The development of health policies is often initiated to meet political objectives, but policies can be, to a great extent, shaped by information found in surveys and other health services research. The following article provides an example of how survey data can be used to shape policy regarding developmental disabilities. It also illustrates how occupational therapists can use the data to adjust the focus of their services to meet consumer demand and implement shifts in policy.

D. Ellek, Contributing Editor

In the past 25 years, many changes have occurred in the lives of persons with developmental disabilities, brought about by federal and state mandates and resulting programs. An opportunity for a free and appropriate education, the removal of architectural barriers, and nondiscriminative practices are a few of the more important advances. Services have become more decentralized with the establishment of community-based programs. Many large facilities with centralized services have been closed. The move to alternative community-based housing to improve community integration and some integration in schools and in workplaces have begun. These changes have brought with them certain problems such as fragmentation of services, lack of appropriate services, and questionable quality of services. Concerned health care professionals and policymakers at the end of President Reagan’s tenure were asking the following questions: Are citizens with developmental disabilities receiving enough services? Are these services satisfactory in the view of the receivers? Are there needs for additional services? What needs to be offered now and where do legislators place program funding emphasis in the future? The purpose of this paper is to report specific findings of a consumer-based survey about current occupational therapy and to discuss the findings in relation to changing health care policy for persons with disabilities.

The National Consumer Survey

To answer the questions posed above and begin to fashion a new public policy in supporting persons with developmental disabilities, updated information was needed about the services available to these citizens, the adequacy of those services in terms of the recipients, and the need for additional services. In 1987, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act Amendments (Public Law 100-146) to provide assistance to governor’s councils of developmental disabilities to collect information about services for persons with developmental disabilities. Part of this effort was to survey consumers of services, that is, clients themselves or their families, in all states. A National Consumer Survey was developed by the National Association of Developmental Disabilities Councils (NADDC), an association representing state councils, and the research staff of the Developmental Disabilities Center at Temple. Funding for development of the survey was provided by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. Data were gathered and analyzed from 46 states, and national reports (NADDC, 1990; Temple University Developmental Disabilities Center/UAP Research and Quality Assurance Group, 1990) were written. Christina Metzler, assistant director of NADDC (C. Metzler, personal communication, January 29, 1992), stated that the National Consumer Survey has had an impact in individual states that have used the data to heighten awareness of policy issues related to persons with developmental disabilities. Also, she indicated that the survey and related policy analyses were influential in the establishment of the Senate Bipartisan Working Group on Disability Policy. She noted that the data from the survey became public while the Americans With Disabilities Act of 1990 (Public Law 101-336) was being crafted and has been used to influence policy. Finally, she reported that the current federal government administration is sponsoring further analyses of the survey to illuminate policy questions related to persons with disabilities.

I was a co-investigator on the survey that was conducted in Michigan. I obtained permission to access the data from NADDC to analyze survey outcomes related to occupational therapy and those services deemed closely related to or a part of occupational therapy services, such as prevocational services. Many of these related services, however, may have been performed for the respondent by some other professional (e.g., a vocational rehabilitation counsel-
or or special education teacher in the case of prevocational activities).

Brief mention of "Forging a New Era: The 1990 Reports on People With Developmental Disabilities" was made in the occupational therapy literature (OT Week, 1990). This article gave a summary of the reports. Mention of limitations reported by those surveyed in terms of economic self-sufficiency and opportunity for independent living was noted. Other needs and problems were listed related to health care, employment, self-determination, and self-help. Occupational therapy was also noted as one of the support services needed. However, no specific data were reported related to amount of current occupational therapy and related service received and reasons for not receiving the service.

In light of recent dwindling resources in many states for health care dollars, a closer look at outcomes of the survey concerning occupational therapy and related services might shed light on where government funding priorities may lie in the 1990s and provide suggestions for program development efforts. Occupational therapy departments in educational programs, medical settings, and schools might develop programming based on survey outcomes.

Limitations of the survey have been noted by its authors (Temple University Developmental Disabilities Center/UAP Research & Quality Assurance Group, 1990). These limitations include lack of representation of the developmentally disabled population due to the ill-defined nature of this population, variations in state sampling methods, the use of surrogate responders who possibly did not reflect the views of the persons with disabilities, and the high satisfaction rates that social scientists have described as accompanying satisfaction surveys. According to the survey authors, strengths of the survey included the large population size and the reflection in the national data that recommended sampling techniques were carried out by each state. For example, distribution by age and disability groups were close to the recommended sizes.

Survey Outcomes and Occupational Therapy

Demographic information related to the National Consumer Survey has been reported by the 1990 Temple University report as follows. Face-to-face interviews were conducted with over 15,000 persons nationwide who met the definition of developmentally disabled. According to guidelines set forth by Temple University and NADDC, each state was responsible for selecting a representative sample of persons with developmental disabilities or their representatives, such as parents or siblings with whom to conduct the interview. The persons with severe, chronic disabilities who were selected must have had their disability begin before age 22 years and have substantial functional limitations in three or more areas of major life activity, such as self-care, mobility, and the capacity for independent living. From the total number interviewed, 13,075 surveys were deemed usable for data analysis. The age of the persons represented in the sample ranged from under 6 months to 90 years, with the mean age being 25 years. Fifty-five percent of the respondents were men; 45%, women. The largest primary diagnosis reported was mental retardation (42.3%), followed by cerebral palsy (14.8%). More than 16 other diagnoses were given, as well as many secondary diagnoses (N = 19,588). The ethnic composition was 79% white, 11% black, 3% Hispanic, and 7% other. Relevant age breakdowns were as follows: 32% were under 18 years; 65% were age 18 to 65 years; 2% were over 65 years; and for 1% of the total sample, age data were missing.

Table 1 shows the percentages and frequencies of those receiving occupational therapy and related services: of those who were satisfied, neutral, or dissatisfied with their service, and of those needing the service. The number and percentage of persons currently receiving occupational therapy and related services is low, although those not currently receiving these services may have received them at some time during their lives. Although the satisfaction rate with occupational therapy was high (78%), 30% were neutral or dissatisfied. As with most of the services related to occupational therapy, the most common reason given for dissatisfaction was that the consumer was not receiving enough service (51%). The next most common reason was that occupational therapy was not suited to individual needs (13%). Almost one third of those responding said they needed occupational therapy. About one third of the recipients of adaptive devices and training reported that they were neutral or dissatisfied with the service, whereas two thirds were satisfied.

The percentages and frequencies of those receiving vocational and adult day services were low; this is a fair assessment in light of the fact that 65% of the persons surveyed were in the working age group of 18 to 65 years. Dissatisfaction and neutral rates were higher in some of these areas, including nondevelopmental adult day services, work adjustment, competitive employment, job placement, and on-site modifications to the work site. The reason most often given for dissatisfaction with the above services was that the services were not suited to individual needs. Other frequent reasons given were that respondents were not receiving enough service or the services were of poor quality. Transportation training, which enables persons to use public transportation to live and work in the community, was also reported often as neutral or dissatisfying.

Another service related to living independently in the community was architectural modifications in residential services, which was rated as satisfactory by more than 50% of the respondents. In contrast, recreational and leisure services were received by almost half of the respondents; even so, 58% said they needed more.

Respondents were also queried about various federal and state programs and agencies with which they had experience. Among the most interesting findings to occupational therapists were that only a small percentage of respondents reported services received from independent living centers, with approximately two thirds reporting satisfaction with these programs and approximately one third reporting dissatisfaction. Of the total sample, 28% reported being involved in vocational rehabilitation programs, with slightly less than two thirds reporting satisfaction and slightly more than one third reporting dissatisfaction. Slightly less than 20% of the respondents participated in Crippled Children Services and Community Mental Health Services, with about
Table 1
Percentages and Frequencies of Respondents Receiving Occupational Therapy and Related Services, Satisfaction With Those Services, and Need for Services*

<table>
<thead>
<tr>
<th>Service</th>
<th>Currently Received</th>
<th>Satisfied or Very Satisfied</th>
<th>Neutral</th>
<th>Dissatisfied or Very Dissatisfied</th>
<th>Service Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>25%(3,291)</td>
<td>70%(2,297)</td>
<td>12%(383)</td>
<td>18%(611)</td>
<td>34%(4,439)</td>
</tr>
<tr>
<td>Adaptive equipment devices and training (recently)</td>
<td>18%(2,373)</td>
<td>68%(1,614)</td>
<td>11%(270)</td>
<td>21%(489)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Vocational/Adult Day Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial rehabilitation</td>
<td>5%(693)</td>
<td>65%(499)</td>
<td>22%(155)</td>
<td>13%(89)</td>
<td>14%(1,805)</td>
</tr>
<tr>
<td>Day treatment</td>
<td>4%(551)</td>
<td>60%(329)</td>
<td>26%(146)</td>
<td>14%(76)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Adult day service (developmental/habilitative)</td>
<td>11%(1,582)</td>
<td>72%(990)</td>
<td>16%(218)</td>
<td>13%(174)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Adult day service (nondisabled)</td>
<td>4%(478)</td>
<td>55%(263)</td>
<td>31%(148)</td>
<td>14%(67)</td>
<td>14%(1,805)</td>
</tr>
<tr>
<td>Work adjustment</td>
<td>4%(558)</td>
<td>59%(332)</td>
<td>24%(135)</td>
<td>16%(91)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Work activities/prevocational</td>
<td>12%(1,598)</td>
<td>76%(1,213)</td>
<td>13%(209)</td>
<td>11%(176)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Sheltered employment (facility-based)</td>
<td>17%(2,162)</td>
<td>75%(1,573)</td>
<td>13%(272)</td>
<td>14%(317)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Sheltered employment (non-facility based)</td>
<td>5%(593)</td>
<td>64%(377)</td>
<td>24%(140)</td>
<td>15%(76)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Supported employment</td>
<td>5%(677)</td>
<td>66%(445)</td>
<td>21%(143)</td>
<td>13%(89)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Competitive employment</td>
<td>5%(418)</td>
<td>56%(355)</td>
<td>29%(123)</td>
<td>15%(60)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>Job placement</td>
<td>6%(840)</td>
<td>58%(489)</td>
<td>19%(163)</td>
<td>22%(188)</td>
<td>25%(3,308)</td>
</tr>
<tr>
<td>On-site modifications to the work site</td>
<td>5%(410)</td>
<td>55%(324)</td>
<td>30%(123)</td>
<td>15%(60)</td>
<td>10%(1,215)</td>
</tr>
<tr>
<td>Residential Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaking assistance or training</td>
<td>9%(1,211)</td>
<td>76%(942)</td>
<td>14%(107)</td>
<td>9%(102)</td>
<td>32%(4,077)</td>
</tr>
<tr>
<td>Architectural modifications</td>
<td>6%(795)</td>
<td>58%(404)</td>
<td>20%(159)</td>
<td>21%(172)</td>
<td>38%(2,507)</td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation training</td>
<td>9%(1,115)</td>
<td>57%(652)</td>
<td>20%(220)</td>
<td>23%(263)</td>
<td>14%(1,825)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recreation/leisure services</td>
<td>4%(5,721)</td>
<td>69%(3,927)</td>
<td>10%(581)</td>
<td>21%(1,213)</td>
<td>58%(7,637)</td>
</tr>
</tbody>
</table>

*Frequencies are cited in parenthesis beside percentages. Data were not collected for need in these areas.

75% satisfaction rates as opposed to approximately 25% dissatisfaction rates.

Discussion and Recommendations

Although conclusions from the survey must be drawn with caution due to the limitations noted above, a trend in the data suggests that services supporting living and working in the community are deficient and that the services related to the work and independent living aspects of community integration that are being offered are not fulfilling the needs of persons with developmental disabilities. Considering the fact that satisfaction surveys generally yield high rates of satisfaction, the question remains of how much of the reported satisfaction is enough to indicate quality, or best services, which are goals in the area of service to those with developmental disabilities. A philosophical and moral question is raised related to satisfaction outcomes, which needs to be voiced in public, professional, and legislative arenas.

Based on National Consumer Survey outcomes, I believe the future directions for occupational therapy in the area of services for persons with developmental disabilities lie in the areas of work and independent living. Given adequate preparation by educational programs, occupational therapists have the potential to assume important roles in community agencies that provide work and independent living services such as independent living centers and mental health facilities with work programs. Implementation of the Americans With Disabilities Act of 1990 will be an opportunity for occupational therapists to develop or seek employment in programs offering job coaching, transportation services, supported employment, adult day services, independent living, on-site job modifications, community programs to create access to public buildings, and the provision of recreation and leisure time activities in creative ways. Current rates of employment of occupational therapists in the various areas related to work such as job placement and competitive employment needs to be monitored as implementation of the act progresses to evaluate the rule occupational therapy plays. In my immediate experience, I have found that employment in specialized areas related to work does not currently appear to be high. Some specific ways in which occupational therapists can get involved in the provision of quality services to the developmentally disabled are as follows:

1. Develop consumer-based needs assessments at the local or regional level related to work and independence.

2. Respond to state and federal requests for proposals to develop model programs in one's area.

3. Write unsolicited grants to state developmental disabilities councils.

4. Establish interdisciplinary programs in agencies and in local businesses.

5. Get involved with advocacy, consumer, and public awareness groups.

6. Develop programs in agencies where employed.

7. Support occupational therapy educational programs in preparing the workforce in the areas of work and independent living.

In summary, the outcomes of the National Consumer Survey indicate that consumers are satisfied with occupational therapy services provided in the past that have emphasized traditional practices of rehabilitation such as activity to increase physical function and activities of daily living. Therapists need to continue these efforts but expand their programming. In changing times and with changing societal needs, occupational therapists must place emphasis...
on work and independent living intervention so that consumers will continue to be satisfied with services. Needs of consumers must continue to be heard and addressed in a biopsychosocial context that supports community integration rather than in a medical context that is problem oriented rather than focused on consumer strengths.

Data derived from the survey described above will be useful to cost-conscious administrators and legislators in making program and policy decisions. Occupational therapists can forge stronger bonds with consumers, increase consumer independence, and hasten consumer community integration by using survey data to refocus and develop new programs in competitive employment and independent living.

References


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