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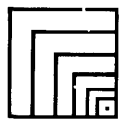
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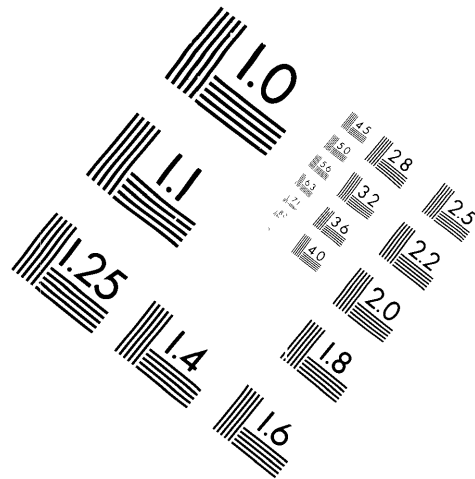
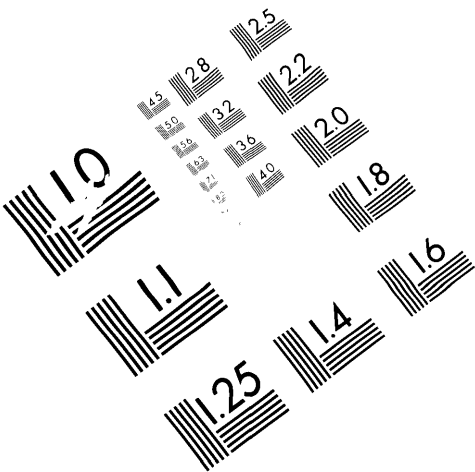
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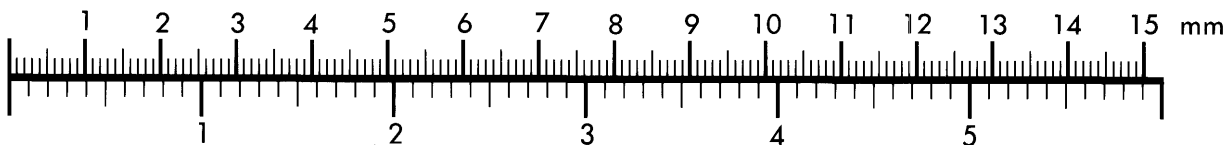


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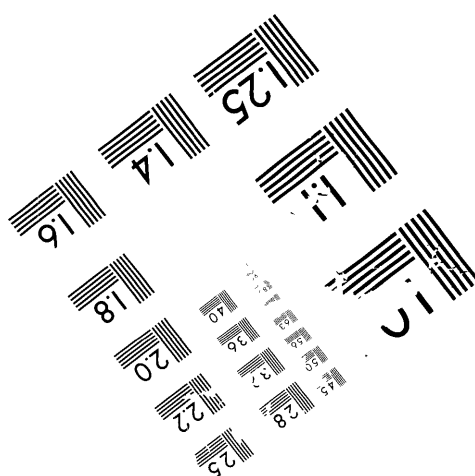
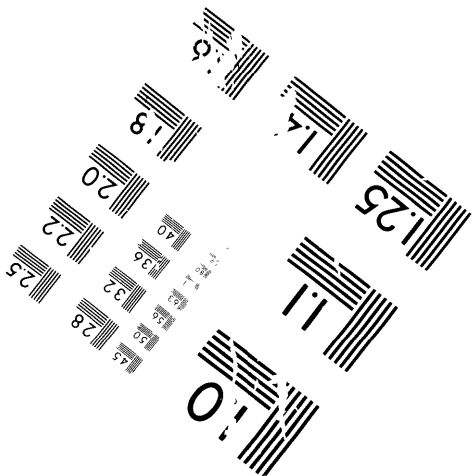
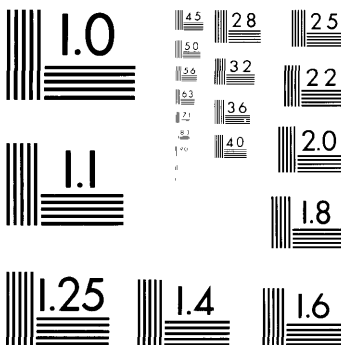
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A REPORT ON INDIVIDUALS
WITH DEVELOPMENTAL DISABILITIES
WHO ARE POSSIBLY HOMELESS



NEW YORK STATE COMMISSION ON QUALITY OF CARE
FOR THE MENTALLY DISABLED
AUGUST 1999

A Report on Individuals with Developmental Disabilities Who Are Possibly Homeless

Gary O'Brien
Chair

Elizabeth W. Stack
Louis J. Billittier
Commissioners

August 1999

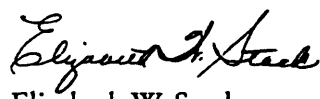


**NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED**

Preface

This report presents the findings, conclusions and recommendations of the New York State Commission on Quality of Care concerning individuals with developmental disabilities who are possibly homeless. The Office of Mental Retardation and Developmental Disabilities was provided an opportunity to review and comment on the report and concurs with the Commission's conclusions and recommendations. A copy of the Office's comments is appended.


Gary D. O'Brien
Chair


Elizabeth W. Stack
Commissioner


Louis J. Billittier
Commissioner

Acknowledgments

The Commission gratefully acknowledges staff, too numerous to mention, of the Office of Mental Retardation and Developmental Disabilities' central office, and the following Developmental Disabilities Services Offices (DDSO), as well as voluntary agencies within these districts, who assisted the Commission in our research:

Bernard Fineson DDSO
Brooklyn DDSO
Capital District DDSO
Central NY DDSO
Fingerlakes DDSO
Letchworth Village DDSO
Long Island DDSO
Metro NY DDSO
Sunmount DDSO
Taconic DDSO
Western NY DDSO

The Commission also wishes to thank members of its staff for their invaluable help in researching and preparing this report:

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Patrice Caldwell
Carol Greene
Randal Holloway
Robert Melby
Jerry Montrym
Kathy Serino

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Executive Summary

This report summarizes the findings, conclusions and recommendations of the Commission on Quality of Care concerning individuals with developmental disabilities who are possibly homeless. Media reports in mid-1998 suggested that approximately 135 individuals with developmental disabilities were homeless and, as this figure was generated by a State Office of Mental Retardation and Developmental Disabilities' (OMRDD) computer, were known to the system. The OMRDD, citing the limitations of its DDP-4 Confidential Needs Identification system which generated the data, disputed the conclusions which were drawn based on the data.

By reviewing the records of a random sample of individuals identified as homeless in the DDP-4 system, and by reviewing a sample of individuals referred to OMRDD as being developmentally disabled and homeless during a recent one-year period, the Commission sought to determine whether 135 developmentally disabled people were indeed homeless in mid-1998 and to develop a profile of service needs of individuals who are developmentally disabled and homeless, and the system's response to those needs.

Findings

1. It would be erroneous to conclude, based on DDP-4 data, that in mid-1998 135 individuals with developmental disabilities were homeless, as these data reflect "perceptions" of service need which require further assessment, are cumulative, and are not regularly updated since other systems are used to track changes in service consumers' situations. The Commission's review of a random sample of the 135 individuals identified as homeless in the DDP-4 system revealed that only eight percent were actually developmentally disabled and homeless in mid-1998; 44% were not developmentally disabled or had never been homeless; 32% were developmentally disabled and homeless at some point between 1993 and 1998, but by early 1998 they were not homeless; and, in 16% of the cases, no records could be found to verify the nature of the individuals' disabilities and service/housing needs. These latter individuals had been registered in the DDP-4 system between 1992 and 1995 and could not be located in 1998.
2. Although OMRDD reported that 62 homeless and disabled individuals were referred to its attention between June 1, 1997 and May 31, 1998, it appears that this number might be somewhat inflated. The Commission's review of a sample of these individuals revealed that 17 percent were not truly homeless; rather they had been provided respite care at an OMRDD-funded program to give their primary caretakers relief. An additional eight percent were not developmentally disabled, but had other disabilities.
3. When homeless individuals with developmental disabilities were brought to OMRDD's attention, the agency or its licensees acted promptly to address the individuals' service and housing needs; the vast majority were provided appropriate housing within two months.
4. According to facility staff interviewed by the Commission, the problem of developmentally disabled people who are homeless is not their numbers, but the complexity of their service needs which go beyond the boundaries of the traditional MR/DD service system. While most of the individuals reviewed by the Commission were mildly retarded or otherwise developmentally disabled, they also suffered from mental illness (50%), serious health problems (44%), alcohol or drug abuse (17%), and legal or criminal justice system problems (22%). A sizable minority (22%) were also parents of dependent children.

5. Finally, the Commission found that various Developmental Disabilities Services Offices (DDSO) across the state had developed programs and/or linkages with other service agencies to better identify and serve homeless individuals who are developmentally disabled; these innovative approaches are worthy of consideration by other DDSOs as possible models to replicate.

Recommendations:

While DDP-4 data should not have been used as an indicator of the number of persons with developmental disabilities known to OMRDD as being homeless, it is clear that some data in this system is flawed. The Commission recommends that the OMRDD take steps to ensure the accuracy of DDP-4 data which is used, in part, as a service planning tool. The Commission recognizes that OMRDD is engaged in an extensive review of its DDP-4 system and, as such, believes it is an opportune time to redouble efforts to ensure the accuracy of data compiled in the system.

The Commission also recommends that the OMRDD examine the approaches developed by its various DDSOs in responding to the problem of homelessness among persons with developmental disabilities as possible models for replication elsewhere.

Noting that the OMRDD has a formal agreement with the Office of Mental Health guiding each agency's responsibility for developmentally disabled people who are mentally ill, the Commission recommends that OMRDD work with the Office of Alcoholism and Substance Abuse Services toward identifying shared roles and appropriate treatment modalities in serving individuals with developmental disabilities who have substance abuse problems, as evidenced by individuals identified in this review.

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Introduction

In 1998, the Commission on Quality of Care initiated a review of the problem in serving persons with developmental disabilities who are homeless or at risk of homelessness. The review was commenced following media reports of between 20 to 30 possibly developmentally disabled individuals living in shelters in Westchester County and an Office of Mental Retardation and Developmental Disabilities (OMRDD) document containing data which reportedly suggested that, since 1994, 135 developmentally disabled people had become homeless across the State. However, OMRDD officials disputed the validity of the conclusions drawn from data in this document, which was generated by the agency's computerized DDP-4 Confidential Needs Identification system. Citing the limitations of the DDP-4 system, OMRDD staff indicated that it would be erroneous to conclude that 135 developmentally disabled people were homeless in mid-1998.

OMRDD officials reported that the DDP-4 is a system used to register individuals possibly in need of service and that information initially entered into the system based on perceptions of service needs may not be accurate and requires further assessment. For example, it may be reported that a person is developmentally disabled and is homeless, and this is recorded in the DDP-4, but upon service contact and further assessment it is determined that the individual does not have a developmental disability or is not homeless. OMRDD staff also cautioned that DDP-4 data are cumulative and not regularly updated, as other data systems are used to track changes in service consumers' situations. Thus, a person who may have been homeless in 1993 may still appear in the DDP-4 system as homeless in 1998 even if s/he moved permanently into an OMRDD residence at some point between 1993 and 1998.

OMRDD staff indicated that a more accurate picture of the problem of homelessness among the developmentally disabled population could be drawn from the 62 referrals the agency received between June 1, 1997 and May 31, 1998 involving disabled individuals who were reportedly homeless.

Methodology

In its review, the Commission endeavored to determine whether 135 developmentally disabled people were indeed homeless and known to the system in mid-1998 and to develop a profile of the service needs of homeless developmentally disabled individuals and the system's response to those needs. To accomplish this, the Commission selected two random samples of individuals for review: one sample consisted of 25 (20 percent) of the 135 individuals whose residential status appeared in the DDP-4 system as "Homeless or Residing in a Shelter" in mid-1998; the second sample consisted of 24, or one-third, of the 62 disabled and homeless individuals who were referred to OMRDD's attention between June 1997 and May 1998.

The individuals selected for Commission review were from 11 of the State's 13 DDSOs, including DDSOs in New York City and Long Island, and New York's northern, central, and western regions. These individuals' records were reviewed and, while on-site, Commission staff spoke with DDSO staff and, in some instances, staff of not-for-profit agencies who served some of the individuals and/or were familiar with issues surrounding homeless developmentally disabled individuals.

Findings

1. DDP-4 Data

The Commission's record review of 25 individuals randomly selected from the DDP-4 report of 135 individuals whose residential status was listed as "Homeless or Living in Shelters," supported the OMRDD's position that it would be erroneous to conclude, based on DDP-4 data, that in mid-1998 there were 135 homeless developmentally disabled people in the State.

The Commission's reviews indicated that in 11 of the 25 cases (44%), the individuals either were not homeless when registered in the DDP-4 system or were not developmentally disabled.

Several case examples are illustrative:

- W.P., a 23-year-old New York City resident, was registered in the DDP-4 system as homeless in the early 1990s when he was referred by the Office of Vocational and Educational Services for Individuals with Disabilities to a not-for-profit agency for vocational testing and job placement. However, intake records from the not-for-profit agency which were reviewed by the Commission indicated W.P. had an apartment (and even reported his monthly rent). W.P.'s full scale IQ was 75. After a period of testing and training, W.P. secured a job in a restaurant and has had no further contact with the OMRDD system.
- According to DDP-4 data, H.O., a Capital District area resident, was homeless in 1995. The Commission's review, however, revealed that since 1991 H.O., now 45 years old, has lived in a single room occupancy apartment program operated by a not-for-profit agency which also runs OMRDD-certified community residences; he also works for the agency. Additionally, the agency's staff reported that H.O. is not developmentally disabled, but has had problems with alcohol abuse in the past.
- P.L., according to DDP-4 data, was homeless in the mid-1990s. The Commission's review indicated that P.L. had lived in a developmental center for 25 years prior to being discharged in 1970. He married, worked in the community, and lived with his wife in an apartment. He was followed by the local ARC. When his wife died, the ARC attempted to find him a roommate. They were not successful and P.L. moved into a DSS-certified adult foster care home, where he continues to live.

Ten (40%) of the 25 sample cases reviewed by the Commission did involve individuals who were developmentally disabled and homeless at some point in time. These individuals became homeless between 1993 and 1998. However, only two of the individuals actually were homeless in mid-1998. Of the remaining eight individuals, six had moved to their own apartments or supervised living settings between 1995 and 1997; one individual died in 1997; and one individual was incarcerated in 1997 and is still in prison.

In four cases, or 16 percent of the Commission's DDP-4 sample, records could not be found. Although DDP-4's completed on these individuals between 1992 and 1995 reported their residential status as "Homeless or Living in Shelters," no other records could be found on the DDSO level to assist the Commission in determining whether the individuals were truly developmentally disabled and homeless between 1992 and 1995 and, if so, how their situations were resolved and when. Nor could these individuals be tracked down through OMRDD's Tracking and Billing System (TABS) to determine whether they received services elsewhere in the system and where records might exist.¹

¹ In commenting on the Commission's draft report, the OMRDD provided additional information on these individuals. However, it was still insufficient in determining whether the individuals were truly developmentally disabled and homeless and, if so, whether their homelessness had been resolved by mid-1998. See OMRDD's appended response.

Since only 2 persons, or 8 percent of the sample DDP-4 cases, reviewed by the Commission were confirmed as having a developmental disability and being homeless in mid-1998, the Commission believes that it would be erroneous to use DDP-4 data as a valid indicator of the number of persons with developmental disabilities who are homeless in the State.

2. Persons Reported by OMRDD to be Homeless

According to OMRDD officials, between June 1, 1997 and May 31, 1998, 62 individuals came to its attention who were reportedly homeless and developmentally disabled: 58 individuals upstate and four in New York City. To review the accuracy of this information, the Commission selected a sample of 24 cases for in-depth record reviews, consisting of 20 individuals randomly selected from the upstate list (or about one-third) and all four individuals reportedly homeless in New York City.

In reviewing these individuals' records, it was found that four (or approximately 17 %) were not truly homeless; rather, they entered OMRDD-funded/operated programs for brief, planned respite stays to provide their primary caretakers (families) relief. It was also found that two individuals (or 8%) were not developmentally disabled. One individual had adult onset Huntington's chorea. The second had a psychiatric disability and was discharged from a psychiatric hospital to a shelter; the local DDSO offered to assist this woman, but she declined the offer and moved in with a friend.

The records of the remaining 18 individuals with developmental disabilities who were deemed homeless revealed that only 11 persons or 46 percent of the cases reviewed were living in homeless shelters. Of the remaining 7 persons, 4 individuals were in hospitals for either medical or psychiatric reasons, and 3 persons were living either at home or in an adult home, and those placements were in serious jeopardy. As such, the Commission only can conclude the nature of the problem of the homelessness of persons with developmental disabilities is less extensive than even reported by OMRDD.

3. Securing Housing for Persons who are Homeless or at Risk of Homelessness

As previously noted, the Commission found 18 persons to be either homeless or at risk of homelessness during its review of 24 cases drawn from the list of 62 people reported to OMRDD to be homeless between June 1, 1997 and May 31, 1998. In reviewing these 18 cases, the Commission found that nearly 95 percent eventually secured a placement. Additionally, the time frame between OMRDD's becoming aware of the individuals' situations and securing appropriate housing was relatively short, as indicated below:

Time Frame to Securing Housing

N = 18

Immediately/Within One Week	2 (11%)
Within Two — Four Weeks	3 (17%)
Within Five — Eight Weeks	7 (39%)
Within Nine — Twelve Weeks	2 (11%)
Within Thirteen — Sixteen Weeks	1 (6%)
Twenty-One — Twenty-Four Weeks	2 (11%)
Never	1 (6%)

As indicated above, 14 of the individuals or 78 percent found placement within three months of OMRDD becoming aware of their situations.

For a majority of the individuals, resolution of their homeless situation was achieved by placement in an OMRDD –operated or –certified facility: seven persons or 39 percent were placed in family care or community residences and four persons or 22 percent in developmental centers, or specialty units thereof. Three individuals or 17 percent were placed in Office of Mental Health (OMH) or Office of Alcoholism and Substance Abuse Services (OASAS) programs (but, for one individual, the OASAS placement was short lived). Two persons or 11 percent were placed in apartments with either financial or other supports, and one person (six percent) was placed in an adult home. Only one person was never placed; she left the shelter voluntarily while placement was being arranged, and her whereabouts is unknown. The individual who had a short-term placement in a residential substance abuse program was subsequently hospitalized at a psychiatric facility, then went to live in a motel. This person is continuing to receive case management services from an OMRDD-funded agency.

In short, the Commission found that OMRDD took prompt action to secure housing for these persons who were homeless or at risk of homelessness.

4. Profiles of Persons with Developmental Disabilities who were Homeless

According to staff of the DDSOs and voluntary agencies with whom Commission staff met during this project, the real problem with developmentally disabled individuals who are homeless is not their number, but the complexity of their service needs, which often go beyond the boundaries of the traditional MR/DD service system. This was illustrated by the cases reviewed. Most of the individuals in the sample were mildly mentally retarded or otherwise developmentally disabled (83%), with the remainder testing in the moderate range. However, 50 percent were also mentally ill; 44 percent had serious health concerns; 17 percent seriously abused alcohol or drugs; 17 percent were parents of young children; and nearly a quarter (22%) had legal problems or brushes with the criminal justice system.

The following cases provide a profile of persons with developmental disabilities who were homeless, and the challenges and difficulties in addressing their needs.

* * *

Mr. S. is a 39-year-old man with moderate mental retardation and a seizure disorder. He lived at home with his elderly father, but would frequently wander off and live in shelters or subway stations. On December 30, 1997, Mr. S. was found unresponsive in a train station. He was brought to Bellevue Hospital which contacted the DDSO on January 29, 1998, once Mr. S. was neurologically stable, as it was felt that Mr. S.'s father could not care for him. During February, Mr. S. was assessed by the DDSO and accepted for residential placement. In March 1998, he was placed in Brooklyn Developmental Center.

* * *

In 1994, 28-year-old Mr. M. sexually molested a little girl and was sent to State prison where he was housed in a special unit for developmentally disabled offenders. In November 1997, Mr. M. was paroled and returned to live with his family. However, the landlord threatened to evict the entire family if Mr. M. stayed, given the nature of his crime. As a result, Mr. M. went to live in a shelter. Following his parole, OMRDD learned from Correction's officials that Mr. M. had been paroled, though OMRDD should have been notified prior to Mr. M.'s prison release in order to aid in his placement. Assessments conducted by OMRDD in January 1998 indicated that Mr. M. was mildly retarded and required placement in an OMRDD facility. In February 1998, Mr. M. was placed in such a facility.

* * *

Ms. C. is a 20-year-old woman who first came to the attention of the DDSO on November 6, 1997 when they were contacted by the Homeless and Runaway Youth Program. Ms. C. has spina bifida, significant adaptive behavior deficits related to the spina bifida, and ambulates with crutches. Ms. C. had left home because of family conflicts; however, during the intake process by the DDSO, she decided to return home. Ms. C. began receiving residential habilitation, as well as service coordination and clinic services from the DDSO. On April 27, 1998, because of continued family problems, she again left home and stayed in Homeless and Runaway Youth Program host families' homes until April 30, 1998, when she went to live in an OMRDD-certified supervised apartment. Ms. C. continues to live in the supervised apartment, and she has applied to Mohawk Valley Community College.

* * *

Mr. M. has a diagnosis of mild mental retardation, and he became homeless on August 29, 1997 when he was thrown out of his home for breaking a window. He showed up on the door step of Heritage Centers, an OMRDD licensed provider. Heritage Centers immediately provided Mr. M. case management services, temporarily placed him in the City Mission, completed needs and skills assessments and also had psychological testing completed during this time period. Heritage Centers' case manager referred Mr. M. to Community Services for the Developmentally Disabled (CSDD), and he was accepted into CSDD's emergency shelter on September 12, 1997. He remained in this shelter until March 10, 1998, at which time he was given a permanent placement in a supported apartment certified by OMRDD and operated by Heritage Centers. Subsequently, Mr. M. moved out of the apartment on May 11, 1998, and married. Mr. M. lives in his own apartment in Buffalo, New York.

* * *

Mr. Q. is a 25-year-old man who has a history of Tourette's syndrome, impulse control disorder and alcohol and cocaine abuse. In June 1997 Mr. Q. came to the Community Services for the Developmentally Disabled's Shelter (CSDD), pending placement at a more permanent residence, from Brylin Hospital where he was treated for substance abuse. He remained at the shelter until July 16, 1997 when he went to live at Oxford House, a drug rehabilitation residence. Mr. Q. remained at Oxford House until August 15, 1997 when he was re-admitted to Brylin Hospital. In September 1997, Mr. Q. was arrested for larceny and was placed on three years probation. Currently, Mr. Q. is living in a motel and receiving case management services from CSDD.

* * *

Ms. B. is a 42-year-old mildly retarded mother of a teenage girl. Over the years she has received case management services and parenting skills training from the DDSO. In November 1997, Ms. B. moved into a shelter because she was evicted from her apartment, and could find no other housing arrangement due to her daughter's behaviors (property destruction and fire-setting). The daughter, who was being followed by Child Protective Services due to prior sexual abuse, was placed by Family Court and Ms. B.'s DDSO case manager assisted her in finding a new apartment, to which she moved in April 1998.

5. Model Approaches

Although not a part of the study design, the Commission's review of individuals with developmental disabilities who were alleged to be homeless found some innovative approaches being taken by DDSO's and others to deal effectively with the problem of homelessness among this population. Given the diversity of New York State, the demographics of its regions, and the nature and history of the service networks within those regions, no single model could be identified as the most effective method in securing housing and other services for this unique group of persons. As such, the Commission provides illustrations of these innovative approaches in order to allow others to determine the appropriateness for replication in their region.

Some DDSOs, like Long Island for example, have formalized agreements with county social service agencies which trigger coordinated responses by the agencies should a person with developmental disabilities come to any party's attention as being homeless.

In Westchester County, a part of the Letchworth DDSO, the county and DDSO have formalized an agreement to refine each party's role in future cases. Other DDSOs have less formalized, but reportedly effective, arrangements. In the Capital District for example, the Acting Director of the DDSO's Community Services is a member of the region's Coalition On Homelessness, a network of Capital District agencies which serve the homeless.

Some DDSOs, as in the New York City region, are providing outreach and training for shelter programs. In Westchester, the DDSO will soon provide shelter officials training on the use of the Slossan Intelligence Scale to better identify individuals within the shelter system who may be developmentally disabled.

Although most DDSO's reported ongoing contacts with OMH authorities in their regions, only the Taconic DDSO had regular (monthly) meetings with Alcohol/Substance Abuse Services authorities.

Within two DDSOs, specialized housing options for homeless developmentally disabled individuals have been developed.

In the Western New York DDSO, the Community Services for the Developmentally Disabled developed an Emergency Shelter for persons with developmental disabilities who were homeless. This program uses funding from DSS for room and board expenses and OMRDD funding for staffing and programmatic costs. This program is intended to be an alternative to the traditional homeless shelter. As such, it serves as an alternative emergency housing program for persons with developmental disabilities who are homeless as well as a source of housing for individuals with developmental disabilities who have children and who often find it difficult to secure placement in a traditional MR/DD residential program.

The Shelter Plus Care program developed in Westchester County offers a similar alternative to the traditional shelter system for individuals with developmental disabilities, who are often unwilling to accept traditional MR/DD residential settings. This program combines HUD funds and the contracted services of mental retardation service agencies to provide housing for this population.

In its efforts to continue to respond to the needs of persons with developmental disabilities who are homeless or at risk of homelessness, OMRDD should consider exploring exemplary practices such as those identified in this report and disseminate this information to its DDSOs for their consideration for possible replication.

Conclusions

As a result of this review, the Commission found that:

- OMRDD DDP-4 data generated in mid-1998, and interpreted by some to indicate the number of homeless developmentally disabled people known to the system, led to an inaccurate conclusion. Many people identified in these data, based on the Commission's review of a random sample, were neither developmentally disabled nor homeless in mid-1998.
- The extent of homelessness of persons with developmental disabilities reported by OMRDD also appears overestimated.
- Efforts to secure housing for persons with developmental disabilities who were homeless or at risk of homelessness were prompt and successful for the vast majority of individuals.
- The profiles of persons with developmental disabilities who were homeless indicate that this population often presents serious challenges in providing appropriate services. Many of these individuals are young and mildly retarded with overlays of serious medical needs, mental illness, substance abuse problems, and involvement with the criminal justice system, who do not fit "neatly" in the traditional MR/DD service system. Given their multi-service needs, or rejection of services offered, these persons pose unique demands for the State's service delivery system.
- Various DDSO's have developed different approaches to this population: some have developed highly formalized agreements with sister service agencies, while others have less formal, but reportedly effective, arrangements. Some have woven various funding streams to create new housing arrangements, while others rely on traditional MR/DD service modalities; and some, to varying degrees, have provided outreach and training to shelter program staff.

Recommendations:

- While DDP-4 data should not have been used as an indicator of the number of persons with developmental disabilities known to OMRDD as being homeless, it is clear that some data in this system is flawed. The Commission recommends that the OMRDD take steps to ensure the accuracy of DDP-4 data which is used, in part, as a service planning tool. The Commission recognizes that OMRDD is engaged in extensive review of its DDP-4 system and, as such, believes it is an opportune time to redouble efforts to ensure the accuracy of data compiled in the system.
- The Commission also recommends that the OMRDD examine the approaches developed by its various regions/districts in responding to the problem of homelessness among persons with developmental disabilities. These approaches differ, region to region, quite understandably, given differences in the demographics and the nature and histories of service networks within the regions. However, approaches developed in certain regions — be they formalizing service relationships with sister service agencies through written agreements; or fostering effective interagency relations through less formal means; weaving funding streams to create non-traditional MR/DD service modalities; or better utilizing traditional MR/DD service modalities creatively — may serve as models for replication in other regions.
- Finally, the Commission recommends that OMRDD work with the Office of Alcoholism and Substance Abuse Services toward identifying shared roles and appropriate treatment modalities in serving individuals with developmental disabilities who have substance abuse problems. Nearly 20 percent of the cases examined by the Commission fit this profile, and service providers indicated such individuals are among the most difficult to serve among the homeless population. They often walk away from service options offered by the OMRDD, but they clearly have service needs related to their developmental disabilities and substance abuse problems. Exploring treatment approaches for this population with the State Office of Alcoholism and Substance Abuse Services seems indicated.

Appendix: Response From the Office of Mental Retardation and Developmental Disabilities



STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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July 20, 1999

Mr. Gary O'Brien
Chair
State of New York
Commission on Quality of Care for the
Mentally Disabled
401 State Street
Schenectady, NY 12305-2397

Dear Mr. O'Brien:

Thank you for the draft of the Commission's report on developmentally disabled individuals who may be homeless. We appreciate the Commission's giving OMRDD the opportunity to review and comment upon the findings and recommendations of the report.

It is OMRDD's opinion that the Commission's report is comprehensive, objective, factual and achieved the objectives it set out to accomplish. The Commission staff conducted their work in a most impressive, professional and competent manner. OMRDD is encouraged that the Commission's findings and conclusions are consistent with OMRDD's contention that media reports were erroneous to conclude that 135 developmentally disabled individuals were homeless in mid-1998.

Please find attached some comments regarding facts of the report, and responses to the Commission's recommendations. Once again, thank you for your excellent survey on behalf of the people we serve. We look forward to the receipt of your final report. We will share it with DDSO staff, and look to act upon your recommendations to improve our service to developmentally disabled individuals who are or may be at risk of homelessness.

If you have any questions, please feel free to contact me.

Sincerely,

Thomas A. Maul
Commissioner

TAM:RPJ

FACTS OF THE REPORT

Based upon OMRDD knowledge of the survey samples and OMRDD staff's presence during the Commission's on site record review and staff interviews, OMRDD concurs with the findings and conclusion of the report. To the extent OMRDD staff were present and privy to information the Commission staff were reviewing, the facts of the report appear to be accurate.

However, we would like to take the opportunity to comment on one aspect of the report. In reference to the 4 cases (16%) of the Commission's DDP-4 sample, it was indicated that "records could not be found," "nor could these individuals be tracked down through OMRDD's TABS to determine whether they received services elsewhere in the system and where records might exist." According to DDSO information regarding the on site visits and information presented for Commission review, the following information is known:

- J.W. - Information from Finger Lakes DDSO indicated that the Keuka School District entered JW in the DDP-4. This was a result of the FL DDSO's 1994 promotional outreach for services initiative. They visited local agencies, hospitals, and school districts to make them more aware of OMRDD and its services. JW was five years old at the time, living with his parents. His parents were residing with friends (there is a documented Penn Yan address) and requested services from Yates County DSS. The family never requested services of FL DDSO. From what the DDSO could determine, JW never lived in a homeless shelter, nor is it certain that he would have been eligible for DDSO services. Previously he was enrolled with Yates County ARC Preschool Program in Penn Yan. In August 1995 he was discharged and Yates County ARC had no additional involvement with JW or the family since then.
- A.B. - DOB 5/31/56, Terence Cardinal Cooke (TCC) of NYC was in possession of the clinical record. AB was known to TCC and VOA mens shelter on Wards Island. He last frequented the shelter 12/95 and is believed to have relocated to South Carolina. TCC closed his case 1/96.
- R.R. - DOB 7/22/84, Lincoln Hospital in NYC enrolled RR in the DDP-4. They would not release any information to the DDSO without consent.
- X.R. - DOB 11/20/89, Sinergia, a NYC agency registered XR on the DDP-4, and indicated that they do not have any information regarding XR or his whereabouts. The DDP-4 information recorded in TABS references need for rent subsidy.

Note: The only information provided to the Commission regarding XR and RR were copies of the DDP-4 Needs Identification History. It is speculated that their families may have been living in a Tier 2 or 3 family shelter. If either child was homeless, ACS should have been involved in assisting with placement for them.

RESPONSES TO CONCLUSIONS AND RECOMMENDATIONS

OMRDD agrees with the Commission's five conclusions contained in this report as a result of their review.

THREE RECOMMENDATIONS

1) OMRDD DDP-4 Data System

Confidential Needs Identification DDP-4 led to an inaccurate conclusion regarding the scope of the homeless/DD population due to limitations with the data system, and a misinterpretation of the purpose of the DDP-4 data. The DDP-4 and its completed information was never intended to imply eligibility or acceptance for services. Even prior to mid-1998, OMRDD was aware of the limitations with the data generated by the DDP-4 system. An extensive review of the system was in process. By winter 1998 to spring 1999, OMRDD completed an overhaul of the DDP-4 Data System and trained staff on its implementation. The revised DDP-4 is now fully operational. It now has the ability to collect more accurate information and function as a more useful service planning instrument.

Revisions made to the form:

- It is more user friendly.
- It has more specific instructions directly on the form itself as opposed to a separate instruction manual.
- It addresses only unmet needs within the next two years.
- It omits needs for individuals already receiving requested services.
- The needs do not accumulate.
- A process has been added, enabling the tracking of length of time a need exists, and updating data.
- Confusing items have been rephrased.

The new system will be able to tell us:

- Basic demographics about a person with an unmet need.
- Who appears to be at risk for immediate need for residential services.
- How long has the person needed this service.
- When the need was met and by what agency.
- If any other needs were met or eliminated when a service was provided.
- What kind of residential support is needed, if any.
- What kind of day activity is needed, if any.
- What kind of other supports this person needs, if any.

2) **Model Approaches**

OMRDD is in agreement that many DDSOs have developed some innovative, effective arrangements with local agencies in addressing the developmentally disabled homeless issues. We also concur that given the diverse demographics of New York State DDSO regions and various service network operations within those regions, no one model approach or effective method is employable. OMRDD will provide a mechanism to share model approaches and best practices with all DDSOs so they can be implemented as applicable.

3) **Office of Alcoholism and Substance Abuse Services**

OMRDD will initiate discussions and investigate a need for a proposal for a cooperative agreement with the Office of Alcoholism and Substance Abuse Services toward identifying shared roles and exploring appropriate treatment/training approaches in serving individuals with MR or DD who have drug and/or alcohol abuse issues. Many of the DDSO staff interviewed by the Commission indicated the need for more services/treatment for individuals with MR/DD who have substance abuse problems, and the need for additional staff training in substance abuse issues with the MR/DD population.

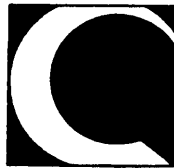
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