An Assessment of Service Needs for Developmental Disability Services in St. Charles County

Executive Summary

Conducted for

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Study Objectives. This needs assessment project was designed to provide quantitatively accurate and reliable data to guide the DDRB in carrying out its mission. The study had two primary objectives: 1) determine the current service needs of St. Charles County residents with developmental disabilities (DD) and their families; and 2) estimate the level of these needs through the end of the decade.

Methodology. The research methodology involved a survey of all families with a person currently in contact with the DD service system in the county. Survey results were adjusted using current prevalence estimates and projected forward through demographic analysis of census and special education data.

Operationally, the study population consisted of two groups of county residents, clients of the Regional Center and consumers served by a community agency funded by DDRB. Eighteen community agencies that provide the bulk of DD services in the county participated in the study. The client lists of the Regional Center and community agencies were merged into a single project data base and duplicates removed. A total of 1,932 unduplicated persons were identified and a survey instrument was mailed to the families or guardians of each. The survey instrument was developed in consultation with an advisory committee established by the Executive Director of the DDRB. Persons preferring a telephone interview were surveyed in that manner. A total of 585 survey responses (31 percent) was received in time to be analyzed, a number well within acceptable statistical limits. Respondents were representative of the population on all available characteristics; weighting was not required in analyses to ensure statistical reliability.

Survey Respondent. For a large majority of cases (82 percent) the respondent was the parent of a consumer. A few consumers (3 percent) themselves responded. Altogether, parents, consumers and close relatives accounted for 94 percent of responses; agency staff completed the survey on behalf of consumers about 6 percent of the time.

Characteristics of Consumers and Families

Agency Affiliation. Nearly three-quarters (73 percent) of the consumers were served by the Regional Center, while 65 percent were served by one or more community agencies; 35 percent were clients of both the Regional Center and a community agency.

Living Arrangements. Over three-quarters (77 percent) of the consumers lived in their family home, 12 percent lived in a group home or other supervised facility, 8 percent lived in a supported living arrangement, 3 percent lived independently without support. Nearly all (99 percent) consumers under 21 lived at home with their families. For older consumers, 45 percent lived in their homes, 30 percent lived in group homes or supervised facilities, 19 percent were in supported living situations, and 5 percent lived independently.

Employment/Work. Altogether, 22 percent of the consumers in the survey population had a paid job. Of those aged 21 and over, 50 percent had a paid job and 50 percent did not. Thirty-one percent of consumers 21 and older worked in sheltered workshops, while 10 percent worked in supported employment situations. Seven percent worked in regular jobs without support. The average weekly wages of consumers in sheltered workshops was $80.17, compared with $121.44 for consumers in supported employment, and $176.95 for those working independently without support.

Family Characteristics. The mean age of family respondents was 44.7. Thirty-nine percent were younger than 40. Seventeen percent were age 60 or older. Nearly three-quarters (74 percent) of respondents were two-parent family households; 21 percent single-parent householders. One household in six (17 percent) had a second household member with developmental disabilities. Among households with preschool-age consumers, this figure was 29 percent. Forty-four percent of family respondents had college degrees and another 27 percent had attended college. Just 4 percent had not completed high school. Over one-third of the respondents (38 percent) had family incomes over $60,000, 26 percent were between $40,000-59,999, 22 percent reported were between $20,000-$39,999, and 14 percent were below $20,000. Income, like education, tended to be inversely related to the age of the consumer.

Service Needs

Study Population. Across the entire study population, high levels of need were found for systemic and planning assistance, special therapies of many types, recreational and leisure-time services of all types, transportation services, dental and medical services.

Consumers 0-5. The most frequent service needs of families with preschool children were special therapies, planning help for future service needs, information about available services, day care, and family support groups.

Consumers 6-18. The most frequent needs of families with school-age consumers were special therapies, service information and planning assistance, respite care particularly in-home, and recreation services especially in the summer.

Consumers 18-54. The most common service needs of these adult consumers were transportation, case management services, dental and medical services, recreation services of all kinds but particularly on weekends and evenings, and help obtaining financial assistance.

Consumers 55 and older. For this group, the most frequent needs were medical and dental services, case management services, help obtaining financial assistance, nursing services and daily in-home personal care assistance, followed by transportation and recreation.

Single-Parent Households. Caregivers in single-parent households frequently reported needs for information about services, assistance in planning for the future, practical help such as respite care and in-home assistance, counseling and behavior management.

Lower Income Families. These families frequently expressed needs for medical and dental services, transportation and financial assistance.

Criticality of Needs. In general, services needed by a higher percentage of respondents was often as critically needed. This convergence within the population as a whole of high incidence of need with higher criticality of need, suggests there is a core set of services that require close attention. These include systemic and planning services, medical and dental services, special therapies, recreation, transportation, and respite care.

Assistance Related to Current Living Situation. A little more than half (55 percent) of the consumers were receiving some services in support of their living situation from a source outside their family. For a majority (70 percent) of this group, the services received were judged sufficient to meet their current needs, while 30 percent needed more assistance than they were receiving.

Less than half of the consumers (40 percent) were not receiving any outside support or assistance related to their living situation. Two-thirds of these (67 percent) did not need any assistance from outside their family while one-third (33 percent) did. (A few respondents were not sure of the adequacy of the supports received or the need for them.)

Changes Needed in Living Arrangements. Five percent of respondents reported a need for an immediate change in a consumer's living arrangements, and 6 percent indicated a change would be necessary within the next two years. For respondents who indicated a change was needed immediately, 48 percent sought a supported living arrangement, while 16 percent sought a group home or supervised facility. For respondents who thought a change would be needed within two years, 41 percent sought supported living and 19 percent sought a group home.

Impact of Support Services for Consumers at Home. A number (46 percent) of family respondents with consumers at home said additional support services would enable the consumer to remain at home longer. Services frequently mentioned as making a difference in this regard were respite care, transportation, nursing and personal care assistance, independent living skills training, socialization support/opportunities, and day care.

Employment. While a majority of consumers currently working were in sheltered workshops, a growing preference was found for supported employment. A clear majority of workers under age 30 prefer something other than sheltered workshops. Overall, one in four consumers currently working was seeking help changing jobs. Many preferred supported employment, including 1 in 8 currently in workshops. No worker with a competitive job in an integrated setting was seeking work in a sheltered workshops.

Service Gaps. Essentially all of the consumers represented in the surveys received some services from the Regional Center and/or a community agency. At the same time many expressed needs for services they were not receiving. Nearly one in three respondents indicated unmet needs related to planning for future service needs and nearly as many sought more information about available services. Across the whole population, service gaps of some significance were also found for recreation and transportation services, respite care and dental services.

The responses of parents with young preschool children were more likely to indicate unmet needs for family support groups, respite care, day care and special therapies. Many parents with children in school, in addition to unmet needs related to service information and planning, indicated unmet needs for recreation, both summer and weekend/evening, as well as for training for living in the community. Adult consumers between the ages of 18 and 54 also had service gaps in the areas of planning assistance, including information about employment options, and many reported unmet needs for recreation, transportation, and dental services. Consumers 55 and older were more likely than others to experience service gaps for occasional in-home personal care assistance and dental services.

Prevalence and Projections

Prevalence of DD in St. Charles County. The study population consisted of .65 percent of the county population. Allowing for persons missed in the study who were on agency waiting lists or served by agencies that did not participate in the study, it was estimated, conservatively, that a minimum of .688 percent of the county population was in contact with the service system. This figure was taken to be the practical prevalence minimum, that is, the percent of the population eligible for services from the public DD service system that is likely to seek services at a point in time.

Currently, special education students represent 16 percent of the county's k-12 school population. Those with a disabling condition that may make them eligible for adult services was .97 percent. This includes all students classified with MR, orthopedic impairments, deafness/blindness, autism, and traumatic brain injury. Assuming that at any point in time some of these consumers may not actually be eligible, may not need or seek services, or will be in transition in or out of the county, it was estimated that a maximum of .90 percent of the school population may be eligible and seek services from the public, non-school service system.

For planning purposes, therefore, it is recommended that a range of "practical" prevalence be used that is between .688 percent on the low end and .900 percent on the upper end. The percent of the county population that is eligible and likely to seek services can be expected to fall within this range.

Census Data and Projections. Between 1990 and 2000, the county population grew by 33 percent. Between 2000 and 2010, the current estimates are that the county will grow by an additional 24 percent, becoming slightly older in the process. The 2002 population is estimated to be 297,503.

Projection of Service Need. In the report, estimates have been made of the numbers of eligible consumers likely to seek particular services for each year of this decade. These estimates were based on 1) the percentages of consumers reported to need specific services in the present needs assessment, 2) the estimate of low and upper-end "practical" prevalence of DD in the county, and 3) current projections for population growth throughout the decade. The projected yearly numbers of eligible consumers likely to seek services ranges from 2,047 – 2,678 for the year 2002 to 2,416 – 3,160 for the year 2010.