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William K. Hubbard,
*Associate Commissioner for Policy
Coordination.*

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Substance Abuse and Mental Health Services Administration

Estimation Methodology for Children With a Serious Emotional Disturbance (SED)

AGENCY: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, HHS.

ACTION: Solicitation of comments.

SUMMARY: This notice describes the proposed methodology for identifying and estimating the number of children with a serious emotional disturbance (SED) within each State. This notice is being served as part of the requirement of Public Law 102-321, the ADAMHA Reorganization Act of 1992.

COMMENT PERIOD: The Administrator is requesting written comments which must be received on or before December 5, 1997.

ADDRESSES: Comments should be sent to Judith Katz-Leavy, M.Ed., Senior Policy Analyst, Office of Policy, Planning, and Administration, Center for Mental Health Services, Parklawn Building Room 15-87, 5600 Fishers Lane, Rockville, MD 20857. (301) 443-1563 fax.

FOR FURTHER INFORMATION CONTACT: A detailed paper outlining the estimation methodology described here is available from: Judith Katz-Leavy M.Ed., Senior Policy Analyst, Office of Policy, Planning, and Administration, Center for Mental Health Services, Parklawn Building Room 15-87, 5600 Fishers Lane, Rockville, MD 20857. (301)443-1563 fax.

Background

Public Law 102-321, the ADAMHA Reorganization Act of 1992, amended the Public Health Service Act and created the Substance Abuse and Mental Health Services Administration (SAMHSA). The Center for Mental

Health Services (CMHS) was established within SAMHSA to coordinate Federal efforts in the prevention, treatment, and promotion of mental health. Title II of Public Law 102-321 establishes a Block Grant for Community Mental Health Services (Block Grant) administered by CMHS, which permits the allocation of funds to States for the provision of community mental health services to children with a serious emotional disturbance and adults with a serious mental illness. Public Law 102-321 stipulates that States estimate the incidence (number of new cases) and prevalence (total number of cases in a year) in their applications for Block Grant funds, see 42 U.S.C. 300 (2). The statute also requires the Secretary to establish definitions for adults with a serious mental illness and children with a serious emotional disturbance. In addition, the Secretary is required to develop standardized methods for the states to use in providing the estimates required as part of their block grant applications. See 42 U.S.C. 300 (2). As part of the process of implementing this new block grant, definitions of the terms "children with a serious emotional disturbance" and "adults with a serious mental illness" were announced on May 20, 1993, in **Federal Register** Volume 58, No 96, p. 29422. Subsequently, a group of technical experts was convened by CMHS to develop an estimation methodology to "operationalize the key concepts" in the definition of children with a serious emotional disturbance. A similar group has prepared an estimation methodology for adults with a serious mental illness.

Serious Emotional Disturbance (SED)

The CMHS definition is that "children with serious emotional disturbance" are persons:

- From birth up to age 18;
- Who currently or at any time during the past year;
- Have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R
- That resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities (p.29425).

The definition goes on to indicate that, "these disorders include any mental disorder (including those of biological etiology) listed in DSM-III-R or their ICD-9-CM equivalent (and subsequent revisions) with the exception of DSM-III-R 'V' codes, substance use, and developmental

disorders, which are excluded, unless they co-occur with another diagnosable serious emotional disturbance" (p. 29425).

Further, the definition indicates that, "Functional impairment is defined as difficulties that substantially interfere with or limit a child or adolescent from achieving or maintaining one or more developmentally-appropriate social, behavioral, cognitive, communicative, or adaptive skills. Functional impairments of episodic, recurrent, and continuous duration are included unless they are temporary and expected responses to stressful events in their environment. Children who would have met functional impairment criteria during the referenced year without the benefit of treatment or other support services are included in this definition" (p. 29425).

The first decision that was made was to focus on community epidemiological studies done in the United States that used either the DSM-III-R, or its predecessor, the DSM-III, and that provided information on the prevalence of mental disorders using a structured interview procedure. The group decided that given the relatively small number of community epidemiological studies that had been conducted in the United States, it would be a mistake to exclude those few studies that had used the DSM-III, given its considerable similarity to the DSM-III-R.

The most frequently used structured interview procedure was the Diagnostic Interview Schedule for Children (DISC), originally developed by A. Costello and his colleagues (A. Costello, Edelbrock, Dulcan, Kalas, & Klaric, 1984), which includes both child and parent versions. Other interview procedures include the Diagnostic Interview for Children and Adolescents (DICA, Herjanic & Reich, 1982), the Child and Adolescent Psychiatric Assessment (CAPA, Angold & E. Costello, 1995), and the Composite International Diagnostic Interview (CIDI, Kessler et al, 1994).

The group elected to consider that a child met the criteria of a diagnosable disorder either if a diagnosis was obtained from his/her own report on the structured interview, or from the parent's report on the structured interview, or from the combination of the youth's report and the parent's report, even if neither one met the criteria separately. While there are other approaches to combining data from two or more sources that were considered and have been used (Cohen, Velez, & Kohn, 1987; Reich & Earls, 1987), the group chose to use this "either/or" approach because it was believed that

discrepant responses can be a source of valuable information.

The greater challenge for the group was operationalizing the concept of "functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities" (Federal Register, 1993, p. 29425). Part of the difficulty was in identifying appropriate measures, and understanding the inter-relationship between the different measures, but the greatest difficulty was in determining the appropriate threshold or cut-off point on a scale for concluding that there was functional impairment that was "substantially" interfering with functioning.

After much discussion, it was decided that in the absence of any "gold standard" that could be used as a basis for establishing such a cut-off point, and in the absence of any social validation process that has established a consensus on what the threshold should be, data would be presented for cut-off points at two levels of functional impairment. This has the benefit of providing additional information to planners and policy-makers to use, and to stimulate further discussion and research to try to better establish an appropriate threshold. The higher prevalence rate to be reported, which uses the more inclusive or less conservative cut-off point, still meets the definition of "seriously emotionally disturbed." The less inclusive and more conservative estimate can be used for more targeted efforts to plan on behalf of a more limited number of children whose level

of functional impairment is especially severe.

A variety of measures of impairment were used in the community studies, and their psychometric properties were reviewed for the group by Hodges (1994). The most frequently used measure is a global measure, the Children's Global Assessment Scale (Bird, Canino, Rubio-Stipec, & Ribera, 1987; Shaffer, Gould, Brasic, Ambrosini, Fisher, Bird, & Ahwalia, 1983), on which a youngster receives a rating ranging from 0 to 100 with lower scores indicating greater impairment. Scores are given in ten point intervals, and for each score there is a narrative description of the meaning of the score.

The group considered several potential cut-off points on the CGAS, and decided to use a score of 60 or lower as the cut-off point for the less conservative definition of serious emotional disturbance. The narrative description for 60 is:

"Variable functioning with sporadic difficulties or symptoms in several but not all social areas. Disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in settings where functioning is appropriate."

This decision was made partly on the basis of the work by Bird and his colleagues that indicates that, "Empirical work has demonstrated that the optimal cut-off score on the CGAS that demonstrates definite impairment is a score lower than 61" (Bird, Shaffer, Fisher, Gould, Staghezza, Chen, & Hoven, 1993, p. 103).

The score of 50 will be used as the more stringent cut-off point to denote the more severe impairment. The narrative description for 50 is: "Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, frequent episodes of aggressive or other anti-social behavior with some preservation of meaningful social relationships".

Data Sources

There are no national epidemiological studies of mental disorders for children and/or adolescents that have been conducted in the United States. This deficit makes it difficult to derive prevalence rates that are generalizable to the entire United States. In the absence of national studies, the group chose to examine the results from eight smaller, and more localized studies including, Kashani, et.al (1987), Costello, et. al (1988) (1994), Bird, et. al (1988), Kessler, et. al (1994), Jensen, et. al (1995), MECA (Lahey, et. al, 1996, Shaffer, et. al, 1996), and Costello, et. al (1995). (see Table 1 for a summary of these studies).

The group of technical experts determined that it is not possible to develop estimates of incidence using currently available data. However, it is important to note that incidence is always a subset of prevalence. In the future, incidence and prevalence data will be collected.

TABLE ONE.—SUMMARY OF STUDIES

Study	Measure and DSM system	System Sample size and age	Measure of impairment
Kashani et al 1987	DICA/DSMIII	N=150, 14-16 yr. olds	Rating of 3 or 4 by Clinicians on 4 Point Scale of Need for Tx and Impairment.
Costello et al 1988	DISC 1.3 DSMIII	Screened=789, Interviewed=278, 7-11 yr. olds.	CGAS 60 or less.
1994 (follow-up)	DISC 2.3 DSMIIIR	Screened=789, Interviewed=263, 12-18 yr. olds.	CGAS 60 or less.
Bird et al 1988	DISC 1.3*/DSMIII	n=777 first stage n=386 second stage 4-16 yr. olds	CGAS 60 or less.
Kessler et al 1994	CIDI/DSMIII-R (adult diagnoses).	n=600 (about) 15-17 yr. olds (Part of study of 15-54 yr. olds).	Aggregation of 5 Measure.
Jensen et al 1995	DISC2.1/DSMIIIR	n=295 6-17 yr. old	<ul style="list-style-type: none"> •In tx or in need of tx. •Internal Impairment (1 or more). •Internal Impairment (2 Domains or more).
MECA (Lahey et al, 1996 Shaffer et al, 1996).	DISC2.1/DSMIII-R	n=1265 9-17 yr. olds	<ul style="list-style-type: none"> •CGAS 60 or Less. •CGAS 50 or less. •Internal Impairment, (3 or more), (5 or more).

TABLE ONE.—SUMMARY OF STUDIES—Continued

Study	Measure and DSM system	System Sample size and age	Measure of impairment
Costello et al 1995	CAPA/DSMIII-R	2 stages n=4500 9, 11, and 13 yr. olds	<ul style="list-style-type: none"> •Internal Impairment, (1 or more), (2 or more), (3 or more). •CGAS (60 or less) CAFAS (20 or higher).

Estimation Procedures

Based on the CMHS definition of serious emotional disturbance, and the existing data bases which provide prevalence rates that can be applied to this definition, it is estimated that the prevalence rate of serious emotional disturbance in children 9–17 years of age is in the range of 9–13 percent. Presently, the data are inadequate to estimate prevalence rates for children under the age of nine. It is also concluded that if a more stringent definition of impairment is desired than was used for the estimated range of 9–13 percent, then the range is from 5–9 percent. The difference between the two estimates is that the measured level of functional impairment is greater in the second estimate and has been characterized in Figure 1 as “extreme functional impairment.” Children at both levels of impairment are considered to have a “serious emotional disturbance” however; the group of children falling into the range of 5–9 percent constitutes a subset of the 9–13 percent.

It should be noted that the estimated prevalence range for 9–17 year olds is higher than the range recommended by Kessler et al. (1995) for serious mental illness in adults (5.7 percent). The higher estimate for 9–17 years olds is consistent with the fact that using the National Comorbidity Study (NCS) data base, which served as the main data base for the estimation of prevalence in adults, Kessler found that the 12 month prevalence for 15–17 year olds was 8.7 percent. The twelve month prevalence for 18–54 year olds was 6.5 percent. To further understand this difference, however, it is important to recognize that within the 18–54 year range there are differences associated with age. For example, in Kessler’s first article, it was reported that “disorders are consistently

most prevalent in the youngest cohort (age range 15–24 years) and generally decline monotonically with age” (Kessler et al., 1994, p. 13). This was also the case with serious mental illness, as reported by Kessler et al. (1995). This finding of highest prevalence rates in youngest adults with rates decreasing with increasing age was not only obtained in the NCS but also in the Epidemiological Catchment Area study, completed in the early 1980s (Regier et al., 1988). Also, the longitudinal research by Cohen et al. (1993), and the findings by Reinherz et al. (1993) on 17–19 year olds point to especially high prevalence rates for older adolescents.

Within the 9–17 year age range, the data are adequate to permit determination of gender and socio-economic differences but are not adequate to permit determination of race differences. The comparative analyses by Costello & Messer (1995) are particularly useful for looking at gender and socio-economic differences. Both for global and specific measures of impairment, they find the prevalence rates of serious emotional disturbance in the samples already mentioned to be about twice as high in low socio-economic groups as in high socio-economic groups. This finding is consistent for every one of the seven data bases included in the analysis by Costello & Messer (1995). Jensen et al. (1995) fail to find different prevalence rates by socio-economic status in their study. However, as they point out the socio-economic range in their sample was limited by the fact that all of the youngsters were military dependents.

The following steps were taken to adjust for the difference in state socio-economic circumstances. The 1995 estimates of children and adolescents with serious emotional disturbance by state are provided in Table 3.

Step 1

States were sorted by poverty rates (1995), in ascending order. Using this sort order, States were initially classified into three groups of equal proportions, i.e., the first 17 states were put into Group A; the next 17 States into Group B; the remaining 17 States, into Group C. However, in reviewing the results, we noted that observations 17 and 18 differed by .01 percent. Observation number 18 was included in group A. For this reason, Group A has 18 cases, Group B has 16 cases, and Group C has 17 cases. Group A is the group that has a relatively low percentage of children in poverty. Group B is the mid point, and Group C is the group with the highest percentage of children in poverty.

Step 2

At a level of functioning of 50 (LOF=50), the number of children and adolescents with SED is calculated to be between 5–7 percent of the number of youth 9–17 years for Group A. For Group B, the estimate is between 6–8 percent of the number of youth 9–17 years. The estimated SED population for Group C is calculated to be between 7–9 percent of the number of youth 9–17 years.

Step 3

At a level of functioning of 60 (LOF=60), the number of children and adolescents with SED is calculated to be between 9–11 percent of the number of youth 9–17 years for Group A. For Group B, the estimate is between 10–12 percent of the number of youth 9–17 years. The estimated SED population for Group C is calculated to be between 11–13 percent of the number of youth 9–17 years.

TABLE 2.—1995 ESTIMATES OF CHILDREN AND ADOLESCENTS WITH SERIOUS EMOTIONAL DISTURBANCE; STATE ESTIMATES ALGORITHMS

States	Estimated population			
	LOF*=50		LOF*=60	
	Lower limit (percent)	Upper limit (percent)	Lower limit (percent)	Upper limit (percent)
Group A, Lowest percent in poverty	5	7	9	11
Group B, Medium percent in poverty	6	8	10	12
Group C, Highest percent in poverty	7	9	11	13

*LOF=Level of functioning from the Children's Global Assessment Scale.

TABLE 3.—1995 ESTIMATES OF CHILDREN AND ADOLESCENTS WITH SERIOUS EMOTIONAL DISTURBANCE BY STATE

State	Number of youth 9-17	Percent in poverty	LOF*=50		LOF*=60	
			Lower limit	Upper limit	Lower limit	Upper limit
Total	33,706,204	2,118,269	2,792,391	3,466,516	4,140,636
1 New Hampshire	147,695	4.07	7,385	10,339	13,293	16,246
2 Alaska	90,955	8.96	4,548	6,367	8,186	10,005
3 New Jersey	932,671	9.60	46,634	65,287	83,940	10,259
4 Utah	349,086	9.76	17,454	24,436	31,418	3,839
5 Minnesota	643,892	11.30	32,195	45,072	57,950	70,828
6 Colorado	491,930	11.34	24,597	34,435	44,274	54,112
7 Nebraska	231,037	11.62	11,552	16,173	20,793	25,414
8 Missouri	709,439	11.74	35,472	49,661	63,850	78,038
9 Kansas	354,722	12.55	17,736	24,831	31,925	39,019
10 Wisconsin	706,004	12.56	35,300	49,420	63,540	77,660
11 Hawaii	143,901	13.97	7,195	10,073	12,951	15,829
12 North Dakota	91,443	14.13	4,572	6,401	8,230	10,059
13 Virginia	790,359	14.38	39,518	55,325	71,132	86,939
14 Nevada	186,695	14.41	9,335	13,069	16,803	20,536
15 Indiana	758,633	15.24	37,932	53,104	68,277	83,450
16 Rhode Island	115,176	15.36	5,759	8,062	10,366	12,669
17 Delaware	85,396	15.56	4,270	5,978	7,686	9,394
18 Maine	160,434	15.57	8,022	11,230	14,439	17,648
19 Vermont	76,500	15.79	4,590	6,120	7,650	9,180
20 Maryland	608,209	15.80	36,493	48,657	60,821	72,985
21 Wyoming	75,106	16.21	4,506	6,008	7,511	9,013
22 Georgia	942,161	16.30	56,530	75,373	94,216	113,059
23 Massachusetts	680,101	17.12	40,806	54,408	68,010	81,612
24 Iowa	385,583	17.39	23,135	30,847	38,558	46,270
25 Washington	714,567	17.81	42,874	57,165	71,457	85,748
26 Connecticut	378,473	18.03	22,708	30,278	37,847	45,417
27 Pennsylvania	1,462,731	18.07	87,764	117,018	146,273	175,528
28 Oregon	411,543	18.22	24,693	32,923	41,154	49,385
29 Michigan	1,275,452	18.36	76,527	102,036	127,545	153,054
30 Ohio	1,451,220	19.33	87,073	116,098	145,122	174,146
31 Idaho	183,829	20.57	11,030	14,706	18,383	22,059
32 South Dakota	108,855	20.74	6,531	8,708	10,886	13,063
33 North Carolina	879,091	21.06	52,745	70,327	87,909	105,491
34 Kentucky	504,373	21.25	30,262	40,350	50,437	60,525
35 Illinois	1,517,182	22.14	106,203	136,546	166,890	197,234
36 Tennessee	658,573	22.23	46,100	59,272	72,443	85,614
37 Montana	126,834	22.39	8,878	11,415	13,952	16,488
38 Arkansas	337,718	22.44	23,640	30,395	37,149	43,903
39 Texas	2,623,654	24.53	183,656	236,129	288,602	341,075
40 California	3,968,950	24.97	277,827	357,206	436,585	515,964
41 Oklahoma	457,496	24.98	32,025	41,175	50,325	59,474
42 Arizona	542,019	25.31	37,941	48,782	59,622	70,462
43 Florida	1,623,697	25.50	113,659	146,133	178,607	211,081
44 New York	2,141,435	25.51	149,900	192,729	235,558	278,387
45 West Virginia	231,390	26.93	16,197	20,825	25,453	30,081
46 Alabama	547,671	27.50	38,337	49,290	60,244	71,197
47 Louisiana	639,158	29.69	44,741	57,524	70,307	83,091
48 South Carolina	470,875	32.11	32,961	42,379	51,796	61,214
49 Washington, DC	48,365	35.33	3,386	4,353	5,320	6,287
50 New Mexico	251,231	36.59	17,586	22,611	27,635	32,660
51 Mississippi	392,694	37.03	27,489	35,342	43,196	51,050

Analyses show very similar prevalence rates for girls and boys in the seven sites. The absence of gender differences is also apparent in the findings of Jensen et al. (1995). Kessler (1995), however, reports a higher prevalence rate in females than males using the adult diagnostic categories, and an older adolescent sample (15–17 year olds). There is no indication that overall prevalence rate of serious emotional disturbance differs by gender within the 9–17 year age range although there clearly are gender differences in prevalence of particular diagnoses, such as conduct disorder and depression, and there are suggestions that the rates may diverge in later years of adolescence.

Overall, there is support for the use of socio-economic status as a correction factor in developing a methodology for the estimation of the prevalence of serious emotional disturbance. There is no empirical basis at this point for using other correction factors.

Conclusions

Of the 33 million children and adolescents between the ages of 9–17 in the United States, 9–13 percent or 3.5–4 million of these youngsters have a serious emotional disturbance at a score of 60 or lower on the Children's Global Assessment Scale. A more stringent definition of impairment, representing a score of 50 or lower on the Children's Global Assessment Scale shows a range of 5–9 percent or 2.1–2.8 million youngsters with a serious emotional disturbance (see Figure 1). Currently there are not sufficient studies to determine the prevalence rate in very young children ages birth–8. Therefore the estimated number of children with serious emotional disturbance presented here is a low estimate since it only included data for 9–17 year olds.

Limitations

There are several limitations for these estimates. First, it must be recognized that these estimated ranges are based on the findings from many modest-sized studies which varied not only in population but often in instruments that were used (particularly for measurement of impairment), methods that were used to collect the data, and even the diagnostic system that was used.

Second, there are only two studies that include youngsters under the age of nine, and these studies are not adequate to provide a base for any estimate of the prevalence of serious emotional disturbance for children under the age of nine. The estimate presented here is intended for children between nine and 17 years of age.

Third, the data are also inadequate to determine prevalence estimates for children of different racial and ethnic backgrounds. Several of the studies included youngsters of color in their sample and two studies were done exclusively on Hispanic youngsters in Puerto Rico (Bird et al., 1988, & one of the MECA sites). However, the sample sizes are too small and not sufficiently representative of African-American, Hispanic, Asian American, or native American populations to permit estimates to be made.

Fourth, with the absence of any large national studies, it is not possible to determine whether rates differ in urban versus rural areas, or different regions of the country.

Scope of Application

Inclusion in or exclusion from the definition is not intended to confer or deny eligibility for any service or benefit at the Federal, State, or local levels. Only a portion of children with a serious emotional disturbance seek treatment in any given year. Due to the episodic nature of serious emotional disturbance, some children and adolescents may not require mental health service at any particular time. Additionally, the definition is not intended to restrict the flexibility or responsibility of the State or local government to tailor publicly funded service systems to meet local needs and priorities. However, all individuals whose services are funded through Federal Community Mental Health Services Block Grant funds must fall within the criteria set forth in these definitions. Any ancillary use of these definitions for purposes other than those identified in the legislation is outside the purview and control of CMHS.

It is anticipated that additional work will be done in future years to refine and update the estimation methodology. CMHS will keep States apprised as this work develops.

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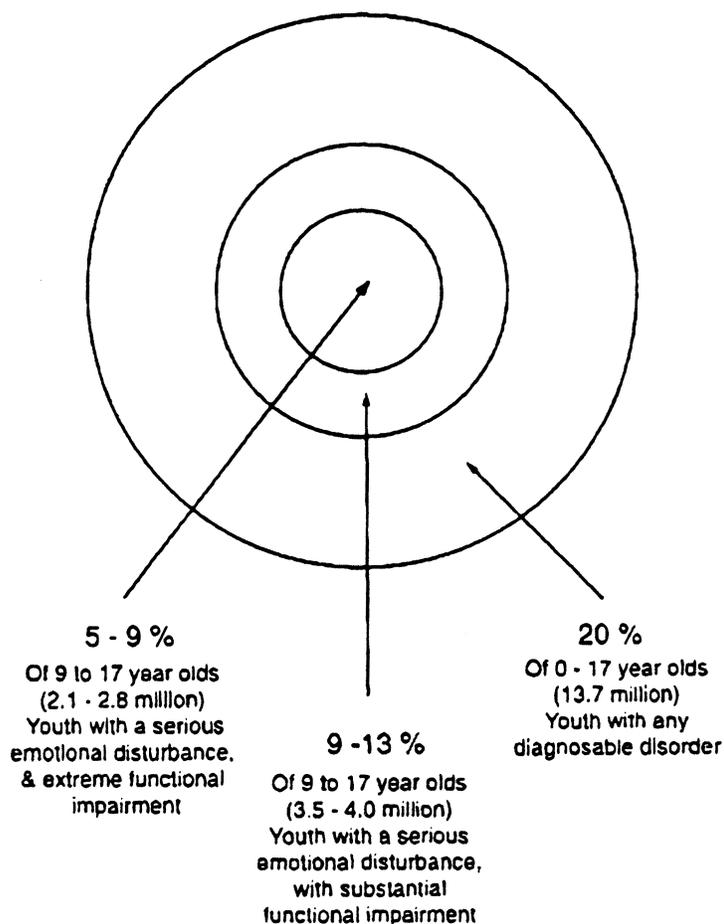
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Figure 1

Population Proportions



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Richard Kopanda,*Executive Officer SAMHSA.*

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DEPARTMENT OF THE INTERIOR

Privacy Act of 1974—Notice of Establishment of System of Records

Pursuant to the provisions of the Privacy Act of 1974, as amended (5 U.S.C. 552a), notice is hereby given that the Department of the Interior proposes to establish a new system of records to be maintained by the Interior Service

Center. The system, entitled "Computerized ID Security System—Interior, OS-01," will include information pertaining to Departmental employees and other individuals who have had access to the Main and South Interior Buildings. The information contained in this system will be used for the purpose of operating and maintaining a computerized security access-card system. The system will enhance the security of the Main and South Interior Buildings, while enabling the Department to assure the safety of building occupants in the event of an emergency. Individuals entering or leaving the Main or South Interior Buildings will be required to scan a computerized identification (ID) card,

equipped with a magnetic device, through a card reading device. The device will identify the card holder based on personal information encoded on the card, and will either authorize entry or deny access to the building in question.

The potential impact on the privacy of individuals covered by the system will be minimal. Data pertaining to the date and time of entry and exit of an Interior employee will not be disclosed to supervisors, managers, or any other persons (other than the individual to whom the information applies) to verify time and attendance records for personnel-related purposes because 5 U.S.C. 6106 prohibits Federal Executive agencies (other than the Bureau of