

Elderly & Disabled Waiver Services:

Important Dimensions From the Client's Perspective

Executive Summary

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Background: Little is known about home and community based services (HCBS) and even less about the quality of those services. As part of a “Real Choice Systems Change” grant received by the Virginia Department of Medical Assistance Services, the Center for Gerontology at Virginia Tech conducted an exploratory survey of clients receiving HCBS under the Medicaid Elderly and Disabled (E & D) Waiver. The goal of the survey was to learn about clients’ experiences with HCBS and to identify the most important dimensions of service provision from their perspectives. An initial focus group with 11 caregivers was first held in Big Stone Gap. Twenty-five telephone interviews were then completed (18 clients and 7 caregivers) in five areas of the Commonwealth. Fifteen were in urban areas (Northern Virginia, Richmond, and Chesapeake) and ten in rural or non-metropolitan areas (New River Valley and Planning Districts 13 and 14).

Sample Population: The sample was comprised of 21 females and 4 males. Two-thirds (64%) were aged 65 or older ($n = 16$). All respondents received personal care and had received services for three years on average. The length of time their current aide had been coming ranged from two weeks to seven years ($M = 12$ months). The majority (83.3%) also received help from family or friends.

Needs: A sizeable percentage of respondents (43.5%) reported their aides did not do all the things they needed. Caregivers were significantly more likely ($p < .001$) than clients to report unmet needs. Unmet needs included care at additional times of the day or week: nights/split shift, weekends, or more hours. Others mentioned transportation, housecleaning, and a need for more information about services. Two-thirds of the respondents (65.2%) saw “maintaining your health so you can stay home” as the most important thing they received from services; seven respondents named “companionship” as most important.

Current Aide: Respondents were generally satisfied with their current aides. The most common problems were aides arriving late, finding it stressful having the aide in the house, and aides doing less than expected. Comparison of the family caregivers’ responses to the clients’ responses revealed the most dramatic differences ($p < .001$) on: “Aide is very thorough,” “I find it stressful to have the aide come in my house,” “Aide does less than expected,” and “Aide

ignores what I tell her about how I like things done,” with the caregivers more critical than the clients on all items.

Past Experiences: The most common problem reported was aides who were lazy (44%). Other problems included aides who did not show up or who arrived late, having many different aides, diversity issues, lack of substitutes, and inadequate training. Nine respondents (36%) reported no problems with past or current aides.

Conclusions: The most important dimensions of the personal care aide from the clients’ perspective are:

- 1) The same aide comes all the time.
- 2) The aide comes when s/he is supposed to, arrives on time, and stays the full time.
- 3) The aide focuses on the client and completion of the tasks necessary to meet the client’s needs.
- 4) The aide does the tasks the way the client wants them done.
- 5) The aide can be trusted.
- 6) The aide is kind, caring, and easy to be around.
- 7) The aide communicates effectively.
- 8) The aide comes well prepared with a good knowledge base.

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