A Study of the Independent Supported Living Arrangements Program in St. Louis County

Study Digest

Conducted for
**The Productive Living Board
For St. Louis County Citizens with Developmental Disabilities**

Conducted by
**Institute of Applied Research
St. Louis, Missouri**

October 21, 1997

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Background

This is a report of a comprehensive study of the Independent Supported Living Arrangements (ISLA) Program in St. Louis County. Independent supported living arrangements (ISLA) are intended to enable people with disabilities to live in the community in a manner of their choice that most closely approximates the experience of people without disabilities, with support and assistance in varying degrees as needed (Marone, 1992). Dufresne has noted that "the concept of supported housing is an attempt to bring supports needed by an individual to his/her home, equal to the support provided in the traditional continuum of services." Continuing, he argues that "the most fundamental creed upon which supported housing is based is that everyone deserves a home. There is no 'readiness' to live in the community."

The Center on Human Policy at Syracuse University has been a useful source of research and policy guidance on independent supported living issues in recent years. Research by CHP staff on issues of residential options, independence, and community integration through the early 1990s showed that housing needs are similar for all disability groups, that supports are a critical factor in housing provision, that housing problems are less related to disability than to economic and social factors, that differences have existed between professionals and people with disabilities regarding perceptions of specific housing and support needs, and that choices and control are critical elements (Racino, 1992, 1991, 1989a, 1989b). This and other research have helped shape the basic themes that drive the independent supported living movement: the importance of living in one's own home, the context of the broader community in people's lives, and the extension of the independent living movement's concept of personal assistance to people with severe developmental disabilities.

Surveys of states indicate independent supported living programs are playing an increasing role in service systems for persons with developmental disabilities (Prouty and Lakin, 1995; Jaskulski et al., 1991). Some of this has been precipitated by the overall trend of deinstitutionalization which has forced states to look at the quality of their placements (Wright, 1995). The quality of programs and the quality of life of participants have become increasingly dominant themes in planning and evaluating services for people with disabilities (Dennis et al., 1993; Lakin, 1993). Quality of life has become an important independent variable in the examination of program outcomes (Halpern, 1993) and has been found to be associated with integration in different residential settings (Lutfiyya et al., 1987). Research indicates that integration opportunities have more to do with where the resident lives than with either the level of disability or the number of disabilities (Parker and Boles, 1990). Social integration itself has come to be viewed as a multidimensional concept whose outcomes need to be measured from multiple perspectives, and this multidimensionality implies that varying interventions are needed to enhance the social lives of persons with disabilities (Barr, 1996; Chadsey-Rusch and Heal, 1995).

"The promise of supported living for individuals with developmental disabilities," O'Brien (1993) notes, "lies in its potential to deal creatively and individually with the complexities arising from the lives of many different individuals." Through the work of Beth Mount (1992) and others (for example, DiLeo and Morton, 1993; Lovett and O'Brien, 1992; DiLeo, 1991; Allen, 1990), person-centered planning has become a mechanism for increasing the individualization and participant-directedness of interventions, "supporting what people want" (Racino, 1992). Concomitantly, there has been an increased understanding of the need for feedback from participants and their families as part of program development (Vermont Systems Change Project, 1993; Patterson and Marks, 1992; Shoultz, 1988) as well as program evaluation (McNulty, 1993, Sechrist, 1993).

Methodology and Data

The results of the study summarized here are based on interviews of 58 persons with developmental disabilities participating in the ISLA program in St. Louis County, 10 interviews and 70 completed surveys of parents of ISLA participants, interviews of administrators and staff of eight agencies in the county that provide ISLA services, participant-specific surveys completed by support professionals on 186 (81 percent) of the ISLA participants in the county, background surveys completed by 65 support professionals, a systematic review of 49 randomly selected person-centered plans of ISLA participants, analysis of data in the county-wide information system covering the previous six years, and a review of the budgets and reports of the eight county agencies that provide ISLA services.

ISLA in St. Louis County

The only source of funding for ISLA support services in St. Louis County is the Productive Living Board (PLB), and ISLA is the sole type of residential service that the PLB funds. Between July 1, 1996 and February 28, 1997 (the principal study period of the research), 248 county residents received ISLA services. Over half of these consumers (59 percent) received support services from one agency, Life Skills Foundation. Seven other agencies also provided ISLA services. These were Gateways (which supported 14 percent of the ISLA consumers); Council for Extended Care (11 percent); START, Willows Way, and Lifestyle Options and Opportunities (4 percent each); United Cerebral Palsy Association (3 percent); and Creative Concepts for Living (1 percent).

The ISLA program has grown steadily in recent years. In calendar year 1992, a total of 119 county residents participated in the program. By calendar year 1996 this number had risen to 256. At the same time the amount of funded support per participant declined from an average of 11.6 hours per week for consumers who entered the program in 1992 to 6.1 hours per week for those who entered in 1996. Participants were able to remain in independent living arrangements despite this reduction in support because of the utilization of natural supports, primarily assistance from family members, and the separation of attendant care from ISLA supports for persons with physical disabilities who also require an assistant for some daily functions. Overall the pattern of support tends to be that persons receive more support as they initially enter the program with some tapering off subsequently. However, there is considerable fluctuation in support provided to individuals over time, apparently in response to changing consumer needs.

The mean age of the consumers in the ISLA program during FY 1997 was 34. Three out of four lived in apartments, and a majority (55 percent) had roommates. Four out of 10 lived with another person with a developmental disability. Over half (56 percent) had jobs in natural settings, most but not all through supported employment programs. The average monthly income of ISLA consumers from all sources was $681. Sixty-eight percent received SSI benefits. Many consumers received other services, often, but not always through the same agency that provided ISLA support. Family members were an important source of support for many consumers. Approximately 40 percent of them, however, could not rely on their parents for assistance because they were either deceased, not living in the St. Louis area, or elderly.

Consumer Satisfaction with ISLA

The most important voice to be heard on the subject of the independent supported living program in St. Louis County are the persons most affected by it, referred to here as the consumer. The consumer interview schedule we developed for this study contained items in five primary areas: 1) questions about their living situation, including questions about their roommate; 2) questions about the support and assistance they were receiving; 3) questions about daily living activities they engaged in, and sources of support for these activities; 4) questions dealing

with issues related to their social life and community inclusion; and 5) questions about their person-centered plan. The interview schedule was designed to give us a thorough understanding of the level of satisfaction consumers had with their supported living arrangement overall. It was also intended to provide information on the participants' involvement and utilization of natural supports, as well as on the overall quality of their lives.

Satisfaction with the Living Situation. The large majority of consumers expressed satisfaction with most aspects of their current living situation. We asked them first of all whether they liked where they lived, the general area or municipality as well as their neighborhood. We also asked if they liked the physical residence in which they were currently living. Nine in ten consumers expressed satisfaction with all three of these location questions, with over 70 percent expressing strong satisfaction. Five percent or less had negative comments, and a few indicated neutral or uncertain opinions.

When asked, just over half (53 percent) said they had had a lot of input in selecting their residence, while 26 percent said they had had some influence on the decision. One in five (21.1 percent) reported that they had not had any influence on the decision about where they would live. Nearly all indicated that they felt safe living where they did: 72 percent said they felt very safe, and 27 percent said they felt generally safe. Only one was unsure. All but one said their residence felt like home to them. Most were enthusiastic on this point, expressing strong feelings—82 percent said it was "very much" like home, and 16 percent said it was "pretty much" like home to them. A large majority (86 percent) reported that they preferred living in their present place to where they had lived previously. Five percent said they did not, while 9 percent were unsure or neutral on the matter. Consumers were equally positive whether they had moved from their family home or from another independent situation.

Roommates. Just over half (54 percent) of the consumers interviewed were living with one or two roommates, and the rest (46 percent) were living by themselves. Most of the interviewees said they got along with their roommates, although not always all the time. Eight in ten consumers said they had had at least some input in the selection of a roommate, and 58 percent said they had a lot of input into the decision. On the other hand, 20 percent said they either had no influence over the selection or were unsure about this.

Satisfaction with Person Providing Support. All consumers interviewed said they got along with the person who provided their ILSA support; 83 percent said they always got along, the rest (17 percent) that they generally got along. All reported they liked this person, with 98 percent saying they liked him or her "a lot." All also reported that they believed their support person liked them as well, with 96 percent saying their worker liked them a lot. Three out of four said their support professionals were always helpful; the rest said she/he was generally helpful. A very large majority (83 percent) said their support person was always friendly, while 17 percent characterized him/her as generally friendly. Most gave a positive evaluation of the job support professionals were doing (see Figure 4.6). More than three in four said the professionals did a good job all the time, and none expressed an assessment that was only negative. Consumers were asked if they were a teacher, what grade would they give to their support person for the job they did. Seventy-six percent said they would give them an "A" and 21 percent said a "B," while a few were uncertain.

Consumers were asked who decided what their support professional did. Twenty-six percent said the consumer herself/himself did. Thirty-two percent said the worker decided what she/he would do, while 32 percent said they both decided this and 10 percent were uncertain. Asked whether they had chosen (hired) this person to provide support to them, 32 percent said yes, and 47 percent said no, and the rest were uncertain. A little over a third of the consumers interviewed (37 percent) said they would like their workers to spend more time with them and give them more support and assistance, 16 percent said they would prefer less involvement and

support from the worker, and 44 percent said they liked the amount of time and support they were currently receiving from their worker.

At the end of the interview consumers were asked to indicate their overall satisfaction with ISLA, from very positive to very negative. Their responses are shown in the following pie chart. In a number of ways these responses may be taken as the most indicative of their feelings about the program. The question came at the end of a long interview process in which many issues were examined and by which time a rapport had been established between the interviewer and consumer. As can be seen, two in three responded positively. Some had mixed feelings, a few were negative (although none said "very negative") and a number remained uncertain.

Overall Satisfaction of Consumers with ISLA
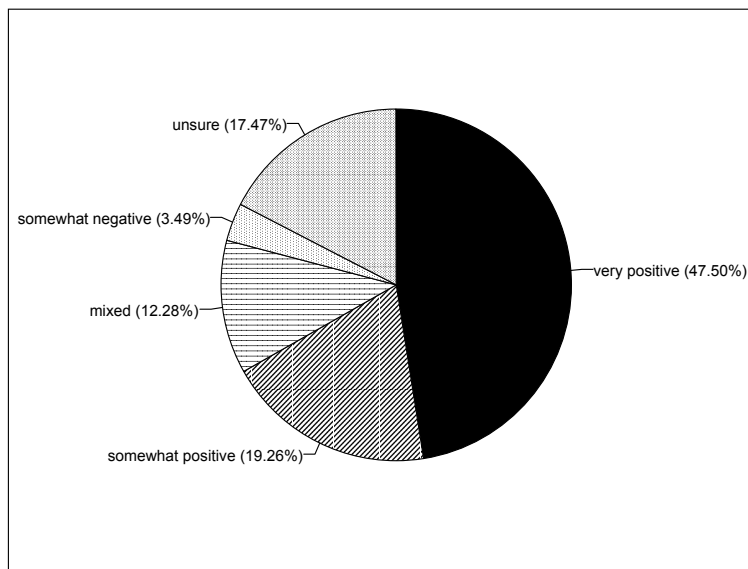
## Satisfaction of the Families of ISLA Consumers

Overall satisfaction with ISLA. Family respondents were asked how satisfied they were with their family member's living situation overall. They were asked to respond as very satisfied, somewhat satisfied, somewhat dissatisfied, very dissatisfied or not sure/no opinion. Forty-eight percent said they were very satisfied, and 37 percent said they were somewhat satisfied. No respondent indicated that they were very dissatisfied, although 7 percent said they were somewhat dissatisfied with ISLA overall. One in ten respondents indicated they were not sure or had no opinion. The level of satisfaction expressed by family respondents varied by the agency providing support services, as can be seen in the following figure.

Overall level of satisfaction expressed by families of consumers
supported by different agencies
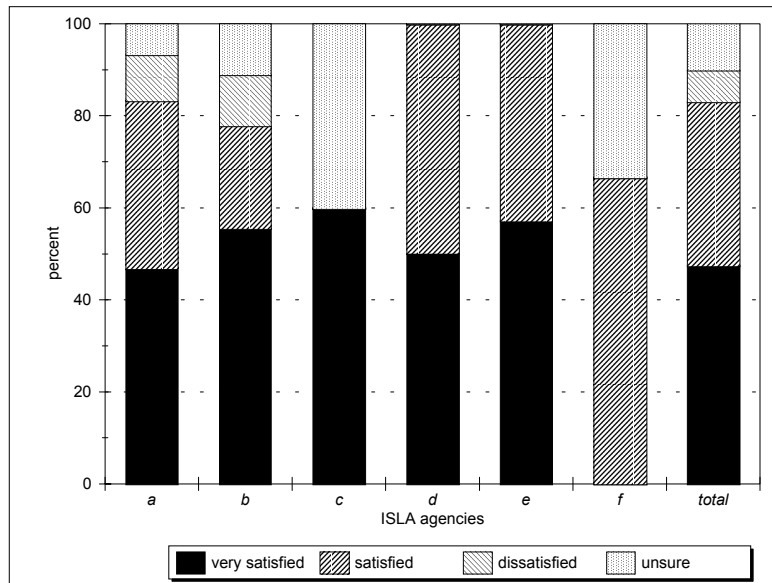
Satisfaction with Specific Aspects of Consumer's Living Situation. The following figure shows the level of satisfaction of family respondents to certain physical characteristics of their family member's current living situation. As can be seen, a majority of respondents indicated they were <u>very satisfied</u> with each item with the exception of the security of the building where slightly under 50 percent felt this way. Highest levels of satisfaction were expressed regarding the general accessibility, suitability, and location of the residence. (Bars in this and subsequent graphs that do not reach 100 percent are due to the response "not sure/no opinion.")

Level of satisfaction expressed by families
with specific physical characteristics of current living arrangements


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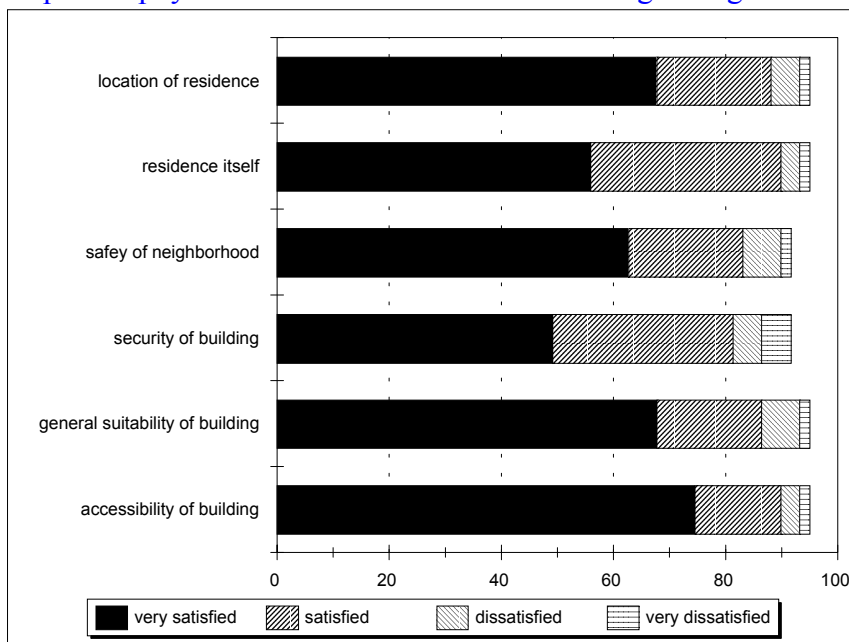
Satisfaction with Support Staff. The following figure shows the level of satisfaction expressed by families toward the support staff responsible for providing assistance to consumers. As can be seen, the staff received high marks from families on their friendliness toward the consumer and the consumer's family. The responses were somewhat less glowing with respect to the competence of the staff, the type of assistance they provided, and the amount of support time they gave consumers. About a third of the family respondents (32 percent) reported that they thought there were services or supports their son or daughter needed that she was not currently receiving. Nonetheless, that the issues of type and amount of support were evaluated as positively as they were, while indicating some hesitancy on the part of families, is, nonetheless, an indication of how far this approach to residential services has come in a relatively small number of years. It was not that long ago that research was finding great resistance on the part of many families to the concept of independent supported living, or, for that matter, to any type of non-congregate living arrangement.

Satisfaction of families with ISLA support staff
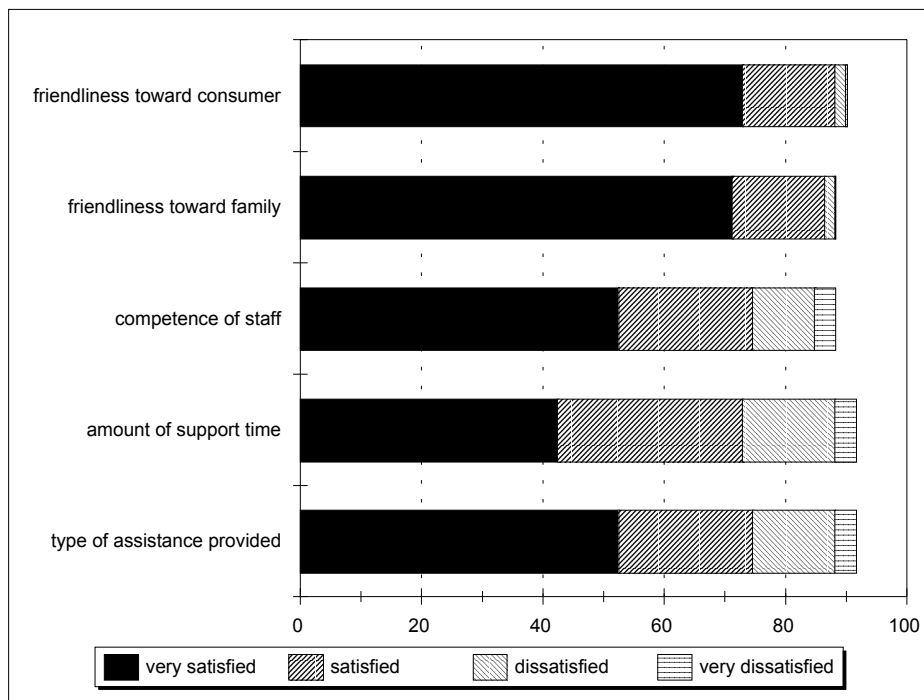
Satisfaction with Quality of Life and Related Issues. The following figure shows the relative satisfaction of families with a set of issues related to the quality of life of consumers as well as issues central to a successful independent living program. These include indicators of relative social integration or community inclusion and opportunities for the consumer to have relevant, functional control over his/her life. Overall the level of satisfaction with these issues was lower among family members than those reported previously. About a third (32 percent) expressed dissatisfaction with the opportunities their children had to meet people and make friends. Nor were family respondents overly sanguine about the opportunities available for their son or daughter to be a part of his or her neighborhood community. Issues related to opportunities to pursue activities of choice did not fair quite as poorly, with fewer expressing dissatisfaction with participants' abilities to pursue their own interests and to engage in recreational and social activities they enjoyed.

Satisfaction with social inclusion and opportunities to pursue interests
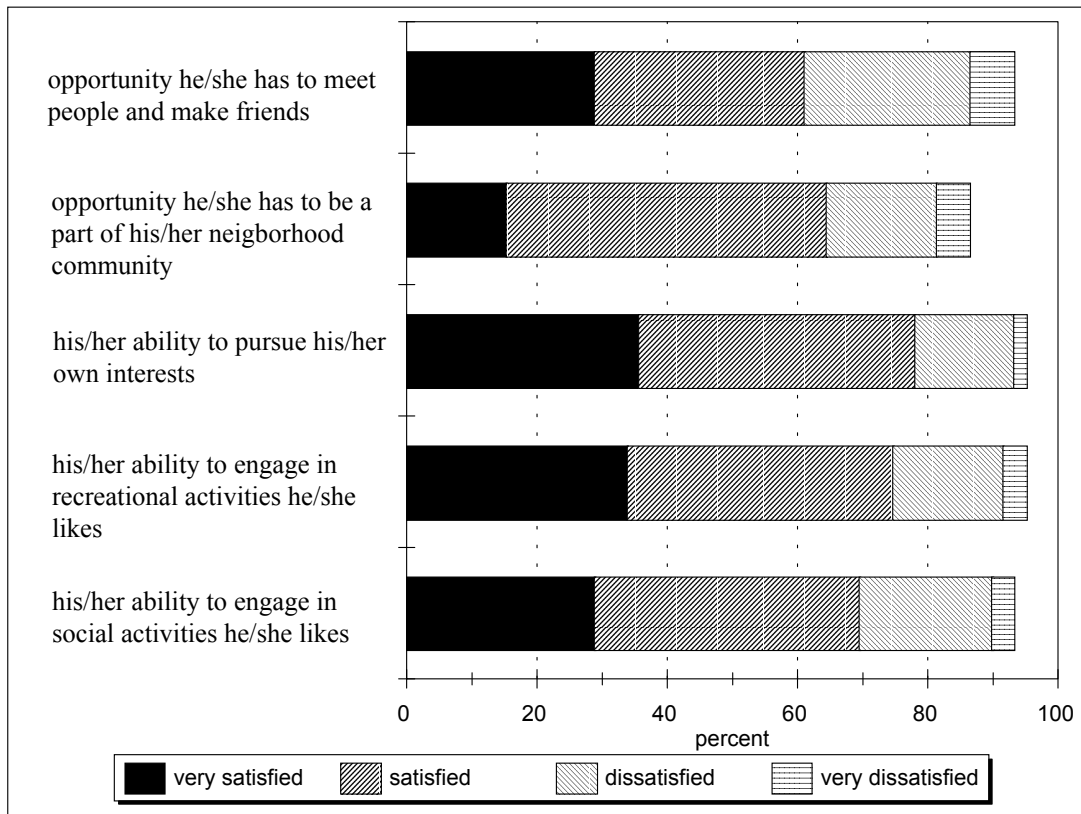
When asked their assessment of the overall quality of life their family members had, 8 out of 10 (81 percent) answered positively, with 41 percent reporting they were very satisfied. Overall the families of consumers served by most agencies expressed satisfaction on the quality of life question. There was considerable variation, however, in family responses by agency.

Satisfaction with Planning Goals. Families were asked to assess the way independent living goals and outcomes were established; essentially this is a question about the person-centered planning process, a process where family members often play an important role. Over 80 percent of the respondents reported that they were satisfied or very satisfied with this process (see Figure 5.9). But as in the case of quality of life, considerable variation was found in the views of respondents whose children were supported by different agencies.

Activities, Services and Natural Supports

Activities. In the interviews we asked consumers about the daily activities they engaged in. Did they cook their own meals, wash their clothes, pay their own bills, buy their own clothes? The figure below shows a list of everyday activities and the percentage of interviewees who said they did these things for themselves. The percentages are quite high: 97 percent said they bought their own food; 95 percent said they kept track of their own money; 93 percent said they washed their own clothes and cooked their own meals; 91 percent said they cleaned their apartment and paid their bills; and 84 percent said they bought their own clothes.

Everyday activities consumers said they did
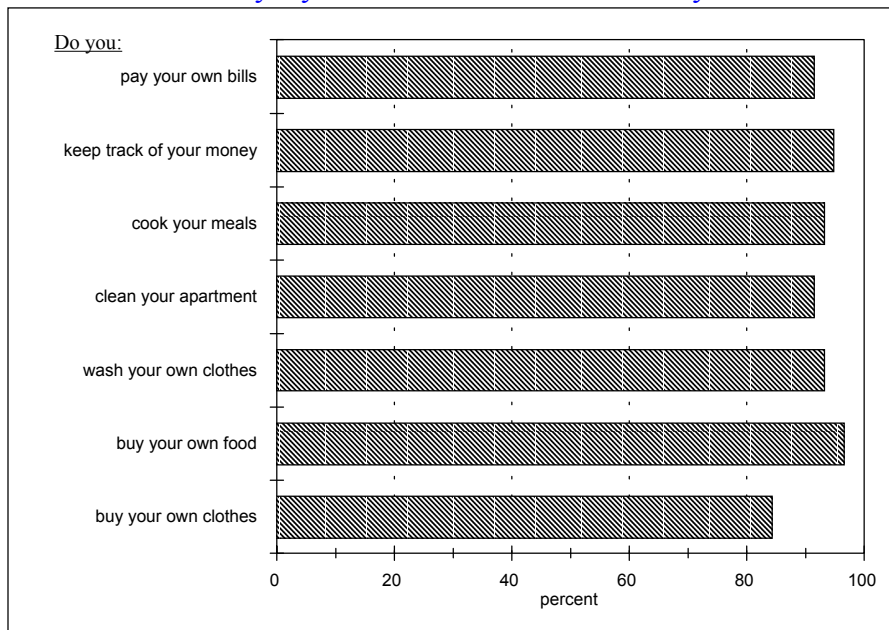
We further asked consumers who, if anyone, helped them do these things. A summary of their responses can be seen in the next figure.

## Source of assistance for everyday activities according to consumers
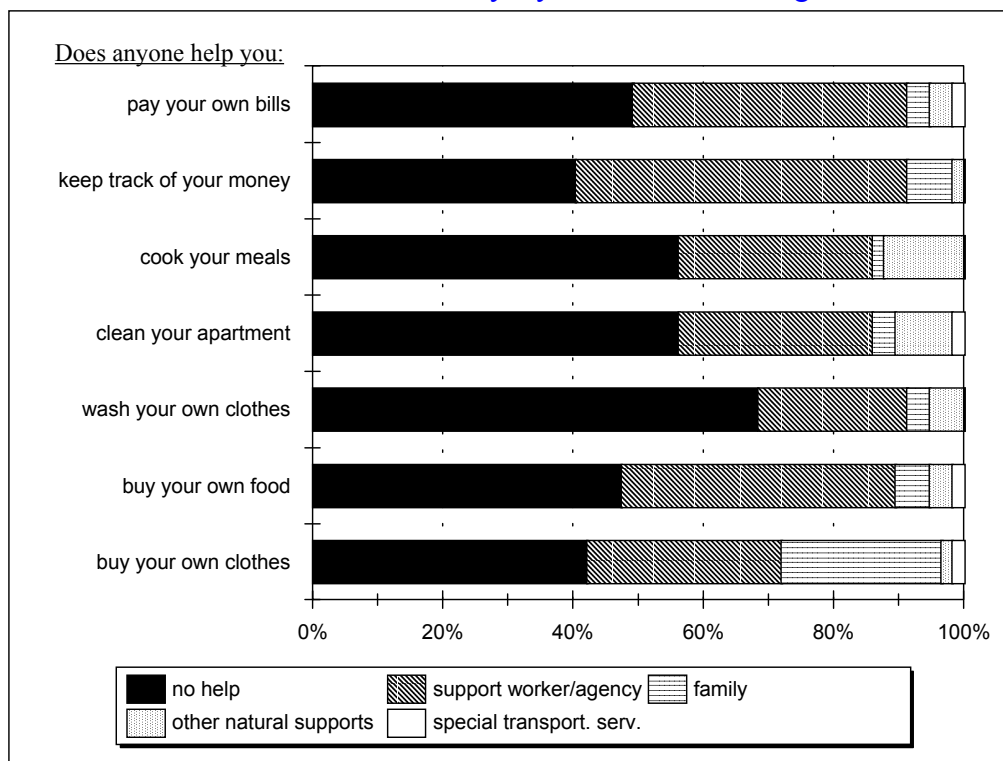
Many consumers indicated they engaged in these activities without assistance; 40 percent or more said this about each of the activities listed. Somewhat fewer consumers said that ISLA support professionals either helped them do these things or did them for the consumer. Workers

frequently assisted with financial matters and food purchases. Family members often helped them buy their clothes. Other natural supports were not utilized very frequently; when they were they usually involved the consumers' roommates, boyfriends, and girlfriends. Transportation services like Call-a-Ride were sometimes used by consumers when they went shopping.

We expressly asked consumers about their mode of transportation when engaging in certain activities, like going to work, to the store, to recreational and social activities, and when they did other things. Their responses can be seen in the following figure.

How consumers said they got to various activities or functions
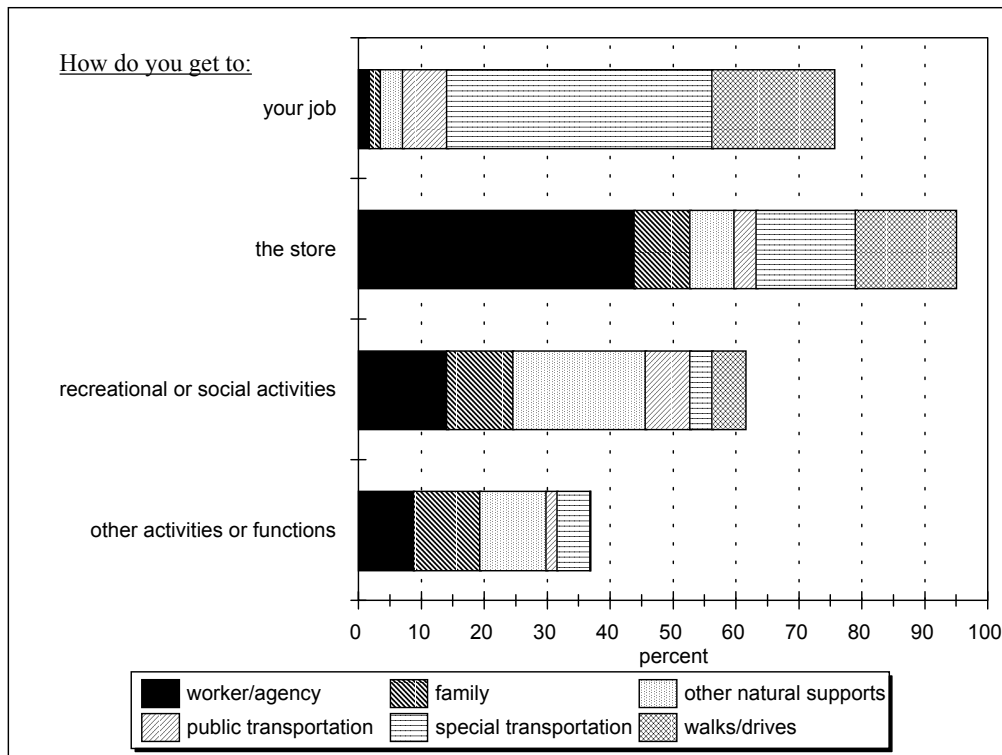
Special transportation services were the most common way consumers got to their job, followed by simply walking or, in one case, driving himself. Assistance from the ISLA support agency was the most common way consumers got to clothing and grocery stores. Natural supports outside the family were most often utilized when consumers were involved in recreational and social activities. Church groups, neighbors, and other friends helped consumers to these functions.

It will be noticed that the bars in this figure do not reach to 100 percent. This is because not all consumers interviewed had a job and a small number did not shop for themselves. The larger gaps in the bars relating to recreational, social and other activities indicate that many consumers may not be engaging in these types of functions with much regularity.

Services. We asked agency staff about the source of the various services consumers received. Among other things, we were interested in learning about any sources they considered to be a natural support. The following figure shows how frequently support professionals indicated the presence of some natural support,[1] including assistance from the consumer's family, when a

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[1] While we allowed great latitude in accepting workers' judgments of what constituted a natural support, we discounted any funded service that targeted persons with developmental disabilities.

specific service was provided. Overall, 22 percent of the non-ISLA services reportedly provided to consumers involved some form of natural support, according to agency workers. There was considerable variation in the role natural supports played in the provision of services from one ISLA support agency to another.

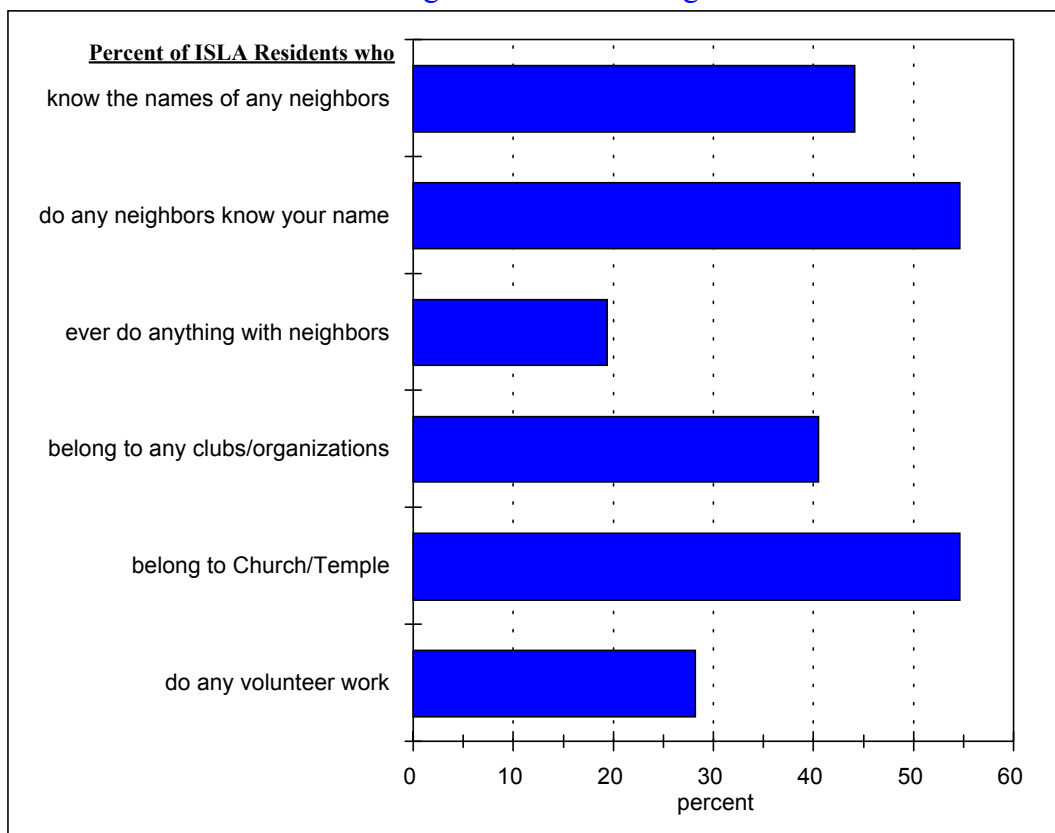**Natural supports as part of service provision**
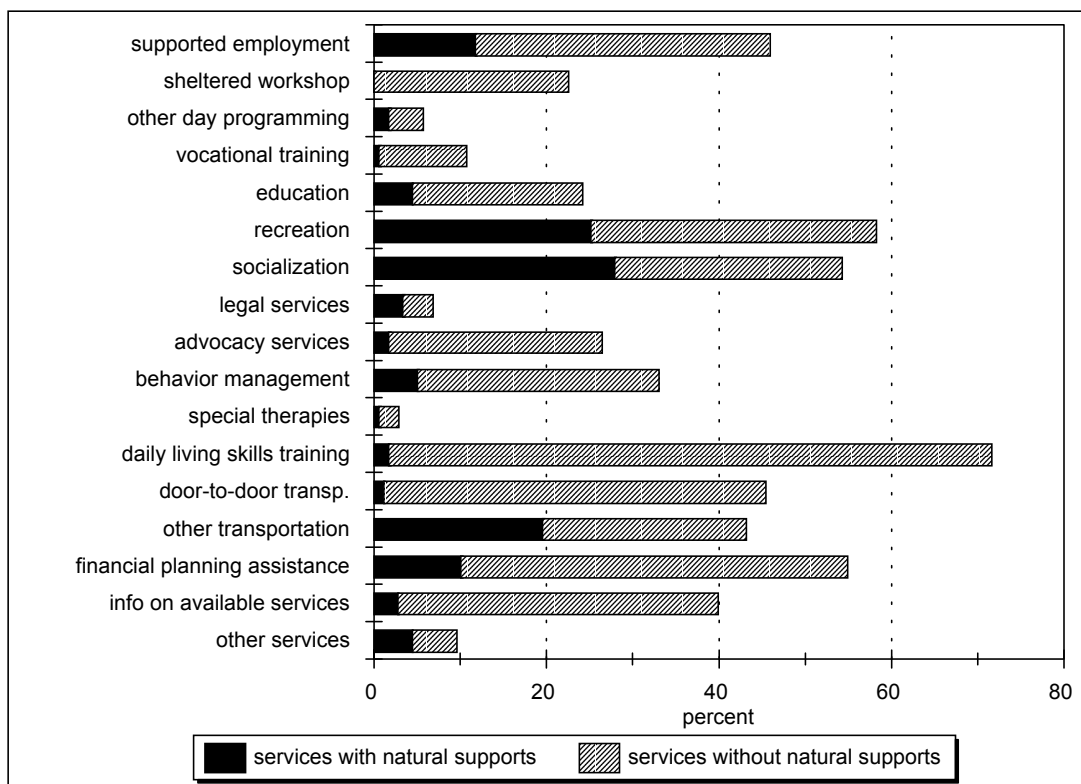
We asked the support professionals whether they had been successful in developing and utilizing any other natural supports around other activities than those listed in this figure. They reported that there were no other natural supports involved in the lives of 71 percent of the consumers but that there were one or more for the other 29 percent. Workers from agencies in which natural supports played a larger role reported more success in developing these additional supports.

Social Integration

There may be no better indicator of quality of life than social integration, the extent to which ISLA consumers have a social life and are a part of the life of their communities.   In both the consumer interviews and in our survey of support professionals we asked a series of questions meant to provide indications of the level of community integration experienced by ISLA residents.

We asked consumers whether they knew the names of any of their neighbors, whether any neighbors knew their names, and whether they ever did anything with their neighbors. We also asked them if they belonged to any clubs or organizations or to a church or temple, or whether they did any volunteer work. Their answers to these questions are summarized in the following figure. Overall, the degree of social integration indicated by their responses to these questions was relatively modest.

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Percent of consumers who answered "yes" to questions indicating relative social integration

Percent of ISLA Residents who

- know the names of any neighbors
- do any neighbors know your name
- ever do anything with neighbors
- belong to any clubs/organizations
- belong to Church/Temple
- do any volunteer work

percent (x-axis: 0, 10, 20, 30, 40, 50, 60)

We asked workers similar questions about the consumers they supported as well as other questions intended to elicit information about the consumer's relative social integration. We were interested in learning whether consumers were involved in any educational or vocational training activities in a natural setting (that is, not one intended only for persons with developmental disabilities), whether they engaged in recreational or other social activities with persons without disabilities on a weekly or monthly basis, whether consumers bought their own food and clothing, and whether consumers had any close friends without disabilities. Their responses are summarized in the next figure. As can be seen, more consumers bought their own food and clothing than engaged in any of the other "social" activities on this list. While these activities are not the same as belonging to a church or club or engaging in leisure pastimes with friends, shopping at a minimum occurs in a social context and involves natural interactions with members of the community. It might be noticed, comparing the responses of workers on these two items with what consumers told us during interviews, that the reports of both groups were quite similar. The next highest positive response came from workers on the question of consumers knowing their neighbors' names. Here, workers were much more likely to answer yes than were the consumers themselves. This was also the case with the issue of engaging in social activities with neighbors; consumers themselves were less likely to say they had than were their workers.

Responses of support professionals about social activities of consumers
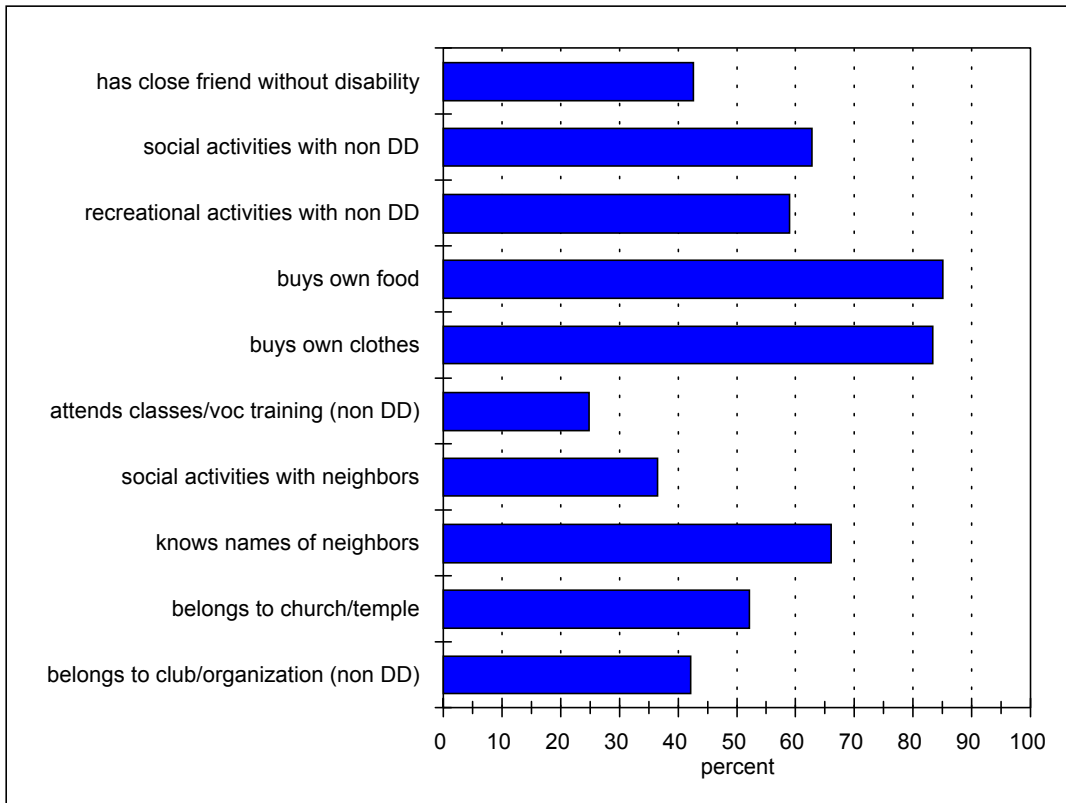
Responses to these items were aggregated to get an overall index of integration. There were twelve items on the survey form (the questions about engaging in recreational and social activities were asked both in terms of "at least once a month" and "at least once a week"). This produced a scale that ran from "0" for consumers for whom none of these were the case, to "12" for consumers for whom all were true. Mean scores were obtained for consumers of the seven agencies to determine how much variation existed. The next figure shows these mean scores. The overall mean was just over 6. Interestingly, the agency with the highest mean score on this scale also received the most positive responses from family members and placed more emphasis than most on integrating natural supports into the provision of services.

Finally, it needs to be explicitly added here that the work environment is another indication of relative social integration. Consumers with jobs in natural settings, as opposed to consumers who continue to work in sheltered workshops, must be considered significantly more socially integrated. Because their jobs are in natural social environments, social encounters and patterns of interaction in these settings are identical in kind to the typical experience of workers without disabilities. By comparison, sheltered workshops can be described as "artificial" social environments, in that they have been constructed specifically for and are occupied predominantly by persons with disabilities. Moreover, work in natural settings is more consistent with the philosophy and goals of an independent supported living approach to residential services that stresses normalization and community integration. Fifty-six percent of the ISLA consumers worked in a natural setting (46 percent with agency support), while 22 percent worked in sheltered workshops. (It should be noted that some ISLA managers interviewed described sheltered workshops as "more appropriate for some consumers.")

Mean number of items checked on social integration scale
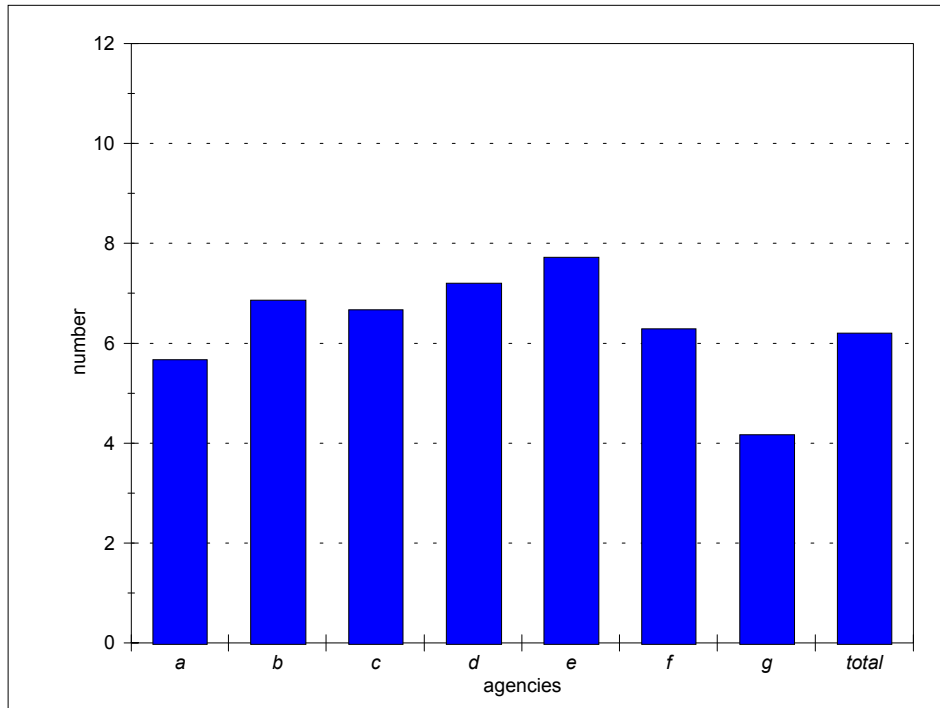
Friends. We asked consumers about their close friends. We attempted to elicit as many as four people considered as friends. Only a few consumers enumerated this many, although a number of interviewees described collectives, such as church groups and bowling teams, or would simply state that they had "many" friends. The modal response was two. About one person in ten could not name a friend or simply said he or she had no close friends. Roommates were identified as close frients by 18 percent of consumers, coworkers were named by 16 percent of consumers, boyfriend/girfriend by 13 percen, agency professional by 13 percent, neighbors by 11 percent, another person with a disability by 6 percent.

**Having Fun.** We took as an important indicator of relative social integration the answer to the question: What do you do for fun? We asked consumers this during the interview primarily to learn with whom they engaged in social activities and how often. In the interview, we attempted to elicit as many as three things the consumer would say he or she liked to do. Sixty percent gave us three different responses to the question, 29 percent gave two responses, and 11 percent mentioned only one thing. More often than not (60 percent of the time), consumers said they engaged in the activities they mentioned one or more times a week. Some items (30 percent) were spoken of in terms of months between doing and others (10 percent) in terms of years.

About 10 percent included watching TV as a favorite activity, by themselves or with others. Some others spoke of things they did by themselves (shopping, playing games on a computer, art activities, etc.), but most talked about doing things with others. Some described activities that people typically do with a companion, but which they did by themselves for lack of someone to do them with.

The next figure shows the percentage of consumers who mentioned specific numbers of people with whom they engaged in activities they enjoyed doing. The chart shows that 25 percent mentioned one person in the course of talking about things they enjoyed doing. Twenty percent described two individuals with whom they did the things they enjoyed, 16 percent mentioned three persons, and 11 percent mentioned four. A small number of consumers talked about

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doing things with five or six other people. Importantly, however, 22 percent of the consumers we spoke with, 1 out 5, did not name anybody with whom they engaged in activities that they liked to do. The table that follows gives the percentage of times consumers mentioned specific types of other people with whom they engaged in fun activities. As in the previous table, specific categories except for "other" should be considered as including minimum percentages only. (It should not be thought, for instance, that only 2 percent of these persons are coworkers.) However, it cannot go unnoticed how often consumers described agency workers, roommates, or other persons with disabilities as the people with whom they engaged in activities they most enjoy. It is not that these are not suitable or worthy companions, but that this is a relative indicator of incomplete social integration.

Percentage of consumers who mentioned specific numbers
of persons they did "fun" activities with
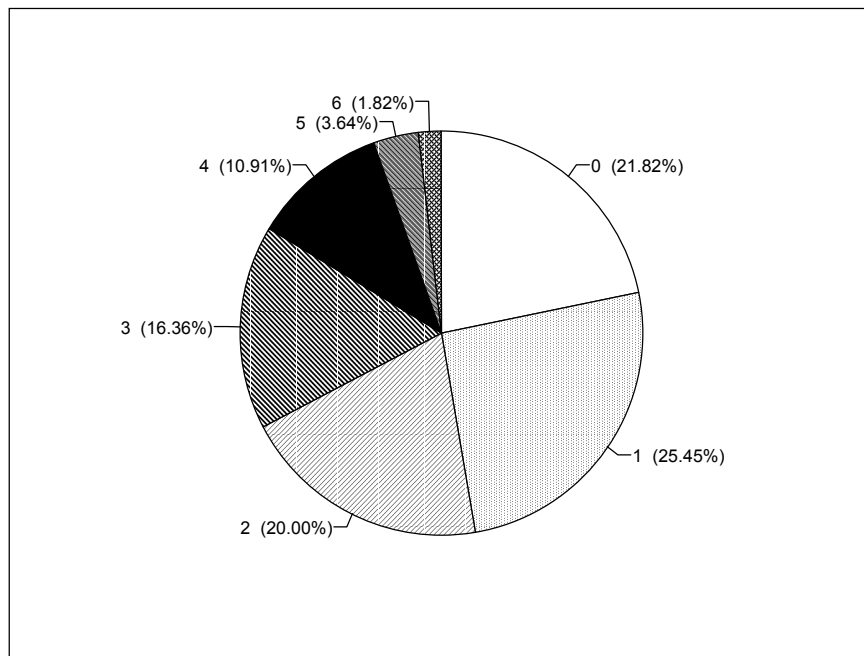
Percent of time specific others were mentioned as "fun" companions

	%
agency worker	30.9
roommate	20.0
co-worker	1.8
person with disability	30.9
neighbor	1.8
family	18.2
boyfriend/girlfriend	7.3
other	45.5

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Person-Centered Planning

Our examination of the person-centered planning process involved four things: asking consumers about the process in our interviews with them; asking workers about it in our background and consumer-specific surveys; discussing the process in our interviews with program managers and agency administrators; and reviewing a sample set of written plans.

Consumer Views. We asked consumers if they were familiar with their person-centered plan and whether they knew what it was and what was in it. We described the plan in the same terms the particular agency used: Independent Living Plan, Personal Plan, Habilitation Plan, etc. Just over half (56 percent) seemed to have a clear understanding of what we were asking them about. One-fourth (26 percent) said they were very familiar with it, 30 percent said they were somewhat familiar with it. Nine percent were unsure and just over one-third (35 percent) said they did not know anything about it. We asked consumers who decided what was written in their plan and what their goals were. Their answers can be seen in the following table.

Who decides what gets written in person-centered plans according to consumers

	%
consumer	21.1
support person	14.0
consumer & support person	7.0
others	3.5
unsure	54.4

Consumers were asked if they were satisfied with their person-centered plan and the goals and outcomes established in it. The majority (58 percent), as can be expected given the level of familiarity already shown, replied that they were unsure. Of the rest, 41 percent said they were satisfied with their plan, most being very satisfied. None of the consumers interviewed expressed dissatisfaction with it. We asked consumers if they got help achieving their goals, the things they wanted to do? Their responses can be seen in the following table.

Percentage of consumer who reported they received help achieving their goals

	%
yes, a lot	47.2
yes, some	26.5
neutral	0.0
no	7.0
unsure	19.3

Participants in the Planning Process. We asked consumers if they could invite the people they wanted to participate in the planning process. Forty-six percent answered yes, 2 percent answered no, and the rest (52 percent) said they were unsure. We asked support professionals who was present at the last comprehensive update of each consumer's person-centered plan. In virtually all cases, the consumer himself or herself was involved along with one or more representatives of the agency providing support. Frequently, in some agencies, a staff coordinator or supervisor participated along with the direct support worker. Two-thirds of the planning

sessions included someone from the consumer's family. And, nearly as frequently, the consumer's case manager from the Division of MR/DD's Regional Center participated. In about one in four planning sessions, there was someone from another agency which was involved in providing other services to the consumer. Roommates sometimes attended meetings, along with friends and neighbors of the consumers. Various "other" participants (such as therapists, instructors, tutors, attendants, etc.) occasionally attended the planning sessions. The mean number of participants across all consumers and agencies was 4.8. The following figure shows the percentage of times particular individuals participated in these planning sessions according to support workers.

Percent of planning meetings with specific types of participants
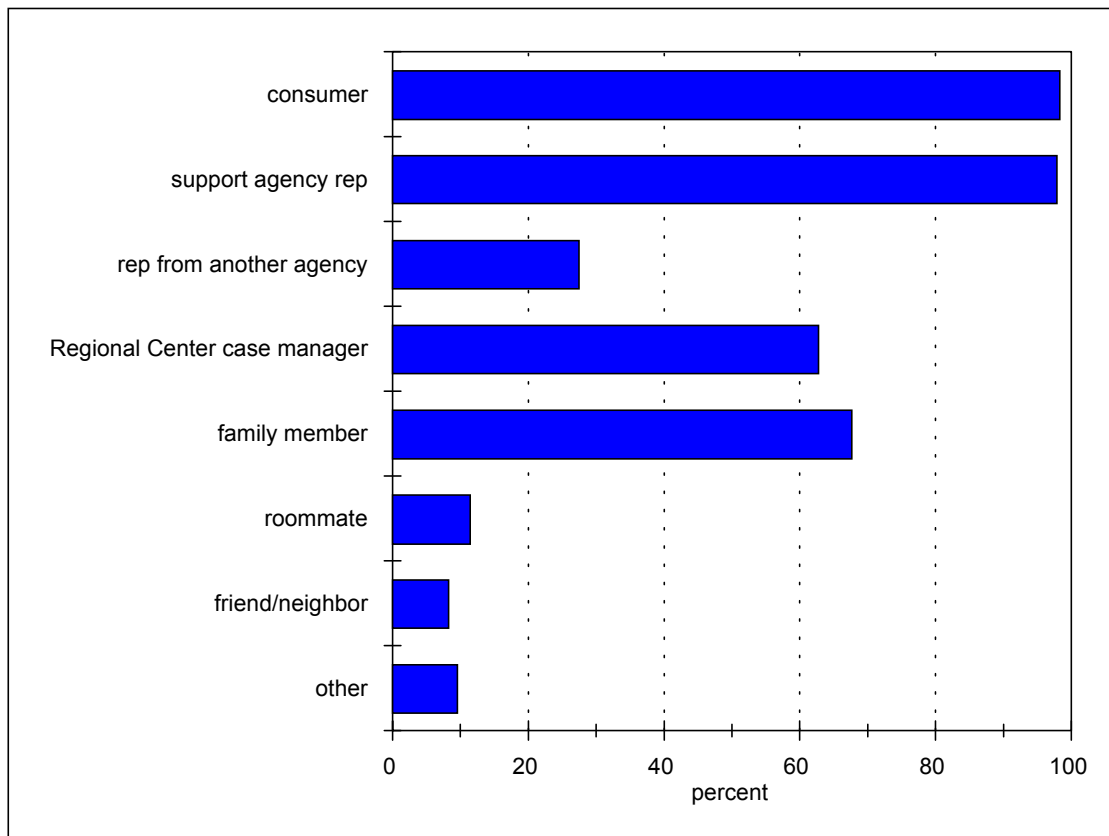
We asked workers how actively involved different participants in planning sessions were. They were asked to indicate this on a four-point scale on which 1 meant very little or not involved, 2 meant a little involved, 3 meant somewhat involved, and 4 meant very involved. Their mean responses for different types of participants can be seen in the next figure. As the figure shows, workers saw family participants and consumers themselves as the most actively involved in the sessions, followed closely by themselves and Regional Center case managers, and then by representatives from other agencies. Workers also indicated that those grouped under the "other" category tended, when they were present, to be as involved as agency representatives. Persons such as roommates and friends tended to be much less involved in the planning sessions and may have been present primarily to provide moral support.

Level of involvement in person-centered planning meetings according to workers
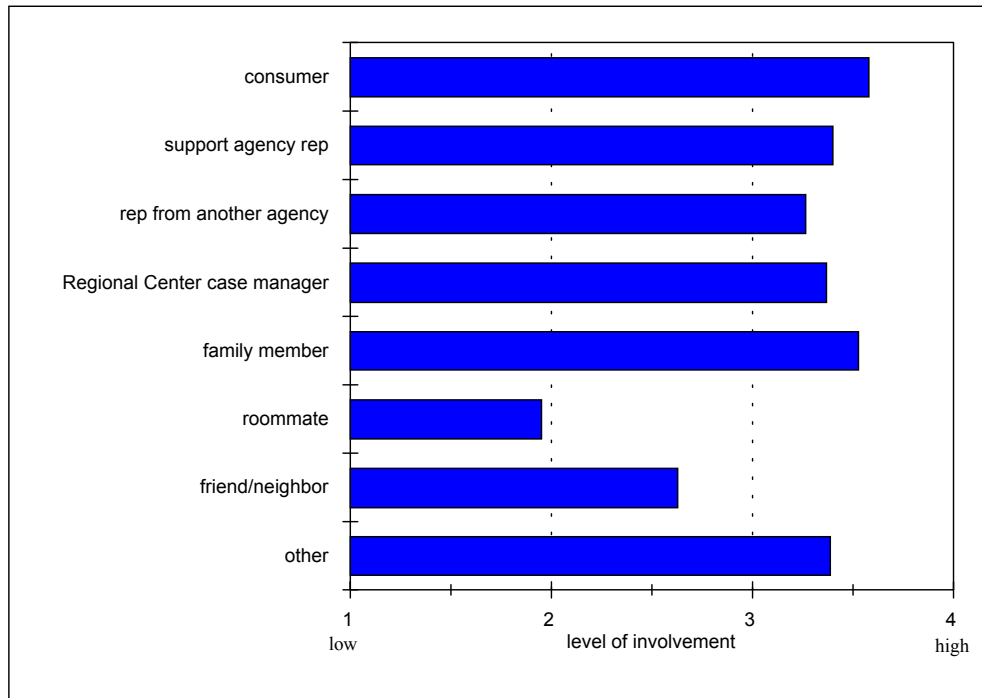
We asked support professionals how many meetings there had been with the consumer and his or her representatives within the last 12 months to review, update, or completely redo the personal plan. The average number across all consumers and agencies was about 1.96. The mean number of meetings ranged from 1.25 to 2.19 across the various agencies.

Consumer Influence Over Planning. We asked support professionals how much influence each of the consumers they supported had over specific ISLA elements. These included: the independent living goals in the consumer's plan; the type of assistance provided by the agency; the location of the residence (the part of town); the specific residence (the apartment or house); choice of roommate; and choice of support staff. The next table shows the relative control consumers were seen by workers as having over these matters. Overall, as can be seen, workers indicated that consumers had the most influence over choice of roommate, followed by the general location of their residence. Workers reported that over half of the consumers had complete control over these matters and that a large majority had considerable influence at a minimum.

**Amount of influence consumers have over ISLA elements
according to support professionals (in percentages)**

	independent living goals	type of support received	location of residence	specific residence	choice of roommate	choice of support staff
none	0.0	1.2	3.0	4.2	4.7	8.9
some	11.9	15.4	10.1	11.9	11.7	33.9
a lot	42.9	50.9	33.1	35.1	25.8	29.2
complete	45.2	32.5	53.8	48.8	57.8	28.0
	100.0	100.0	100.0	100.0	100.0	100.0

Consumer influence on the specific residence they would live in and on their independent living goals was also high as viewed by workers. Control over the type of support they would receive was somewhat less, according to workers, although still high—over 80 percent of consumers were seen as having a lot of influence or complete influence over this. The area over which consumers exerted least control was choice of support staff. According to workers 9 percent of consumers had no influence over this at all and another third had some but not a lot of influence on it. On the other hand, workers indicated that nearly 3 in 10 had complete control over who their support person would be and another 3 in 10 had a lot of influence over it.

By turning responses into scale scores (where 1 stands for no influence and 4 stands for complete influence) we can more easily see the degree of influence consumers had according to workers:

Degree of influence of consumers over ISLA elements
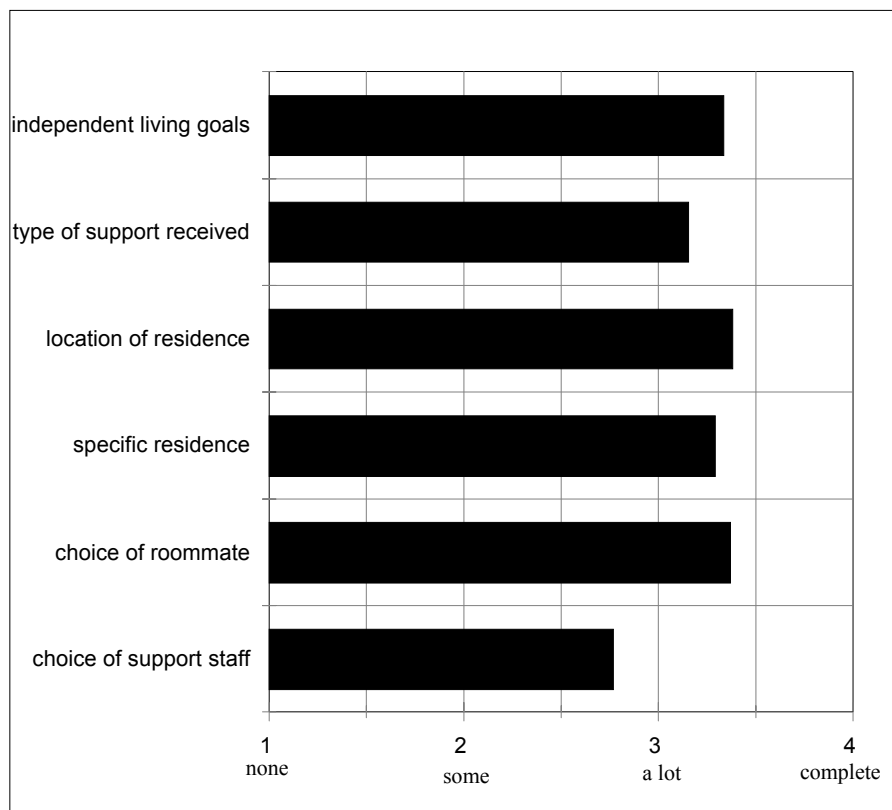
Agency Planning Tools. In our background survey of support professionals, we asked about the tools or formal procedures made available or required by their agency to assist or guide their work. We presented them with a list of activities that ISLA support professionals are regularly called upon to do and asked if their agency provided them with any of the following to help them: a form, instrument, or tool; written guidelines or procedures; formal unwritten guidelines; or informal guidelines. The ISLA-related activities we asked them about were the following: developing a person-centered plan, assessing progress in achieving outcomes/goals in the plan, reviewing and updating plans, assessing consumers' social skills, assessing consumers' daily living skills, assessing consumers' level of community or social integration/inclusion, and ensuring the quality of ISLA support and services provided.

Support professionals with two of the agencies indicated that their organizations made available or required a form or instrument for each of these activities, although workers from one were more unanimous in their view of this, and some other workers from the second agency reported having something more like written guidelines than formal instruments. Workers with a third agency were split in their responses about whether their agency provided them with an instrument or tools for these types of activities or instead had issued written guidelines. Workers from a fourth agency varied in their responses considerably but their modal responses were that they had informal guidelines for developing person-centered plans and instruments or written guidelines for the other activities. Workers with a fifth agency indicated they were given informal guidelines for most of these activities, with written guidelines for assessing social skills and quality control. At a sixth agency, workers similarly indicated the availability of unwritten guidelines for person-centered planning and formal unwritten guidelines for most of the other activities, except assessing social skills, for which a tool was utilized. At the seventh agency, workers indicated that written guidelines were in place for most activities, including developing a person-centered plan, with unwritten guidelines for reviewing and updating plans and informal guidelines for quality control.

One agency had adopted a comprehensive set of tools for workers to use in guiding consumers' ISLA programs. These included tools to 1) facilitate increased social integration, 2) maximize use of natural supports and develop a support network, and 3) assess needs and competencies of consumers in evaluating current plans and preparing for upcoming planning sessions.

Plan Reviews. We reviewed the person-centered plans of 49 consumers in the administrative offices of the ISLA agencies. The plans were selected randomly from a list of consumers served by each agency. We have no reason to believe this sample of plans is not representative.

We reviewed plans for evidence of person-centered planning and consumer choice, the utilization of natural supports, and the extent to which the plans were outcome driven. We also looked for evidence that the consumer had been aided in making informed choices when specific outcomes or goals were targeted. In addition, our review included an examination of basic elements of planning—who, what, where, when, why, and how. The following is a list of factors we attended to in our reviews:

- who was involved in the planning process
- the specification of responsibilities (who would do what)
- what specific life areas were covered
- the extent to which the plans sought to promote the independence, productivity, and social integration of the consumer
- where activities and strategies were to be carried out
- the timeframes established for activities and goal achievement
- the rationale and motivation behind the goals
- specification of strategies (how the plan was to be enacted and how the goal was to be achieved)
- the inclusion of benchmarks (how progress toward the goals/outcomes was to be measured)
- the nature of pre-planning assessment and other preparations prior to planning conferences
- how the well-being of the consumer was being considered and protected
- the enactability of the plans

Overall, the plans reviewed varied significantly from one agency to another and, in some cases, differed substantially in form from one worker to another within agencies. The variance involved overall quality as well as in degree of comprehensiveness, specificity, and general enactability. Nearly all the plans reviewed showed evidence of considerable sensitivity to the issue of consumer choice.

The matrix on the following page summarizes the results of our review. It shows whether and the extent to which specific plan elements or items were found to be addressed or included in the specific plans reviewed. In the matrix, "all" means each plan reviewed contained this item, "none" means that none of them did (or at least the item was interpreted as not being included), "most" means that nearly all contained an item (such as 4 of 5), "some" means something less than this, and "unclear" means we could not ascertain whether the issue was addressed or not. For a few cases we have included footnotes that further elaborate on what was found. (It should be noted that the order in which the agencies are listed in this matrix has nothing to do with how they are listed in any other table or figure.)

All plans contained essays or lists of statements describing the consumer and his or her likes, dislikes, needs, and desires. Some contained concrete information about the context of the consumer's life—information about family, friends, activities, and other sources of services and support; others did not.

Individual goals listed in plans often included direct indications that these were outcomes desired by the consumer. In some plans there was a clear link between the likes and dislikes of consumers included in the profile section and the specific goals included in the outcome section. In other plans such linkage was either unclear or simply not present.

In most plans it was clear that most of the goals represented the expressed interest of the consumer, although often goals were written in a way in which this could not be determined or which seemed to represent the views of others about what was deemed in the best interest of the consumer. When these latter types of goals predominated, plans looked less like person-centered plans and more like habilitation plans, in which maintenance of the consumer's current situation took precedence over development of increased independence (or greater social integration or economic productivity), and in which outcomes related to health and safety issues were often the most common.

While we considered consistency in form and type of content important characteristics of an agency's plans, too much similarity in outcome statements in some cases caused us to wonder whether consumer individuality was adequately informing the planning process.

Some goals included in plans were clear and coherent statements that could direct behavior of the consumer or a support person. The following is a goal written as an outcome to be achieved with steps that were detailed, logical and enactable:

"Outcome: obtaining a credit card. (The consumer) will:
step 1. identify which stores accept what credit cards
step 2. decide what type of card (if any) that he will apply for
step 3. find out if his credit card can be added to his 'pay by phone' list of bills
step 4. decide where he will keep his credit card when not in use."

On the other hand many goals were written as very general statements or phrases and did not include actions steps that could either inform specific behavior or yield to measurement—for example, *"(consumer) participates in leisure activities of her choice;" "(consumer) will improve social skills and enhance relationships;" "(consumer) will receive supported living services*

Plan Review Matrix

plan elements	agency	agency	agency	agency	agency	agency	agency
background info on consumers	all	all	all	all	all	all	all
participants in planning	some	some	some	some	all	all	all
other services	some	some	none	some	all	all	all
other		some		some	all	all	all
description of person/history	all	all	all	most	all	all	all
consumer wants/desires/dreams	all	all	all	all	all	all	all
consumer needs	all	all	all	all	all	all	all
consumer choice	all	all	some	fn[1]	all	all	all
assurance of informed choices	none	none	none	none	unclear	unclear	all
well-being addressed/assured	unclear	unclear	unclear	all	all	unclear	all
natural supports indicated (other than family)	none	none	none	none	some	most	all
who does what/who is responsible	none	none	none	some	all	all	all
consistent life areas (goals) for all consumers	none	none	none	none	fn[2]	fn[3]	all
goals/outcomes that increase independence	all	some	none	some	all	all	all
goals that increase productivity	fn[4]	none	fn4	none	most	most	all
goals increase social integration	fn4	none	fn4	none	all	most	all
goals focus on management of daily life	all	all	fn4	all	all	all	all
indicates where things happen	none	none	none	some	all	some	all
time frame for goals	none	none	none	none	all	some	all
strategies and activities specified	none	none	none	none	all	some	all
inclusion of benchmarks or ways of marking progress	none	none	none	some	fn[5]	none	some
quality assurance procedures	none	none	none	some	none	some	all
pre-entry assessment done	all	all	some	some	unclear	all	all
regular updates of assessment	none	some	none	unclear	unclear	some	all
outcomes written as enactable statements	none	none	none	some	all	all	all
goals clear and specific	some	some	some	some	all	most	all

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[1] It is unclear how objectives are related to consumer's dreams/wants/likes. No direct indication consumers chose objectives.
[2] Consistency in description of the supports in place and needed. Goals are unique to consumer but reflect needs and wants.
[3] Goals listed are numerous and pertain to consistent areas, but specific areas included vary across consumers.
[4] Does not apply because goal as written is not enactable.
[5] Nothing in addition to steps/strategies, although these could be used.

from (ISLA agency);" "(ISLA agency) will ensure that (the consumer) receives quality commu-nity support and job services;" "(the consumer's biggest challenge at home is keeping her apartment clean. She tends to rely on her attendants to do things she is capable of doing for her-self". Goal statements such as these cannot be enacted, although they may be useful in guiding the general interaction between consumer and support professional.

It was unclear in most cases whether there had been adequate assurances that the choices made by consumers were sufficiently informed or whether the well-being of the consumer was considered as a condition of the planning process. One ISLA manager told us that all considera-tions were secondary to consumer choice, including consumer wellbeing, overall independence and productivity, and social inclusion. However, another said it was important to distinguish be-tween person-centeredness and personal control or direction: "The program cannot be shaped simply by what the consumer says he wants or likes at a particular moment. It is not our job to buy the consumer pizza because that's what he wants, but to help establish some system for him to be able to satisfy his food desires even when the support professional is not present, which is going to be most of the time." The role of agencies in this view is not to provide specific support so much as to help consumers become more independent of such support through the develop-ment of support networks. One person interviewed noted that some of the dissatisfaction on the part of parents arises out confusion with this—that the support person is not seeing to specific things in the consumer's life, solving specific problems. (At the same time it should be said that some concerns expressed by family members arise out of very legitimate concerns: problems that result from staff turnover, or from staff who have not been fully trained—who, for example, may lack a full understanding of the concept of natural supports or not know how to develop them.)

While the consumer plans of some agencies addressed the involvement of natural sup-ports, the plans of most did not. Plans varied on whether they indicated who would be responsi-ble for specific actions to ensure a goal was achieved or an outcome attained.

Only one agency addressed outcomes over a consistent schema for all consumers. And only one included goals that touched on the consumer's independence, productivity, and social integration for every consumer, although two others did so in most instances. Many goals seemed to have as their objective not increasing independence so much as the maintenance or management of the present situation.

The plans reviewed in some of the agencies included time frames indicating when activi-ties were to be carried out or when outcomes were to be attained, and some included the specifi-cation of where activities were to be carried out. Some included strategies for achieving goals or described actions to be taken to ensure an outcome. Few included benchmarks helpful for moni-toring or marking progress. Most agencies have initial assessment processes at program entry, but only a few have clear, structured, routinized assessments after ISLA has begun. Only one agency's plans contained information on the attainment of goals previously established. In most cases, it was not possible to evaluate goal attainment without daily or weekly log notes of sup-port professionals. Some agencies are clearly concerned about quality assurance and have taken steps to monitor and ensure it.

The person-centered plans of one agency in particular were considered exemplary. They were consistent in form across consumers and contained the following areas:
1. a consumer data sheet,
2. a list of natural supports (indicating the relationship to the consumer and the specific sup-ports provided),
3. agencies currently providing programs and services,
4. a sociogram listing social linkages in four areas: community, family, friends, and paid supports,

5. a page listing likes, dislikes, and competencies from consumer's point of view,
6. a list of wants within a set of fixed categories (housing, employment, transportation, health and medical areas, social and leisure) and the supports needed to obtain them,
7. the strategic plan to attain personal goals—including specific goals, obstacles to goal attainment, strategic activities for overcoming obstacles, the person responsible for these activities, starting and ending dates, and a summary of progress in achieving the strategic activity.

Significant attention was paid to facilitating social networks for consumers, and a social and community inclusion protocol plan was utilized. A quality assurance system was instituted that could be a model for others. Consumer feedback was solicited in a systematic way. Tools had been developed, borrowed, and modified for staff to use in conducting detailed and comprehensive assessments of clients and their needs, interests, and competencies. A six-step problem-solving model in the person-centered planning process was utilized to assist consumers with identifying their goals and developing supports to reach them. The plans of this agency also typically contained an annual review of progress in achieving the prior year's outcomes.

Conclusions and Recommendations

The overall level of satisfaction among ISLA consumers with the Independent Supported Living Arrangements program administered by the Productive Living Board is high. They tend to like where they live, generally preferring it to their previous living arrangement, whether in their parent's home or in another situation. Nearly all consumers interviewed have a sense of place, feel secure in their residence, and look upon it as their home. Most see themselves having effective control over their homes and their lives.

Families of consumers likewise have an overall high level of satisfaction with the ISLA program, the support and assistance provided by vendor agencies and staff, and the program's administration. Although a third of the family respondents believe a greater amount of support and assistance is needed, their overall response is an indication of how far this approach to residential services has come—how much it has come to be understood, accepted and appreciated—in a relatively small number of years.

Agency administrators and program directors have a high respect and regard for the manner in which the ISLA program is administered by the PLB. These agency administrators share the underlying philosophy of the program as articulated by the PLB and reflected in the literature summarized in the introduction. The agencies appear to be built on strong organizational values--values consistent with this philosophy. Agency administrators tend to be reflective, open to new ideas and mutual learning, and accepting of the consumer-centered nature of the program. Some, in particular, struck us as very able managers. And consumers gave their highest marks to the professional support workers that assist them.

These findings are indicative of a program that is fundamentally sound and healthy, and responsive to the needs of participants.

At the same time, a minority of participants in the program are only minimally integrated into their communities and some appear to lead lives in relative social isolation. Utilization of natural supports outside of assistance from families is quite limited. And many consumers cannot depend upon their families because of the age of their parents or where they live, and others will not be able to count on their family's help indefinitely. Sheltered workshops are viewed by some staff as appropriate work situations for certain consumers on a more-or-less permanent basis, even though such employment may limit their community integration and potential productivity. ISLA staff tend to see Regional Center personnel as generally having an inadequate understanding of the program, leading, among other things, to inappropriate referrals. Importantly, person-

centered planning varies greatly in quality from agency to agency, as does staff training and the familiarity of staff with best practices in areas related to their work.

It is our judgment, based on this study and the knowledge we have of the literature and exemplary programs, that every person eligible for Regional Center and PLB funding needs an integrated whole life plan, a plan for today, next month and the rest of his or her life: a plan in which all central aspects of the consumer's life are addressed in a unified, consistent, comprehensive manner. This includes daily living activities as well as work, continuing education, interpersonal relations, social integration, community inclusion, transportation, financial planning, recreation and leisure time, and personal interests at a minimum. Some person-centered plans we reviewed touch on all these areas now. But unless an agency is the principal provider, for example, of both ISLA and employment-related services, the latter are unlikely to be fully integrated into the person-centered plan of their consumers.

Issues related to productivity and social integration cannot be separated from issues related to independence, and independence cannot be conceptualized let alone planned for apart from productivity and social integration. It would seem, then, that all three must form a central part of a unified whole life plan. Natural supports, likewise, are not ancillary planning elements, but central ones. They are the necessary mechanisms through which other key values can be realized, as well as required by a service system that must find ways of leveraging its impact in the face of too few resources for too many needs.

Because of the centrality of independent supported living in the service galaxy it makes sense to have the ISLA agency as the central or lead agency in whole life planning. But, beyond this, integrated, unified and comprehensive whole life planning is more likely to be easier to do, and to be done at all, if a single agency is involved in delivering the entire package of essential services a consumer needs. Roles and responsibilities are likely to be more clear and accountability more sure. This is most apparent with respect to melding such services as attendant care, socialization, and supported employment with ISLA support. And if a unified service package approach were to be implemented it makes sense for the ISLA agency to become the responsible provider for all non-technical services (which is likely to exclude such things as medical treatments and financial planning), while maintaining a caseworker role. The relatively new, combined ISLA and supported employment programs being operated by Gateways and Willows Way represent movement in this direction.

Finally, while the quality of ISLA programs varies from agency to agency, there are exemplary programs and program elements to be found in St. Louis County. There is much that agencies can learn from each other in seeking to improve their programs, in person-centered planning, emphasis on the social and community integration of consumers, development and utilization of natural supports, the application of best-practice techniques, as well as in the effective utilization and organization of staff and staff training.

Recommendations

1. Administrators and supervisors of ISLA agencies, in conjunction with direct support professionals, should conduct a review of their programs of staff training and determine what steps can be taken to improve them. This review should encompass both new-worker and ongoing training. It should also address how supervisors and direct support professionals will be helped to stay abreast of best practices in the field. At a minimum this process should target three program areas for close analysis:
    a) the development and utilization of natural supports,
    b) improving person-centered planning, and
    c) addressing the social and social psychological needs of consumers (including community integration).
2. Administrators, supervisors and direct support professionals of ISLA agencies should review their person-centered plans with respect to a set of criteria they judge to be minimally necessary and acceptable. As part of this review, questions asked should include:
    a) Are these plans enactable and could anyone determine whether or not particular goals have been achieved?
    b) Are the values of productivity, independence, social integration and community inclusion represented in the goals articulated? If not, why not?
    c) Is there a basic consistency in the structure and content of all consumers' plans?
    d) Are the roles and responsibilities of all involved parties clearly stated?
    e) Do the goal statements show sufficient respect for the personal interests and abilities of individual consumers?
    f) Are time tables detailed enough and are benchmarks present to assess progress towards the goals?
    g) Have the possible involvement of non-family natural supports been fully explored with respect to each goal listed?
    h) Do staff have sufficient instruments and tools to conduct adequate and ongoing assessments of the person's capabilities, interests, needs and progress?
    i) Is there convincing evidence that the consumer's choice was informed and that his or her well-being has been assured?
    j) Are the major wants, needs, desires, and dreams of the consumer that are contained in the profile section of the plan represented in some fashion in the outcome section.
    k) If a consumer works in a sheltered workshop or is not working, does the plan describe steps that are to be taken to normalize this area of the consumer's life over time and ensure informed choice (which requires some knowledge of, if not experience with, alternatives in the natural world of work)? What has been tried and what will be tried and who is involved in this process?
3. Beyond the areas of worker training and person-centered planning, ISLA administrators and staffs should review other aspects of their programs and identify a) those they consider to be their strengths, and b) those in which improvements are needed and where technical assistance would be helpful.
4. The results of these three reviews and a response plan should be made available to PLB administrators who have responsibilities for the integrity and quality of the ISLA program in the county. This report should include a description and explanation of any specific technical assistance the agency believes it needs.
5. Once each agency has completed its individual reviews, representatives from each ISLA agency should meet to assess:
    a) any practical ways in which the agencies can help each other;

b) the feasibility of joint or cross-agency training;

c) the kind of technical assistance that would be beneficial for one, some, or all the agencies.

This joint assessment should target, but not be limited to, the areas of person-centered planning, natural supports, and the social and community integration of consumers. The results of this assessment should be shared with PLB administrators and, in consultation with the PLB, a plan of action developed.

6. This or a second group of agency representatives should meet in order to:

a) establish minimal standards or guidelines for the person-centered planning process including planning criteria, plan structure and content areas,

b) establish a method of ongoing quality control of person-centered plans,

c) establish a routinized process for sharing information with each other related to instrumentation, protocols and procedures related to person-centered planning,

d) explore agency attitudes about the benefits and feasibility of regular staff contact among agencies, and

e) explore the possibility of establishing channels of communication and procedures for inter-agency referrals.

Tasks a and b (relating to person-centered planning) should be finalized in consultation with PLB administrators.

7. To facilitate employment of ISLA consumers in regular/natural jobs (to enhance their community integration and personal productivity) and to promote informed choice related to employment and personal productivity, a cross-agency work exploration and/or work experience program should be established.

8. To better inform family members about the ISLA program, particularly those of consumers who are new to the program, and to more directly involve the whole family in the expansion of the consumer's support network and in the utilization of natural supports (both from within the family, but also and importantly from other sources) establish a cross-agency family education program or augment a program that may already exist.

9. To increase the probability that consumers' outcomes are achieved, we recommend that all ISLA agencies in the county follow the practice of one of them and establish individual staff outcomes. For example: "Each consumer you work with will have at least one natural relationship."

10. Because of the key role played by Regional Center in the service system—in terms of general case management responsibilities and the linchpin referral function—it is imperative that administrators and field workers with the state agency have a full, accurate, and up-to-date understanding of ISLA programming. The agency, perhaps with assistance from the Governor's Planning Council on Developmental Disabilities, should be encouraged to upgrade its staff training in this program area. Beyond this, we recommend:

a) that a program of joint education and training of ISLA support personnel and Regional Center case managers be developed, and

b) that administrators of the Regional Center be brought together with administrators of ISLA agencies and the PLB to discuss the process whereby consumers are judged to be appropriate for ISLA and referred to support agencies. This discussion should continue until agreement is attained on these issues and guidelines established through consensus.

11. Finally, as discussed in this chapter, we recommend consolidating and unifying services within and around ISLA programming and ISLA support agencies whenever possible.

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