

**STUDY OF THE IMPLEMENTATION
OF INDEPENDENT SERVICE COORDINATION
UNDER BOGARD V BRADLEY**

July 1995

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I. INTRODUCTION

In September 1994, the Office of the Court Monitor in re: Bogard v Bradley contracted with Human Services Research Institute (HSRI) to study the implementation of the service coordination stipulations in the Bogard consent decree, issued in 1992. The major issue of concern was the decree's mandate that service coordination ratios not exceed 1:30. HSRI proposed to examine the broader question of how independent service coordination agencies (ISC agencies) can best fulfill their role while staying within the decree stipulations. In particular, we explored the following pertinent issues:

- ◆ The extent to which the ISC agencies are out of compliance with the 1:30 caseload ratio, and why;
- ◆ The current composition of independent service coordinators' (ISC) caseloads;
- ◆ Tasks typically performed by ISCs, and how important the tasks are; and
- ◆ Supports for ISCs in working with Bogard class members.

These areas of investigation not only shed light on the question of optimum caseload size, but they also provide insight to the merits/disadvantages of a model of *independent* service coordination. The Bogard decree required that all agencies providing service coordination to Bogard class members divorce themselves from any direct service responsibility, to assure that the services and supports offered to an individual are tailored to the individual's needs and desires, rather than to the availability of services through a particular agency. Indeed, the arguments for independent service coordination are well established in the literature¹: only through independence from both the funding source and the direct service provision can a service coordinator truly serve as the personal agent and advocate for the individual, thus freeing the service coordinator from the systems demands of cost containment and efficient use of available contracted services. Going hand in hand with independent service coordination in many of the states where it is being implemented is a consumer-driven approach to service delivery, where the individual has control of the purse strings and can purchase needed services from a provider of choice, and where providers must compete for the opportunity to serve individuals – no paid "slots" are guaranteed. This model has only been implemented in a few states, in all or a portion of the state and only for particular consumer populations. In its ideal form, the independent service coordination approach takes time and commitment to implement, because it does represent a significant change from conventional provider-driven

¹ see Kimmich, M. (in press), *Family-centered service coordination: Linchpin to integrated services*, Salem, OR: HSRI.

arrangements. Although this study does not directly examine the success of independent service coordination, it is clearly a relevant factor, especially regarding the viability of the 1:30 ratio.

Methodology: HSRI's methodology relied heavily on interviews with Bogard class members (BCM), with independent service coordinators (ISC), and with the directors of ISC agencies. The interview information was supplemented by data on the entire caseloads served by selected ISC agencies.

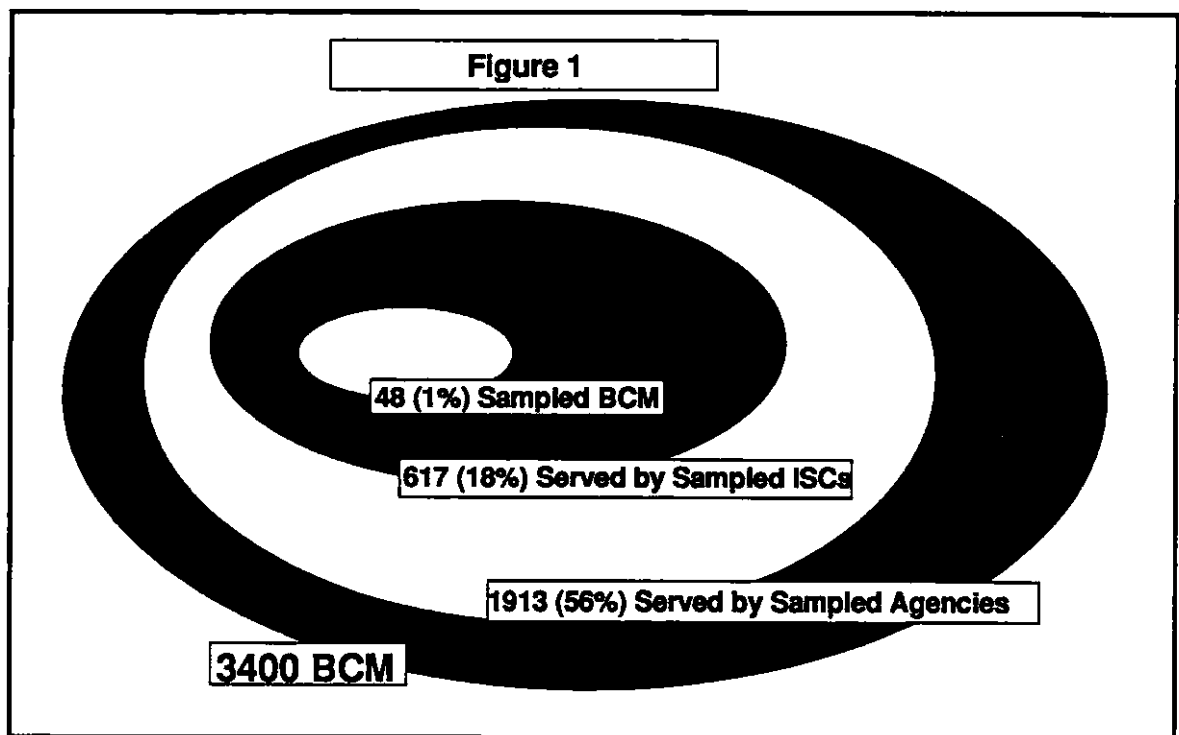
- ❖ *BCM interviews:* HSRI staff trained interviewers from People First of Illinois, who then conducted face-to-face interviews with Bogard class members throughout the state. The interviews lasted approximately one hour, and typically took place at the workplace or the residence of the individual. The interviews were done between December 1994 and March 1995.
- ❖ *ISC interviews:* HSRI staff conducted telephone interviews with selected ISCs, at times chosen to minimize the disruption of their normal schedules. Each interview lasted approximately an hour, and were done in February and March 1995.
- ❖ *Agency director interviews:* HSRI conducted telephone interviews with the directors of the selected ISC agencies, at times chosen by the interviewee. Each interview lasted approximately one hour, and were done in April and May 1995.
- ❖ *Supplemental information:* HSRI developed two information forms to facilitate the Bogard class member interviews; these were completed by the ISC of each selected class member in December and January. In addition, HSRI created two charts to describe caseload composition, one for the agency as a whole and one for each selected ISC to complete. These were done in February 1995, with some of the information trickling in since that time. Appendix B contains the interview guides and the supplementary information forms.

HSRI utilized a multi-level sampling strategy, to obtain reasonably representative (but not statistically representative) samples of ISC agencies, ISCs working for those agencies, and Bogard class members being served by those ISCs. Figure 1 below illustrates the sampling frame used.

- ◆ There are approximately 3400 Bogard class members, currently being served by 22 independent service coordination agencies. Nine of these agencies (41%) were invited and agreed to participate in the study; they were selected to be representative of (a) the various sizes of ISC agencies, (b) the mix of urban and rural caseloads served by the agencies, and (c) the various geographic areas of the state. (Appendix A lists the names of the agencies and the contact person for the study). The nine selected agencies serve 1913 Bogard class members, or 56% of the total Bogard population.
- ◆ Within the nine selected ISC agencies, there are 88 people who work as service coordinators/case coordinators. The vast majority of them serve *some* Bogard class members; in the larger agencies, many of them serve *only* Bogard class members. HSRI selected between two and six ISCs in each of the sampled agencies,

depending on the size of the agency and its Bogard caseload. Of the 27 ISCs selected, interviews were completed with 26. The 26 ISC respondents serve 617 Bogard class members, 32% of those served by the sampled agencies and 18% of the total Bogard population.

- ◆ From the Bogard caseloads of each of the sampled ISCs, HSRI selected two to three Bogard class members. Because some ISC caseloads had changed from the lists used for sampling, the final sample includes between one and four Bogard class members for each of the selected ISCs. The original sample was 60 Bogard class members. Attrition led to the resulting sample of 48 Bogard class members², which represents 8% of the caseload of the selected ISCs and 1% of the total Bogard population.



Format of the Report

The following section of the report presents the principal findings from the study. The findings are presented as answers to seven key questions:

1. *Who is in the study samples?*
2. *Are the ISC agencies in compliance with the 1:30 ratio?*
3. *What is the composition of current caseloads?*
4. *What tasks do service coordinators perform?*

² Of the original 60 sampled Bogard class members, four refused to participate, seven were interviewed but the data were too incomplete to use, and one person died before the interview was done; the completion rate was 80%.

5. *What supports and constraints affect ISCs in performing their jobs?*
6. *How accessible are ISCs to Bogard class members?*
7. *What has resulted from Bogard service coordination?*

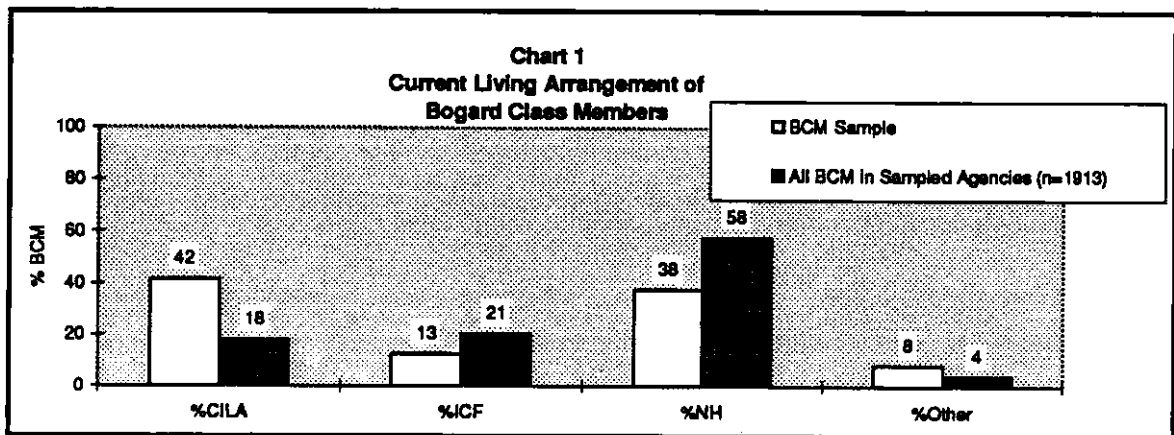
The final section of the report discusses the implications of the findings and proposes some recommendations for improving Bogard service coordination.

II. FINDINGS

A. Who is in the study samples?

The 48 Bogard class members reasonably represent the various geographic areas of the state as well as the demographic characteristics of the Bogard class member population as a whole.

- The majority (63%) of the Bogard respondents reside in rural areas³. Although this percentage is considerably higher than in the overall Bogard population, it was important to the study to be able to fully understand the rural implications of independent service coordination, hence rural residents were deliberately oversampled. Fifteen percent live in urban areas, and the remaining 22% in suburban areas.
- Bogard class members tend to be older, and this is reflected in the study sample. Over half (56%) are 60 years old or older, while the remaining 44% are between age 21 and 59.
- The Bogard respondents currently live in a variety of settings. Over half (42%) live in Community-based Independent Living Arrangements (CILA), while only 13% live in Intermediate Care Facilities (ICF) and 38% live in nursing homes. Because of the explicit intent of the Bogard decree to give people with developmental disabilities the opportunity to leave the nursing home, the class member sample deliberately overrepresents people who live more independently. As Chart 1 illustrates, the Bogard class member sample includes substantially more people living in CILAs than does the population of Bogard class members served by the study agencies, 42% compared to only 18%; conversely, the sample respondents are much less often residing in nursing homes (38% compared to 58%) or in ICFs.



- Most Bogard respondents made the move to their current living situation a fairly short time ago, in response to the opportunity afforded to them through the Bogard decree: 42% have been in their current residence for one year or less, and

³ The geographic location of Bogard class members reflects where the individual resides, not where the ISC agency is located.

another 36% have lived there for three to five years; only 21% have been in the current setting for more than five years.

- Many Bogard class members have severe and/or multiple disabilities. Virtually all the Bogard study respondents have mental retardation. In addition, as Table 1 indicates, nearly half have speech or communication difficulties (48%) and display challenging behaviors (46%), and 38% have mobility impairments. A surprisingly low proportion of respondents (about 20%) have vision or hearing disabilities or severe medical involvement.

<u>Type of Disability</u>	<u>Percentage Having It</u>
Severe medical involvement	19%
Challenging behavior	46
Speech/communication	48
Mobility	38
Vision	21
Hearing	17

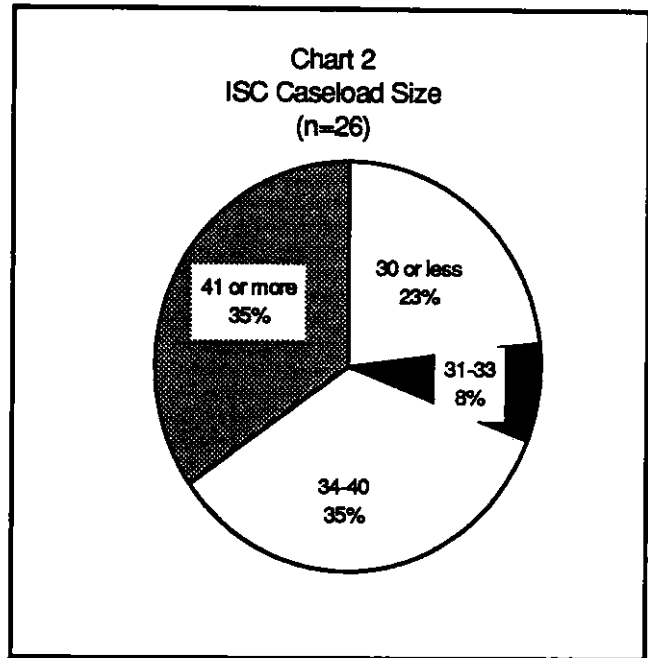
The sample of ISC agencies and ISCs similarly appear to be fairly representative of the larger population of agencies and staff serving Bogard class members.

- Many of the ISCs are relatively new to the job of independent service coordination. Over a third (38%) have been service coordinators for one year or less, and an additional 23% have two to three years of experience in the job.
- The vast majority of the ISC respondents (69%) like their work and plan to continue in their job indefinitely. Among the factors that keep them in the job are: the challenging and rewarding work, the variety in the work, the opportunity to be an advocate for people with disabilities, and the colleagues.
- The ISC agencies in the sample have varied amounts of experience doing service coordination, ranging from two to 15 years, with an average of nine years. Seven of the nine sampled agencies did direct service work as well as service coordination prior to the Bogard decree, and so had to separate the two functions in order to meet decree requirements. Many also expanded their geographic region, sometimes by merging with another existing agency. Some of the most problematic aspects of the transition included restructuring the boards of directors, setting up separate accounting and tracking processes, and adjusting to having no direct service responsibilities.

B. Are the ISC agencies in compliance with the 1:30 ratio?

The Bogard v Bradley decree mandates that service coordinators serving any Bogard class member will not have a *total caseload* in excess of 30 individuals. This 1:30 ratio applies equally to service coordinators who have a caseload that is 100% Bogard class members or which contains only one Bogard class member; in addition, it is an absolute ratio, not an average across all service coordinators in an agency. The findings reinforce the existing view that most agencies are not in compliance with the 1:30 ratio; they go further to explore some of the reasons for this lack of compliance.

- Of the 26 ISCs studied, six comply with the 1:30 caseload ratio and another two come within 10% of the goal, for a total of 8 ISCs (31%) having a caseload of 33 individuals or less⁴. Chart 2 illustrates that roughly one third of the ISCs have a caseload of between 34 and 40 people, and the same proportion carry a caseload of over 40 cases.
- Compliance with the 1:30 ratio does not appear to vary with the proportion of the caseload which is Bogard class members, nor with the complexity of the caseload, suggesting that there is *not* a conscious adding of cases to ISCs who perhaps already have cases which are easier to deal with. Indeed, agency directors commented that they do not even *have the option* of shifting the more complex cases to ISCs with lower caseloads, because (a) the geographic location of the cases makes it unworkable, and (b) all caseloads are equally large.
- The Bogard stipulation that every caseload must not exceed 1:30 is clearly more difficult to achieve than is an agency average of 1:30. The sampled agencies show average caseloads which are *somewhat less problematic* than the caseloads of the sampled ISCs: three of eight agencies (38%) have average caseloads of 33 or less, and another 38% have an average caseload of between 34 and 40 cases.
- Agency directors cited a number of major difficulties they face in coming into compliance with the 1:30 ratio. Many have not hired the additional service coordinators needed to bring the caseloads down to 1:30; others struggle with doing all that needs to be done even for the 30 cases allowed, suggesting that in some situations 30 cases may be too many. Among the difficulties:
 - Funding is insufficient to cover training, benefits and salary, including provision for 24-hour on-call service;
 - The sudden addition of Bogard class members is hard to promptly accommodate;



⁴ The caseload calculation includes both Bogard and non-Bogard cases, and is adjusted for the percent time the ISC spends on service coordination/case coordination duties.

- The rural dispersion of Bogard class members' residences makes it hard to justify a full-time person and hard to find a skilled part-time person;
- The uncertainty of future funding makes them reluctant to hire new ISCs;
- Specialized Services was not originally part of ISC responsibilities, making the workload even more demanding.

C. What is the composition of current caseloads?

The difficulties which ISCs have in fully serving a caseload of 30 individuals may be alleviated or aggravated, depending on the characteristics of the individuals on the ISC's caseload. ISCs argue that Bogard class members require more time than some other types of individuals, and that individuals who are in the process of moving to or already live in more independent settings need more assistance. Current caseloads are extremely varied along these dimensions, as Table 2 indicates:

	Average for Selected ISC's (n=26)	Average for all ISC's in Selected Agencies (n=88)
Bogard Class Members as % of Caseload	67%	55
Living Arrangements:		
% in CILA	19	19
% in NH	52	60
% in ICF	28	21
Choice		
% moved	15	24
% stay	69	64
% waiting to move	16	12

- The proportion of the sampled ISC's caseload that is Bogard class members varies from a low of 3% to a high of 100%; the average is 67%. This compares to an average Bogard proportion of 55% across the sampled agencies, indicating that the selected ISCs tend to have somewhat more Bogard class members on their caseloads than do their colleagues in the sampled agencies.
- The mix of living arrangement among Bogard individuals on the caseload of sampled ISCs⁵ is virtually identical to that among all ISCs in the sampled agencies: about one-fifth of each group live in CILAs, and over half live in nursing homes.

⁵ ISC caseload percentages reflect proportions of the ISC's Bogard cases, even if they carry other cases as well.

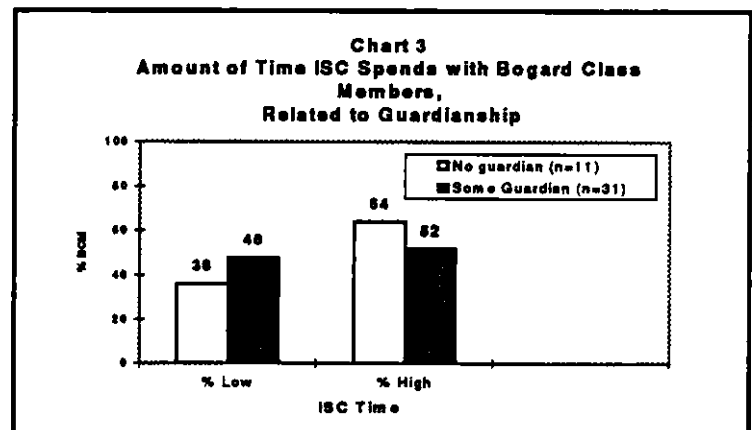
- The choice which Bogard class members make regarding moving is a crucial element of Bogard service coordination; the more individuals on a caseload choose to move, the more work is immediately required of the ISC. The sampled ISCs run the full gamut, from having none of their Bogard caseload choose to move, to having all choose to do so. The average proportion of the ISC caseload who chose to move is 31%; half of these (15%) have done so, and the others (16%) are still waiting to move. The vast majority (69%) chose to stay where they were living when identified as a Bogard class member. These average proportions are roughly comparable to the proportions of caseloads averaged across all ISCs in the sampled agencies – 24% have moved, 12% are waiting to move, and 64% chose to stay.
- ISCs have a surprising degree of variation in the geographic location of the individuals they serve. Only one agency has exclusively all-urban Bogard caseloads, and only three have exclusively all-rural caseloads; the remaining five agencies have ISCs with mixed caseloads. On the average, an ISC caseload is 33% urban, 29% suburban and 38% rural.
- Equally varied is the mix of individuals' severity of disabilities. The proportion of ISC caseloads with severe medical involvement or with challenging behavior ranges from 0 to 100 percent, with the average being 14% and 30%, respectively.

These findings add up to a service coordination environment with very little specialization and considerable potential for ISC discretion, in terms of giving differential attention to individuals on their caseload depending on the individual's needs. ISCs were outspoken about the types of cases and the kinds of situations that require more of their time and attention:

- People who choose to move to a CILA, because it takes time to find a place;
- People living more independently, because the ISC does all the plans;
- People who need to have specialized services arranged;
- People who do not have a guardian and have trouble speaking for themselves;
- People with more physical limitations and behavioral problems.

The study supports some of these hypotheses and not others:

- People who do not have a guardian report that their ISC does more things for them and contacts them more often, defined as "higher ISC time", than do people who have a guardian (Chart 3): 64% of those with no guardian report that their ISC spends a high amount of time with them⁶, compared to only 52% of people with a guardian who have such ISC attention. This suggests that ISCs respond to the greater need for advocacy support among people with no legal guardian.



⁶ High number of tasks/amount of time is defined as 12 or more of 17 specific tasks; see definitions at the end of this report.

- ISCs do more tasks and spend more time with individuals who live more independently and who have more recently changed their living situation (Table 3): 68% of Bogard class members who live in CILAs report that their ISCs spend a high amount of time with them, compared to only 40% of those living in nursing homes or ICFs; and a similar contrast is evident between those who have moved within the past year and those who moved more than one year ago (69% compared to 43%).
- The data reveal no relationship between level of disability and ISC time, nor between receipt of specialized services and ISC time, suggesting that either those factors *do not require* greater ISC time, or that ISCs *do not respond* to the increased need for attention.

Table 3

Amount of Time ISC Spends with
Bogard Class Members,
Related to Living Situation

	<u>% Getting Low Time</u>	<u>% Getting High Time</u>
BCM living in CILA (n=19)	32%	68%
BCM living in NH or ICF (n=20)	60	40
BCM who moved w/in 1 year (n=13)	31	69
BCM who moved more than a year ago (n=16)	57	43

D. What tasks do service coordinators perform?

Drawing on HSRI's knowledge of the field and materials prepared by the Bogard Case Coordination Panel concerning the job responsibilities of individual service coordinators, HSRI developed a list of service coordination tasks. This list was used in interviews with both Bogard class members and ISCs.

1. Difficulty and Importance of Tasks

The sampled ISCs were asked to judge the difficulty and the importance of the various tasks they perform for Bogard class members. The hardest and the most time-consuming tasks are often not the ones considered to be most important; and the most important tasks, from the ISC perspective, are not necessarily those which policy makers see as the strongest element of the Bogard decree (Table 4).

Table 4
ISC Views of
the Tasks They Perform
(n=26)

<u>Task</u>	<u>Percent of ISC's Who Say</u>		
	<u>Task is Most Important</u>	<u>Task is Most Time-Consuming</u>	<u>Task is Hardest</u>
Visit BCM	46%	30%	0%
Link to Existing Services	34	26	26
ISP Meetings	23	15	19
Choice Protocol	46	7	15
Find New Services	15	7	65
Develop Community	15	3	15
Crisis Resolution	26	15	26
Problem-Solving (ind)	34	19	7
Problem-solving (prov.)	30	15	7
Contact w/Providers	30	15	3
Transportation	11	3	42
Paperwork	15	46	23

- The hardest tasks for ISCs are finding new services and arranging transportation; the easiest are visiting the Bogard class member and keeping in contact with service providers.
- The most time-consuming tasks are dealing with paperwork, visiting class members, and linking them to existing services.
- The most important tasks are visits to class members and offering choices about living situation.
- Perhaps most striking is the perceptions ISCs have about finding new services and developing "community" around an individual. These two activities, rated among the lowest in importance and the lowest time-consumers, are central goals

of *person-centered planning*, which set it apart from traditional approaches which fit people into existing program slots.

- ISCs with larger caseloads are more likely to judge their service coordination tasks as being difficult to do and time-consuming to do (Table 5). Two-thirds (67%) of high-caseload ISCs say many tasks are hard⁷, and 44% say that many tasks are time-consuming; none of the ISCs with caseloads of 33 or less say many tasks are hard, and only 12% say many tasks are time-consuming. These data suggest that ISCs carrying caseloads within mandated levels are much more able to cope with the various aspects of the job.

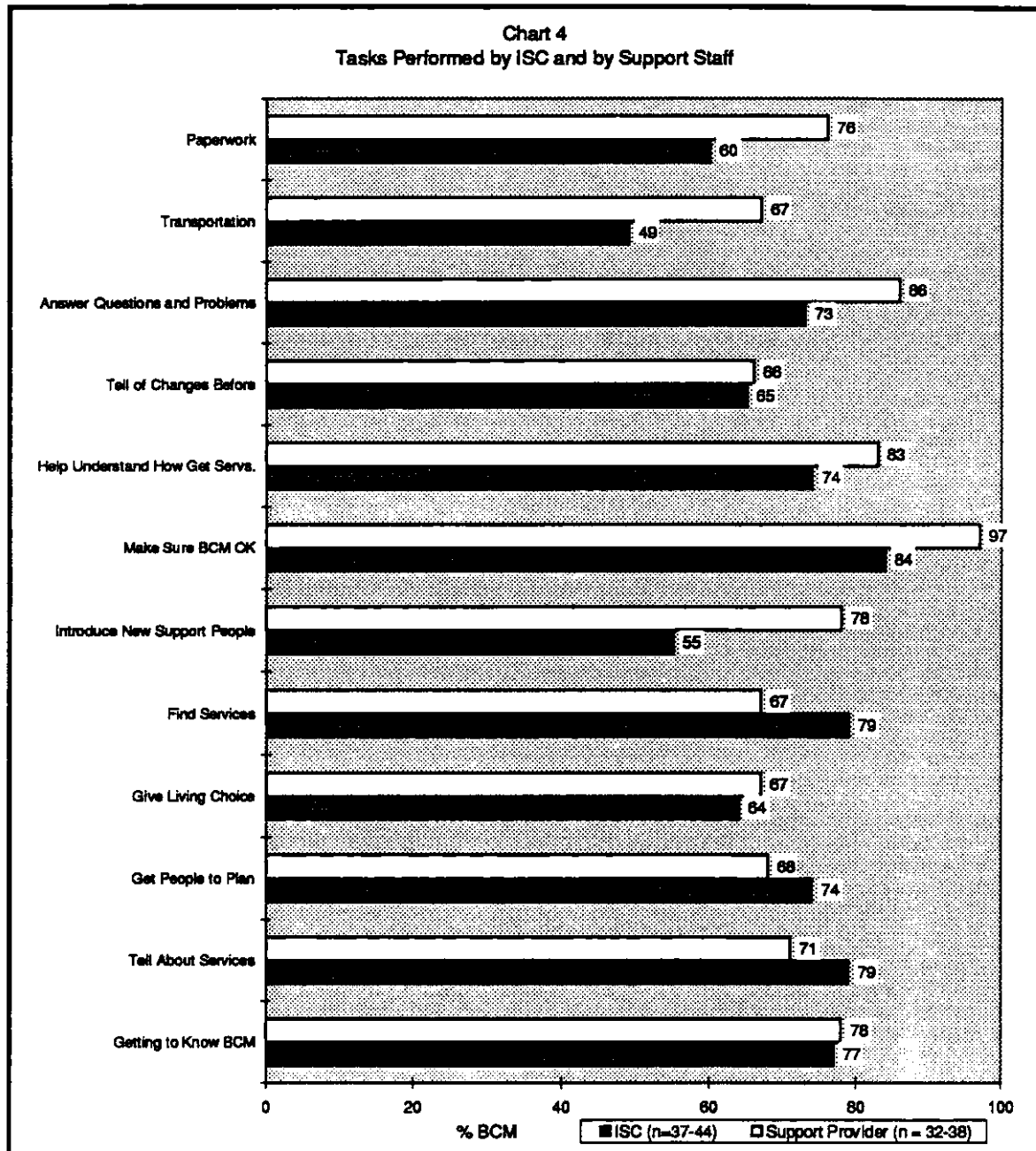
<u>ISC Perception of Tasks</u>	ISC's with Caseload ≤33 (n=8)	ISC's with Caseload of 34-40 (n=9)	ISC's with Caseload >40 (n=9)
Few tasks are hard*	100%	56%	33%
Many tasks are hard	0-	44	67

Few tasks are highly time-consuming*	88	78	56
Many tasks are highly time-consuming	12	22	44

⁷ "Many tasks are hard/time-consuming/important" means that 3 or more of 7 tasks were judged by the ISC to be such; see definitions at end of report.

2. Role of ISC Compared to Support Staff

Bogard class members were asked about the service coordination tasks performed for them by their ISC, as well as whether any other staff working with them helped with these tasks. The results (Chart 4) paint a picture of significant involvement by support staff⁸, sometimes exceeding that of the designated ISC.



⁸ Support staff include a wide range of paid people who work with Bogard class members; see definitions at end of report.

- The major tasks that class members say their ISCs perform for them include:
 - getting to know them (77% do so),
 - telling them what services they can and cannot get (79%),
 - help them find services they need (79%), and
 - talking to them to assure that things are going well (84%).
- Bogard class members say support staff do many tasks more often than do ISCs:
 - introducing them to new people to help them (78% compared to 55%),
 - making sure that things are going well (97% compared to 84%),
 - helping them understand how to get what they need (83% compared to 74%),
 - answering questions (86% compared to 73%),
 - arranging transportation (67% compared to 49%), and
 - doing paperwork (76% compared to 60%).

It seems entirely appropriate that support staff play a greater role in arranging transportation and in answering day-to-day questions, but these data open up additional avenues of exploration. In light of the large caseloads that most ISCs are carrying, it may be possible that support staff could more clearly shoulder responsibility for some ISC tasks (such as helping class members learn to work the system) and thus alleviate the workload of the ISC. However, other tasks central to the concept of an independent service coordinator as advocate for the individual – getting people together to plan with the class member, and telling the class member about service options – should remain the purview of the ISC.

Of particular concern in these findings is a pattern of relative inattention to two key Bogard activities – giving the class member a choice about where to live and tapping a rich array of individuals to provide individualized supports, under the rubric of specialized services. Although offering choice is identified as one of the most important activities, only 64% of ISCs are seen as doing this, and only 7% of ISCs see it as a time-consuming task (which it necessarily is, if the class member is to make an informed decision). Even more problematic is the development of individualized supports: finding new services is considered one of the hardest tasks, but not one of the most important; and finding new providers is reportedly done by only 55% of ISCs (which is much less often than it is done by support staff).

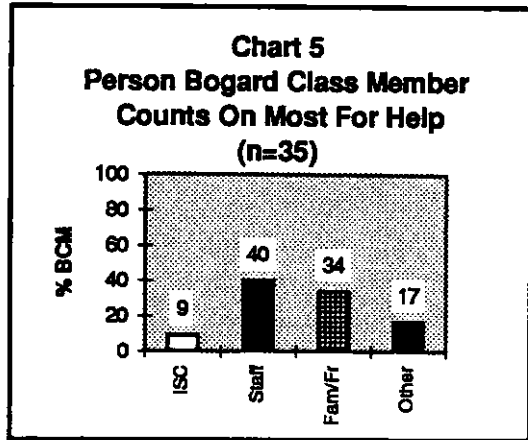
The potential for the ISC to work in collaboration with the primary support provider is considerable. ISCs report greatly varied relationships with service providers; in general, they recognize the need for a shared responsibility to support the Bogard class members, but they also emphasize that providers do not well understand the nature of the ISC role and need to be educated/oriented.

3. Importance of ISC to Bogard Class Members

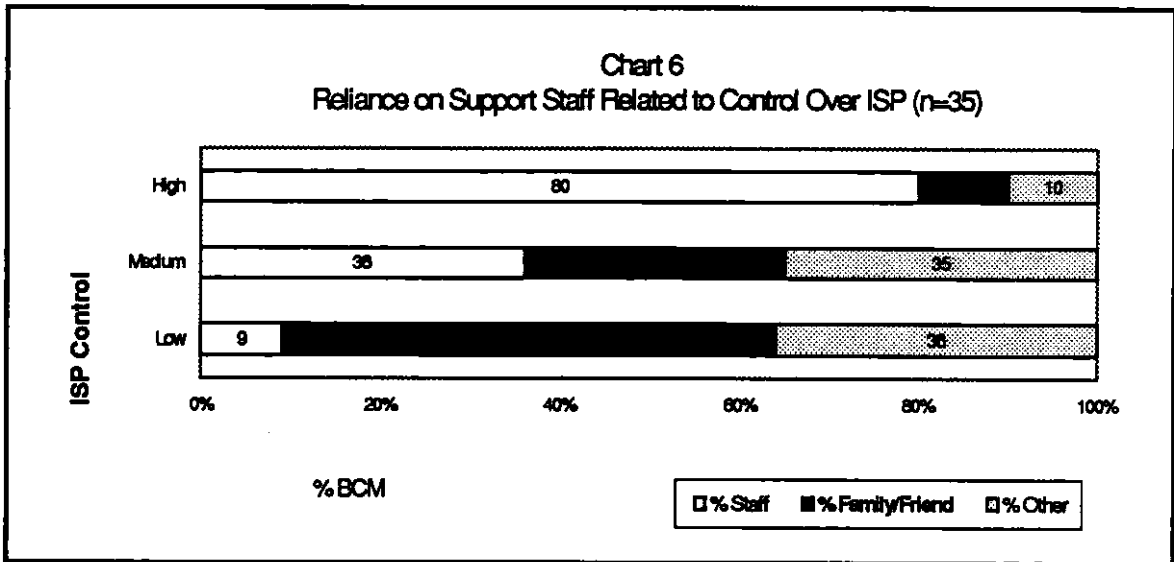
Although the ISC is meant to be the primary advocate as well as the central coordinator of services and supports for Bogard class members, it is important to look at the situation from the class members' perspective.

- Half of the Bogard respondents (51%) say that they have someone who helps them speak up for themselves.

- The person who the Bogard class members count on the most tends *not* to be the ISC (Chart 5): staff were mentioned by 40% of Bogard respondents, followed by family members or friends (34%); ISCs were the group least often mentioned, by only 9% of respondents.
- Support staff *are* well trusted by Bogard class members: 90% of class members feel that support staff show them respect, and 85% feel that support staff listen to their views and ask them when and how they want to do things.



- Reliance on support staff appears to have an empowering effect on Bogard respondents (Chart 6): 80% of those who experience a high degree of control over their ISP meeting⁹ are respondents who count on support staff, while only 9% of those with low ISP control are those who count on support staff.



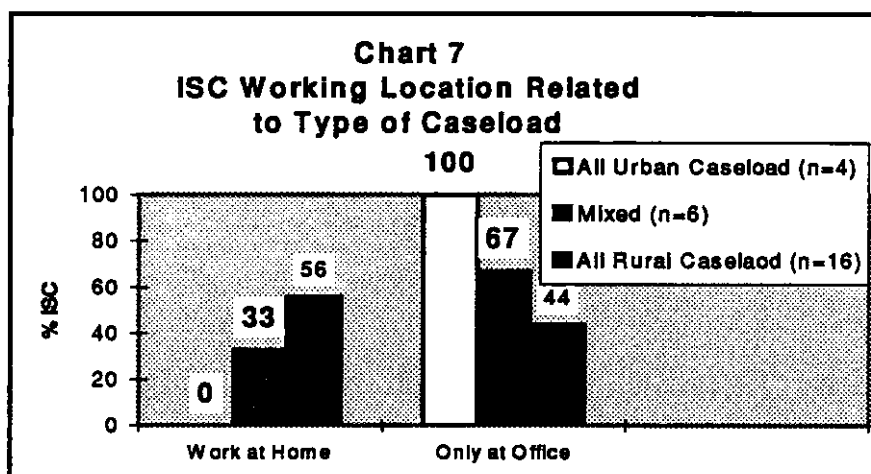
E. What supports and constraints affect ISCs in performing their jobs?

Just as Bogard class members need support to live a life of quality, so too service coordinators need support to do their job well. The work environment, the supervision, and the training they receive all play an important role in making service coordinators motivated and successful in their work.

⁹ High control over ISP means the class member gave a positive response to 6 or more of 8 questions about the most recent ISP meeting; see definitions at end of report.

The flexibility of the working environment has three key aspects -- flexibility in when and where ISCs work, and flexibility in case assignment.

- The work environment appears to be quite flexible, with 42% of ISCs having the opportunity to work out of their home if they choose; the other 58% are restricted to working out of the office.
- There is a strong relationship between this "location flexibility" and the geographic make-up of the ISC's caseload (Chart 7): 56% of ISCs with a totally rural caseload can work out of their homes, while none of those with a totally urban caseload are allowed to do so. [This pattern does not reflect the policy of any particular agency -- all the agencies in the sample allow some of their ISCs the work-at-home option.]



- In terms of working hours, 76% of ISCs say their job is highly flexible, including actual time of day to work, and the opportunity for overtime pay and compensatory time; only 8% say that their work hours are not flexible.
- Much less flexibility is evident in the assignment of cases. Nearly nine-tenths (88%) of ISCs say their cases are assigned on a geographic basis, with the rest saying the decision is made based on the type of needs the individual has. Interestingly, this policy applies equally regardless of the geographic make-up of the caseload.

Employment supports are somewhat more difficult to quantify. ISCs were asked about the various types of job supports they have, in terms of whether they receive any such support and whether it is valuable to them. Table 6 reveals significant availability of the full range of job supports, but widely varying perspectives on the value of those supports.

	<u>% Receiving Any</u>	<u>% Seeing It as Valuable</u>
Supervision	100%	88%
Clerical assistance	85	69
Training opportunities	96	58
Technical assistance	92	73
Networking opportunities	88	81
Written guidance	88	54
Salary + benefits	100	81

- Well over three-quarters of ISCs report that they receive some amount of all the different job supports; most common are supervision, benefits and training.
- The most valuable supports are judged to be supervision, networking opportunities, and benefits; supervision and benefits rank high in both availability and usefulness. [Staff-supervisory ratios in the sampled agencies range from 3:1 to 20:1, with an average of 7:1.]
- Perhaps most striking is the contrast between the availability of training and written manuals, the mainstays of most jobs, and their perceived value -- only slightly more than half the ISCs value these supports.
- Despite the ambiguous value of many of the job supports for ISCs, the sampled agencies have not experienced very much ISC turnover in the past year. Only 6 of 82 service coordination positions were vacated in 1994, despite the potential tensions that could be expected to result from agency mergers. Agency directors clearly attribute their ability to retain ISCs to three factors: salary and benefits, job autonomy, and good communication between ISCs and their supervisors.

Training for ISCs is clearly a complex area. Training and mentoring are readily available, and typically include a basic agency orientation, various training components provided by the state DMHDD, and on-the-job training through pairing new ISCs with experienced ones, for up to 6 months time. While some of the agencies offer more individualized training opportunities, most rely heavily on the standard offerings to convey the unique features of Bogard service coordination. In some ways ISCs demonstrate a clear understanding of their job; in others, their understanding of the

connection between their role and improvements in class members' quality of life seems more tenuous.

- In response to questions about monitoring and reviewing individual service plans, the majority of ISCs emphasized personal contact and communication with the class member, as well as the need to review written documents about the individual (progress notes, charts, reports). Annual reviews are reportedly more problematic to do for class members residing in nursing facilities, where the focus is less on quality of life and more on aspects of medications and physical care. In addition, a few ISCs spoke of difficulty in determining what the individual wants, and of the frustration with services not being available to meet the identified needs of the individual.
- Questions regarding developing needed services and supports, especially generic services, seemed problematic for most ISC respondents. Many did not appear to fully understand the concepts of generic services and natural supports, giving examples of generic services as being segregated Boy Scouts, Senior day programs, and existing (segregated) service providers. This attitude seems to reflect the fact that service models and thinking are still deeply rooted in segregated approaches, and that training and information is more focused on regulations than on facilitating community inclusion and networking within the broader community.

Despite their limited vision, ISCs demonstrated strong persistence. When asked how they go about meeting needs when services and supports do not exist in the community, ISCs repeatedly commented that they "make phone calls until they get sick of me", "just keep looking until you find someone", and "speak to 7 million people."

- When asked about how to nurture a network of supports around an individual, ISCs emphasized communication among the various players in a person's service plan and the family or guardian, but few mentioned taking an active role in developing an interrelated support group around an individual which might also include previously uninvolved or marginally involved acquaintances or even strangers to the individual. A few speculated about such an enlarged support group, but more seem to prioritize supporting family members to become more actively involved. "I have a number of family members who became guardians as a result of the Bogard decree, and are now seeing the person more often."
- The advocacy role for ISCs seems to be underdeveloped, although the ISCs well understand it to be a valid and necessary role for them. Isolated examples highlight the potential that mentoring holds for increasing ISCs' advocacy involvement.
- ISC agencies and individual ISCs take widely varying approaches to the task of offering choices. Some agencies appear more highly structured than others in enumerating steps for the choice process and making these firm agency policy. Typically, the ISC describes the different living arrangements to the individual and guardian, invites providers to make presentations, and visits some places. ISCs note that individuals "cannot choose unless they've seen and experienced the possibilities themselves"; they also comment that it is important to "become really familiar with the person to make it a genuine choice. I offer choices based on what I know about the person." ISCs varied in how often they raise the issue with Bogard class members; only one stated that they "make sure we give choice at least once a year".

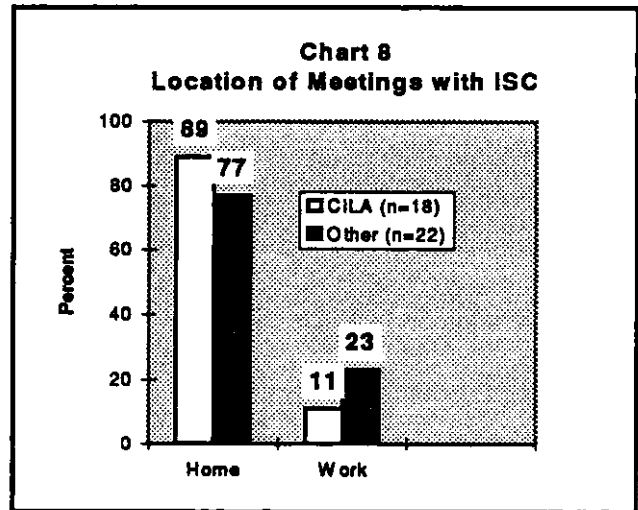
Several ISCs pushed the question deeper, expressing resignation or anger about what they see as a scarcity of appropriate residential choices, and slow

development of CILAs due to disincentives in the rate-setting mechanisms and state policies toward providers. Comments included: "I don't even offer them choices if there is no chance they can move"; "[Agency X] is the *only* provider"; "It is hard to offer choices when people can't see what you are offering. There are no CILAs out there!"

F. How accessible are the ISCs to Bogard class members?

Key to ISCs doing their job with Bogard class members is their being recognized by and accessible to class members. The large caseloads they carry and the significant role which is played by support staff make this issue even more salient. Most Bogard class members seem to know and have regular contact with their ISCs, although not always as often or in the location that might be most desirable.

- Sixty-one percent of Bogard respondents know who their ISC is; these individuals are more likely to be living in CILAs (63% of CILA residents know their ISC, compared to only 52% of those living in ICFs or nursing homes).
- Most Bogard class members (57%) see their ISC monthly. Another 25% see their ISC weekly; half of these are people who have recently moved to a CILA, making weekly visits mandatory, but the others are people in ICFs or nursing homes. The remaining 18% of Bogard respondents *do not* see their ISC at least monthly; these tend to be people who are living in CILAs.
- Nearly three-fourths of the Bogard respondents (72%) meet with their ISC in the place where they live; only 15% meet in their place of work. Even though people living in CILAs are more likely to be working, this pattern is even more pronounced for them (Chart 8): only 11% of CILA residents meet their ISC at their workplace, compared to 23% of people in other living arrangements.
- In addition to meeting with the ISC, Bogard respondents also talk on the phone with their ISC. Over a third do so (35%), and 24% talk by phone monthly or more often.



G. What has resulted from Bogard service coordination?

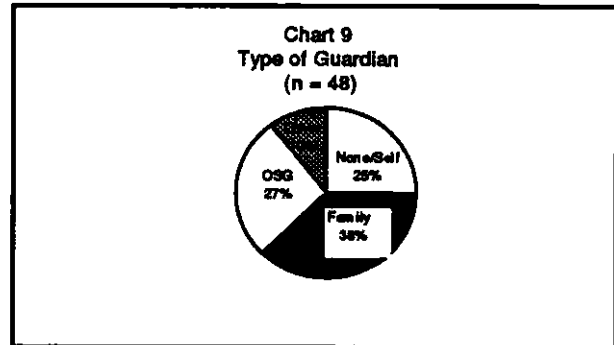
The ultimate measure of whether service coordination is working is the quality of life of Bogard class members. The study explored several types of positive outcomes for Bogard respondents: feeling happy about where they live, exercising choice about where they live, exercising control over their service plan, participating in integrated activities, and receiving specialized services.

Where individuals live is a significant part of the overall quality of their lives.

- As in most survey responses to direct questions about satisfaction, nearly all Bogard respondents (94%) say they are happy with where they currently live.
- Nearly half the Bogard respondents (46%) say that family, friends, or they themselves chose the place where they now live; only 20% say the ISC chose, and only 17% say that staff chose for them.
- Despite the very high level of satisfaction with current living situations, 18% of respondents say they would like to move; these tend to be people who already live in CILAs and/or are happy with where they are now living. It appears that moving is a learned experience, which raises expectations and leads to further desire for improvement.
- Saying they would like to move and formally choosing to do so are very distinct steps along the way to a move. Sixty percent of the sampled Bogard class members have chosen to move; 46% have already done so, the other 14% are awaiting the actual move¹⁰. Surprisingly, the people who have chosen to move include a disproportionate number of individuals with severe medical involvement (67% compared to 59% of people without severe medical issues).

The extent to which Bogard class members have *control over decisions affecting their lives* hinges on two factors: their guardian and the control they exercise in the individual service plan (ISP) process. Having a guardian theoretically increases the ability of the class members to assert their own desires and needs.

- The most common type of guardian (Chart 9) is a family member (38%), followed by an official in the Office of the State Guardian (27%). A quarter of Bogard respondents have no legal guardian; this includes a mix of people who are able to speak for themselves, as well as individuals who need a guardian but for whom one has not yet been appointed.
- Bogard respondents state that they have substantial control over some elements of the ISP meeting¹¹ and only modest control over others (Table 7). Most notable is their sense that others listen to them (86%) and that they feel a part of the meeting (82%) – fairly modest goals, but perhaps a significant improvement over what they have experienced in the past. Just over two-thirds of respondents said they understood what went on at the most recent ISP meeting, and that they got what they wanted.

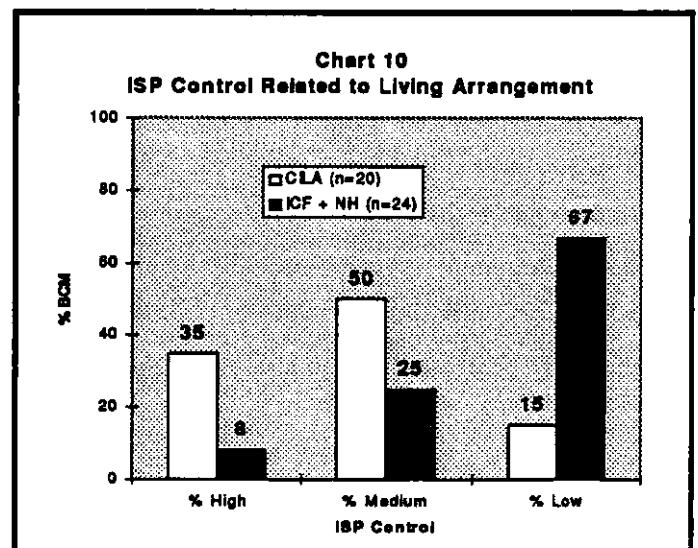


¹⁰ These proportions represent a sample bias toward people choosing to move. The proportion of all Bogard class members served by the sampled agencies who chose to move is only 36%, with 24% having already moved. This deliberate sampling bias allowed full exploration of both groups of individuals, those choosing to move and those choosing to stay.

¹¹ Bogard class members may have answered the questions about their most recent ISP meeting by remembering the last time they met with their ISC to *some* type of planning, so Table 7 may reflect more than a formal ISP meeting.

People other than ISC + self came	47%
BCM invited others to come	25
BCM decided who would come	25
BCM understood what was talked about at ISP meeting	67
BCM had chance to talk	81
BCM felt others listened and gave respect	86
BCM felt part of meeting	82
BCM got what wanted in ISP	67
Index of ISP control:	
Low control (0-2 items)	44
Medium control (3-5 items)	35
High control (6-8 items)	21

- Combining the responses to all the items concerning the ISP meeting creates an index of ISP control. Less than a fourth of respondents (21%) scored high on this index, and 44% scored low¹².
- Those with high control tend to be individuals who do not have a guardian (42% of them have high control), suggesting that ISCs make more effort to engage the individual in ISP decisions if there is no one else formally speaking for the individual.
- Those with high control are also disproportionately individuals who live in CILAs (Chart 10). Over a third (35%) of CILA dwellers experience high control over their ISP, compared to only 8% of people in ICF or nursing homes; and, conversely, a much higher



¹² High ISP control means the individual gave a positive response to 6 or more of 8 questions; see definitions at end of report

proportion of ICF and nursing home residents experience low ISP control (67%) than do CILA occupants (15%).

The extent to which Bogard class members *participate in integrated activities* is a crucial measure of the improved quality of their lives. Although it is not a mandate of the Bogard court decree, increased community integration is certainly a major result to be expected from movement to a more independent living situation, and is an explicit goal underlying the emphasis on specialized services.

- Daytime activities of Bogard respondents are primarily work-related (45%); another 23% say their daytime activities are recreational, and the remaining 32% say they do ADLs, watch TV, or "do nothing".
- When asked *where* they spend their day doing these activities, the vast majority (60%) respond with a segregated setting, primarily the ICF or nursing home where they live. Another 32% who do not live in segregated settings say they do the activities in their own home, hence they do not go out into the community. Only 8% go into the general community on a daily basis.
- A similar question about how they spend their evenings and weekends revealed the same pattern of isolation: 74% of Bogard respondents say they watch TV, sleep or do some other passive stay-at-home activity. The 26% who do go on evening or weekend outings are disproportionately CILA residents – 73% live in CILAs although CILA residents constitute only 42% of the sample.
- Forty-four percent of Bogard respondents are eligible for specialized services; 37% are currently receiving specialized services. These proportions are even greater among the total Bogard population served by the sampled agencies: 57% are eligible and 75% of those eligible currently receive specialized services. [These latter figures are very close to the March 1995 data provided by the Office of the Court Monitor, indicating that 58% of Bogard class members were eligible and 85% of eligibles were receiving specialized services.]¹³
- Among the Bogard respondents receiving specialized services, ISCs report that most of these individuals (69%) are receiving the services outside of the facility, suggesting that ISCs are trying to increase community integration for people who have chosen to stay in the nursing home. In addition, over half (57%) of those individuals receiving services have been receiving some type of specialized services for more than six months. This is comparable to Office of the Court Monitor figures for February 1995, indicating that 56% of Bogard class members receiving specialized services of any type had been receiving them for three months or more.

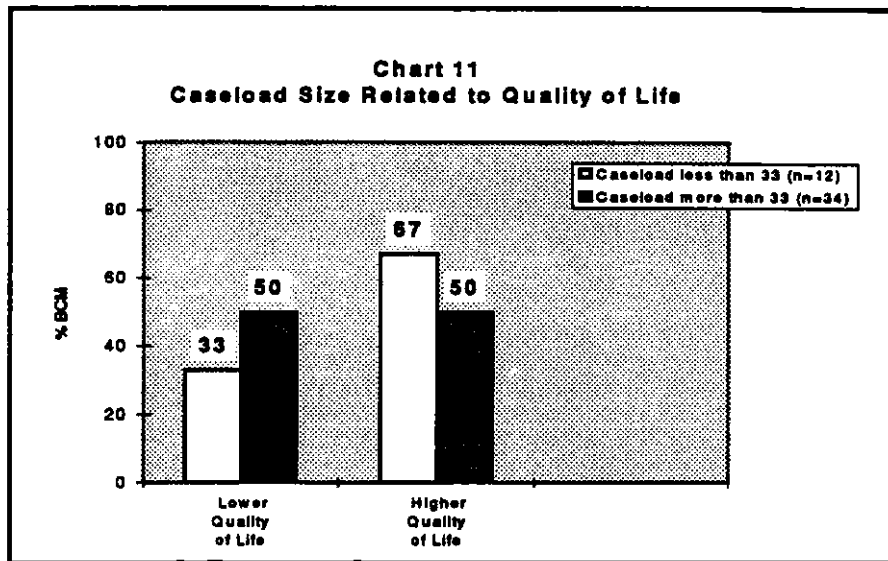
These many different outcomes discussed thus far in this section can be roughly combined to create a measure of overall quality of life for each Bogard class member. This measure can then be more easily associated with ISC caseload characteristics.

- On a scale of 0-8, only 4% of Bogard respondents experience a high level of quality in their lives; 50% have a medium level, and 46% experience low quality of life¹⁴.

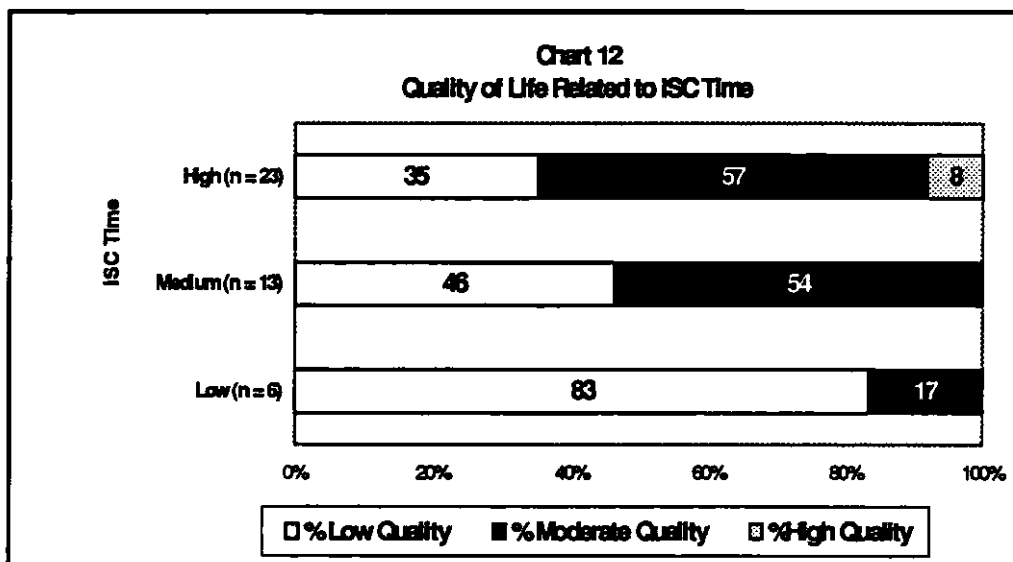
¹³ May 25, 1995 memo from Office of the Court Monitor; data do not include figures for three of the larger ISC agencies, hence the percentages overrepresent the proportion of those eligible who are receiving specialized services.

¹⁴ High quality of life is a score of 6 or more on a scale of 8, medium is 3-5, low is 0-2; see definitions at end of report.

- Bogard respondents who are part of a smaller caseload experience greater quality of life (Chart 11): 67% of those on caseloads of 33 or less have a high or medium quality of life, compared to only 50% of class members on large caseloads.



- Similarly, Bogard respondents whose ISCs spend more time with them are more likely to have higher quality of life (Chart 12): 8% of those who have the highest ISC time have a high quality of life, while none of the individuals getting less time from their ISCs have high life quality. The converse is also true – those whose ISCs spend a low amount of time with them are much more likely to have low quality of life (83%) than individuals whose ISCs spend more time with them.



These findings clearly highlight the importance of caseload size and ISC time to class members achieving a range of positive outcomes.

III. IMPLICATIONS AND RECOMMENDATIONS

The findings above have significant implications for Bogard service coordination policy and practice.

- ◆ The Bogard class member sample well represents the demographic and geographic variation in the Bogard population; even though it is not statistically representative of the universe of Bogard class members, the sample provides valuable insights on supporting people with disabilities who have lived in nursing homes. The study also testifies to the ability of these individuals to respond to detailed questions about their experiences, suggesting that such surveys should be used regularly to assess program success.
- ◆ Less than a third of the sampled ISCs are currently in compliance with the 1:30 ratio, suggesting that coming into compliance is not easily within the agencies' grasp. Responsibility for improving compliance should be equally shared by agencies and DMHDD.
- ◆ The lack of caseload specialization does not seem to hinder service coordination, and offers an avenue for ISCs to cope with high caseloads, by differentially assisting individuals.
- ◆ Two groups of Bogard class members – those who have no guardian, and those who live in CILAs – receive more time from their ISC and experience greater control over their ISP, suggesting that ISCs take more seriously their role as advocate when there is no legal guardian and/or less staff support for individuals. These findings argue for giving ISCs the discretion to spend more or less time with individuals based on their needs, and providing ongoing assistance to ISCs in making these judgments.
- ◆ The tasks performed by ISCs do not appear to differ significantly from conventional case coordination activities, with the more innovative and challenging tasks (such as developing new services and support networks) being less well understood and less often done. As Bogard class members settle into their changed lives and ISCs become more comfortable with their role, increased attention should be given to hands-on training and mentoring for ISCs, to enable them to better foster meaningful life changes for class members.
- ◆ Flexibility in performing the job and availability of supervisors and peers to consult with are key factors for ISCs in successfully doing their work, suggesting that agencies should be encouraged (and rewarded) for their support to ISCs.
- ◆ The quality of life of Bogard class members is enhanced by smaller caseloads and by ISCs spending more time with the individual; smaller caseloads also make ISCs feel less overwhelmed by the tasks confronting them, thus enabling them to focus more clearly on individuals' needs. While a 1:30 ratio does not seem to be a "magic number", it is clear that caseloads in excess of 40 clearly inhibit successful service coordination.

These observations point to several particular changes which could enhance the independent service coordination function for Bogard class members.

- ☛ Make the mandated ratio (1:30 or something close to that) an *average* for an agency as a whole, allowing the agency and the individual ISCs to carry a few more (or a few less) cases depending on the pressing issues facing the individual.

- ☛ Accompany this increased flexibility in caseload size with increased *specificity* about what tasks should be highest priority for ISCs to perform, such as developing innovative and varied supports for class members.
- ☛ Take advantage of the potential for shifting some ISC tasks to providers, since the support staff are doing much of it anyway and the Bogard class members count on them. Among the tasks that could be shifted include: seeing that things are going well, answering day-to-day questions, and arranging transportation.
- ☛ Give prompt attention to training and mentoring opportunities for ISCs; they are committed to the work, persistent, and could greatly benefit (as would the Bogard individuals they serve) from hands-on assistance with the more innovative and unfamiliar aspects of service coordination, especially building community and quality of life for Bogard class members.

DEFINITIONS

Support staff: includes individuals who provide supports, residential staff, and day program staff.

Difficulty/importance/time-consuming nature of ISC tasks: a measure of the number of tasks the ISC judges to be among the hardest to do, the most important, or the most time-consuming. The tasks include:

- arranging and holding ISP meetings
- keeping in touch with service providers
- visiting the individual at residence and day locations
- filling out required forms
- implementing the choice protocol
- connecting the individual to needed services and supports which exist
- finding needed services/supports which do not yet exist
- developing “community” around individuals
- crisis resolution
- problem-solving for the individual or guardian
- problem-solving for service providers
- arranging needed transportation.

Each item counts 1, for a maximum of 12. *Low* is a score of 0-2, and *high* is a score of 3 or more.

ISP Control: a measure of the extent of decision-making control the Bogard class member experiences in ISP meetings, created by summing the positive responses to a series of questions about the most recent ISP meeting. Specifically, it includes the following items:

- Did anyone come other than you and ISC?
- Did you invite others to come?
- Did you decide who came?
- Did you understand what people were talking about?
- Did you get a chance to talk?
- Did other people listen, and respect your wishes?
- Did you feel a part of things?
- Did you get what you wanted?

Each item counts 1, for a maximum of 8. *High* is a score of 6-8, *medium* is a score of 3-5, and *low* is a score of 0-2.

ISP Time: a measure of the number of tasks the ISC is reported doing for the Bogard class member and the frequency the ISC sees and talks with the individual (all of which together constitutes a proxy for the amount of time the ISC spends on the individual). Specifically, it is the sum of the following values:

- Score 1 for each of the tasks “which the ISC does for you”, including:
 - spend time to get to know you
 - tell you what services you can and cannot get
 - get people together to plan for you
 - help you find services you need
 - introduce you to new people to support you
 - make sure things are going well for you
 - help you understand how to get what you need
 - keep you informed of changes before they happen
 - answer your questions and help you solve problems
 - arrange for transportation
 - give you a choice about where you live
 - do necessary paperwork for you

- Score 1-4 for “how often you see your ISC”: weekly (4), monthly (3), every few months (2), less than that (1)

- Score 1 if “you speak on the phone with your ISC”

The maximum is 17. *High* is a score of 12-17, *medium* is a score of 6-11, and *low* is a score of 0-5.

Quality of life: a measure of overall quality of life of Bogard class members, created by summing the positive responses to questions concerning satisfaction with living situation, control over ISP meetings, and inclusiveness/integration of day and weekend activities. Specifically, it includes the following items:

- Would you like to move somewhere else? (reversed)
- Are you happy here?
- ISP control index (recoded to 0-2)
- How did you come to be living here? (scored 1 if response was “own choice”)
- Where do you go for daytime activities? (scored 1 if response was “integrated”)
- Where do you go for evening and weekend activities? (scored 1 if “integrated”)
- Where do specialized services occur? (scored 1 if “outside of facility”)

Each item counts 1, except for ISP control as noted, for a maximum of 8. *High* is a score of 6-8, *medium* is a score of 3-5, and *low* is a score of 0-2.

Appendix A

List of Service Coordination Agencies and Agency Contact People

Steve Deusinger, Don Bowers
& Mary Riddle
Central Illinois Service Access
1491 Valle Vista
Pekin, IL 61554
309-347-7202

Betty Ghent & Gary Hake
Southern Illinois Case Coordination
519 South Locust
Centralia, IL 62801
800-828-7422

Roberta Grawe
West Central Service Coordination
120 East Second Street
Beardstown, IL 62618
217-285-5227

Pat Pella & Marina Oliphint
Champaign County Reg'l Planning
Commission
1303 N. Cunningham Avenue
Urbana, IL 61801
217-328-3313

Joanell Voight, Steve Zider &
Mary Andrews
Community Alternatives Unlimited
800 W. Bryn Mawr (Ste. 500 South)
Chicago, IL 60631
312-714-9400

Mary Jane Friedrich
Western Ill. Service Coordination
440 N. Lafayette St. (Ste. 4)
Macomb, IL 61455
309-833-1621

David Gorenz
Access Service Inc.
1009 Main Street
Mendota, IL 61342
800-447-8869

Louise Nash & Rich Ebbens
South Suburban Access
925 W. 175th St. (3rd Floor)
Homewood, IL 60435
708-799-9190

Janice Prunier-King
Options & Advocacy of McHenry
County
P.O. Box 305
Crystal Lake, IL 60039-0305
815-477-4720

Appendix B:
Data Collection Forms

Interview guides:

- Bogard Class Member Interview Questionnaire
- Telephone Interview Questions for Service Coordinators
- Telephone Interview Questions for Agency Directors

Supplemental information forms:

- Background information on Bogard Class Members
- Letter to facilities
- Informed Consent Form
- Charts on caseload composition
 - ⇒ agency-wide
 - ⇒ Independent Service Coordinator

**BOGARD CLASS MEMBER
INTERVIEW QUESTIONNAIRE**

Note to interviewers: Before going to the interview, look at questions #3 & 4 to see if they are applicable; if not cross them out now. Also, in items # 1,3,6,9,14,20d.,23,24,25,26,27a, fill in the name of the Independent Service Coordinator (ISC). Where there is not enough space for an answer, use the back of the page or attach an additional sheet. Brief point form answers are fine. Try to stay with the questions if possible, but reword them if necessary. Thank you!!

1. Do you know the name of your service coordinator? (or the person who helps you with planning and arranging things about where you live, work, or get places?)

YES; (note answer here) _____
 NO; (or if answer doesn't agree with what you have, say, This is who we were told is your service coordinator. and give ISC name.) _____

2. How did you come to be living here? (or: Who decided you would live in this house,apartment, ICF, nursing home? or: Who picked this particular place for you to live?)

3. (If the person has moved, ask this question:)

Did _____ (ISC name) help you move here? YES NO

4. (If the person lives in a group home or apt. :) How many other people live here with you? _____
 Did you choose to live with these people? YES NO

5. Are you happy here? YES NO

6. Has _____ (ISC name) talked to you about moving? YES NO

7. Would you like to move somewhere else if you could? YES NO (SKIP to # 10)

8. Where to? _____

9. Is _____ (ISC name) working with you to find a place?

YES; (SKIP TO # 11) NO; (SKIP TO # 11)

10. What is it that keeps you here? (or: ..What do you like about living here?)

11. Have you had any other service coordinator since you moved here? YES NO (SKIP to # 14)

12. Who was this? _____

13. Why did you change service coordinators? _____

14. How did you get _____ (ISC name)?

15. How often do you see him/her? (Circle one.)

- a. once a week
- b. once a month
- c. every few months
- d. less often

16. Where do you meet when you see him/her? (Circle one.)

- a. your home
- b. service coordination office
- c. your workplace
- d. other _____

17. How much time do you spend together when you meet? (Circle one.)

- a. a few minutes
- b. a half hour
- c. an hour or more

18. Do you also speak to him/her on the phone? NO (SKIP to # 20)

YES; how often? (Circle one.)

- a. every day
- b. weekly
- c. monthly
- d. less often

19. When did you last speak with him/her on the phone? (Circle one.)

- a. in the past week
- b. in the past month
- c. longer ago

20. When you want to get in touch with him/her, how do you do it? (Circle one.)

- a. ask residential or day counselor to do it
- b. ask advocate or family to do it
- c. phone yourself
- d. wait for _____ (ISC name) to contact you
- e. other _____

21. Is it easy to reach him/her? YES NO

22. If you leave a message, does he/she call back promptly? YES NO

23. I'm going to name some things that service coordinators may do and I'd like you to tell me if _____ (ISC name) does any of these things with you or for you. Does he/she...

- | | | |
|--|-----|----|
| a. spend time with you to get to really know you | YES | NO |
| b. tell you what services you can and cannot get | YES | NO |
| c. get people together to make a plan for you | YES | NO |
| d. help you find services you need | YES | NO |
| e. introduce you to new people to help you in new or different ways | YES | NO |
| f. make sure that things are going well for you, by talking to you and by being with you at home and at work | YES | NO |
| g. help you understand how to get what you need | YES | NO |
| h. keep you informed about changes <i>before</i> they happen | YES | NO |
| i. answer your questions and help you solve problems as they come up | YES | NO |
| j. arrange for transportation to get you places you need and want to go | YES | NO |
| k. give you a choice about where you live | YES | NO |
| l. do necessary paperwork for you | YES | NO |

24. What is the most important thing _____ (ISC name) does for you?

25. Are there other things you would like _____ (ISC name) to help you with?

26. When you first met with _____ (ISC name), did you talk about what you wanted to do in your life, your hopes, dreams and goals? YES NO

27. When was your last meeting? (May need to use the terms IHP, ISP, or planning meetings.)

Let's talk about that meeting:

- | | | |
|--|---|---|
| a. Did any people come, other than you & _____ (ISC name)? | Y | N |
| b. Did you invite these or other people to come? | Y | N |
| c. Did <u>you</u> decide who came to the meeting? | Y | N |
| d. Did you understand what people were talking about? | Y | N |

- e. Did you get a chance to talk? Y N
- f. Did other people listen, and respect what you wanted? Y N
- g. Did you feel part of things? Y N
- h. What did you say you wanted? _____

28. Did you get what you wanted? YES NO
29. How long did it take to get what you wanted? (*Circle one.*)
- a. a few days
 - b. a few weeks
 - c. a few months
 - d. longer

30. If you didn't get what you wanted, what did you do about it? _____

31. Do you have family who visits you?
- NO
- YES; how often? (*Circle best answer.*)
- a. daily?
 - b. weekly?
 - c. monthly?
 - d. less often?

32. Do you have someone who helps you speak up for yourself? YES NO

33. When you have a question or a problem, who do you turn to? _____

34. Who can you count on the most to help you, to be there when you need something, to listen to you? _____

35. What do you do during the day?

36. Where do you go for these things?

37. Is it the same every day? YES NO
(*Note other services, if any:*) _____

38. What about weekends and evenings? _____

39. Who does these things with you (*helps you*) Prompt: *Are there people in your family, from your services, or church friends who help you or do these things with you?*

- | | | |
|--|-----|----|
| 40. Do all the people who support or help you show respect for you? | YES | NO |
| 41. Do they ask you when and how you want to do things? | YES | NO |
| 42. Do they take time to be with you, and to listen to you? | YES | NO |
| 43. Do any of these people who help you: | | |
| a. tell you what services you can and cannot get | YES | NO |
| b. get people together to make a plan with you | YES | NO |
| c. help you find services you need | YES | NO |
| d. introduce you to new people to help you in new or different ways | YES | NO |
| e. make sure that things are going well for you | YES | NO |
| f. help you understand how to get what you need | YES | NO |
| g. keep you informed about changes <i>before</i> they happen | YES | NO |
| h. answer your questions and help you solve problems as they come up | YES | NO |
| i. arrange for transportation to get you places you need and want to go | YES | NO |
| j. give you a choice about where you live | YES | NO |
| k. do necessary paperwork for you | YES | NO |
| l. spend time with you to get to really know you | YES | NO |
| 44. Are there other things you would like to do or learn, that you haven't been able to yet? | | |
| 45. Is there anything else you'd like to tell us about your service coordination? | | |

Thank you very much for talking to us about your services and the people who help you! The information you gave us today will help the state know more about what people with disabilities in Illinois need from their service coordinators.

**TELEPHONE INTERVIEW QUESTIONS
FOR SERVICE COORDINATORS**

1. How long have you been a service coordinator?
2. What brought you to this type of work? What keeps you here?
3. How much longer do you expect to be a service coordinator?
4. The information you provided to HSRI prior to this interview shows that you currently have ___ people on your caseload. What is the largest caseload you have ever had, as a service coordinator? _____ What is the smallest one? Which of the three – current, largest, or smallest – has been the toughest to carry, and why?
5. How do people get assigned to be on your caseload? Do you specialize in working with people with any particular disability, or types of needs, or geographic region?
6. What types and amounts of support do *you* get as a service coordinator? How valuable are each of these in motivating you to do your job?
 - a. Supervision:
 - b. Clerical assistance
 - c. Training opportunities
 - d. Technical assistance activities
 - e. Opportunities for networking with peers
 - f. Access to a resource development specialist
 - g. Written guidance (manuals, etc.)
 - h. Salary and benefits
 - i. Other: _____
7. Where do you work from, your home or an office? _____

8. How much flexibility does your job have, in terms of the time of day (or night) you work, getting compensatory time, getting overtime, etc.?

9. Of all your assigned responsibilities, which ones take the most time? which are the hardest to do? which do you think are the most important?

	Most time	Hardest	Most important
a. Arranging and holding ISP meetings			
b. Keeping in touch with service providers			
c. Visiting the individual at residence and day locations			
d. Filling out required forms			
e. Implementing the Choice protocol			
f. Connecting the individual to needed services and supports which already exist			
g. Finding needed services and supports which do not yet exist			
h. For individuals who live in the community, developing "community" around them			
i. Crisis resolution			
j. Problem-solving, responding to calls from the individual or guardian			
k. Problem-solving, responding to calls from service providers			
l. Arranging needed transportation			
m. Other: _____			

10. Of the people on your current caseload, which types of people need the *greatest* amount of support from you? Describe why.

11. Of the people on your current caseload, which types of people need the *least* support from you? Describe why.

12. Describe how you spent your past week:

13. How do you "monitor progress in relation to the service plan"? What does this involve -- observing individual, talking by telephone with service providers and family/guardian, reviewing written records, talking with the individual, etc.? (use most recent example of an informal review or monitoring)

14. What is involved in conducting a "formal review" (annual)?

15. How do you determine whether appropriate generic services and/or "natural supports" exist which could meet the individual's needs?

16. If the needed services or supports do not exist in the community, how do you go about meeting the needs?

17. How do you nurture a network of supports for the individual?

18. What types of advocacy activities do you generally perform?

19. How do you go about offering genuine choices to individuals regarding where they live? How do you decide what options are available? Do you invite all providers to the Choice meeting to make presentations? Do you go on all site visits with the individual?

20. How much time does it usually take between when the individual chooses the place he/she wants to live, and the time he/she actually moves in? _____
What barriers exist to this process happening even more quickly?

21. In these activities (items 13-20), how closely do you work with service providers? How much responsibility do they have for these activities?

TELEPHONE INTERVIEW QUESTIONS FOR AGENCY DIRECTORS

1. How long has your agency been doing service coordination?

2. What changes, if any, did your agency have to undergo to come into compliance with the Bogard decree regarding independent service coordination?

How difficult was this process?

3. How many FTE service coordinators does your agency currently employ? _____
How many additional FTE positions are vacant? _____

4. How many FTE service coordination supervisors does your agency currently employ? _____ How many additional FTE positions are vacant? _____

5. How do you find service coordinators? How do you recruit people to be service coordinators?

6. What types of training, mentoring, and supervision does your agency provide to its service coordinators?

a.. Training opportunities:

b.. Mentoring activities:

c. Supervisory activities:

7. How many different people have worked as service coordinators with your agency in the past year (calendar 1994)? _____
How many of these people have left your organization? _____ How many of these people have ceased or decreased their service coordination responsibilities? _____

8. What factors have the greatest impact on your agency's ability to retain service coordinators?

9. How does your agency decide who will be the service coordinator for each Bogard class member? (e.g. geography, specialization, space available on caseload, etc.)

10. What training and/or technical assistance is *available* to service coordinators from outside your agency, relating to Bogard or other service coordination concerns?

To what extent do your agency's service coordinators take advantage on these opportunities?

11. Regarding the caseload information your agency provided to HSRI prior to this interview: What do you see as the biggest barriers to coming into compliance with the Bogard 1:30 ratio?



Human Services Research Institute

525 Glen Creek Road (#230), Salem, OR 97304 Phone: (503) 362-5682 Fax: (503) 362-7729

Confidential Background Information for Interviewers

1. Name of Bogard class member to be interviewed _____

2. Where does this person currently live?
 - a. CILA(24-hour)
 - b. CILA (intermittent)
 - c. ICF-DD or ICF-MI
 - d. Nursing facility
 - e. Other _____

3. Name of Independent Service Coordinator (ISC) _____
4. Name of residence (if any) _____
5. Address _____
Directions: _____

6. Phone number _____

7. Name of staff person to contact to arrange interview, if any _____

8. Does _____ have a legal guardian? Yes No

9. Is there someone who is a special friend or support person? Yes No

10. Name of support person _____
Relationship _____
Phone number _____

11. Disabilities which may affect the interview situation (circle letter of any limitation & make note)
 - a. speech / communication:
 - b. mobility:
 - c. vision:
 - d. hearing:
 - e. medical involvement:
 - f. challenging behaviors:

Additional Information To Be Obtained From ISC's

1. Geographic location currently: urban suburban rural

2. Where was he/she living when identified as a Bogard class member?
 - a. Own home or parent's home
 - b. Institution
 - c. ICF-DD or ICF-MI
 - d. Nursing facility
 - e. Other _____

3. Date of birth of class member _____

4. When was person identified as a Bogard class member? _____

5. Type of disability: MR not MR (Circle)

6. Additional disability labels or categories: _____

7. When did individual move from this location to the current location?

8. How long have you been service coordinator for this person? _____

9. How long has your service coordination agency been serving this person?

10. In the past, did your agency provide services in addition to service coordination? YES NO

11. What services/ supports is the person currently receiving?

12. What agency or individuals provide the services and supports the person receives?



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December 19, 1994

Dear Residential Administrator;

Under the auspices of the Illinois Office of the Court Monitor, Human Services Research Institute (HSRI) is studying various aspects of the service coordination provided to class members under the Bogard v. Bradley consent decree. As part of this study, HSRI will be conducting interviews with 60 Bogard class members throughout the state.

This letter is to notify you that someone from People First of Illinois will be calling you to arrange an interview with the Bogard class member(s) listed below. If feasible, the interviewer would like to talk directly to the class members to explain the following:

- The purpose of the interview is to learn about service coordination.
- We are notifying all legal guardians of our request for interviews with individuals they represent.
- It is not necessary to have staff present for this interview; in fact to assure the class member complete confidentiality of his/her responses, we would prefer that staff from the agency only be present if absolutely necessary.
- Individuals are encouraged to have a family member or other person present for support; we prefer that it not be a person providing direct services.

For your information, we attach a copy of the consent form which our interviewer will go over with the class member prior to doing the interview.

Thank you for your assistance in this effort to assure that service coordination is working for people with disabilities in Illinois. Please feel free to call me at the above number if you have any further questions.

Sincerely,

Lynda D. Brown, M.S.
Research Associate



Human Services Research Institute

525 Glen Creek Road NW, #230, Salem, OR 97304 Phone: (503) 362-5682 Fax: (503) 362-7729

INFORMED CONSENT FORM

Under the auspices of the Illinois Office of the Court Monitor, Human Services Research Institute (HSRI) is studying the quality of the service coordination provided to class members under the Bogard v. Bradley consent decree. HSRI will be conducting interviews with 60 Bogard class members throughout the state living in various types of living arrangements, in rural and urban areas, and who are being served by small and large agencies.

We would like to interview you for this study. Our main questions for you are about your *Independent Service Coordinator* and how she or he works with you. This interview should take about 30 minutes.

Any information you give will be kept strictly confidential. Your interviewer is a member of People First of Illinois, but the confidential information you provide today will be sent, in its entirety, to Human Services Research Institute in Salem, Oregon. If you have any questions, you may contact Lynda Brown of HSRI at (503) 362-5682 or Leigh Ann Reusche of People First of Illinois at (708) 365-6996.

Your participation in this project is entirely voluntary. You are free to withdraw your consent and discontinue your participation at any time. Your participation or your refusal will in no way affect your receipt of services.

I agree to participate in this study of independent service coordination.

(Signature)

(Date)

Please complete by 1/20/95 and fax to 503-362-7729 Human Services Research Institute, 525 Glen Creek Rd. (Ste. 230), Salem, OR 97304 503-362-5682 Phone
 Please complete for all Independent Service Coordinators working in your agency and all Bogard class members being served by your agency. Thank you!

Agency _____
 Person Completing Form _____

**SERVICE COORDINATION INFORMATION
 FOR ENTIRE AGENCY**

Name of Service Coordinator	% time spent on service coord.	Number of individuals on caseload by type. (use categories below)					Names of all Bogard class members	Current living arrangement ¹	Choice ² as of 1/1/95
		Bogard	OBRA	Prgm 50	CSLA	Other			

¹ code as follows: NH= nursing home; ICF= ICF-DD or ICF-MH; CI= CILA 24-hour; C2= CILA Intermittent.
² code as follows: 1= chose to move and have done so; 2= chose not to move; 3= chose to move but have not done so yet; (If have moved, but want to again, code as 1.)

Name of agency _____
 Name of person completing form _____

To be completed by all agency service coordinators. Please complete and return to your agency Bogard supervisor by 1/20/95. Thank you!
 (Note to Agency Supervisor: Please fax to 503-362-7729 Human Services Research Institute, 525 Glen Creek Rd. (Ste. 230), Salem, OR 97304 503-362-5682 Phone.)

**Bogard Service Coordination Information
 For Each Service Coordinator**

Names of all Bogard individuals receiving service coordination from you	Living location			Characteristics of individual		Currently receiving specialized services? Yes, 1 No 2
	Urban	Suburban	Rural	Severe medical involvement (Y/N)	Mental health or behavioral issues (Y/N)	

¹ code as follows: in = specialized services provided in the residential facility
 out = specialized services provided in another location in the community

² Add date that specialized services began

³ If not eligible, put N/A.

If services have not yet begun, leave blank.