

Quality Assurance of the Community Placement of Institutional Residents

James Robert Brašić^{1,2}, Hiten Vithal Kisnad³, Leonard I. Leven⁴, James W. Nettleton⁵, Jorge Luis Arzola⁶, Yun Zhou¹

¹Division of Nuclear Medicine, Russell H. Morgan Department of Radiology and Radiological Science, Johns Hopkins University School of Medicine, Baltimore, Maryland, United States of America

²Department of Psychiatry, Bellevue Hospital Center and the New York University School of Medicine, New York, New York, United States of America

³Jacksonville, Florida, United States of America

⁴Old Greenwich, Connecticut, United States of America

⁵Philadelphia Mental Retardation Services, Philadelphia, Pennsylvania, United States of America

⁶San Juan, Puerto Rico, United States of America

Corresponding author: James Robert Brašić, M. D., M. P. H., Division of Nuclear Medicine, the Russell H. Morgan Department of Radiology and Radiological Science, Johns Hopkins Outpatient Center, 601 North Caroline Street, Room 3245, Baltimore, Maryland 21287-0807, United States of America, brasic@jhmi.edu

Abstract

Background: Residence in the least restrictive appropriate environment facilitates the attainment of one's maximal potential for a satisfying and rewarding life. Since some persons with mental retardation and other developmental disabilities manifest repeated problems on institutional discharge, methods to identify likely difficulties on release from institutions are desirable. **Objective:** To introduce a questionnaire that may help to predict the successful placement of persons with mental retardation and other developmental disabilities. **Method:** To facilitate surveys of individuals residing in institutions in preparation for discharge, we developed the Discharge Planning Quality Rating Survey (DPQRS), a chart review instrument for trained raters to evaluate the relevant clinical information. The charts of all 189 residents of an urban intermediate care facility for people with mental retardation were reviewed by one of three physician raters who then completed the DPQRS. **Results:** Data obtained with the DPQRS are presented, including sex, age, ethnicity, IQ, developmental milestones, activities of daily living, medical and mental disorders, behavior problems, physical appearance, medications, Axis IV and V scores using the Diagnostic and Statistical Manual (DSM) for Mental Disorders, and others. The interrater reliabilities of the items are presented. **Conclusions:** The DPQRS is a valuable tool for surveys to predict the successful community placement of mentally retarded individuals. Further studies are needed to establish the external validity of the instrument (German J Psychiatry 2002; 5(4): 95-114).

Keywords: data collection, deinstitutionalization, developmental disabilities, mental retardation, psychiatric status rating scales, reproducibility of results

Received: 16.01.02

Published: 26.11.02

Acknowledgements: An earlier version of this paper was presented at Child and Adolescent Psychiatry Grand Rounds at the Mount Sinai School of Medicine in New York, New York, on January 8, 1988 (Brašić et al., 1988). This study was supported by the Medical Fellows Program of the Consortium for Medical Education in Developmental Disabilities (CMEDD) of the Office of Mental Retardation and Developmental Disabilities (OMRDD) of the State of New York, the Essel Foundation, Family and Friends of Chelsea Coenraads, the National Alliance for Research on Schizophrenia and Depression (NARSAD), and the Rett Syndrome Research Foundation (RSRF). This research was sponsored by the Department of Psychiatry at Bellevue Hospital Center and the New York University School of Medicine in New York, New York. The cooperation of Bellevue Hospital Center, Columbia University in the City of New York, and the Health and Hospitals Corporation of the City of New York is gratefully acknowledged.

Introduction

The principle of normalization, that optimal social functioning of people with physical and psychological handicaps is more likely in community rather than institutional settings, provides a motivating force behind the deinstitutionalization of people with mental illness, mental retardation, and other developmental disabilities (Wolfensberger, 1970). However, unsuccessful attempts to place people with mental illness in the community have resulted in their entry to the criminal justice system (Bachrach, 1983) or the homeless population (Bachrach, 1987a, b). Since the deinstitutionalization of persons with mental retardation continues at a slower pace than the deinstitutionalization of persons with mental illness (Vitello, 1986), measures can be taken to both facilitate the appropriate placement and to assure the quality of the process of deinstitutionalization of people with mental retardation by anticipating the problems resulting from the deinstitutionalization of those with mental illness.

Thus, a major goal of public health policy is to foster the optimal personal growth of people with mental retardation and developmental disabilities in the least restrictive setting. Several obstacles hinder the attainment of this goal. There may be resistance to change exhibited by both staff and residents at institutions. Some communities may be reluctant to accept individuals with obvious handicaps. In order to facilitate the successful community placement of the residents of institutions, the identification and correction of possible impediments are desirable. Clients with mental retardation who have long institutional histories often exhibit challenges including self-injurious behaviors, aggression, and property destruction (Hill and Bruininks, 1984). Self-injurious behaviors, in particular, constitute a serious problem in residences for individuals with severe mental retardation (Brašić et al., 1997a, 1999a, 2001b, forthcoming a, b; Farber, 1987). Also, demographic traits including age and ethnicity, the degree of mental retardation, and the existence of multiple physical handicaps including visual and hearing impairments (Ellis, 1986), are associated with long institutionalization, as are problems in ambulation, toileting, and speech (Borthwick-Duffy et al., 1987). Although individuals with mental retardation under 18 years of age are likely to be kept in their family home, those above 30 years of age are more likely to reside in institutions. Non-white families are more likely to keep affected individuals at home than white families (Borthwick-Duffy et al., 1987).

To assess the variables likely to predict the successful community placement of individuals with mental retardation and other developmental disabilities, we constructed the Discharge Planning Quality Rating Survey (DPQRS), an instrument for chart review by trained raters appropriate for clinical, administrative, and research purposes (Appendix).

The items of the DPQRS (Appendix) are drawn from assessments performed in developmental centers in the State of New York (American Psychiatric Association, 1987, 2000; Brown et al., 1987; ICD-9-CM, International Classification of Diseases, 9th Revision, clinical modification, 4th ed, 1994, 1993; Jacobson, 1998; United States Department of Commerce, Bureau of the Census, 2000). Data obtained by the DPQRS include (1) demographic information, (2) admissions to developmental centers and psychiatric hospitals, (3) developmental milestones, (4) a history of abuse or neglect, (5) physical traits, (6) activities of daily living, (7) intelligence quotient (IQ), (8) psychiatric diagnoses (Axis I psychiatric diagnoses, Axis II developmental and personality diagnoses, Axis III neurological and medical diagnoses, Axis IV Psychosocial and Environmental Problems, and Axis V Global Assessment of Functioning (GAF) (American Psychiatric Association, 1987, 2000), (9) current status (behavior problems, treatment program, and medication), and (10) self-injurious behaviors including type and other features (Appendix). Therefore, since the DPQRS (Appendix) is a survey protocol requiring only record review to identify the problems likely to impede successful community placement of people with developmental disorders and mental retardation, we seek to test the hypothesis that the DPQRS (Appendix) is suitable for institutional chart reviews for administrative, clinical, reimbursement, regulatory, research, and other purposes.

Methods

Subjects

A simple random sample of 19 residents discharged between 1985 and 1987 from a developmental center, an intermediate care facility for mental retardation (ICF-MR), in a city on the Atlantic coast of North America, the site of later studies of the movements, behaviors, and psychopharmacology of individuals with mental retardation and developmental disabilities (Barnett and Brasic, 1995; Barnett et al., 1998; Brašić et al., 2001a), was utilized for a study of the inter-rater reliability of the DPQRS (Appendix). Two child and adolescent psychiatrists with a year of training in developmental disabilities independently completed the DPQRS (Appendix) after reviewing the complete records, including the medication and program charts, of each subject. After the reliability study, several items were reworded to clarify the concepts, and several additional items were added.

Between September, 1987, and June, 1988, the medication chart, the program chart, and the old medical record of all 189 residents of the urban developmental center of the reliability study on October 1, 1987, were reviewed by one of the same two child and adolescent psychiatrists with

a year of training in developmental disabilities or by a developmental pediatrician with two years of formal training in developmental disabilities. Since the records lacked codes for Axes IV and V of the Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R) (American Psychiatric Association, 1987), the reviewers estimated scores for Axis IV (Severity of Psychosocial Stressors) and Axis V (Global Assessment of Functioning) for each subject after reviewing the chart (American Psychiatric Association, 1987).

Statistical Analysis

The inter-rater reliability of each item of the DPQRS (Appendix) was assessed by estimates of the statistic κ (kappa). Estimates of κ greater than 0.75 demonstrate excellent agreement beyond chance, in the range 0.40 to 0.75 demonstrate fair to good agreement beyond chance, and below 0.40 demonstrate poor agreement beyond chance (Fleiss, 1981).

Because the underlying distributions of the traits examined in this study may not be normally distributed, the results were analyzed descriptively and nonparametrically. Data were analyzed for associations beyond chance using cross-tabulations (SAS Institute Inc., 1985) and the χ^2 (chi-square) test for goodness of fit (Conover, 1980).

Results

The statistic κ (kappa) was estimated for each item of the DPQRS (Appendix) utilizing the ratings of both raters on the simple random sample of 19 clients discharged from the study ICF-MR between 1985 and 1987. Table 1 shows that adequate inter-rater reliability indicated by $\kappa \geq 0.40$ (Landis and Koch, 1977) was attained by 20 (91%) of the 22 items of the original version of the DPQRS (Appendix).

Sample Characteristics

On October 1, 1987, the study date, 189 individuals resided at the developmental center. In the study population, 69 subjects (37%) were women, and 120 (63%), were men. The average age was 33.8 (SD 11.1) for women, 34.4 (SD 9.6) for men, and 34.2 (SD 10.1) for the total sample. Subjects ranged in age from 17 to 67 years. In the study population, 65 subjects (34%) were under 30 years of age, and 121 subjects (64%) were at least 30 years of age. The age was missing for 3 subjects (2%). The majority of residents of the study facility were adult men primarily aged 24 to 67 years, while the majority of residents aged 17 to 23 were female.

Table 1. Estimates of the Statistic κ (Kappa) Utilizing the Scores of Two Child and Adolescent Psychiatrists for Items of the Discharge Planning Quality Rating Survey (DPQRS) (Appendix) on a Simple Random Sample of 19 Clients Discharged from an Intermediate Care Facility for Mental Retardation (ICF-MR) in a City on the Atlantic Coast of North America between 1985 and 1987. An asterisk (*) indicates items with poor inter-rater reliability ($\kappa < 0.40$). κ , estimate of kappa

Items of the DPQRS (see Appendix)	κ
13. Full scale intelligence quotient (IQ)	1.0
16. Total number of admissions to this facility including current admission	0.6
17. Total number of admissions to developmental centers excluding current admission	0.6
20. Number of psychiatric consultations during the current admission	1.0
24. Age when the person first walked in months	0.3*
25. Age when the person spoke first words in months	0.1*
27. Does the person exhibit dysmorphic facies (unusual facial appearance)?	0.6
28. Does the person have any physical deformities excluding dysmorphic facies (unusual facial appearance)?	0.6
29. Is the person toilet-trained?	0.7
30. Can the person feed self in a socially acceptable manner?	0.5
31. Can the person dress self without assistance?	0.5
32. Can the person walk without assistance?	1.0
33. Does the person effectively communicate daily needs through speech?	0.4
35. Does the person have Down's syndrome?	1.0
36. Does the person have epilepsy?	0.8
38. Does the person have visual impairments excluding congenital cataracts?	0.8
40. Does the person have hearing impairments excluding bilateral hearing loss?	0.7
56. Does the person have a head injury?	0.6
59. Does the person have any other physical handicap?	0.5
60. Has the person ever had schizophrenia?	1.0
89. Has the person ever exhibited head-banging?	0.6
108. Has the person ever exhibited other self-injurious behaviors (SIBs)?	0.8

Ethnicity

The percentages of individuals of Hispanic origin in the general population of the county, 17.6% in 1980 and 26.0% in 1990 roughly match the study population, 27.5% in 1987 (Tables 2 and 3). Direct comparison of the other ethnic categories is hindered by the utilization of a primary ethnic category of "Hispanic" for the study ICF-MR population, but not for the general population of the county of

Table 2. Ethnic Classifications of the 189 Residents and of the County of the Intermediate Care Facility for Mental Retardation (ICF-MR) by the United States Bureau of the Census in 1980 and 1990. An asterisk (*) indicates that the designation "Hispanic" is (1) a secondary category overlapping all the other primary ethnic groups, "Asian or Pacific Islander," "African-American," "American Indian, Eskimo, or Aleut," "white," and "other" for the 1980 and 1990 Census data for the general population of the county of the study, and (2) a discrete primary category not overlapping all the other primary ethnic groups for the study population. Therefore, the Hispanic population is included in the total population for the study ICF-MR, but not for the general population of the county. A dagger (†) indicates that the percentages do not total 100% due to rounding

Ethnic Category	1980 Census Data for the General Population of the County of the Study ICF-MR (United States Bureau of the Census, 1982)	Population of the Study ICF-MR on October 1, 1987†	1990 Census Data for the General Population of the County of the Study ICF-MR (United States Bureau of the Census, 1994)
Asian or Pacific Islander	0 (0%)	5 (2.6%)	5728 (0.4%)
African-American	722, 812 (32.4%)	78 (41.3%)	326,967 (22.0%)
American Indian, Eskimo, or Aleut	0	1 (0.5%)	110,629 (7.4%)
Hispanic*	392, 118 (17.6%)*	52 (27.5%)*	386, 630 (26.0%)*
White	1, 249, 486 (56.0%)	52 (27.5%)	867,227 (58.2%)
Other	258, 638 (11.6%)	1 (0.5%)	178,515 (12.0%)
Total*	2,230,936 (100%)*	189 (99.9%)*†	1,489,066 (100%)*

the ICF-MR in the United States Census in 1980 and 1990. In other words, the six separate nonoverlapping primary categories for ethnicity for the study population were Asian or Pacific Islander; African-American; American Indian, Eskimo, or Aleut; Hispanic; white; and other. By contrast, in 1980 and 1990, the United States Census did not include Hispanic as a separate primary category. Only the other five ethnic categories were primary groups in the United States Census in 1980 and 1990. For the United States Census in 1980 and 1990, Hispanic was a secondary category independent of all the five primary categories. In order to estimate the upper and lower bounds of the white population of the developmental center, we perform two calculations. First, we assume that all Hispanic subjects at the developmental center are white; second, we assume that none of the Hispanic subjects at the developmental are white.

If all Hispanic subjects at the developmental center were white, then there was no significant difference between whites and non-whites in the developmental center and in the county ($\chi^2 = 0.783$, $df = 2$, N.S.) (Conover, 1980). On the other hand, if none of the Hispanic subjects in the developmental center were white, then the number of white residents of the developmental center was significantly less than in the county ($\chi^2 = 73.171$, $df = 1$, $P < 0.001$) (Conover, 1980). We assume that the majority of Hispanic subjects at

the developmental center were not white. We therefore conclude that the white population of the developmental center was likely markedly less than the white population of the county.

Intelligence Quotient (IQ)

In the study population, 142 subjects (75%) had intelligence quotients (IQs) under 20, and 46 subjects (24%) had IQs in the range 20 to 69. The IQ of one subject (1%) is missing. At the study center, formal individual psychological assessment was performed on each client every three years. A variety of psychological assessments were performed by different psychologists. Since different tests, including the Bayley (Bayley, 1969) and the Vineland (Sparrow et al., 1984), were used by different psychologists, the psychological assessments of the clients were not uniform. While some psychologists scored IQ as simply under 20, others gave specific numerical values for IQs including IQs under 20.

Admission Data

Table 3. Ethnic Classifications of the 189 Residents and of the County of the Intermediate Care Facility for Mental Retardation (ICF-MR) by the United States Bureau of the Census in 1990.

Ethnic Category	Study population of ICF-MR assuming that all Hispanic residents on October 1, 1987 were white	Study population of ICF-MR assuming that none of the Hispanic residents on October 1, 1987 were white	1990 census data for county of developmental center (United States Bureau of the Census, 1994)
White	104 (55.0%)	52 (27.5%)	867,227 (58.2%)
Other	85 (45.0%)	137 (72.5%)	621, 839 (41.8%)
Total	189 (100.0%)	189 (100.0%)	1,489,066 (100.0%)

Table 4. Admission and Psychiatric Data

Characteristic of Resident	Number	%
A single admission to the study ICF-MR	174	92.1
Prior admissions to the study ICF-MR	15	7.9
Prior admission to another ICF-MR	167	88.4
A single psychiatric hospitalization	45	23.8
Three psychiatric hospitalizations	1	0.5
Six psychiatric hospitalizations	1	0.5
A single psychiatric consultation at another facility	17	9.0
Twelve psychiatric consultations at another facility	1	0.5

Admissions of the 189 residents to the study ICF-MR are summarized in Table 4. Typically subjects were admitted to an ICF-MR at approximately five years of age and lived in an ICF-MR until death. Half of the study subjects had lived at the study ICF-MR for at least five years. A tenth of the study subjects had lived at the study ICF-MR for at least fifteen years. The longest length of stay was 53 years.

The mean length of stay was 6.1 years (SD 8.3) for women and 5.9 years (SD 4.7) for men. Although a general psychiatrist worked full-time at the study ICF-MR, several of the residents required psychiatric consultation and psychiatric hospitalization at other facilities (Table 4). In the six months before the survey only one subject (0.5%) was physically restrained for a single episode. No subjects were in seclusion or time-out in the six months preceding the survey.

Physician Notes on Chart

The number of physician (MD) notes in the past month are recorded in Table 5.

Table 5. Total Number of Physician (MD) Notes on the Chart in the Past Month

Total Number of Physician (MD) Notes	Number of Residents	%
0	25	13.2
1	65	34.4
2 to 4	78	41.3
5 to 10	13	6.9
16	1	0.5
50 to 51	2	1.1
Missing	5	2.6

Historical Characteristics

Historical data about developmental milestones (walking and talking) and about abuse and neglect are summarized in Table 6.

Table 6. Historical Data

Characteristic of Resident	Number	%
First walked at 24 months of age or later	85	45.0
Never walked	12	6.3
Spoke first words at 18 months of age or later	45	23.8
Never spoke	82	43.4
Experienced physical or emotional abuse or neglect	27	14.3

Physical Appearance

Subjects ranged in height from 42 to 76 inches (mean = 62.41, standard deviation = 6.40) and in weight from 34 to 245 pounds (mean = 127.05, standard deviation = 39.45). In this sample of 189 residents of an ICF-MR, 150 (79.4%) had dysmorphic facies and 103 (54.5%) had physical deformities excluding dysmorphic facies. Thus, stigmatization in the community was likely occur for several subjects due to unusual facial and physical appearances including extremely short stature and low weight (Goffman, 1963).

Activities of Daily Living (ADL)

The activities of daily living (ADL) skills of the subjects are summarized in Table 7.

Table 7. Activities of Daily Living (ADL)

Characteristic of Resident	Number	%
Toilet trained	100	52.9
Feeds self in socially acceptable manner	130	68.8
Dress self without assistance	57	30.2
Ambulate without assistance	137	72.5
Communicate daily needs through speech	58	30.7

Medical Disorders

The medical disorders of the subjects are summarized in Table 8. None of the clients had karyotypes or fragile X testing.

Table 8. Medical Disorders

Medical Disorder	Number	%
Down's syndrome	7	3.7
Epilepsy	110	58.2
Congenital cataracts	25	13.2
Visual impairments other than congenital cataracts	108	57.1
Bilateral hearing loss	37	19.6
Hearing impairments other than bilateral hearing loss	45	23.8
Spastic quadriplegia or quadripareisis	29	15.3
Spastic diplegia or triplegia	11	5.8
Cerebral palsy other than spastic diplegia, triplegia, quadriplegia, or quadripareisis	5	2.6
Kyphoscoliosis	49	25.9
Obesity	28	14.8
Flexion contractures	44	23.3
Microcephaly	23	12.2
Hepatitis B antigen positivity	25	13.2
Hepatitis B antibody positivity	104	55.0
Positive Tine Test	24	12.7
Bacillus Calmette-Guérin (BCG) vaccination	4	2.1
Stereotypies	0	0.0
Tardive dyskinesia	6	3.2
Withdrawal dyskinesias	4	2.1
Other movement disorders	37	19.6
Head injuries	37	19.6

Mental Disorders

The mental disorders of the subjects are summarized in Table 9.

Table 9. Mental Disorders

Mental Disorder	Number	%
Schizophrenia	14	7.4
Autism or other pervasive developmental disorder	9	4.8
Major depression	3	1.6
Bipolar disorder	2	1.1
Tourette's disorder	1	0.5
Other tic disorders	0	0.0
Conduct disorder	6	3.2
Oppositional disorder	2	1.1
Intermittent explosive disorder	4	2.1
Other personality disorder	1	0.5
Eating disorders including rumination	5	2.6
Primary degenerative dementia of the Alzheimer type	0	0.0

Current medications

The current medications of the subjects are summarized in Tables 10 and 11.

Table 10. Medications

Class of Medication	Number of Subjects	%
Psychoactive	103	54.5
Antiepileptic	73	38.6
Other	153	81.0

Table 11. Medications by Gender

Characteristic	Men	%	Women	%
Receives at least one medication	115	96	68	99
Receives psychoactive medication	74	62	32	46

Behavior Problems

The behavior problems of the subjects are summarized in Tables 12 and 13.

Table 12. Behavior problems

Behavior Problem	Number of Subjects	%
Assault	119	63.0
Self injury	107	56.6
Tantrum	82	43.4
Property destruction	69	36.5
Elopement	11	5.8
Hyperactivity	91	48.1
Withdrawn	74	39.2
Anxiety	10	5.3
Theft	46	24.3
Sexual problem, e. g., public masturbation and inserting pencils and other items into the urethra of the penis	32	16.9
Relationship problems with peers	109	57.7
Relationship problems with staff	68	36.0
Head banging	23	12.2
Pica	23	12.2
Self biting	21	11.1
Rumination	12	6.3
Self scratching	35	18.5
Face slapping	11	5.8
Hair pulling	1	0.5
Eye poking	0	0.0
Other self injury	38	20.1

Table 13. Head-banging Characteristics

Characteristic	Number	%
Onset of head-banging at 0 years	1	0.5
Onset of head-banging at 1 year	1	0.5
Onset of head-banging at 4 years	1	0.5
Onset of head-banging at 5 years	1	0.5
Onset of head-banging at 9 years	4	2.1
Frequency of head-banging less than weekly	1	0.5
Frequency of head-banging between daily and weekly	5	2.6
Frequency of head-banging more than daily	4	2.1
Duration of head-banging less than a year	2	1.1
Duration of head-banging for a year or more	12	6.3
Treatment with behavior modification for head-banging	6	3.2
Treatment with medication for head-banging	6	3.2

Estimated Scores for Axes IV and V

Estimated scores for Axes IV (Severity of Psychosocial Stressors) and V (Global Assessment of Functioning) of the Diagnostic and Statistical Manual of Mental Disorders, 3rd, Revised (DSM-III-R)(American Psychiatric Association, 1987) are summarized in Table 14. A higher score on Axis IV indicates more psychosocial stressors (American Psychiatric Association, 1987).

An Axis V score is missing for two subjects. A higher score on Axis V indicates a better level of functioning. Although scores can possibly range from 0 to 100, for these subjects the Axis V scores ranged from 0 to 50. The vast majority of subjects, 178 (94.2%), had scores ranging from 0 to 10.

Associations of Subject Characteristics

The majority of the residents of the developmental center were adults with profound mental retardation. Gender was strongly associated with IQ in this population. The vast majority of the women in this population (85%) had IQs less than 20, while only 70% of the men had IQs less than 20 ($\chi^2 = 5.494$, $df = 2$, $p = 0.019$). While an IQ consistent with the diagnosis of mental retardation was a requirement for admission to the center, other behavioral, emotional, or physical problems requiring the intensive services of an ICF-MR were also required. Thus, most of the women admitted to the center had severe physical needs, while most of the men had severe behavioral problems.

Discussion

In order to facilitate the community placement of people with mental retardation and other developmental disabilities residing in institutions, we developed the DPQRS (Appendix) to ascertain by chart review by trained raters a person's suitability for successful community placement. Satisfactory reproducibility of results was demonstrated by the attainment of scores greater than or equal to 0.40 for the estimates of the statistic κ (kappa) (Fleiss, 1981; Landis and Koch, 1977) for the vast majority (91%) of the items of the DPQRS (Appendix) (Table 1). As demonstrated in Table 1, the inter-rater reliability of the ages of first walking and first talking are poor. However, since these are potentially important items and since we anticipate that adequate inter-rater reliability can be attained with a larger sample size, we have retained items in the DPQRS (Appendix) despite the poor reliability attained on this pilot study. The sample size for the initial assessment of reliability was too small to utilize κ for most items of the DPQRS due to the low frequency of occurrence of the traits in this population (Brasic, *et al.*, 1997d).

After the reliability of the DPQRS was studied, additional items were added to clarify specific problems identified during the inter-rater reliability study. Inter-rater reliability has not been assessed for the additional items added after the preliminary reliability study. The full instrument is presented at this time due to its expected usefulness as a survey instrument, and as a tool to assess the likely problems to be encountered when persons with mental retardation and other developmental disabilities are placed in community settings. Detailed evaluation of the psychometric properties of the DPQRS (Appendix), including reliabil-

Table 14. Estimated Scores for Axis IV and Axis V (Severity of Psychosocial Stressors) of the (DSM-III-R), Based on Chart Review by Two Child and Adolescent Psychiatrists and a Developmental Pediatrician

Axis IV Score	Frequency	Percent (%)
0	118	62.4
1	44	23.3
4	1	0.5
5	23	12.2
6	1	0.5
Axis V Score		
0	162	85.7
1	3	1.6
4	1	0.5
5	3	1.6
8	1	0.5
9	7	3.7
10	1	0.5
11	2	1.1
15	1	0.5
26	1	0.5
30	2	1.1
40	2	1.1
50	1	0.5

ity and validity (Brasic and Young, 1994), are needed. Additionally, follow-up studies after community placement are needed to ascertain whether subjects fare as anticipated in actual community placements.

Although direct comparison with the ethnic distribution of the general population is challenged by the use of Hispanic as a primary ethnic class in the institution and as a secondary class in the United States Census (United States Bureau of the Census, 1982, 1994; United States Department of Commerce, Bureau of the Census, 2000), we assume that the Hispanic residents of the developmental center are not white, so that the proportion of non-whites at the institution was likely markedly greater than in the general population (Table 4). We hypothesize that many white families in this county utilized their resources to place their severely disabled family members in well-respected out-of-state private facilities for the disabled. While both white and non-white families likely recognized the atrocious conditions in the public developmental center documented in this article, minority families typically lacked the money and the power to place their family members in the esteemed voluntary agencies for the developmentally disabled located in other states. Thus, there was likely a two-class system of care for individuals with developmental disabilities. The privileged apparently arranged for their disabled family members to go to fine out-of-state private facilities, while the disadvantaged disabled are apparently placed in state institutions with the multiple problems documented in this survey. We hypothesize that similar inequities continue in the community. Surveys utilizing the DPQRS (Appendix) are needed to investigate the conditions in community placements. Also researchers, administrators, clinicians, and others working with disabled populations need to gather information about ethnicity and Hispanic status to facilitate direct comparison and contrast with census categories. We now ask all subjects to complete the demographic coding sheet utilized by the United States Census (United States Department of Commerce, Bureau of the Census, 2000). The DPQRS (Appendix) contains multiple items concerning ethnicity including Hispanic heritage so that all subjects can be classified according to the current categories of the United States Census (United States Department of Commerce, Bureau of the Census, 2000).

In the study developmental center, female subjects were likely to exhibit profound mental retardation and the inability to perform the activities of daily living. The deficits in self-help skills are consistent with profound mental retardation (Eyman et al., 1984). Planners must recognize the great needs of these individuals in general communities. Care must be exercised to prevent the physical and sexual abuse of these vulnerable people. Both biologic and socio-environmental conditions may contribute to the occurrence of disabled females in this institutionalized, profoundly retarded population. First, although women with X-linked disorders usually have milder symptoms than men, males die *in utero* in some X-linked disorders and only affected females survive (Vogel and Motulsky, 1986). Second, some

multi-handicapped women in this population may be affected by severe X-chromosome conditions unique to women, e. g., Rett's disorder (American Psychiatric Association, 2000). Third, the illnesses of the subjects in this study may represent the influence of other genetic mechanisms involving a "dose" phenomenon such that a greater "dose" in females may lead to greater handicaps than in affected males. For example, a threshold phenomenon may be operant, in which a greater genetic "dose" is required to reach the threshold for penetrance in females, resulting in fewer affected females who have more severe symptoms. Similarly, variable expressivity in which females have more severe symptoms, may occur in these disorders. Reduced penetrance and variable expressivity are more common in autosomal dominant than autosomal recessive disorders. Generally, the variable expression of traits between males and females may be instances of sex-influenced traits, in which traits are present in both sexes, but with differing frequencies (Young et al., 1990). Future research is needed to assess if there are significantly more non-ambulatory women than men among individuals with mental retardation.

These findings also suggest that odd, inappropriate, or disruptive behaviors of mentally retarded women are more readily tolerated by their families and friends than are similar behaviors in mentally retarded men among whom there may be a greater perceived threat. We hypothesize that only the markedly abnormal or highly aggressive multi-handicapped women are placed in institutions, while less severely affected women remain at home. Thus, both genetic and social considerations may contribute to these findings. We must learn from the deinstitutionalization experiences of mental hospitals, which led to the population of our streets with homeless, mentally ill women (Bachrach, 1984, 1985, 1987a). Additionally mentally ill residents of adult homes and nursing homes (Anonymous, 2002a, b; Archibold and Cooper, 2002; Levy, 2002a, b, c; McKinley, 2002) often receive only many psychoactive medications without social and psychological stimulation (Levy, 2002d). Community placement is under consideration for most institutionalized retarded citizens, so clinicians, planners, administrators, and public officials must recognize the particular needs of multi-handicapped retarded women when planning community living arrangements.

Since the majority of the subjects had dysmorphic facies (79.4%) and physical deformities excluding dysmorphic facies (54.5%), they tend to stand out in the general population. Some have marked low weight and short stature. These physical traits may impede the ability of some of the subjects to blend into the general community. Many may therefore also face stigmatization in the community merely because of physical appearance (Goffman, 1963).

The paucity of physician notes on the charts of these severely disabled subjects is disturbing. The majority of subjects (N = 155; 82.0%) did not even have at least a single physician note on the chart every week (Table 5). This find-

ing suggests that most clients were not receiving physician attention every week. The dearth of physician notes on the medical records of the subjects may reflect assumptions of stability or futility on the part of the physicians, but these results are in striking contrast to the severity of problems exhibited by the majority of the clients. In this sample apparently only clients with the ability to make known their needs received close physician attention. The vast majority of clients who could not verbalize needs were not seen regularly by the physicians nor conceivably brought to the attention of their physicians by their nurses. Careful physician monitoring of the behavioral and physical symptoms of the clients is needed. These subjects with multiple physical and emotional disorders deserve regular medical care.

The need for frequent second opinions by psychiatrists is another striking finding of this population. Although a full-time psychiatrist worked at the center, 18 (9.5%) of the subjects were referred by the clinical staff for psychiatric consultation at other facilities (Table 4). These suggest that some subjects continued to manifest serious behavioral problems despite in-house psychiatric assessment. The clinical staff were apparently dissatisfied with the continued psychiatric services provided by the staff psychiatrist to some subjects. In particular, one subject (0.5%) was referred for 12 prior psychiatric consultations at other facilities during the current admission (Table 5). These findings suggest that almost a tenth of the subjects in this institution exhibited serious psychiatric disorders refractory to the interventions of a psychiatrist dedicated full-time to their treatment. The behavioral and emotional problems of several clients are complex and challenging. Some subjects may be better able to control their behavior disorders in the more structured therapeutic milieu of a psychiatric facility. There is a need for specialized psychiatric units for the intensive evaluation and treatment of behavioral and emotional problems of people with mental retardation and developmental disabilities. The administrative separation of state services for mental retardation from mental health services hinders the effective management of some individuals with both developmental disabilities and psychiatric disorders.

The history of physical or emotional abuse or neglect in 27 (14.3%) (Table 6) of the residents is evidence of the vulnerability of these subjects for inappropriate activity with others. Although not assessed in this study, there is likely an additional risk for sexual abuse in this population (Brasic, 2002). In community settings they are at risk of perpetrating or becoming victims of assaults, rapes, and other criminal behavior. The presence of additional social and environmental stressors is substantiated by the high scores of some residents on Axis IV (Severity of Psychosocial Stressors) of the Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R) (American Psychiatry Association, 1987) (Table 14). Since many residents are unable to communicate their basic needs (Table 7), they are likely to have additional social and environmental stressors, including sexual and physical abuse,

that are unknown to staff. Administrators, neighbors, law enforcement officials, and others in their communities need to be aware of the likelihood of criminal activity involving some individuals.

A remarkable finding in this sample is the absence of adequate etiologic assessment. The multiple medical, behavioral, and psychiatric problems suggest that genetic disorders are likely. Down's syndrome was diagnosed by physical appearance in 7 (3.7%) of the subjects (Table 8). However, laboratory genetic analysis was absent from all charts. None of the individuals had karyotypes or testing for fragile X. These are serious deficits in the medical evaluation of the subjects because of the high prevalence of genetic disorders in populations of people with mental retardation and developmental disabilities. Careful genetic evaluations are needed to identify treatable disorders that can be readily identified through established laboratory procedures (Young et al., 1990).

The scores of the Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R) Axis V (American Psychiatric Association, 1987) based on chart review by the raters are extremely low. The vast majority of the clients (178; 94%) had scores 10 or lower indicating that the subjects were acutely in serious risk of harm to self or others (Table 14). These scores are typically interpreted as indications for acute psychiatric hospitalization. As in Pennsylvania (Conroy and Bradley, 1985), the residents of this developmental center are likely to require extensive future mental health treatment. Additionally, individuals with mental retardation and developmental disabilities may benefit from psychological interventions including individual (Gair et al., 1980), group (Monfils and Menolascino, 1984), and family therapy, as well as behavior therapy (Gardner and Cole, 1984). Effective means to deliver the necessary psychotherapeutic interventions to people with mental retardation and developmental disabilities are needed.

There are several limitations to this study. The data presented in this article were collected more than a decade ago. Therefore, the relevance of the data today may be questioned. Nevertheless, this article describes the remarkable conditions typical of North American developmental centers (institutions) in the past century. This report portrays the frank acknowledgement of the atrocious conditions that led to the movement to close developmental centers and to place cognitively handicapped people in communities. The challenges described in this report are relevant currently because people with the conditions and needs of the study institution still exist today. Furthermore, new individuals with the handicaps of the study population are born every day. Many individuals with the severe handicaps of the study population still reside in institutions today. Unless the extreme needs of handicapped persons and the limited resources of developmental centers are described explicitly, public planners cannot appropriately take the necessary corrective action. The results of this study are evidence of

the marked shortcomings of the study institution. Other studies were conducted at this institution during the course of deinstitutionalization (Barnett and Brasic, 1995; Barnett et al., 1998; Brašić et al., 2001a) to document the continued problems of the study population. The conditions experienced by the residents of the study institution were frightening to observe. However, the current study does not address the present state of the study individuals. How are they faring since they left the institution? Comparable studies are needed to identify the problems of persons with mental retardation and developmental disabilities in community settings. The serious problems of excessive treatment with psychoactive medications without other social, psychological, and medical interventions encountered by adults with mental illness in community placements (Levy, 2002d) suggests that the status of people with developmental disabilities in community placements may be far from optimal. Contemporary assessments utilizing the current nomenclatures (American Psychiatric Association, 2000) will help to evaluate the present state of individuals with mental retardation and developmental disabilities. Future surveys are needed with the DPQRS and other instruments to ascertain the status in group homes of people with mental retardation and other developmental disabilities, mental illness, and other chronic conditions. We fear that community residences exhibit problems comparable to the study institution.

Another limitation of the current study is the incomplete psychometric analysis of the DPQRS (Appendix). The validity of the DPQRS (Appendix) cannot be determined due to the absence of external criteria. Future studies of the DPQRS are needed to ascertain its validity utilizing other measures of psychiatric status including the Brief Psychiatric Rating Scale (Overall and Gorham, 1962), Clinical Global Impressions (Guy, 1976), the Global Assessment Scale (Endicott et al., 1976), and the Children's Global Assessment Scale (Shaffer et al., 1983, 1985). Future psychometric evaluation of the DPQRS is needed utilizing both (1) factor analysis to ascertain associations among items and (2) multiple and logistic regression to relate items to external criteria. We present this instrument for use by others because of the dearth of tools to predict the problems of community placement of individuals in institutions. Although full investigation of the reliability and the validity (Brasic and Young, 1994) of the DPQRS are needed, its publication now is needed to fulfill the urgent need for this assessment protocol. Complete evaluation of individuals with mental retardation and developmental disabilities who face possible community placement includes the administration of multiple assessment procedures specifically developed for the needs and limitations of this population (Brašić, 2002, forthcoming; Brasic and Barnett, 1997; Brasic and Gianutsos, 2000; Brasic et al., 1994, 1997a, b, c, d, 1998a, b, c, 1999a, b, c, 2000a, b, c, 2001a, b, c, forthcoming a, b; Mendonca et al., 2001) including the DPQRS (Appendix), the Family Compliance Checklist (FCC) (Brašić et al., 1998c, 2001c), the Movement Disorder Checklist

(MDC) (Brasic and Bronson, 2002; Brašić, forthcoming), the Psychoactive Medication Quality Assurance Rating Survey (PQRS) (Brašić, forthcoming; Brasic et al., 1997d, 1999b, c, forthcoming a, b; Brasic and Bronson, 2002), the Serotonin Syndrome Checklist (SSC) (Brašić, 2002, forthcoming; Brasic et al., 1998b), the Timed Self-Injurious Behavior Scale (TSIBS) (Brašić, forthcoming; Brasic et al., 1997a, 1999a, 2001b), and the Timed Stereotypies Rating Scale (TSRS) (Brašić, forthcoming; Brasic and Bronson, 2002; Campbell, 1985).

We conclude that the DPQRS (Appendix) is a reliable instrument to identify the potential problems that may hinder the successful community placement of people residing in institutions. The DPQRS (Appendix) will help clinicians to identify those individuals whose needs require intensive services unavailable in the community. Utilization of the DPQRS (Appendix) is likely to be helpful for clinicians and administrators caring for multiple populations being evaluated for placement in communities, including people with mental retardation and other developmental disabilities, people with mental illness, prisoners, and nursing home residents. On-going evaluation of individuals living in communities is needed to determine the suitability of the less-structured environment. Follow-up administration of the DPQRS (Appendix) to these populations after community placement is therefore indicated to verify the suitability of the placement and the adequacy of the services provided.

Acknowledgements

This research was supported by the Medical Fellows Program of the Consortium for Medical Education in Developmental Disabilities (CMEDD) of the Office of Mental Retardation and Developmental Disabilities (OMRDD) of the State of New York, the Essel Foundation, Family and Friends of Chelsea Coenraads, the National Alliance for Research on Schizophrenia and Depression (NARSAD), and the Rett Syndrome Research Foundation (RSRF). This research was sponsored by the Department of Psychiatry at Bellevue Hospital Center and the New York University School of Medicine in New York, New York. The cooperation of Bellevue Hospital Center, Columbia University in the City of New York, and the Health and Hospitals Corporation of the City of New York is gratefully acknowledged.

References

- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 3rd ed revised (DSM-III-R). Washington, DC: American Psychiatric Association; 1987

- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 4th ed text revision (DSM-IV-TR™). Washington, DC: American Psychiatric Association; 2000
- Anonymous. Facilities for mentally ill. The New York Times. October 6, 2002a. <http://www.nytimes.com/2002/10/06/nyregion/06TERM.html>
- Anonymous. New York's mentally ill deserve better. The New York Times. October 9, 2002b <http://www.nytimes.com/2002/10/09/opinion/09WED3.html> [editorial]
- Archibold RC, Cooper M. McCall, citing report, criticizes Pataki on care for the mentally ill. The New York Times. October 7, 2002 <http://www.nytimes.com/2002/10/07/nyregion/07GOV.html>
- Bachrach LL. Concepts and issues in deinstitutionalization. In: Barofsky I, Budson RD (eds) The chronic psychiatric patient in the community: principles of treatment. New York: Spectrum Publications; 1983:5-28
- Bachrach LL. Deinstitutionalization and women: assessing the consequences of public policy. *Am Psychol* 1984;39:1171-1177
- Bachrach LL. Chronic mentally ill women: emergence and legitimization of program issues. *Hosp Community Psychiatry* 1985;36:1063-1069
- Bachrach LL. Homeless women: a context for health planning. *Milbank Q* 1987a;65:371-396
- Bachrach LL. Loena Bachrach speaks: selected speeches and lectures. *New Directions for Mental Health Services*, number 35. San Francisco: Jossey-Bass; 1987b
- Barnett JY, Brasic JR: Movement disorders and cognitive deficits in mental retardation. *Arch Clin Neuropsychol* 1995;10:296-297 [abstract]
- Barnett JY, Brašić JR, Zelhof R, Tarpley H: Neurocognitive correlates of dyskinesia in cocaine abstinent adults with mental retardation. *Mov Disord* 1998;13(supplement 2):223 [abstract]
- Bayley N. Bayley Scales of Infant Development. New York: Psychological Corporation; 1969
- Borthwick-Duffy SA, Eyman RK, White JF. Client characteristics and residential placement patterns. *Am J Ment Defic* 1987;92 (1): 24-30
- Brasic JR. Pervasive developmental disorder: autism. *eMedicine Journal* August 28, 2002 ;3(8) <http://www.emedicine.com/ped/topic180.htm>
- Brašić JR. Treatment of movement disorders in autism spectrum disorders. In: Hollander E (ed) Autism spectrum disorders: practical management. New York: Marcel Dekker, forthcoming
- Brašić JR, Barnett JY. Hyperkinesias in a prepubertal boy with autistic disorder treated with haloperidol and valproic acid. *Psychol Rep* 1997;80:163-170
- Brasic JR, Barnett JY, Ahn SC, Nadrich RH, Will MV, Clair A. Clinical assessment of self-injurious behavior. *Psychol Rep* 1997a;80:155-160
- Brašić JR, Barnett JY, Aisemberg P, Ahn SC, Nadrich RH, Kaplan D, Ahmad R, Mendonça M de F. Dyskinesias subside off all medication in a boy with autistic disorder and severe mental retardation. *Psychol Rep* 1997b;81:755-767
- Brasic JR, Barnett JY, Kaplan D, Sheitman BB, Aisemberg P, Lafargue RT, Kowalik S, Clark A, Tsaltas MO, Young JG. Clomipramine ameliorates adventitious movements and compulsions in prepubertal boys with autistic disorder and severe mental retardation. *Neurology* 1994;44:1309-1312
- Brašić JR, Barnett JY, Nadrich RH, Kaplan D, Ahmad R, Rodriguez M, Mendonça MF. Evaluation of self-injurious tics. 3rd International Scientific Symposium on Tourette Syndrome, Poster Abstracts, June 4-6, 1999, Marriott World Trade Center Hotel, New York City. Bayside, New York: Tourette Syndrome Association, Inc.; 1999a:19 [abstract]
- Brašić JR, Barnett JY, Sheitman BB, Lafargue RT, Ahn SC. Clinical assessment of adventitious movements. *Psychol Rep* 1998a;83:739-750
- Brašić JR, Barnett JY, Sheitman BB, Lafargue RT, Kowalik S, Kaplan D, Tsaltas MO, Ahmad R, Nadrich RH, Mendonça MF. Behavioral effects of clomipramine on prepubertal boys with autistic disorder and severe mental retardation. *CNS Spectrums: The International Journal of Neuropsychiatric Medicine* 1998b;3(10):39-46
- Brašić JR, Barnett JY, Sheitman BB, Tsaltas MO. Adverse effects of clomipramine. *J Am Acad Child Adolesc Psychiatry* 1997c;36:1165-1166 [letter]
- Brašić JR, Barnett JY, Will MV, Nadrich RH, Sheitman BB, Ahmad R, Mendonça MF, Kaplan D, Brathwaite C. Dyskinesias differentiate autistic disorder from catatonia. *CNS Spectrums: The International Journal of Neuropsychiatric Medicine* December 2000a;5(12):19-22
- Brašić JR, Barnett JY, Zelhof R, Tarpley H. Dopamine antagonists ameliorate the dyskinesias, aggression, and inattention of persons with mental retardation referred to psychiatric clinics. *German Journal of Psychiatry* 2001a;4(1):9-16 <http://www.gipsy.uni-goettingen.de/gjp-article-brasic3.pdf>
- Brasic JR, Bronson B. Tardive dyskinesia. *eMedicine Journal* September 27, 2002;3(9) <http://www.emedicine.com/neuro/topic362.htm>
- Brašić JR, Furman J, Conte RM, Baisley WE, Jaslow RI. Assuring the quality of the utilization of psychoactive medication by people with mental retardation and developmental disabilities by assessing dosages. *German Journal of Psychiatry* 2000b;3(3):7-12 <http://www.gipsy.uni-goettingen.de/gjp-article-brasic2.pdf>
- Brašić JR, Furman J, Conte RM, Baisley WE, Jaslow RI. Psychoactive Medication Quality Assurance Rating Survey (PQRS) Screening Criteria. *Journal of Developmental and Physical Disabilities* forthcoming a

- Brašić JR, Furman J, Conte RM, Baisley WE, Jaslow RI: Improving the quality of the utilization of psychoactive medication. *Journal of Developmental and Physical Disabilities* forthcoming b
- Brašić JR, Furman J, Conte RM, Baisley WE, Nadrich RH, Kaplan D, Ahmad R, Rodriguez M, Mendonça MF, Will MV. Quality assurance of treatments for Tourette syndrome and other tic disorders. 3rd International Scientific Symposium on Tourette Syndrome, Poster Abstracts, June 4-6, 1999, Marriott World Trade Center Hotel, New York City. Bayside, New York: Tourette Syndrome Association, Inc.; 1999b:20 [abstract]
- Brašić JR, Furman JW, Conte RM, Baisley WE. Continuous quality improvement in child and adolescent psychopharmacology. *Child and Adolescent Psychopharmacology News* 1999c;4(3):9-10
- Brašić JR, Gianutsos JG. Neuromotor assessment and autistic disorder. *Autism: An International Journal of Research and Practice* 2000;4(3):287-298
- Brašić JR, Kisnad HV, Barnett JY, Kowalik S, Ahn SC, Nadrich RH, Mendonca MF. Clinical assessment of self-injurious behaviors in people with movement disorders. *Mov Disord* 2001b;16(supplement 1):S46 [abstract]
- Brašić JR, Kisnad HV, Leven LI, Nettleton JW, Young JG. Characteristics of individuals with prolonged institutionalizations. *Child and Adolescent Psychiatry Grand Rounds, Division of Child and Adolescent Psychiatry, Department of Psychiatry, Mount Sinai School of Medicine, New York, New York. January 8, 1988.*
- Brašić JR, Nadrich RH, Kleinrock S, Brathwaite C. Do families comply with child and adolescent psychopharmacology? *Child and Adolescent Psychopharmacology News* 2001c;6(2):6, 7, 10
- Brašić JR, Will MV, Ahn SC, Nadrich RH, McNally G. A review of the literature and a preliminary study of family compliance in a developmental disabilities clinic. *Psychol Rep* 1998c;82:275-286
- Brašić JR, Young JG. Research design, measures, and statistics. In: Robson KS (ed) *Manual of clinical child psychiatry*, rev ed. Washington, DC: American Psychiatric Press, Inc.;1994:435-463
- Brašić JR, Young JG, Furman J, Conte RM, Baisley WE, Jaslow RI. Psychoactive Medication Quality Assurance Rating Survey (PQRS). *Journal of Developmental and Physical Disabilities* 1997d;9:311-336
- Brašić JR, Zagzag D, Kowalik S, Prichep L, John ER, Barnett JY, Bronson B, Nadrich RH, Cancro R, Buchsbaum M, Brathwaite C. Clinical manifestations of progressive catatonia. *German Journal of Psychiatry* 2000c;3(2):13-24
<http://www.gjpsy.uni-goettingen.de/gjp-article-brasic.htm>
- Brown MC, Hanley AT, Nemeth C, Epple WA, Bird W, Bontempo A. The Developmental Disabilities Profile. Reference manual. Instructions for completion of the Registration/Movement Form and the Developmental Disabilities Profile. Albany, New York: Program Research Unit, Policy and Planning Office, New York State Office of Mental Retardation and Developmental Disabilities; 1987
- Campbell M. Timed Stereotypies Rating Scale. *Psychopharmacol Bull* 1985;21:1082
- Conover WJ. *Practical nonparametric statistics*, 2nd ed. New York: Wiley; 1980
- Conroy JW, Bradley VJ. *The Pennhurst Longitudinal Study: a report of five years of research and analysis*. Philadelphia, Pennsylvania: Temple University Developmental Disabilities Center; 1985
- Ellis D. *Sensory impairments in mentally handicapped people*. London: Groom-Helm, 1986
- Endicott J, Spitzer RL, Fleiss JL, Cohen J. The Global Assessment Scale: A procedure for measuring overall severity of psychiatric disturbance. *Arch Gen Psychiatry* 1976;33:766-771
- Eyman RK, Borthwick SA, Tarjan G. Current trends and changes in institutions for the mentally retarded. In: Ellis NR, Bray NW (eds) *International review of research in mental retardation*, vol 12. New York: Academic Press Inc., 1984:177-203
- Farber JM. Psychopharmacology of self-injurious behavior in the mentally retarded. *J Am Acad Child Adolesc Psychiatry* 1987;26:296-302
- Fleiss JL. *Statistical methods for rates and proportions*, 2nd ed. New York: Wiley, 1981
- Gair DS, Hersch C, Wiesenfeld S. Successful psychotherapy of severe emotional disturbance in a young retarded boy. *J Am Acad Child Psychiatry* 1980;19:257-269
- Gardner WI, Cole CL. Use of behavior therapy with the mentally retarded in community settings. In: Menolascino FJ, Stark JA (eds) *Handbook of mental illness in the mentally retarded*. New York: Plenum Press; 1984:97-153
- Goffman E. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, New Jersey: Prentice-Hall; 1963
- Guy W. *ECDEU assessment manual for psychopharmacology revised*, 1976. DHEW Publication No. (ADM) 76-338. Rockville, Maryland: U. S. Department of Health, Education, and Welfare, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration; 1976: 217-222
- Hill BK, Bruininks RH. Maladaptive behavior of mentally retarded individuals in residential facilities. *Am J Ment Defic* 1984;88 (4):380-387
- ICD-9-CM, *International Classification of Diseases*, 9th revision, clinical modification, 4th ed, 1994. Los Angeles: Practice Management Information Corporation (PMIC); 1993
- Jacobson JW. Psychological services utilization: relationship to severity of behaviour problems in intellectual disability services. *J Intellect Disabil Res* 1998;42:307-315

- Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977;33:159-174
- Levy CJ. Democrats fault decision to move mentally ill. *The New York Times*. October 10, 2002a
<http://www.nytimes.com/2002/10/10/nyregion/10HOME.html>
- Levy CJ. McCall calls for disclosures on units holding mentally ill. *The New York Times*. October 8, 2002b
<http://www.nytimes.com/2002/10/08/nyregion/08HOME.html>
- Levy CJ. Mentally ill, and locked away in nursing homes. *The New York Times*. October 6, 2002c: 1, 29
<http://www.nytimes.com/2002/10/06/nyregion/06HOME-WEB.html>
- Levy CJ. Panel urges change in New York homes for the mentally ill. *The New York Times*. September 24, 2002d: A1, A28
<http://www.nytimes.com/2002/09/24/nyregion/24HOME.html?todayshadlines>
- McKinley JC, Jr. McCall calls for investigation of state's policies on treatment of the mentally ill. *The New York Times*. October 11, 2002
<http://www.nytimes.com/2002/10/11/nyregion/metrocampaigns/11GOVE.html?todayshadlines>
- Mendonca MF, Brasic JR, Perry R, Kringsman S, Lucien M, Petty CB. Risperidone ameliorates large amplitude complex stereotypies and high activity level in a boy with autistic disorder. *Mov Disord* 2001;16(supplement 1):S36 [abstract]
- Monfils MJ, Menolascino FJ. Modified individual and group treatment for the mentally retarded-mentally ill. In: Menolascino FJ, Stark JA (eds) *Handbook of mental illness in the mentally retarded*. New York: Plenum Press; 1984:155-169
- Overall JF, Gorham DR. The Brief Psychiatric Rating Scale. *Psychol Rep* 1962;10:799-812
- SAS Institute Inc. *SAS/STAT guide for personal computers*, version 6 ed. Cary, North Carolina: SAS Institute; 1985
- Shaffer D, Gould MS, Brasic J, Ambrosini P, Fisher P, Bird H, Aluwahlia S. A Children's Global Assessment Scale (CGAS). *Arch Gen Psychiatry* 1983;40:1228-1231
- Shaffer D, Gould MS, Brasic J, Ambrosini P, Fisher P, Bird H, Aluwahlia S. A Children's Global Assessment Scale (CGAS) (for children 4 to 16 years of age). *Psychopharmacol Bull* 1985;21(4):747-748
- Sparrow SS, Balla DA, Cicchetti DV. *Vineland Adaptive Behavior Scales*. Circle Press, Minnesota: American Guidance Service; 1984
- United States Bureau of the Census. *County and city data book*, 1994. Washington, DC: United States Government Printing Office;1994
- United States Bureau of the Census. *State and metropolitan area data book*, 1982. Washington, DC: United States Government Printing Office;1982
- United States Department of Commerce, Bureau of the Census. *United States Census 2000. Long Form Questionnaire. Form D-2*. Washington, DC: United States Department of Commerce, Bureau of the Census;2000:3
<http://www.census.gov/dmd/www/pdf/d02p.pdf>
- Vitello SJ. Deinstitutionalization progress in the United States. *Med Law* 1986;5:273-278
- Vogel F, Motulsky AG. *Human genetics: problems and approaches*, 2nd ed. Berlin: Springer-Verlag;1986:119-123
- Wolfensberger W. The principle of normalization and its implications to psychiatric services. *Am J Psychiatry* 1970;127:291-297
- Young JG, Brasic JR, Leven L. Genetic causes of autism and the pervasive developmental disorders. In: Deutsch SI, Weizman A, Weizman R (eds) *Application of basic neuroscience to child psychiatry*. New York: Plenum Medical Book Company;1990:183-216

Appendix

Discharge Planning Quality Rating Survey (DPQRS)

	Asterisk (*) indicates: 0 = no, 1 = yes, 9 = unknown	
	Person's Full Name _____	
	INSTRUCTIONS: Answer all items after reviewing the chart of the person. If the information about an item is unknown, leave the item blank unless instructed otherwise. You may write any additional information on the backs of the pages.	
	IDENTIFYING PERSONAL INFORMATION	
Number	Item	Rater's response
1	Case number	
2	Form number	
3	Time number	
4	Rater code number	
5	Subject number	
6	Today's date	
7	Person's date of birth	
8	Person's sex (0 = female, 1 = male)	
9A	Is the person Spanish, Hispanic, or Latino?*	
	If no, skip to 9B1.	
9A1	Is the person Mexican, Mexican American, or Chicano?*	
9A2	Is the person Puerto Rican?*	
9A3	Is the person Cuban?*	
9A4	Is the person any other Spanish, Hispanic, or Latino race?*	
	If the answer is no, then skip to 9B1.	
9A5	Please print all other Spanish, Hispanic, or Latino races.	
9B1	Is the person white?*	
9B2	Is the person black, African American, or Negro?*	
9B3	Is the person American Indian or Alaska Native?*	
	If no, skip to 9B5.	
9B4	Please print the names of all enrolled or principal American Indian or Alaska Native tribes.	
9B5	Is the person Asian Indian?*	
9B6	Is the person Chinese?*	
9B7	Is the person Filipino?*	
9B8	Is the person Japanese?*	
9B9	Is the person Korean?*	

9B10	Is the person Vietnamese?*	
9B11	Is the person Native Hawaiian?*	
9B12	Is the person Guamanian or Chamorro?*	
9B13	Is the person Samoan?*	
9B14	Is the person any other Pacific Islander race?*	
	If no, skip to 9B16.	
9B15	Please print the names of all other Pacific Islander races.	
9B16	Is the person any other Asian race?*	
	If no, skip to 9B18.	
9B17	Please print the names of all other Asian races.	
9B18	Is the person any other race?*	
	If no, skip to 10.	
9B19	Please print the names of all other races.	
10	Person's height in inches	
11	Person's weight in pounds	
12	Person's level of mental retardation 1 = Profound (IQ below 20 or 25) 2 = Severe (IQ 20 - 25 to 35 - 40) 3 = Moderate (IQ 35 - 40 to 50 - 55) 4 = Mild (IQ 50 - 55 to approximately 70) 5 = Borderline (IQ 71 to 84) 6 = Not retarded 9 = Unknown	
13	Full scale intelligence quotient (IQ), as measured by standard individual test	
13A	Please print the name of the IQ test used in 13.	
14	Person's dominant hand 1 = right 2 = left 3 = ambidextrous 4 = other 9 = unknown	
	ADMISSION DATA	
15	Date of current admission to this facility	
16	Total number of admissions to this facility including current admission	
17	Total number of admissions to developmental centers excluding current admission	
18	Total number of psychiatric hospitalizations excluding this institution and other developmental centers	
19	Total number of physician (MD) notes on chart in past month	

20	Number of psychiatric consultations during the current admission	
21	Total number of times the person was in seclusion in the past six months	
22	Total number of times the person was in time-out in the past six months	
23	Total number of times the person was in restraints in the past six months	
	DEVELOPMENTAL HISTORY	
24	Age when the person first walked in months	
25	Age when the person spoke first words in months	
	HISTORY OF ABUSE OR NEGLECT	
26	Has the person ever experienced physical or emotional abuse or neglect?*	
	If no, skip to 27.	
26A	Please print all known occurrences of physical and emotional abuse or neglect of the person.	
	PHYSICAL APPEARANCE	
27	Does the person exhibit dysmorphic facies (unusual facial appearance)?*	
28	Does the person have any physical deformities excluding dysmorphic facies (unusual facial appearance)?*	
	ACTIVITIES OF DAILY LIVING	
29	Is the person toilet-trained?*	
30	Can the person feed self in a socially acceptable manner?*	
31	Can the person dress self without assistance?*	
32	Can the person walk without assistance?*	
33	Does the person effectively communicate daily needs through speech?*	
	If yes, skip to 35.	
34	Does the person effectively communicate daily needs through nonverbal means including gestures and sign language?*	
35	Does the person have Down's syndrome?*	
36	Does the person have epilepsy?*	
37	Does the person have congenital cataracts?*	
38	Does the person have visual impairments excluding congenital cataracts?*	
39	Does the person have bilateral hearing loss?*	
40	Does the person have hearing impairments excluding bilateral hearing loss?*	
41	Does the person have spastic quadriplegia or quadriparesis?*	
42	Does the person have spastic diplegia or triplegia?*	
43	Does the person have cerebral palsy excluding spastic diplegia, triplegia, quadriplegia, or quadriparesis?*	
44	Does the person have kyphoscoliosis?*	
45	Does the person have obesity?*	
46	Does the person have flexion contractures?*	
47	Does the person have microcephaly?*	
48	Is the person hepatitis B antigen positive?*	
49	Is the person hepatitis B antibody positive?*	
50	Does the person have a positive skin test for exposure to tuberculosis, e. g., Tine or	

	purified protein derivative (PPD)?*	
51	Has the person ever received a vaccination for the bacillus Calmette-Guérin (BCG)?*	
52	Does the person have stereotypies?*	
53	Does the person have tardive dyskinesia?*	
54	Does the person have withdrawal dyskinesia?*	
55	Does the person have other movement disorders?*	
	If no, skip to 56.	
55A	Please print all other movement disorders.	
56	Does the person have a head injury?*	
	If no, skip to 57.	
56A	Please print all head injuries.	
57	What is the person's karyotype? 0 = 45 X0 1 = 46 XX 2 = 46 XY 3 = other 9 = unknown If karyotype is not 3 = other, then skip to 58.	
57A	Please print all other karyotypes.	
58	Does the person have fragile X?*	
59	Does the person have any other physical handicap?*	
	If no, skip to 60	
59A	Please print all physical handicaps.	
	MENTAL DISORDERS	
60	Has the person ever had schizophrenia?*	
61	Has the person ever had autism or another pervasive developmental disorder?*	
62	Has the person ever had major depression?*	
63	Has the person ever had bipolar disorder?*	
64	Has the person ever had Tourette's disorder?*	
65	Has the person ever had other tic disorders?*	
66	Has the person ever had primary degenerative dementia of the Alzheimer type?*	
67	Has the person ever had atypical psychosis?*	
68	Has the person ever had oppositional disorder?*	
69	Has the person ever had conduct disorder?*	

70	Has the person ever had intermittent explosive disorder?*	
71	Has the person ever had a personality disorder?*	
	If no, skip to 72.	
71A	Please print all personality disorders.	
72	Has the person ever had eating disorders, including rumination?*	
73	Has the person ever had any other psychiatric disorder?	
	If no, skip to 74	
	CURRENT MEDICATIONS	
74	Does the person currently receive psychoactive medication?*	
75	Does the person currently receive antiepileptic medication?*	
76	Does the person currently receive other medication?*	
76A	Please print all current medications.	
	BEHAVIOR PROBLEMS	
77	Does the person assault other people?*	
78	Does the person exhibit self-injurious behavior (SIB)?*	
79	Does the person exhibit tantrums?*	
80	Does the person destroy property?*	
81	Does the person run away?*	
82	Is the person hyperactive?*	
83	Is the person withdrawn?*	
84	Is the person anxious?*	
85	Does the person steal?*	
86	Does the person exhibit sexual behaviors, e. g., masturbation in public?*	
87	Does the person have relationship problems with peers?*	
88	Does the person have relationship problems with authority?*	
89	Has the person ever exhibited head-banging?*	
	If no, skip to 101.	
90	Age of onset of head-banging in years	
91	Frequency of head-banging in the past year 1 = less than weekly 2 = weekly to daily 3 = more than daily 9 = unknown	
92	Duration of head-banging 0 = less than one year 1 = one year or more 9 = unknown	
93	Please print all conditions known to precipitate head-banging.	

94	Please print all conditions known to ameliorate head-banging.	
95	Has head-banging ever been treated with behavior modification?*	
	If no, skip to 97.	
96	What is the effect of behavior modification for head-banging? 0 = Head-banging stopped. 1 = Head-banging decreased without stopping. 2 = Head-banging continued unchanged. 3 = Head-banging increased. 9 = unknown	
97	Was medication used to treat head-banging?*	
	If no, skip to 100.	
98	Please print all medications and dosages use to treat head-banging.	
99	What was the effect of medication for head-banging? 0 = Head-banging stopped. 1 = Head-banging decreased without stopping. 2 = Head-banging continued unchanged. 3 = Head-banging increased. 9 = unknown	
100	Please print all medical and surgical complications of head-banging.	
101	Has the person ever exhibited pica, eating inedible substances?*	
102	Has the person ever exhibited self-biting?*	
103	Has the person ever exhibited rumination, vomiting food and eating the vomitus again?*	
104	Has the person ever exhibited eye-poking?*	
105	Has the person ever exhibited self-scratching?*	
106	Has the person ever exhibited face-slapping?*	
107	Has the person ever exhibited hair-pulling?*	
108	Has the person ever exhibited other self-injurious behaviors (SIBs)?*	
	If no, skip to 109.	
108A	Please print all other forms of self-injurious behaviors (SIBs).	
109	Diagnostic and statistical manual for mental disorders, fourth edition, text revision (DSM-IV-TR™) Axis IV (Psychosocial and Environmental Problems) (American Psychiatric Association, 2000)	
109A	Please print all psychosocial and environmental problems.	

110	Diagnostic and statistical manual for mental disorders, fourth edition, text revision (DSM-IV-TR™) Axis V (Global Assessment of Functioning) (GAF) (American Psychiatric Association, 2000) current	
111	Diagnostic and statistical manual for mental disorders, fourth edition, text revision (DSM-IV-TR™) Axis V (Global Assessment of Functioning) (GAF) (American Psychiatric Association, 2000) highest level in past year	

The German Journal of Psychiatry · ISSN 1433-1055 · <http://www.gipsy.uni-goettingen.de>
 Dept. of Psychiatry, The University of Göttingen, von-Siebold-Str. 5, D-37075 Germany; tel. ++49-551-396607; fax:
 ++49-551-392004; e-mail: gipsy@gwdg.de