Safety and health of individuals have been closely connected to the overall availability of medical and social services to individuals with ongoing or chronic medical conditions. DePaepe and Hayden (1990) studied the utilization of medical services in institutions and in community homes by disabled persons. They concluded that medical and social services were available throughout the community. They also reported that persons in state institutions utilized the services of professionals more frequently than individuals with comparable medical conditions in both small community institutions and community homes. Crain and Millor (1978) indicated few communities had developed adequate support services for mentally retarded parents and children in her study in the United States.

In addition to being affected by the total availability of services, safety and health of individuals were also connected to parental and family ability to gain access to available community services to care for their children with disabling conditions. This was particularly evident when Seagull and Scheurer (1986) found that parents with limited cognitive abilities who had abused their children continued to have difficulties, despite the availability and provision of public assistance and medical care. Only eleven of the thirty-four children were still with their parents in the

follow-up survey. Other children had been placed in adoptive homes, foster homes, with other family members or had died.

Garbarino, Authier and Brookhouser (1987) discussed policy issues underlying the development of safe environments for children with handicapping conditions at home or in institutional care. They summarized conclusions from a working conference sponsored by the Boys Town Center for abused handicapped children involving a large group of human services professionals and made recommendations that applied regardless of the setting. Concern with the health and safety of individuals with mental retardation and developmental disabilities was recognized as critical when abuse was acknowledged as a primary cause of permanent intellectual impairment. Removal from abusive environments resulted in overcoming of intellectual impairment and evidence of catch-up growth. Eppler and Brown (1977) and Money (1982) found neglect and abuse in fifteen percent of cases prior to a diagnosis of mental retardation. Abuse and neglect in young handicapped children also was found in the occurrence of other conditions such as low birth weight (DHEW, 1980) physical neglect and emotional depression (Oswin, 1979).

Continuing research began to highlight the existence of health and safety problems affecting individuals living in the community, while at the same time stricter institutional controls and monitoring were established. Data from incidents in public residential facilities reviewed by Marchetti and

McCartney (1990) showed that incidents of abuse were relatively small and that direct care staff conscientiously reported most incidents that occurred.

More intense efforts, however, were needed to rehabilitate families members in communities, according to Morse (1970). The New York State Commission on Quality of Care for the Mentally Disabled (1987) found that the annual reported rate of abuse and neglect was five times higher in mental health and mental retardation residential facilities compared to the state as a whole, or compared with rates in community mental health agencies. From the available data, the Commission concluded that more accountable reporting procedures were needed to enhance prevention and oversight efforts in community services for person with disabilities. The need for better community reporting systems, coordination between local agencies and ongoing training for child protective workers was acknowledged by Schilling, Kirkham and Schinke (1986) to protect the health and safety of children with handicapping conditions living outside larger facilities in small residential settings. Overcoming fragmentation of community quality assurance services and assigning responsibilities to a single community agency was also recommended when abuse and neglect of family members was evident. The scope of such available research led to the conclusion that health and safety considerations were not confined to institutional placement. They were also a concern

for persons with handicapping conditions whether they lived in state institutions, community residential alternatives or with their natural families. There was no clear basis for the public perception that small community facilities were safer and healthier for persons with handicaps than larger residential facilities in studies concerning abuse, neglect and monitoring of services.

Quality of Care

There was a growing acknowledgement that persons with mental retardation were highly vulnerable to exploitation and in need of intervention services such as legal protection, protection from abuse through reporting systems and special training for staff (Tharinger, Horton, Millea, 1990). Such protections were usually in effect within state monitored systems but very few comparable protections existed for disabled adults living in communities. Hemming (1986) reported that institutional size, per se, was not related to quality of care. Although depersonalizing practices were found more frequently in large institutions, small homes were also found to be restrictive and limiting in their provision of opportunities for social interactions when physically located in, but not an integral part of, neighborhoods and communities (Bjaanes and Butler, 1974). Landesman-Dwyer, Sackett, and Kleinman (1980) in analyzing the daily behavior

of 240 individuals with mental retardation and the staff in smaller facilities with six to twenty residents, found staff behavior was more homogeneous from facility to facility and not necessarily responsive to the individual needs of residents. Individualized programming did not follow as a function of small facilities, contrary to public policy assumptions. Hemming (1986), using the American Association Of Mental Deficiency (AAMD) Adaptive Behavior Scale (Nihira, Foster, Shellhaas and Leland, 1969) and the Illinois Test of Psycholinguistic Abilities (Kirk, McCarthy and Kirk, 1971), found that adults with mental retardation who were transferred to small living settings showed skill regression after an average of five and one-half years in the new setting. Baroff (1980) examined the size question from two perspectives: first by reviewing the relationship between size and the degree to which care practices were resident-oriented versus. institution-oriented and, secondly, by consideration of resident adjustment in settings of different size. The examination indicated the effect of a locational factor rather than a size factor. Individuals had greater opportunity for access to community-based activities and relationships because of the proximity of smaller settings to communities, while larger settings, by location, usually isolated individuals from the general population.

With growing questions as to whether small facilities were necessarily better or safer than large facilities,

Thompson, Robinson, Graff and Ingenmey (1990), also raised a question concerning the concept of "home-like" that was associated in the public mind with smaller facilities. Twenty adults with no experience with mental retardation rated residential settings as to their "home-likeness". Twenty-six architectural features of residential facilities were reviewed. The study found that furniture position, lighting type and lighting flexibility correlated with their concepts of home-likeness. Items that were minimally correlated were building code-specific items and seating furniture types. Home-likeness appeared to be related to simple architectural or design features rather than whether the facility was small or large. These conclusions were significant for public policy purposes in that building code items have, by their requirements, dictated an institutional aspect to a building regardless of size where there were mandated non-homelike features as part of zoning or architectural requirements.

Landesman (1986) also argued that a community residential facility could have negative functional components that created an institution-like environment. Identified were functional aspects and components such as rigid administrative organization and inadequate social interaction. Positive components included the quality of staff and resident interactions and the types of activities that took place in a residential home. The study concluded that particular programmatic features could not be assumed to be based on a

specific community residential structure. Meador, Osborn, Owens, Smith and Taylor (1991) drew similar conclusions in their research. Whether the facility was an institution or group home, large facility or small in size, a valid conclusion could not be drawn about home-likeness, quality of care, health or safety as has generally been reflected in public policy and public expectations.

Changes in Adaptive Behavior

Changes in adaptive behavior were tied to facility size in some instances. Individuals requiring around-the-clock intensive staffing and medication to control inappropriate behaviors exhibited marked behavioral improvement, decreases in medication and reduction or elimination of supervisory staff when the person moved to a smaller facility. Relocation from large institutional settings with minimal paid supervision was associated with reduction in inappropriate behavior and an increase in successful vocational experiences. (Bruney, 1991). The effect of size was, to some extent, also a product of a change in a staff-to-resident variable. Changes in adaptive function in thirty-two older adults with mental retardation showed an overall increase in both adaptive and maladaptive behaviors as measured on the AAMD Adaptive Behavior Scale administered two times, a year and a half apart, when the individuals moved from a state operated ICF-MR

to a community ICF-MR facility (Fine, Tangeman, and Woodard, 1990). While improvement took place, it appeared to be a function of a facility variable rather than a size variable in this situation. Causby and York (1991) found that levels of physical and verbal aggression exhibited by persons leaving state facilities and moving to community placements were strong indicators of failure in community adjustments. Adaptive behaviors, gender and intellectual levels were not significant in predicting community placement success or failure. Johnson, Glick, and Young (1980) reported data from fifteen community facilities of three sizes involving 156 individuals. They reported that people in larger institutions stayed longer than people in smaller facilities due to differences in adaptive behavior.

Conroy, Efthimiou and Lemanowicz (1982) compared two matched groups of individuals, one deinstitutionalized and the other not. They found that deinstitutionalized clients displayed significant changes as measured on the AAMD Adaptive Behavior Scale. Residents exhibited increases in adaptive behavior and showed no significant increases in frequency or type of maladaptive behavior. Hemming, Lavender and Pill (1981) reported moving from large to small living units produced positive changes in individuals of both high and low ability nine months after the transfer. Participation of all individuals increased in areas of culturally normative activities and adaptive behaviors. Hill, Rotegard and

Bruinink's (1984) national survey of 236 public and community residential facilities in five size categories indicated that, in general, small community facilities had the most positive treatment environments, more home-like environments, lower costs, more satisfied staff, more able residents and fewer non-ambulatory residents. Their research did not draw conclusions concerning health and safety of individuals.

Community Supports

When successful integration of large numbers of individuals with mental retardation and developmental disabilities into the mainstream of society has occurred, there have often been community based training or employment preparation programs for individuals involved (Stodden and Browder, 1986). Social support of such placements was necessary. Social support was defined as the provision of assistance by individuals, groups or institutions by Collins and Pancoast (1976). Social supports were also described as material aid, behavioral assistance, close personal interaction, guidance, feedback and positive social interaction (Barrera and Ainlay, 1983). These variables are crucial regardless of size or setting.

Community living seemed to allow more flexibility in living styles for individuals. Increased independence and lifestyle normalization were more clearly evident in

supervised apartments even when compared with persons living with their natural families (Burchard, Hasazi, Gordon and Yoe, 1991).

Lakin, Anderson, Hill and Bruininks (1991) found that little specific accommodation was made in either state or community facilities for the needs of older persons sixty-three years of age or above. Services tended to be a continuation of general facility programs and were, therefore, generally shaped by the facility whether large or small and not by resident needs. Foster homes and group homes were alternatives that provided comparable services except that community residents were able to participate in leisure and recreational activities more frequently in small community settings. However, the question arose whether in the age group sixty-three years of age or older the significant factor may have been the actual functional ability of persons still able to live in small community settings. Persons living in large facilities, such as nursing homes, may have made this selection based on their need for more specialized medical services and a known reduction in their mobility.

Types of available community supports in group homes made a difference in the abilities of adults to adjust to community living (Meador, Osborn, Owens, Smith and Taylor, 1991). Siperstein, Reed, Wolraich and O'Keefe (1990) found that seven basic skills were essential in supervised apartment living. This number increased to a need for nineteen basic skills in

unsupervised apartment living. Training to develop such basic skills was essential to successful community living.

Employment was often described as "the glue that holds a person together." Preparing for work, commuting, producing, interacting with co-workers and supervisors and earning a living were all hallmarks of successful adult adjustment (Halpern, Close and Nelson, 1986). Schutz (1988) identified vocational competence as a critical variable in determining society's acceptance of an individual, but also found that persons with severe disabilities were generally distinguished by their absence in the workplace. Cost effectiveness has also been identified as a significant positive attribute for supported employment for individuals with mental retardation (Heal, McCaughrin and Tines, 1989).

Possible Research Bias

Landesman, Dwyer, Sackett and Kleinman (1980) asserted that the historical association of big with bad had not been separated from social, political and economic decisions that still influenced public residential institutions. Eastwood and Fisher (1988) also injected a note of caution regarding vested interests in the big versus small controversy. They cautioned that the validity of much of the research may have been skewed by rater bias or response set. For example, Hill, Lakin, Bruininks, Amado, Anderson and Copher (1989) reported

that the most predictable way to social involvement, personal development, community participation and independence for people with developmental disabilities of all types in residential settings was achieved through providing the opportunity to live in small community settings, despite their own finding that the community residential facility sample in the study was generally much less well integrated into the community than was a sample of the general population.

Community and Family Opinion

Many individuals lived in institutions because local housing alternatives were not available. Sometimes a community was unable or unwilling to provide such community living arrangements. Oswin (1979) pointed out that this was partly a function of a long standing belief that severely handicapped individuals should be in institutions and that they needed the type of medical or nursing care provided in hospitals. Earlier reported instances of emotional deprivation or physical neglect in large facilities argued toward living arrangements in smaller community settings. The opinion of families regarding the size of community residential settings continued to be varied and reflected in public policy decision making. Support of larger institutional settings and initial negative attitudes toward the movement of family members from large to smaller settings

tended to change and become more positive over time (Grimes and Vitello, 1990; Heller, Bond and Braddock, 1988) when a family member moved to a community home. However, Grimes and Vitello (1990) also noted that although the attitudes became generally more positive, families sustained concerns such as the quality of smaller programs, staff turnover, inadequate recreational facilities, availability of dental services, psychological services and transportation.

Community placement success was affected by many dynamic factors including access to medical care (Boyle and Comer, 1990), social support, parent-child attachment, family adjustment variables, child characteristics, family resources and family needs (Blacher and Bromley, 1990; Schilling and Schinke, 1984; Valentine, 1990). However, the impact of such variables as they related to the size of residential arrangements was not considered.

Summary

Public investment in examining the value, efficiency and effectiveness of public policy on residential placements has been limited (Braddock, 1983). Schopler (1989) described the situation as an ongoing argument with continuous polarization in which the best researchers were pitted against the most strident and articulate advocates in the public policy arena. Walker (1987) argued that the public policy choices affecting

individuals with developmental disabilities were often predicated on the widely-held belief that the public sector is inherently wasteful, inefficient and unproductive. Economic objectives such as profit maximization, economic growth and cost-efficiency were considered to be automatically legitimate. Social objectives, however, such as good health, well-being and community care held little intrinsic value of their own, resting ultimately on economic policy for their achievement.

It was clear that public policy makers were limited in their abilities to make empirically-based decisions because the total picture was not addressed by research. The humanistic drive toward smaller facilities may not be humane. The health and safety of disabled sons and daughters may be at risk in these facilities. The purpose of this study was to provide a basis for better informed decisions regarding allocation of resources relating to the size of the residential setting.

CHAPTER III

METHODS AND PROCEDURES

The purpose of this study was to examine indicators of relative health and safety levels of individuals living in large and small facilities for persons with MR/DD in Ohio. This was accomplished by sampling, collating and analyzing data available in major unusual incident reports submitted in Ohio as required by law (Appendix B).

MUI Report System

As a means of monitoring the health and safety of individuals with mental retardation and developmental disabilities in Ohio, the legislature adopted a Major Unusual Incident reporting system in 1986. The format of the MUI report was prescribed by the Ohio Revised Code, Annotated, Chapter 2907 (Appendix A). The instrument remained unchanged over the period of this study (Appendices B and C). Explanatory guidelines that included suggestions for completing reports (Appendix D) and a tracking system (Appendix E) were added to assure consistency among reports and procedures.

This legislative mandate initiated a standard system to report and investigate alleged abuse, neglect and other major unusual incidents that affected persons with MR/DD who lived in licensed residential facilities in Ohio, beginning on July 1, 1986.

Mandated reports were required from law enforcement officials, other professionals, parents, advocates and the public. On-site investigations were conducted by case management staff of the local County Board of Mental Retardation and Developmental Disabilities. Copies of the reports were sent within 24 hours to the Ohio Department of Mental Retardation and Developmental Disabilities and to other agencies as needed (Appendix F). Reports were entered into an ODMR/DD data base and accumulated since that time. The unanalyzed data provided an indicator of basic health and safety for the population of Ohioans with developmental disabilities for the time period examined.

Source of Data

The MUI reporting system within the Ohio Department of Mental Retardation and Developmental Disabilities and the information it contained was the primary source of data for this study. The MUI data base was sampled and analyzed for frequency of occurrence of the variables within the study. Summative information from the data base, without client

personal identification, was in the public domain and was made available to the researcher through the Ohio Department of Mental Retardation and Developmental Disabilities.

The Sample

Following electronic receipt of summative data from ODMR/DD, information was entered into a specially designed computer data base for statistical analysis. From the 5,959 MUI reported in Ohio during the four-year period covered by the study, a theoretical minimum sample of 361 MUI incidents was calculated (Hauskin, 1963).

Sample Size Determination

Applying Hauskin's Equation

$$s = \frac{[X^2 N p (1-p)]}{[d^2(N-1) + X^2 p (1-p)]}$$

Where: d = alpha or level of significance
 p = population proportion
 N = population size
 s = sample size determined
 X² = chi-square with 1 df & set at infinity
 X² = 3.84
1 df at α = .05

Application of Equation for
Sample Size Determination of MUI

$$\begin{aligned}
 s &= \frac{[3.84 * 5959 (.5)(.5)]}{[(.05)^2 * 5958 + 3.84 (.5)(.5)]} \\
 s &= \frac{[5720.64]}{[15.855]} \\
 s &= 360.809 \\
 s &= 361
 \end{aligned}$$

Where: d = .05; p = .5; N = 5959;
 1 df with α set at .05; $X^2 = 3.84$

As a result of post hoc considerations, the sample size was subsequently increased by randomly sampling 250 MUI for each of the state fiscal years involved, from July, 1986 through July, 1990. This was done in order to increase the probability of the presence of sufficient data elements for analysis of each cell variable. In addition, increasing the sample size beyond the minimum number of 361 reduced the probability of Type II errors (Ferguson, 1981). All selections and analyses were computer generated using standard SPSS procedures for calculation of percentage, chi-square, analysis of variance and correlation. A conventional alpha level equal to or less than 0.05 was chosen (Ferguson, 1981, p. 175).

Research Design and Data Analysis

Comparisons were made between small and large facility MUI occurrences using chi-square analysis of frequencies. Analysis of variance was utilized to test for differences in means of MUI occurrences between facility sizes. Chi-square was also applied to examine types of MUI occurrences by facility size for indications of significant differences by category.

Inter-year differences of MUI in facilities for the period of the study were analyzed using chi-square to test for differences. The correlation of year and MUI occurrences with facility size was also tested using the Pearson Correlation Coefficient.

The data were analyzed using the Statistical Package for the Social Sciences (SPSS). This widely used computer software package has database capabilities for producing descriptive and inferential statistics. This statistical analysis presents descriptive statistics concerning the data.

Information collected consisted of:

1. Facility size;
2. Client classification characteristics;
3. Major unusual incident frequency and type;
4. and, dates of occurrence.

Information concerning facility size and major unusual incident data were computer-merged to create a data base for

analysis. This facilitated examination of the relationships between MUI and facility size, MUI type and facility size and year to year variations of MUI frequency by facility size for the period of the study. Descriptive data were arranged in tables.

The following null hypotheses were tested through analysis of the data:

1. There was no significant relationship between facility size and reported frequency of major unusual incidents in those facilities.

2. There was no significant relationship between facility size and reported type of major unusual incidents.

3. There was no significant year-to-year variation in reported frequency of major unusual incidents in large and small facilities.

Employment of publicly accessible information combined with the use of a standard and readily available statistical analysis system was intended to allow appropriate, reliable, valid and convenient replication of this study as needed.

CHAPTER IV

FINDINGS, ANALYSIS AND INTERPRETATION OF THE DATA

The purposes of this study were: to attempt to discover whether the bed capacity of a residential facility is a valid criterion for consideration when living arrangements for individuals with mental retardation and developmental disabilities are evaluated; to provide individuals, families and public policy makers with additional empirical information for residential decision making purposes. Chapter IV contains the findings of the study, an analysis and interpretation of the data, and a summary of significant findings.

Findings

A sample of 1,000 MUI, 250 per year of the study, was randomly selected from MUI reported in state fiscal years, July, 1986 to July, 1990, inclusive, in Ohio. The resulting frequencies were summarized for small and large facilities, and represented in Table 1. As indicated in Table 1 subtotals, the frequency of MUI was greater in small facilities (fewer than sixteen residents) than in large (sixteen residents or more). There were 544 MUI in small

Table 1

**Sample of 1000 Major Unusual Incidents
Selected for State Fiscal Years 1987-1990**

Facility Size	State Fiscal Year	Number of MUI	Cum. Percent of Sample
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Small Facilities	1987	139	25.6
	1988	153	53.6
	1989	137	78.9
	1990	115	100.0
	Sub Total	544	100.0

Large Facilities	1987	111	24.3
	1988	97	45.6
	1989	113	70.4
	1990	136	100.0
	Sub Total	456	100.0

Total Sample Size Large + Small		1000	100.0
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facilities and 456 in large facilities for the four-year period of the study. See Table 1.

Research Hypothesis One: There was no significant relationship between facility size and reported frequency of major unusual incidents in those facilities.

Inspection of data in Table 1 indicates a greater apparent occurrence of MUI in small facilities than in large as reflected in respective frequencies of 544 and 456 for the period of the study. A contingency table was constructed and chi-square analysis was performed to test the null hypothesis. See Table 2.

A chi-square value of 7.774 with one degree of freedom was obtained. This exceeds the critical value of 3.84 necessary for significance at the .05 level. The differences between the observed and expected frequencies of MUI are significant.

In addition to chi-square, an analysis of variance was used to test whether there was a significant difference between large and small facilities in terms of number of MUI per year. Small facilities had significantly more MUI per year than large facilities; the means were 137.36 and 115.62, respectively, and are shown in Table 3. The calculated F value of 639.96 with one degree of freedom exceeded the critical value for significance at the .05 level. Based on

Table 2

Calculation of Chi-square
Comparing Observed and Expected
Frequencies of MUI by Facility Size

Facility Size	Observed Frequ.	Expected Frequ.	df	Value of Chi-square
Small	544	500	1	7.744 *
Large	456	500		

* Significant at the .05 level

Table 3

**Analysis of Variance Test of Significance
of the Relative Frequency of Occurrence of MUI in
Small and Large Facilities
for the Period of the Study.**

Facility Size	Number of MUI in Sample	Mean of Sample of MUI	Standard Deviation
Small	544	137.360	13.249
Large	456	115.623	13.866
Total	1000	127.448	17.329

Sample Variation Source	Sum of Squares	df	MS	F Score
Within** Years	182792.51	998	183.16	639.96*
Between** Years	117214.79	1	117214.79	

* Significant at the .05 level.

** Within Years = variance within all years
 Between Years = variance among the years

chi-square and analysis of variance results, the number of MUI that occurred in small facilities was significantly greater than in large facilities. The null hypothesis was rejected.

Research Hypothesis Two: There was no significant relationship between small and large facility size and type of major unusual incidents.

Reported frequencies in all twelve categories of MUI were sorted by facility size and presented in Table 4. Chi-square analysis of MUI type by size of facility using the sample cases was performed. It should be noted that 115 of the 1000 MUI reports in the sample failed to identify the MUI type within the incident report.

The chi-square analysis was significant at the 0.05 level, yielding a value of 49.08 with 11 degrees of freedom. This exceeded 19.68, the value of chi square associated with a .05 level of significance. The occurrence of MUI by type can be significantly related to facility size. The null hypothesis was rejected.

Although the overall occurrences of MUI were greater in small facilities than in large for nine of the twelve types of MUI, three categories differed. Accidents, criminal acts and fire occurred more often in large facilities.

It is also noteworthy that fire constituted 30.6 percent of all reported types of MUI in the sample. Fire, neglect and accident were the most frequently reported MUI and accounted

Table 4

**Chi-square Analysis of Types of MUI Incidents
Occurring in Small and Large Facilities
for the Period of the Study, 1987-90**

MUI #	MUI Type	Number of MUI Incidents in Facilities			
		Small	Large	Total	%
1	Absence	31	3	34	3.8
2	Accident	75	80	155	17.5
3	Sexual Ab.	25	9	34	3.8
4	Abuse	22	16	38	4.3
5	Neglect	111	64	175	19.8
6	Beh. Prob	12	5	17	1.9
7	Crim. Act	14	21	35	4.0
8	Death	3	3	6	.7
9	Fire	121	149	270	30.5
10	Illness	5	1	6	.7
11	Theft	48	37	85	9.6
12	Other	18	12	30	3.4
Total # MUI Incidents		485	400	885*	
% of Sample Incidents		54.8	45.2	100	100

Value of Chi-Square	df	Level of Sign.of Sample
49.08495	11	.00000**

* This sample includes 885 of the 1000 cases. 115 cases did not specify type of MUI in the MUI reports.

** Significant at the .05 level

for 67.8 percent of the reports. Of these, fire and accident reports occurred with greater frequency in larger facilities. Forty eight percent of all MUI were either fires or accidents.

Research Hypothesis Three: There was no significant year-to-year variation in reported frequency of major unusual incidents in large and small facilities.

The sample of 1000 MUI was examined using chi-square. The 250 case sample for each of the four years was sorted to indicate occurrences in small and large facilities for each year. See Table 5. The obtained chi-square value was 11.9 with 3 degrees of freedom. This exceeded the value of 7.82 necessary for significance at the .05 level. This indicated a significant year-to-year difference in MUI attributable to factors other than chance. The null hypothesis was rejected.

In addition, the correlation between the mean number of MUI and facility size from year-to-year for the period of the study was examined and displayed in Table 6. The Pearson Correlation Coefficient of $-.6251$ obtained was significant. This indicates an inverse relationship between facility size and MUI from year to year for the period of the study. MUI decreased with facility size and increased

Table 5

**Difference in the Occurrence of MUI
in Small and Large Facilities
Using a Chi-square Analysis of a
Random Sample with 250 Incidents for
Each State Fiscal Year**

State Fiscal Years in Study	Number of MUI Incidents Reported			
	Small Facilities	Large Facilities	Sample Size	% of Sample
1987	139	111	250	25
1988	153	97	250	25
1989	137	113	250	25
1990	115	135	250	25
Total for Sample	544	456	1000	100
% of Sample	54.4	45.6	100	100

Value of Chi- square	df	Level of Sign. of Chi-square
11.9324	3	.00762**

* Significant at the .05 level

Table 6

**The Relationship between Facility Size
and the Mean Number of MUI
Using Pearson Correlation Coefficients
for Sample with 250 Incidents Per State Fiscal Year**

Variables	MUI Mean for SF Years	Facility Size
MUI Mean for SF Years	1.0000	-.6251*
Facility Size	-.6251*	1.0000

* Significant at the .05 level

as facility size decreased. Rejection of the null hypothesis was supported by the inverse correlation.

Summary of Significant Findings

There were several significant findings which resulted from this study, many of which are of practical importance to consumers and public policy makers:

1. Major Unusual Incidents involving individuals with mental retardation and developmental disabilities represented in this study occurred with greater than expected frequency in small facilities.

2. Several types of MUI occurred much more frequently than others in both large and small facilities. These three categories were fire, neglect, and accidents and represented more than two-thirds of all MUI in the study.

3. Despite four years' reporting of MUI information, occurrence patterns were largely unchanged until the final year of the study period.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

The final chapter of this study presents discussion of the results of the research and recommendations for public policy concerning residential settings for individuals with mental retardation and developmental disabilities that can be drawn from the literature and research. The publication and dissemination of these findings could assist consumers, advocates, professionals and public policy-makers in choosing options that will respond to health and safety considerations for the greatest number of individuals needing alternative residential options.

Review of literature on this topic revealed a wide divergence of views concerning the impact of the size of residential settings on the lives of individuals with mental retardation and developmental disabilities. The literature generally supported, as a viable alternative, the growing movement of individuals from large traditional settings to smaller ones located in communities across the United States. Primary discussions in the literature centered on the value to individuals of integration into community life through

proximity and increasing participation in a variety of everyday activities. These included activities such as school, work, recreation and activities of daily living. While undifferentiated access to community living and, indeed, full civil rights is long overdue, one of the major stumbling blocks to community access has been basic concerns and attitudes about health and safety. Families' greatest concerns associated with the movement of their relatives from larger to smaller settings usually centered on the loss of fixed, visible and readily available institutional services which they equated with higher levels of health and safety for their loved ones. In addition to staffing levels, there was a focus on readily available dental, medical and nursing care.

The general absence of health and safety information in the literature may be attributed to a lack of attention, the relative newness of the community movement and the difficulty of gathering large amounts of data regarding outcomes for individuals who have moved. Fortunately, the Ohio General Assembly created a data set of considerable proportions by mandating the major unusual incident reporting system in 1986. This is now the largest consistently gathered data set concerning health and safety of individuals with mental retardation and developmental disabilities available. This study represented the first analysis of those data.

Conclusions

Analysis of a sample of recorded MUI data generated in Ohio from July, 1986, through June, 1990, was performed and involved examination of the relationships between small and large facilities, MUI frequency and MUI types and inter-year differences by facility size.

From the analysis and synthesis of the data it was found that there were statistically significant relationships among the reported variables. Differences in the number of reported MUI were related to facility size for the period of the study.

Research Hypothesis One: There was no significant relationship between facility size and reported frequency of major unusual incidents in the facilities.

Hypothesis one was rejected. Size did indeed appear to be related to individual health and safety when measured on the basis of MUI occurrences. As expressed in the literature, and as one might expect, health and safety were continuing concerns in living arrangements of all kinds. Unexpectedly, however, analysis of the data indicated that smaller facilities generated significantly more MUI than larger ones. This trend, reflected in this study, affirmed what the literature has indicated as the minority concerns of many parents and family members as well as some advocates and labor

organizations and was present in the literature surrounding continuation or closing of large facilities. While the benefits of community integration of individuals living in smaller settings were well documented, resistance to movement into community living is likely to continue until there is marked improvement in the areas of health and safety, especially since MUI frequencies seem to suggest that there is a basis for concern about small facilities and that optimum facility size for health and safety may currently be in the large range. It is also apparent from the literature that the growing national trend toward movement of individuals to smaller settings will almost certainly continue given current direction.

Also, a wide range of MUI occurred more frequently in smaller facilities. As indicated in the literature, residents in small facilities tended to be higher functioning with fewer multiple and severe handicapping conditions. Their greater motor skill levels, increased mobility and social interaction in less supervised community activities may be associated with producing this disparity. It was not clear from the results of this study whether the small size of the facility, the individual characteristics or both were more strongly related to the pattern of MUI reports. Staff-to-client ratios in smaller facilities were also smaller than in larger facilities and residents often had larger amounts of unsupervised time

available to them. In some part, this may have contributed to the greater number of MUI reports in small facilities.

Research Hypothesis Two: There was no significant relationship between facility size and reported type of major unusual incidents.

Hypothesis two was rejected. Smaller facilities generated more MUI than large ones. Certain MUI occurred more often in small facilities: absence, alleged sexual abuse, alleged other abuse, behavior problems, illness, neglect theft and the category of other. Deaths occurred with the same frequency in large and small facilities. Three categories occurred with greater frequency in larger facilities: accidents, fires and criminal acts.

This pattern seemed to indicate that residents of larger facilities generated MUI consistent with characteristics associated with profound levels of intellectual functioning in individuals including seizure disorders and accidents consistent with significant motor dysfunction. This pattern may also reflect the increased community interaction of severely handicapped individuals in community settings and activities. Conversely, individuals living in smaller facilities generated types of MUI that one could associate with higher individual functioning levels and fewer chronic and severe health problems. In addition, staffing levels for more seriously involved individuals were higher and more

intense, including twenty-four hour care and supervision in the larger facilities.

The differences in MUI type related to facility size may also have been associated with the relative differences in levels of confinement, containment and supervision related to the size of facilities. This may also have affected the frequencies of each type of MUI by facility size. Additional research in the area of health and safety is suggested by these results.

Research Hypothesis Three: There was no significant year-to-year variation in reported frequency of major unusual incidents in the facilities.

Hypothesis three was rejected. Results obtained indicated a year-to-year variation in the occurrence of MUI that was related to facility size. This may have resulted from the fact that individuals with less severe handicapping conditions may have been placed in smaller facilities with fewer constraints on their behavior and with less supervision, particularly during the later years of the study.

Federal and state standards were applied primarily to larger facilities operated at different, more stringent staffing and supervisory levels than others. An additional factor may have been the extent to which individuals within small facilities are subject to less intense supervision and external control. Conversely, individuals living in large

settings were more severely handicapped, had greater health needs, were less mobile, had fewer opportunities for unsupervised activity and had larger numbers of staff available to them in environments specifically equipped to respond to their needs on site. Given the long term nature of many traditional large facility programs in Ohio and elsewhere, large facility settings also tended to have longer histories of service delivery and greater experience in addition to well established operating procedures. The converse was generally true among the newer, smaller settings resulting from recent changes in the development of community options. Larger facilities also tended to have not only more employed staff, but more experienced, highly paid and trained staff. The possible impact of these variables was not the focus of this study, but may merit further investigation.

Because of the significance of this study, there is an apparent need to encourage ongoing research in order to determine precise interactions' of individual living arrangements and health and safety considerations. The ongoing MUI reporting system will continue to provide a rich and growing source of data for future analysis. Other public domain data sets are available to compare staffing ratios, salaries, relative provider experience, service delivery standards and deeper analysis of individual resident characteristics. The available data set also may be suitable for examination regarding such variables as population density,

regional differences, economic, fiscal and demographic factors and their relationships to individual health and safety.

Recommendations

The challenge of appropriately serving the growing number of Americans with mental retardation and developmental disabilities within communities across the nation is greater today than ever before. As citizens with disabilities increasingly organize and speak for themselves, a growing civil rights movement is being generated. This has been most recently evidenced in the enactment of the Americans with Disabilities Act in the summer of 1990. Pressures on public policy-makers to speed the growth of programs and necessary related services essential to enable access to full citizenship for everyone is increasing. The findings in this study have suggested that the traditional larger settings for serving individuals were often safer than newer, smaller ones. The literature, while essentially silent on the health and safety issues, documents the positive benefits of smaller settings to individuals in virtually every other aspect of their lives. Clearly, previously reported findings underscore the need for public policy-makers to develop answers to the health and safety questions as individuals increasingly exercise their choices for community living settings. Taken seriously, their implementation could allow thousands of

parents and other family members sufficient peace of mind to sleep better, knowing that their family members are healthy and safe.

The following recommendations concerning health and safety issues that produce an impact on the development of public policy regarding programs for individuals with mental retardation and developmental disabilities are derived from the results of this study:

1. Health and safety conditions continue to be strong areas of concern. As such, they should be increasingly addressed and clearly represented to those making choices. Decisions between individual freedoms and health and safety factors must be carefully weighed and supported with information. A balance between personal growth and safety must be consciously and thoughtfully sought and not left to chance.

2. A growing array of residential alternatives are a necessary part of a viable residential program and all indicators point to increasing selection of smaller residential settings. In order to provide true individual choice, health and safety concerns must be removed as barriers to integrated community living. True choices and options are impossible in the presence of personal danger or threats to individual health.

3. The movement of individuals from large to small community-based facilities is likely to continue or even

accelerate. The current rationale and justification must be expanded beyond factors of integration to include the factors of health and safety identified in this study. The addition of viable mechanisms for monitoring, evaluation and quality assurance should be expanded to include consumer information related to health and safety.

4. The continuation and development of MUI reporting and concomitant management review of data should be an ongoing gauge of the quality of residential systems.

5. Acceptable standards of health and safety should apply to individuals regardless of the size of their living arrangements or personal characteristics. The establishment of standards to which all settings adhere should be the result of thoughtful public discussions involving all stakeholders. Compliance with these standards should be measured and reported to the public.

6. Appropriately trained staff, support professionals and other service providers must be made available in sufficient numbers, regardless of facility size.

7. State governments should produce descriptive information concerning residential health and safety factors for all community residential facilities. This information should be made readily available to assist consumers in making informed residential choices.

This study and the recommendations stemming from it have the potential to bring about a greater focus on the use of

empirical information to provide balance in the formation of crucial public policy in Ohio and elsewhere. An important test of the worth of this study will be the reflection of these recommendations in the public policy of Ohio and other states. The critical measure will be the continuous improvement in the quality of life of individuals with mental retardation and developmental disabilities and their families.

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APPENDICES

APPENDIX A

OUTLINE FOR MAJOR UNUSUAL INCIDENT REPORTING

The Office of Case Management Services system of reporting Major Unusual Incidents, alleged abuse and neglect in particular, is based on Ohio Department of Mental Retardation and Development Disabilities Licensure Rule Section 5123: 2-3-25 and 26, H.B. 66, ORC 2151.421 and ORC 5123.62, the Rights of Persons with MR/DD.

The system is triggered by the Unusual Incident Initial Report which is taken by the local case management system within the County Board of Mental Retardation and Developmental Disabilities program. This report is to be completed immediately and sent to Ohio Department of Mental Retardation and Developmental Disabilities Office of Case Management Services. Major Unusual Incidents involving serious situations shall be called in to the Office of Case Management Services immediately. At this point coordination of the investigation is made to assure that appropriate referral is made to law enforcement, DHS/APS, licensure personnel, parent/guardian, et al. . . . county case management must call assigned licensure specialist as applicable within twenty-four (24) hours.

On-site investigation is made by the local county board case manager in conjunction with other appropriate agencies. Completion of the follow-up report is to be done seven (7) days following the initial report. This report is also to be sent to Central Office Ohio Department of Mental Retardation and Developmental Disabilities, Office of Case Management Services.

Dependent on the severity and complexity of the case, additional follow-up and final reports may be required in order to close the case.

Ohio Department of Mental Retardation and Developmental Disabilities, Office of Case Management Services tracks and logs all reports to their completion. Significant cases are flagged with timelines to assure steady flow of needed action and information. In February, 1985, a Policy/Procedure Advisory Committee was established to review major unusual incidents reports. All reports are filtered through this committee for monitoring procedural reporting systems and for tracking major unusual incidents. County case management systems should devise their own logging systems for major unusual incidents.

It is the governing principle of the Office of Case Management Services in the serious and sensitive area of abuse and neglect that all necessary effort be directed to prompt and thorough processing of these cases in protection

of the clients safety and welfare and the fulfillment of the Department's mandated responsibility.

STATE OF OHIO DEPARTMENT OF MENTAL RETARDATION AND
DEVELOPMENTAL DISABILITIES

POLICIES AND PROCEDURES

POLICY: ALLEGED ABUSE/NEGLECT INVESTIGATION/MAJOR UNUSUAL
INCIDENTS

PURPOSE

To establish a standardized system for investigation of reports of alleged abuse and/or neglect/major unusual incidents of mentally retarded and developmentally disabled children and adults who reside in Ohio Department of Mental Retardation and Developmental Disabilities licensed community-based residential case facilities or other community residences.

APPLICATION: Case Managers (County Boards)

DEFINITIONS:

"Abuse" means any act or absence of action inconsistent with human rights which result or could result in physical injury to an individual, except if the act is done in self-defense or occurs by accident; any act which constitutes sexual activity, as defined under Chapter 2907 of the Ohio Revised Code, where such activity would constitute an offense against an individual under the Chapter; insulting or course language or gestures directed toward a person which

subjects the person to humiliation or degradation; or depriving a person of real or personal property by fraudulent or illegal means.

"Case Manager" means the County Board of Mental Retardation and Developmental Disabilities person(s) who is responsible for accessing, coordinating, and mobilizing supportive services for eligible clients and monitoring their progress.

"Exploitation" means the unlawful or improper act of a caretaker or any other individual using a person or his/her resources for monetary or personal benefit, profit, or gain.

"Neglect" means a purposeful or negligent disregard of duty imposed on an employee by statute, rule, or professional standard and owed to a client by that employee.

"Child" means a mentally retarded or substantially developmentally disabled person under the age of eighteen (18). For the purposes of investigating abuse/neglect, section 2151.421 defines child as under 21 if the individual is physically or mentally handicapped.

"Adult" means a mentally retarded or substantially developmentally disabled person age eighteen (18) or over.

"Eligible Individual" means an individual who has mental retardation or other developmental disability(ies) who was placed directly into community settings from a facility operated by the Department of Mental Retardation and Developmental Disabilities, who is currently on the County Board rolls, or who may be referred from the community for services.

Alleged Abuse/Neglect Investigations/Major Unusual Incidents

- A. "Mental Retardation" means having significantly subaverage general intellectual functioning existing concurrently with deficiencies in adaptive behavior, manifested during the developmental period.
- B. "Developmental Disability" means having a disability that originates before age eighteen (18), has continued or can be expected to continue indefinitely, and constitutes a substantial handicap to the individual's ability to function normally in society, and is attributable to one (1) of the following:
 - 1. Mental retardation, cerebral palsy, the epilepsies, or autism;
 - 2. Any other condition found to be closely related to mental retardation because it results in impairment of general intellectual functioning or adaptive behavior similar to

that or mentally retarded persons or requires treatment and services similar to those required for such persons;

3. Dyslexia resulting from a disability described in this definition.

As used here "substantial handicap" means a handicap that results in significant deficits in two (2) or more areas of adaptive behavior. Individuals are developmentally disabled under this definition, when deficits in two (2) or more areas of adaptive behavior are commensurate with those of an individual diagnosed as moderately, severely, or profoundly mentally retarded.

POLICY STATEMENT

This policy defines and fixes the responsibility regarding all reports received by the Case Manager(s) concerning alleged abuse/neglect/major unusual incident to mentally retarded and developmentally disabled individuals. ALL REPORTS ARE CONFIDENTIAL.

IMPLEMENTATION PROCEDURE:

A. Case Managers

1. Initial Report

The Initial Report on alleged abuse/neglect or major unusual incident should be filled out immediately and sent to Ohio Department of Mental Retardation and Developmental

Disabilities Office of Case Management Services. A telephone call should also be made to the Office of Case Management Services.

Should a referral be received after normal working hours, or on the weekend, the on-call person shall contact the supervisor on call to ascertain his/her judgment relative to assigning the case for investigation at this time. The Ohio Department of Mental Retardation and Developmental Disabilities shall be notified the next normal working day.

2. Upon receipt of the referral, the County Board Case Manager will contact the referent to obtain additional necessary information as follows:

- a. Any evidence or reports of previous injury(ies), physical neglect, or condition to indicate alleged abuse/neglect, and any other information which may be helpful in establishing the cause of the alleged abuse/neglect.

If the alleged abused/neglected individual is residing in a Ohio Department of Mental Retardation and Developmental Disabilities

licensed residential facility, the County Case Managers shall notify the licensure specialist responsible for the facility within twenty-four (24) hours of the initial report.

3. The County Board Case Manager shall ensure that the alleged abuse/neglect has been reported, by telephone or in person, to the appropriate law enforcement agency or investigatory body and followed-up by a written report. If the alleged abused/neglected individual has a court-appointed guardian or is a minor, the guardian/parent(s) shall be notified.

CHILD

- A. Reports of alleged abuse/neglect of children shall be reported to the county Department of Human Services, with Children Protective Services, or the Children Services Board within twenty-four (24) hours, and law enforcement, and the report shall include the following:
 1. The names and addresses of the child and the parent(s) or

person(s) having custody of such child;

2. The child's age and the nature and extent of the child's injuries, abuse or neglect; including any evidence of previous injuries, abuse or neglect;
3. Any other information which might be helpful in establishing the cause of the injury, abuse or neglect.

If requested, the County Case Manager shall participate in the investigation with the ODHS/CSB. The County Case Manager will request a copy of the investigation report from the ODHS/CSB on any case in which he/she has participated.

ADULT

- B. Reports of alleged abuse/neglect of adults shall be made to the appropriate law enforcement agency. Reports of alleged abuse/neglect of adults over that age of sixty (60) must also be reported to the Ohio Department of Human Services, Adult Protective Services.

These reports shall include the following:

1. The names and addresses of the mentally retarded/ developmentally disabled adult and person or persons having legal guardianship of such person, if applicable.
2. The mentally retarded/developmentally disabled adult's age and the nature and extent of his/her injuries or physical abuse/neglect, including any evidence or reports of previous injuries or physical abuse/neglect;
3. Any other information which might be helpful in establishing the cause of the injury, abuse/neglect.

ADULT

- C. County Case Manager shall investigate each report referred to them to determine the circumstances surrounding the injury or injuries, the cause thereof, and the person or person responsible. Investigations shall be made in cooperation with any reporting law enforcement agency, which shall have

the primary responsibility for the investigation(s). The County Case Manager shall submit a report(s) of its investigation, in writing, to the law enforcement agency and shall provide/ensure such protective services as are necessary to protect the mentally retarded adult (Ohio Revised Code, Section 5123.611).

CHILD AND ADULT

- D. The County Case Manager may conduct a preliminary interview with the alleged abused/neglected individual and/or referent prior to initiation of the formal, cooperative investigation, as long as DHS/CSB, Adult Protective Services, or local law enforcement agency is notified within twenty-four (24) hours of the initial report. The County Case Manager shall determine whether prior reports concerning the alleged abused/neglected individual have been made to the Department of Mental Retardation and Developmental Disabilities or the appropriate law enforcement agency.

2. FOLLOW-UP REPORT

1. The County Case Manager shall submit a follow-up report within seven (7) days of the initial report (Unusual Incident Initial Report) to his/her supervisor and designated person at Ohio Office of Case Management Services. This follow-up report may be shared with the other investigative agencies upon approval from the supervisor.

3. FINAL REPORT

- a. Most often cases do not require a final report; however, Ohio Department of Mental Retardation and Developmental Disabilities, Office of Case Management Services may ask for specific additional information in order for a case to be closed by the procedure/advisory committee. The County Board Case Manager will complete a final report only if requested by Ohio Department of Mental Retardation Office of Case Management Services.

4. The Office of Case Management Services (ODMR/DD) will close the investigations by written correspondence and may include a

brief description of the results of the
conclusion of the case.

IMPLEMENTATION RESPONSIBILITIES: County Board of Mental
Retardation and Developmental Disabilities Case Manager.

REFERENCES: Ohio Revised Code, Section 5123.61, H.B. 66

Ohio Revised Code, Sections 2151.421

Ohio Administrative Code,

Sections 5123:2,3,25 and 26

Rules for Licensure, Ohio Department of Mental

Retardation and Developmental Disabilities

APPENDIX B

INITIAL MAJOR UNUSUAL INCIDENT REPORT FOR COUNTIES



DEPARTMENT OF MENTAL RETARDATION
AND DEVELOPMENTAL DISABILITIES

PAGE 1 OF 2

ddds DEVELOPMENTAL
DISABILITIES
DATA SYSTEM

INITIAL MAJOR UNUSUAL INCIDENT REPORT FOR COUNTIES

County (345) _____

Form (003): 200

Initial Report Date (2001) ____ - ____ - ____
YY MM DD

Incident # (001) ____ - 0 ____ - ____
YY COUNTY #

Office Use Only:
1 Follow Up Date ____ - ____ - ____ 1
1 (2066) YY MM DD 1 Action: A
.....
1 Case Closed Date ____ - ____ - ____ 1
1 (2067) YY MM DD 1
.....

ODMR/DD Client
Client # (004) _____ Name (005) _____
Last First Middle

Date Of Birth (152) ____ - ____ - ____ Social Security Number (151) ____ - ____ - ____
YY MM DD

Agency ID Facility
Number (346) _____ Name (340) _____

Address (341) _____

City (342) _____ State (343) ____ Zip (344) _____

Date of Incident: ____ - ____ - ____ Time: ____ : ____ (circle) AM Telephone Call Made Y or N
(2002) YY MM DD (2003) (2004) PM (2009) to ODMR/DD? circle

Location of Incident (2005) _____

Other Social Security
party (2070): _____ Number (2071): ____ - ____ - ____

Enter Y (Yes) in at least one field for each column

INCIDENT:	RESULT:	NOTIFICATION MADE TO:	Office Use Only:
(2010) Absences	(2025) Admin Action	(2036) Case Manager	1 (2080) Attorney General 1
(2011) Accident	(2026) Criminal Charges	(2038) Law Enforcement	1 (2081) Licensure 1
(2021) Alleged Sexual Abuse	(2027) Hospitalization	(2039) Licensure	1 (2082) Technical 1
(2012) Alleged Abuse	(2028) Injury	(2040) OUIS - CSB	1 Assistance Team 1
(2013) Alleged Neglect	(2029) No Injury	(2041) OUIS - APS	1 (2083) Health Department 1
(2014) Behavior	(2030) Property Loss/Damage	(2042) ODMR/DD Case Management Services	1 (2084) Dev. Ctr. 1
(2015) Criminal Act	(2031) Other	(2044) Relatives / Legal Guardian	1 (2085) Nurse Consultant 1
(2016) Death		(2045) Supervisor	1 (2086) Children Service 1
(2017) Fire		(2046) Other _____	1 Board 1
(2018) Illness			
(2019) Theft			
(2020) Other			

Case Manager Assigned Case
To Case (2050) _____ Manager Phone (2051) () - ____ - ____

Brief Incident Statement (2079) _____



DEPARTMENT OF MENTAL RETARDATION
AND DEVELOPMENTAL DISABILITIES

PAGE 2 OF 2

ddds DEVELOPMENTAL
DISABILITIES
DATA SYSTEM

INITIAL MAJOR UNUSUAL INCIDENT REPORT FOR COUNTIES

County (345) _____

Form (003): 201

Initial Report Date (2001) ____ - ____ - ____
YY MM DD

Incident # (001) ____ - 0 ____ - ____
YY COUNTY #

Action: A

DDMR/DD

Client

Client # (004) _____ Name (005) _____

Last

First

Middle

Summarize the Incident: (who, what, when, where, other agencies/persons caller has spoken to):
(2075)

.....
-1121 (4/87)

APPENDIX C

FOLLOW-UP MAJOR UNUSUAL INCIDENT REPORT FOR COUNTIES



DEPARTMENT OF MENTAL RETARDATION
AND DEVELOPMENTAL DISABILITIES



PAGE 1 OF 1

DEVELOPMENTAL
DISABILITIES
DATA SYSTEM

FOLLOW-UP MAJOR UNUSUAL INCIDENT REPORT FOR COUNTIES

Do. y (345) _____

Form (003): 202

Follow-Up Report Date (2006) ____ - ____ - ____
YY MM DD

Incident # (001) ____ - 0 ____ - ____
YY COUNTY #

Office Use Only:

1 Follow Up Date ____ - ____ - ____ 1
1 (2066) YY MM DD 1 Action: A

1 Case Closed Date ____ - ____ - ____ 1

1 (2067) YY MM DD 1

DMR/DD, Client
Client # (004) _____ Name (005) _____

Last First Middle

Specific Injury/Injuries
(2077)

valuation (type of evidence, person(s) responsible, Case Manager recommendations and monitoring)
(2078) (Attach sheet if necessary)

NATURE OF INVESTIGATING CASE MANAGER _____

DATE _____

NATURE OF SUPERVISOR _____

DATE _____

.....
-1122 (4/87)

APPENDIX D

FLOW CHART--COUNTY BOARD MAJOR UNUSUAL INCIDENT

NOTIFICATION

		Referent
Call/Send copy of		
Initial Report to	CASE MANAGER	Supervisor
	ODMR/DD CM Services	
CHILD	.	ADULT
Notifies DHS/CSB		Notifies local law
within 24 hours		enforcement agency
& law enforcement		& DHS/APS if over 60
INVESTIGATION		INVESTIGATION
Submits follow-up		Submits follow-up
report to ODMR/DD		report to ODMR/DD
CM Services		CM Services
INVESTIGATION		INVESTIGATION
(Continue as necessary)		Continue as necessary)
Submit final		Submit final
report to ODMR/DD		report to ODMR/DD
(if requested)		(if requested)
ODMR/DD reviews initial		Involved parties
and follow-up reports		notified of case
with Committees as received		status (open, closed,
and corresponds with Case		pending) upon request
Manager as necessary		to the Case Manager

APPENDIX E

MAJOR UNUSUAL INCIDENT TRACKING SYSTEM

ODMR/DD Case Management

Incoming Cases--Major

Unusual Incidents--by

mail or phone

Coordinator read and review cases--call CM if need more info or have questions	Major cases to Chair and/or other appropriate personnel i.e. licensure, communications
--	--

Review week's presentations with Chairperson of Committee (Friday) and medical concerns with Nurse Consultant	Make copies for committee members--categorize as updates and /or new cases
---	--

Secretary put on CRT

TO COMMITTEE FOR REVIEW

(weekly)

Closed	Continue
Log and notify involved parties file	Notify involved parties of need for further information with times for next meeting
	Coordinator holds file for next

APPENDIX F

SUGGESTED GUIDELINES FOR REPORTING

MAJOR UNUSUAL INCIDENTS

Reference: Case Management
Rule 5123:2-1-11

Major Unusual Incident means the following:

Case Management Rule A-S Definition	Requirements and who it applies to	Procedures
A. Suicide	All suicides or attempted suicides must be reported. Includes community clients not living in licensed facilities	1. Call appropriate agency, i.e., local law enforcement CSB or APS & guardian. 2. Call ODMR/DD and make written report. 3. Obtain death certificate for ODMR/DD report (if applicable).
B. Accidental death regardless of cause including apparent or possible suicide	All accidental deaths must be reported. This includes community clients not living in licensed facilities.	1. Same 2. Same 3. Obtain death certificate for ODMR/DD report.
C. Any suspicious or unusual death as a result of criminal or violent means, casualty or sudden adverse change of an eligible individual's apparent health	All suspicious or unusual deaths must be reported. This includes community clients not living in licensed facilities.	1. Same 2. Same 3. Obtain death certificate for ODMR/DD report.
D. Alleged criminal act of an employee involving an eligible individual committed on facility grounds or while performing occupational duties which may result in a felony charge.	All alleged criminal acts of an employee involving an eligible individual must be reported. The criminal act should suggest possible felony charges. If doubtful felony in nature--report anyway. This includes all MR/DD individuals.	1. Same 2. Same 3. If charges can be filed ensure that client understands his/her rights. 4. If situation is sexual and/or physical abuse make sure client receives immediate medical attention.

E. Alleged criminal act of an eligible individual that may result in a felony charge.	Report any criminal acts an eligible individual is involved in--if doubtful that it is a felony, report anyway. This includes all MR/DD clients.	1. Same 2. Same 3. Same 4. Same 5. If situation is sexual and/or physical abuse to another client make sure that client receives immediate medical attention.
F. Alleged criminal act within the facility by a visitor, or person other than employee or an eligible individual which may result in felony charges.	Report any criminal act by visitor or other person within the facility which may result in felony charges. The facility could include school and/or the workshop setting.	1. Contact local law enforcement agency. 2. Call ODMR/DD and make report.
G. Attempted suicide or any serious action of self abuse by an eligible individual.	Report all attempted suicides (see "A") and any self-abusive behaviors serious in nature, i.e., injury requiring hospitalization. Report if inappropriate interventions used, behavior plan not in place. This should include ODMR/DD clients.	1. Contact guardian 2. Call ODMR/DD and make written report. 3. If injury happened to another client or staff find out if charges might be filed.
H. Property damage due fire, explosion, or natural disaster shall be investigated where applicable by the state fire marshall or the local fire department. Bomb threats or other threats made, written or telephoned to the facility shall be considered as unusual incidents subject to investigation for determination of major/minor classification.	Report property damage, fire, explosions, etc. This mostly refers to licensed facilities, but could include all community clients.	1. Call appropriate agency, i.e., fire marshall, local law enforcement. 2. Report to ODMR/DD and make written report.

I. Serious injury caused by another person whether another eligible individual, employee or any other person.	All serious injuries should be reported. Reports should always be made if the client is sent to the hospital, if inappropriate or lack of medical treatment is received and if there is suspicious origins of injury. This could include all ODMR/DD clients.	1. Contact guardian. 2. Make written report to ODMR/DD.
J. Accidental injury of an eligible individual considered to be serious that was not caused by the direct action of another person or inaction of an employee.	All accidental injuries considered serious should be reported. Reports should always be made if the client is sent to the hospital, inappropriate or lack of medical treatment is received and if there is suspicious origin or injury. This could include all ODMR/DD clients.	1. Same as above.
K. Adverse reaction by an eligible individual to a life-threatening degree because of an administered drug.	All adverse reactions to administered drugs should be reported. Check with the facility nurse for input regarding life-threatening degree. This could include all MR/DD individuals.	1. Same as above.
L. A medication error that results in serious consequences for an eligible individual which is an apparent administration of an unprescribed drug or a prescribed drug at an incorrect frequency or dosage.	All medication errors should be reported. Check with medical resource regarding consequences of medication error. This includes all individuals with MR/DD.	1. Same as above.
M. Actions of an eligible individual which may result in probate commitment proceedings.	All actions which may result in possible probate (commitment) proceeding should be reported as soon as case manager is aware of situation. This includes all MR/DD individuals.	1. Contact guardian. 2. Contact placement coordinator. 3. Make written report to ODMR/DD.

N. Actions of an eligible individual which pose a threat to the safety and well-being of others.	All actions of an eligible individual that pose a threat to others should be reported. This could include injury, property damage resulting from behavioral outbursts, etc. This includes all MR/DD individuals.	1. Same as "I".
O. A serious illness that required medical treatment.	Serious illnesses that require medical treatment should be reported. Unexpected, unexplained illnesses are examples to be reported. (On-going medical care may not necessarily be serious for some clients.) This should include all ODMR/DD clients.	1. Same as above.
P. Extended and unauthorized absence of an eligible individual.	All extended and unauthorized absences must be reported. The amount of time before reporting may vary procedurally according to the individual's IHP and home policies. This pertains to all individuals with MR/DD.	1. Call the local law enforcement agency and file a missing persons report. 2. Contact guardian. 3. Call ODMR/DD, make a written report.
Q. Removal of the eligible individual from the facility by any person or agency other than the placing agency.	Removal of an eligible individual from a facility by any person must be reported. (This does not include client who are their own guardian who wish to leave.) This refers to licensed facilities, but could pertain to the school population as well.	1. Call the local enforcement agency or other inv. agencies (CSB, APS). 2. Contact guardian. 3. Call ODMR/DD, make a written report.
R. Any involvement of the eligible individual with law enforcement authorities.	Report any involvement an eligible individual may have with law enforcement. This should include all ODMR/DD individuals	1. Contact guardian. 2. Make report to ODMR/DD.

S. Abuse/Neglect	All reports of suspected abuse/neglect must be reported immediately. This pertains to all individuals with MR/DD.	1. Call appropriate agencies, i.e., CSB, APS, law enforcement. 2. Call ODMR/DD, make a written report.
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Note: If a MUI occurs in a licensed ODMR/DD facility your licensure specialist should be contacted.

APPENDIX G

ODMR/DD LETTER OF AUTHORIZATION



Ohio Department of
Mental Retardation and Developmental Disabilities

Richard F. Celeste, Governor

30 East Broad Street, Columbus, Ohio 43266-0415

March 29, 1990

Terry W. Wallace, Deputy Director
Ohio Department of MR/DD
30 East Broad Street, Room 1220
Columbus, Ohio 43215

Dear Terry:

After discussing your proposed research involving analysis of Public Domain MUI and related information, I am pleased to not only approve but endorse your work in this area. This department regularly cooperates in research at the doctoral level whenever it appears that the individuals we serve will benefit and this is no exception. I hope your work through the University of Tennessee will result in new and helpful information upon which we can formulate enlightened public policy both in Ohio and nationally.

Please let me know if I can be of help to you in any way with this project.

Sincerely,

A handwritten signature in cursive script that reads "Robert E. Brown".

Robert E. Brown
Director

REB:ef

cc: Dr. Dan Quarles
UTK/UTC Graduate Center
University of Tennessee at Chattanooga
105 Hunter Hall
Chattanooga, Tennessee 37402



ODMR/DD does not discriminate in provision of services or employment because of handicap, race, color, creed, national origin, sex, or age.

VITA

Terry Allen Wallace was born in Bellaire, Ohio on May, 29, 1947. He attended public schools in that area and was graduated from Bellaire High School in June, 1965. He then entered Ohio University, receiving his Bachelor of Education degree in June, 1970, and Master of Education degree in August, 1971.

After three years as a special education teacher in West Virginia and Ohio, he entered George Peabody College for Teachers in Nashville, Tennessee and was granted the Educational Specialist degree in 1974. Following twelve years as an administrator in education and rehabilitation programs, he entered the University of Tennessee, Knoxville, in the Doctor of Education program and received the degree in 1993.

He is married to Carol M. Wallace and has two children, Jeffrey Allen and James Robert. He is currently heading the strategic planning effort for the New Directions education reform with the Delaware Department of Public Instruction and serves as president of Effective Management Associates, a Columbus, Ohio, management consulting firm.