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A.J. Pappanikou Center for Developmental Disabilities
A University Center for Excellence in Developmental Disabilities Education, Research and Service

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Consumer and Family Perspectives on Services Provided by Connecticut's State Agencies

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Do citizens with disabilities perceive agency activities as supportive of self-determination and consumer empowerment?

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PURPOSE OF THIS REPORT

One of the goals of the Real Choice System Change grant is to "work with state agencies to enhance their capacity to provide services by including persons with disabilities and their families as partners and decision makers in service design and delivery." The findings profiled here are one effort to achieve that goal. This report examines data that several state agencies have collected from Connecticut consumers with disabilities and their families. In a historical period when old assumptions about persons with disabilities have been discarded and new practices and policies are still being formulated, our aim is to learn whether the intended beneficiaries of agency policies and practices are finding themselves more respected as partners, more empowered as decision makers, and moving farther in the direction of leading self-determined lives.

This report is a follow-up to an earlier report issued in reference to this same goal.[1] Our aim in the earlier study was to learn to what extent several key state agencies and bureaus in Connecticut that serve citizens with disabilities have embedded concepts such as partnerships with families and consumers, consumer decision making and self-determination into the training of their staff. That publication was meant to be a "view from the top." Our informants, that is, were leaders involved in crafting and implementing training and professional development within various state government divisions, bureaus, and agencies.

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[1] Beyond services to clients: Are we training staff to support self-determination and consumer decision making? was issued in the summer of 2004. It is available on the web site of the A. J. Pappanikou Center, http://www.uconnucedd.org/Projects/RCSC/Default.htm.

As a follow-up, the Real Choice Steering Committee wanted to develop a companion report that would provide a “view from the grass roots.” We hoped to capture the perspectives of consumers (and their families) receiving services from the same agencies that were profiled in the earlier study. We soon learned that several of the agencies in which we were interested had invested resources in soliciting feedback from consumers of their services--some quite substantial in their scope and others more modest. We decided that rather than gathering our own independent input from consumers and families, we would conduct a review and analysis of these data that had already been collected. This effort, we hoped, would provide a good window onto the grass-roots perspective, and would also inform the agencies themselves about how their particular efforts at capturing consumer perspectives were similar to or different from those undertaken by other agencies.

OVERVIEW OF AGENCIES AND DOCUMENTS

We started the earlier project by selecting eleven bureaus and agencies. For the current inquiry, we once again sought information from each of them except for the Office of Policy Management (OPM).[2] We obtained responses from nine of the ten.[3] Among the nine responding divisions or agencies, the data provided by six of them form the centerpiece of this report. These were BESB, BRS, CDHI, CSDE, DMHAS, and DMR. Table 1 lists these six agencies and the types of data generated from consumers or families that we received from them.

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[2] The consumers of the services of OPM are not individual Connecticut citizens and families but other state-level entities. Therefore, OPM would not ordinarily seek feedback directly from consumers with or without disabilities.

[3] The agency that did not respond to our queries was the Division of Health Systems Regulation, Bureau of Health Care Systems, Department of Public Health (DPH).

Table 1. State Agencies that Systematically Gathered Data from Consumers with Disabilities, Families, or Both

AGENCY NAME	TYPES OF DATA
Bureau of Education and Services for the Blind (BESB)	• Evaluation of BESB's vocational rehabilitation (V.R.) services by University of Connecticut's Center for Survey Research and Analysis (CSRA) • CSRA evaluation of BESB Birth to Three Program. • BESB's V.R. consumers were surveyed along with consumers of V.R. agencies across New England by a Maine-based firm.
Bureau of Rehabilitation Services/ Department of Social Services (BRS), Vocational Rehabilitation Division	• Consumer Satisfaction Survey (2002) • Connecticut BRS Quality Assurance Survey (2004)
Connecticut State Department of Education (CSDE), Bureau of Special Education	• Parents' Perceptions of the P.J. Settlement Agreement • Secondary Transition Study: Statewide follow-up survey of Year 2000 special education students exiting High School • Connecticut Special Education Program Review, Summary of Student Surveys, 2000-2003. • Part B 2003 Annual Performance Report • Connecticut Special Education Program Review, 2002-2003 Parent Survey Summary
Commission on the Deaf and Hearing Impaired (CDHI)	• Survey data from higher education students who used sign language interpreters funded by the agency.
Department of Mental Health and Addiction Services (DMHAS)	• FY 04 Consumer Survey Questionnaire • DMHAS Consumer Survey FY 03 Executive Summary • Voice Your Opinion/What Did Consumers Say? Highlights and Data Details from the "Voice Your Opinion 2000-01" Consumer Survey
Department of Mental Retardation (DMR)	• National Core Indicators surveys • Data on number of persons involved in self-directed supports • Information about employment of self-advocates as DMR staff • Complaints or concerns lodged with the Office of the Ombudsperson, Annual Report 2003

Table 2 lists the other agencies that responded to our queries and the types of information we obtained from them. Some of their data helped to further refine the picture but none of them accessed the opinions of consumers or families in a systematic fashion.

Table 2. State Agencies with Limited Data from Consumers or Families

AGENCY NAME	RESPONSE TO OUR REQUEST
Children's Mental Health Division, Department of Children and Families (DCF)	• Information about support for parent advocacy • Information about Community KidCare Administrative Services Organization Request for Proposals
Connecticut Council on Developmental Disabilities (CCDD)	• The agency is operated by a council composed primarily of consumers. Its grantees are often involved in gathering data from consumers but the agency itself does not.
Office of Protection and Advocacy (OPA)	• Described methods they use to solicit consumer feedback but did not provide us with the substantive contents of such feedback.

OUR FOCUS

Our priorities in reviewing the data were distinct from the priorities the agencies had when they collected these data. For instance, a survey of consumers making use of the BRS vocational rehabilitation services would logically ask about their satisfaction with employment counselors and employment plans. One would expect surveys of individuals using DMHAS services to ask about their satisfaction with the quality of medical and counseling services. But questions like these, specific to each agency's mission, were not our priorities. Our focus was driven by the principles underlying the Real Choice System Change project. Were agencies asking consumers with disabilities and their families if they were satisfied with their levels of involvement and decision making? Did citizens with disabilities indicate whether they perceived themselves as partners (and believed they were treated as such) rather than just clients? Did the data collected by the selected public agencies tell us anything about the progress of persons with disabilities (and their families) in Connecticut in shaping their own self-determined lives? In sum, our emphasis was on examining the process that citizens experienced as they utilized state services and on the roles and relationships they took on in connection with these services, rather than on the quality, range, or efficacy of the services.

AGENCIES THAT SYSTEMATICALLY GATHER DATA FROM CONSUMERS AND FAMILIES

BRS (Division of Vocational Rehabilitation, Bureau of Rehabilitative Services, Department of Social Services)

BRS completed two consumer surveys in recent years that profiled consumer perspectives on vocational rehabilitation services. In the fall of 2002, BRS engaged an independent research center (University of Connecticut's Center for Survey Research and Analysis, CSRA) to conduct a telephone survey of a random sample of consumers. Roughly 800 respondents completed the survey published under the title Consumer Satisfaction Study. Among the questions they answered were several that touched directly on self-determination principles. The survey asked each respondent to indicate the importance to him or her of any given aspect of the services received, and then to state how well their expectations had been met.

Respondents by frequencies of 71% rated "feeling like a full partner" to be very important. A similar 73% rated "developing a plan which reflected your talents" to be very important. By lower margins (61% and 59% respectively) the respondents pronounced themselves satisfied with their BRS services on these specific dimensions. Fully 96% of respondents indicated that "involving you in decisions" was important to them, and 90% found the agency doing well by that measure. When asked to rate their own vocational counselor on that point, 77% rated them with the highest possible "very good" score (10 on a scale of 1 to 10) with another 11% of the sample giving their counselors an 8 or a 9. By contrast, only 7.5% reported they were "not at all satisfied" that their plan reflected their talents, and 5.7% were "not at all satisfied" that they felt like a full partner.

Less affirming of BRS practices promoting self-determination was the response to the question, "Were you offered a selection of choices as your Employment Plan was developed?" Exactly half (49.8%) said yes, but one out of four (24.5%) said no, and others were not sure. When asked to comment on how "your own goals were included" in the Employment Plan, there were mostly but not entirely positive data. More than 4 out of 10 respondents (43.6%) said very well, and another one of four (26.3%) said somewhat well. Small proportions responded that their goals were included in their Employment Plans somewhat poorly (3.4%) or very poorly (also 3.4%). Nearly one of four respondents was not sure how well his or her goals had been included.

More recently, BRS joined with nine other public agencies across New England (including Connecticut's BESB) in the fall and winter of 2003 to 2004 to engage an independent researcher for the purpose of accessing the perspectives of those currently or recently utilized the agency's services. The surveys were completed both by telephone and mail. The Connecticut BRS Quality Assurance Survey (the portion of the report produced specifically for BRS) details the responses of nearly 700 randomly drawn BRS consumers, breaks down the data statewide and by BRS Region, and also compares the

Connecticut BRS responses to the broader sample, which included over 5000 respondents in five states.

Some survey questions touched on the principles of interest to the Real Choice project, with questions constructed differently from the ones in the earlier survey. For instance, the survey asked how BRS respondents felt about the degree of control and involvement they had in their V.R. experience. More than 8 of 10 responded that they were either very satisfied (41%) or satisfied (41%). There were 4% very dissatisfied on this point and another 7% dissatisfied.

Fully 83% of respondents strongly agreed that division staff treated them with dignity and respect, and another 12% agreed, compared to 1% who disagreed and 2% who strongly disagreed.

Asked "how satisfied were you with the kind and amount of information you were given about the choices you had?" there were 38% very satisfied and 41% satisfied. There were also 3% very dissatisfied and another 10% dissatisfied. In each instance where dissatisfactions are noted, the survey report details them by region. For instance, in Region 1, the main source of dissatisfaction on this question was that 'there was a need to broaden programs." However, in the other four regions, the main source of dissatisfaction was that "there was not enough information about the choice of services available."

The least positive feedback that emerged from the survey, from the point of view of consumer empowerment, was among that portion of the sample (approximately one-fourth of the respondents) who had experienced some kinds of problems with their services. This subsample was asked, "Did the Connecticut BRS work to resolve this problem?" Only one out of four (25%) answered yes, while 64% (almost two out of three) answered no. Others were not sure.

BESB (Bureau of Education and Services for the Blind)

BESB engaged University of Connecticut's Center for Survey Research and Analysis (CSRA) to evaluate their vocational rehabilitation (V.R.) services in 2003 and again in 2004. The 2004 study succeeded in completing telephone interviews with 141 out of a universe of 190 participants in BESB's V.R. services, a response rate of 74%. The interviews were carried out in the fall of 2004.

Most of the data described the services respondents received (e.g., 18% used readers, 87% used low vision services) and their levels of satisfaction. For instance, of those using reader services, 73% were very satisfied and the remaining 27% were satisfied. Of those using low vision services, 85% were very satisfied, and another 11% were satisfied.

A few questions touched on issues of consumer empowerment. The survey asked how satisfied respondents were with their counselor's assistance in helping them understand their rights and responsibilities within the vocational rehabilitation system, how satisfied respondents were with the way their counselor helped them to identify career goals and services needed to achieve the goals, and the extent to which the services they received have met their expectations in accordance with their Individualized Plan for Employment (IPE). Compared to the questions that asked about specific services, however, a much higher proportion of respondents answered that they did not know. A plurality of respondents who gave answers were very satisfied, (44% with the help they received in understanding their rights, 44% in the help they received in identifying career goals, and 45% with the match between services received and the IPE.) Very small percentages (never more than 6%) expressed dissatisfaction in these areas. But for each of these three questions, there were 35% to 40% who stated they did not know (and a few others who skipped the question).

In 2003 to 2004, BESB joined with nine other public V.R. agencies across New England (including Connecticut's BRS, as discussed earlier in this report) to engage an independent researcher from out-of-state, largely for the same purposes as the studies carried out by the CSRA (i.e., monitoring the satisfaction levels and viewpoints of those who currently or recently utilized the agencies' V.R. services.) The surveys were completed mostly by telephone with a small number completed by mail. BESB released for our review the executive summary of the <u>Quality Assurance Survey</u> (the portion of the report produced specifically for BESB). It profiles the responses of 162 completed surveys from recipients of BESB Vocational Rehabilitation services. This was a strong 69% response rate.

As with the in-state study, most of the data described the services respondents received and their levels of satisfaction (e.g., "adaptive equipment and low vision aids were the most helpful services provided;" "75% indicated that the services provided met their expectations.") The report also determined the proportion of BESB respondents that were employed (31% either full- or part-time)—something not addressed in the other survey.

As in the other survey, some of the questions touched on the principles that are of interest to the Real Choice project, such as knowing their rights, feeling a sense of control, and being given adequate information about choices. For instance, 88% of respondents rated their counselor positively in "helping them to understand their Rights and Responsibilities as a vocational rehabilitation client." Also, 81% reported that they were either very satisfied or satisfied with their "control and involvement" in their V.R. experience. They also reported in very large proportions (93% of respondents agreed or strongly agreed) that agency staff "treated them with dignity and respect." Asked "how satisfied were you with the kind and amount of information you were given about the choices you had?" there were 84% either very satisfied or satisfied.

As with the BRS respondents to the same survey, the strongest negative feedback was among that portion of the sample (approximately one-third of the respondents) that had experienced some kinds of problems with their services. This subsample was asked, "Did the Connecticut BESB work to resolve this problem?" Only one out of four (23%) answered yes.

Infants and toddlers with visual impairment

The agency also engaged the CSRA to evaluate the services received through the Birth to Three program operated by BESB. The total universe of such cases when the study was undertaken in the spring of 2004 was 25. Of these, the evaluators were able to gain the cooperation of 18 families, a 72% response rate. Nearly all (94%) were very satisfied with how much "BESB teacher values their opinions and input," and 100% were very satisfied that BESB teachers respected the target child. These questions are as close as the survey came to measuring the respondents' sense of empowerment or self-determination.

CDHI (Commission on the Deaf and Hearing Impaired)

The executive director of CDHI explained that the services CDHI provides most frequently are sign language interpreting for college and university students. As this service represents their major effort, this is the only one on which they regularly seek consumer feedback. They do so by hand delivering a survey and a self-addressed, stamped envelope to each participating student at the close of a semester. The survey asks the student to identify the name of the interpreter they are rating as well as the name of the educational institution and course name, but not their own name. The cover letter provided with the survey promises to keep their responses confidential. They are asked to indicate what language the interpreter used, to rate the interpreter on a five-step scale, from poor to excellent, and to indicate by yes or no whether they would like to have the same interpreter in the future. There is also a space for open-ended comments.

CDHI referred us to their web site for the data collected from these forms. The web site states that the percentage of "satisfied interpreting clients" was 98% for fiscal years 2001 and 2002. The numbers for more recent years were not yet posted as of spring 2005. Although further details are not posted, the executive director of the agency informed us that in each year, the surveys were distributed to 76 or 77 students, and that the return rate was 80% each year.

The agency does not ask the students any questions directly related to making decisions, other than the decision to request the same interpreter again. However, a notation in small print on the survey states that the "completion of survey does not guarantee student's interpreter preference in scheduling."

CSDE (Connecticut State Department of Education, Bureau of Special Education)

The Bureau of Special Education does not provide the educational services that are the focus of its mission. Those services are provided to children and families by local school districts (also known as LEAs). The Bureau serves these children and families in indirect ways, by working with the personnel of the LEAs. Thus, unlike other agencies treated in this report, the consumer feedback that CSDE receives does not concern its own efforts but the efforts of the districts whose services it monitors and supports.

The Bureau sometimes directly solicits the ideas and perspectives of adolescents and young adults with disabilities from ages 14 and up. For younger students from age three and up (and sometimes for older students too), it solicits input and feedback from parents or guardians, not the children themselves. When it comes to school children, the premise of many advocates for persons with disabilities is that inclusion in regular classrooms is the route most likely to lead, eventually, to full-fledged membership in society and an empowered, self-determined life.

2003 Annual Report to the federal Department of Education (Submitted in 2004 and covering the year that ended June 30, 2003)

The Bureau reports annually to the federal government on numerous aspects of Connecticut's educational services to students with disabilities. We examined the data in the 2003 Annual Report. A section of the annual report addresses how parents/guardians "participate as full partners in the planning and implementation of their child's educational program." In order to report on this matter, the Bureau collected data from parents of students with IEPs in the 26 LEAS located in the region labeled ACES. Districts were given a 32-question instrument developed by CSDE and used a variety of different means to disseminate the surveys. The overall response rate was reported as approximately 18%. Parents were asked if the school "listens to my suggestions and ideas when developing my child's IEP" (83% said yes) and also whether "I feel I am an equal partner…when we plan my child's program" (81% said yes).

Perspectives of Families Subject to the P.J. Settlement

Another area in which the Bureau has collected consumer/family input is in reference to the "P.J." settlement. The case referred to as P.J. was initiated by a small number of families of children classified as having mental retardation in 1991 and later widened to become a class-action suit. The settlement, reached in 2001, required the CSDE to facilitate greater inclusion at the district level of students with intellectual disabilities (the lexicon had changed since the case was first filed) in regular classrooms and extra-curricular activities. In the spring of 2004, the Bureau worked with research partners in mailing a survey to every household identified as having a student in Connecticut schools classified in the "intellectual disability" category. (The total came to a bit more than 3000.) Their intention was to determine whether these families were aware of the case and its settlement, and to find out if (in the perception of families) progress was being made towards full-fledged inclusion within and outside the classroom.

Approximately 21% returned the survey, with Blacks and Hispanics substantially under-represented in the returns.[4] As to the families' knowledge about the P.J. case, an impressive 74% of respondents had received information about the case, but it was not clear how many of them were referring to the information that arrived in the mail along with the survey.[5] Not surprisingly, a lower proportion (48.5%) stated they were specifically familiar with the five goals of the settlement.

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[4] The population of students with intellectual disabilities included nearly 28% Black non-Hispanics as well as 21% Hispanics, but the survey respondents included 13% African-Americans and 12% Hispanics.

[5] A summary of the settlement were mailed with the survey. Two-thirds of those who knew about the case reported they had received their information in the mail.

One of ten respondents (11%) disagreed with the settlement and a plurality of 45% were "not sure" if they agreed. As the settlement was widely understood to favor greater inclusion in the regular classroom curriculum, this finding suggests that there is among families of children with intellectual disabilities a substantial number who are not convinced that greater inclusion will be beneficial for their sons and daughters. Another intriguing finding (and certainly one bearing a relationship to consumer empowerment and self-determination) was that 10% of respondents either rejected (4.9%) or questioned (5.2%) their child's designation as having intellectual disabilities.

The study did not permit conclusions as to whether progress was being made towards greater inclusion. Among respondents, one-quarter (25%) said their children were in regular classes and 71% said they attended the neighborhood school that they would attend if they had no disability, but the survey didn't ask if either of these circumstances had changed since the P.J. settlement.

A question related to participation in extra-curricular activities was posed in the future tense: "My child will participate in school-sponsored extracurricular activities this year." Nearly half (42%) said yes, but these respondents were indicating their hopes rather than reporting on something that had actually taken place. The question unfortunately failed to distinguish between those who said <u>no</u> because there were no opportunities for extra-curricular activities (for instance, parents of preschool-aged children and those in the youngest grades) and those who were aware of opportunities but did not anticipate their children would participate. Not surprisingly, parents of children in middle school and high school, where extra-curricular activities abound, were most likely to answer <u>yes</u>.

Follow-Up of Students Who Exited High School

The Bureau engaged independent researchers to collect data on secondary transitions (i.e., transitions of individuals receiving special education from secondary school into independent living and/or the work force). Researchers attempted to contact every (former) high school student who had exited special education (and left school) in the year 2000.[6] Either the former student or the family/guardian was considered a potential respondent.

The response rate was approximately 13.5% of the universe of roughly 2700 former students in the pool. The questions were designed to provide a profile of their current lives in the areas of living, employment, and leisure that could serve as baseline data in the hope that improving transition practices would also improve these outcomes. The questions were largely objective and ranged across numerous aspects of life (e.g., type of residence, type of school program if any, type of employment, most recent wage.)

None of the questions related directly to principles such as empowerment or self-determination. They did not ask, for example, whether these young adults felt that they were currently making key decisions and choices for themselves. There were also no questions asking respondents whether their high school program had prepared them to make decisions and choices, to advocate for their own needs, to pursue their aspirations, or other questions germane to leading self-determined lives. Numerous respondents wrote quite colorfully and at length about their perspectives towards their high school

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[6] Another part of the same study involved surveying administrators of secondary education programs involved in the transitions of special education students. We are not considering that report as it did not directly solicit feedback from individuals with disabilities.

experiences in response to an open-ended question at the end of the survey and some did touch on these matters in spite of the fact that no such questions were posed.

DMHAS (Department of Mental Health and Addiction Services)

DMHAS surveyed a sample of its huge base of service recipients through a uniquely designed survey project titled “Voice your Opinion 2000-01.” This was the first and (as of spring 2005) most recent statewide sampling of mental health consumers’ opinions taken by DMHAS. Data were gathered from the fall of 2000 through the spring of 2001.

On multiple levels, this initiative reflected an unusually strong commitment to consumer empowerment. First, the survey took place as a result of recommendations from a consumer workgroup. Secondly, the survey instrument was produced with input from individuals in recovery from mental illness and substance abuse, along with professionals, advocates, and others. Third, “peer-surveyors” conducted the survey. Consumers who were selected for this role attended two days of training offered by Advocacy Unlimited, Inc., a consumer group. They then went in teams of two to four to sites where they could encounter DMHAS service recipients. As they encountered potential respondents, they offered to assist them in completing the survey on-the-spot or to mail out the survey. Finally, some of the content of the survey directly addressed issues of empowerment and self-determination, and did so using language that was unusually free of jargon.

Altogether, the peer-surveyor teams visited 42 sites, which accounted for 38% of all the facilities in the DMHAS system (including those operated directly by DMHAS and those operated privately with DMHAS funds). They collected surveys from 1169 respondents, or about 4% of all the agency’s service recipients at that time. They included somewhat higher percentages of those receiving residential services, vocational services, and social rehabilitation programs as compared to those receiving case management or outpatient services.

The survey was wide-ranging, asking not only about use of and satisfaction with agency services but also touching on such matters as whether respondents were employed, how frequently they had relocated, whether they have seen a doctor or nurse in the past year, and whom they called in a crisis.

One question asked explicitly about self-determination. Respondents were asked to indicate if they agreed with this statement: "I, not the staff, decided my treatment goals." Nearly two-thirds (65%) agreed. A higher proportion (77%) agreed they were treated with respect. In addition, they were asked if they knew about the DMHAS grievance procedure. It turned out that 57% of respondents did not know DMHAS had such a procedure. Of those who knew about it, fully 19% had used it. One might conjecture that such a high proportion of service recipients (nearly one of every five) submitting grievances means that in terms of satisfaction with services or outcomes, there is a serious problem. But as a measure of self-determination, the fact that so many consumers are using the grievance procedure seems very robust.

DMR (Department of Mental Retardation)

DMR consumers and their families have been surveyed in recent years in connection with a project called the National Core Indicators (NCI). It is co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) in Cambridge, Massachusetts. The project was launched in 1997, with Connecticut's DMR as one of the original six "charter" participants. In 2005, it had grown to include 23 participating states. Its purpose is to track a number of agreed-upon indicators in order to assess the overall performance of service systems for persons with developmental disabilities. Data from surveys of consumers and families are analyzed along with surveys of provider agencies and a variety of data from each state's system to track outcomes and to compare any given state's performance on the indicators over time and across states.

NCI Consumer and Family Survey Data

NCI requires participating states to distribute three mailed surveys: an Adult Family Survey; a Children Family Survey; and a Family/Guardian Survey. As the project has evolved, Family Indicators have been developed and approved by a national Steering Committee. Survey questions are then designed to assess these indicators. As of 2005, the surveys were subdivided into the following Domains: Information and Planning; Choice and Control; Access and Support; Community Connections; Family Involvement; Satisfaction; and Outcomes.

The NCI asks that each participating state mail out 1000 surveys to randomly selected consumers of services from the developmental disabilities system, in the expectation of receiving back approximately 400 (i.e., 40% response rate). In Connecticut, there were 1200 of each of the three surveys mailed for the 2003 data collection effort.[7] For the Children Family Survey, there were 326 completed (26% response rate). For the Adult Family Survey, there were 404 returned (i.e., 34% response rate). A higher 578 completed the Family/Guardian Survey (48% response rate). There are numerous questions on each of the surveys that pertain to issues such as self-determination, choice making, and decision making.

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[7] These figures were made available in 2005 and are the latest available at time of this report.

States also conduct face-to-face interviews with a sample of 400 persons who receive supports from the state's developmental disabilities agency to collect data for the Consumer Survey. The interview is preceded by a "pre-survey" in which, among other things, it is determined how the consumers to be interviewed can best participate in the interview; for instance, in what language, with what kinds of augmentative communication, whether they engage in behaviors that might need to be addressed in the course of an interview, and whether a caregiver should be present. For one section of this survey, even if a caregiver is present, there is not supposed to be any response recorded other than one that reflects what the DMR consumer is able to clearly and directly state.

Questions in the consumer survey are very concrete. For example: "Who chose the place where you live?[8]" "How many places did you visit before moving here?" "Are you allowed to use the phone when you want?" "Can you be alone if you want to?" "Do people let you know before they come into your bedroom?" "Can you see your family when you want to?" "Do you choose what to buy with your spending money?" "Do you know how much money is spent on paying for your staff" (The latter question is asked only if the pre-interview has established that the individual has an individualized budget.)

Family Data from NCI

The data from these surveys are quite extensive and germane to the goals of the Real Choice System Change project. For this report, a few examples from the 2003 Family/Guardian survey will have to suffice. Among Connecticut respondents, three-fourths (73.8%) said that "the staff who assist you with planning" <u>always or most of the</u>

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[8] The interviewer would not record the names of persons involved in this decision, but would indicate whether the consumer made the decision, had some input into the decision, or someone else made the decision; alternatively, that the consumer doesn't know or doesn't respond. or the question is not applicable (i.e., lives with parents).

time “respect your choices and opinions.” However, 10.1% said the staff seldom or never respected their opinions. More than half (55.2%) said they always or usually chose the agencies or providers that worked with the person receiving services. The remainder were about equally divided between those who sometimes chose and those who seldom or never chose the agency. A smaller portion of Connecticut respondents (29%) always or usually chose the support workers who worked with their family, while 48% seldom or never did.

Just 28% of Connecticut respondents to the Family/Guardian survey stated that the person receiving services or their family usually or always has control and/or input over the hiring and management of support workers, while 58% seldom or never had control or input. This latter did not reflect the aspirations of the respondents: 56% would have liked to have control over hiring and management of support workers; just 17% would not have wanted control.[9]

Fully 74% of Connecticut respondents did not know how much money was spent by DMR on behalf of the family member with a developmental disability, while nearly 19% stated they usually or always knew. A substantially higher proportion (33.6%) said they usually or always got to decide how the DMR money was spent, while nearly half of Connecticut respondents (48.3%) reported that they seldom or never got to decide how the funds were spent.

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[9] It appears that a large percentage (nearly half) of Connecticut respondents ventured no opinion on this question, perhaps because they are not familiar with models in which consumers have control over hiring and management.

Empowering Consumers within the DMR Service System

Aside from gauging the perceptions of consumers and family members by way of surveys and participation in the NCI, DMR views other activities as reflecting its commitment to promoting self-determination. The option for individuals eligible for services to direct their own supports is central to this commitment. As of 2005, the number doing this had climbed to nearly 800, out of a total adult clientele of roughly 13,700.

Another way the agency believes it is empowering consumers and assuring that the input of consumers shapes agency practice is by hiring self-advocates. They hired 9 self-advocacy coordinators (SACs) in 2004 (three per region) who themselves were self-advocates receiving services and supports from the department. Some of them directed all or a portion of their own supports. Among their duties were training staff and other consumers about self-determination, self advocacy, and human rights. Some of the self-advocate coordinators have conducted consumer interviews as part of the state's participation in the National Core Indicators (NCI) initiative (described above).

Quality System Review (QSR) and New Proposed Waivers for In-Home Supports

In recent years, DMR has developed and launched a new quality management system called Quality System Review (QSR). This is grounded in (and closely tracks) a Quality Framework laid out by the Centers for Medicare and Medicaid Services (CMS). This framework spells out clear expectations for consumer choice, control, self-direction, and involvement. One method of collecting information will be face-to-face consumer interviews. Other methods include staff interview, observation, and record reviews. Key quality focus areas of the QSR include Planning and Personal Achievement, Choice and Control, Relationships and Community Inclusion, Safety, Health and Wellness and

Consumer Satisfaction. This has in turn set the stage for the updating and re-design of waivers that allow Medicaid dollars to flow towards services and supports of eligible individuals.

Working with the Braceland Center for Mental Health and Aging at Hartford Hospital, DMR has engaged service recipients and their families in approximately a dozen focus groups around the state (including two conducted in Spanish) to get input into the revision of standards for Medicaid waivers. This Individual and Family Support (IFS) waiver falls under a template that CMS calls "Independence Plus," and will facilitate the expansion of consumer-directed service options for DMR clients. Individuals and / or their families attending these focus groups brainstormed about what waiver services could or should be available for in-home supports and how the reviewing and monitoring of these services could take place. A subset of these focus groups (approximately 25 family members and 40 consumers) addressed quality management for people who are managing their own in-home supports. DMR was interested in family and consumer input so that the agency oversight required by CMS could take place without making the process unnecessarily intrusive for consumers and families.   The waiver application reflected the input from these discussions and also became the basis for a second, comprehensive waiver. If CMS accepts it, the new comprehensive waiver replaces one that was set to expire in the fall of 2005. As currently conceived, it will mirror the IFS waiver described above and will allow for consumer-directed services as well.

Office of the Ombudsperson

Another way to gain insight into the perspectives of DMR consumers is to examine the data from the Independent Office of the Ombudsperson for Mental

Retardation (known as the Office of the Ombudsperson), which was established in 2001. Its data for the calendar year 2003 included 370 complaints or concerns lodged by clients, family members, or advocates. Taking advantage of such an office might be viewed in itself as evidence of empowered consumers; knowing the nature of these complaints might also provide some insight into whether individual service recipients were making decisions (or were being frustrated in their efforts to make decisions for themselves). The Office divided the complaints into 22 categories. The largest category, accounting for over one-third (34%) of all concerns, was "information and reference." The next most frequent types of calls to the Ombudsperson were classified as "placement inquiries," accounting for nearly 14% of calls. Other topics that drew numerous calls were case management (over 6%), quality assurance (nearly 6%) and housing (nearly 6%). The complaints that sounded the most closely related to the principles promoted by Real Choice were under the categories of "self-determination" (3 calls, or less than 1% of all complaints) and "Client Rights" (4 calls, or 1% of all complaints). However, without more detail about the classification scheme, these data shed very little light.

OTHER AGENCIES

DCF (Department of Children and Families)

DCF has five distinct legislative mandates and each division (corresponding to these separate mandates) has its own obligations and practices related to gaining input from consumers. We attempted to gather data from the division of Mental Health, not from Protective Services, Juvenile Justice, Substance Abuse, or Prevention. Dr Karen Andersson, who is the Director of that division, which operates under the nomenclature of KidCare, clarified that it is mostly the parents/guardians from whom they are soliciting input or feedback, rather than the children receiving services.

The mental health division of DCF has for about 10 years embraced the concept of “systems of care, “a concept promoted (as she explained) by the federal agency, SAMHSA (Substance Abuse and Mental Health Services Administration). “Parents as partners” is one of the underpinnings of “systems of care.” Services are supposed to be community-based, family-focused, and culturally sensitive.

One of the major ways they believe they have empowered consumers is by funding family advocacy through a consortium of grass-roots parent organizations under the umbrella of an organization called FAVOR. FAVOR has a staff of DCF-funded family advocates who provide technical assistance to individual parents whose children are involved with DCF services, and they have convened focus groups and public forums to generate recommendations for changes in the service delivery system.

Another mechanism touted by DCF as promoting consumer empowerment is a new Administrative Services Organization, a kind of nonprofit Managed Care plan designed to capture Medicaid mental health funds and combine them with DSS funds. The language in the RFP was heavily laced with references to “families as partners.” Also, parent/consumers were heavily represented on the panel that reviewed responses to the RFP.

CCDD (Connecticut Council for Developmental Disabilities)

The Council responded to our inquiry by noting that the Developmental Disabilities Act which created all the Disabilities Planning Councils across the United States more than 30 years ago, including the CCDD, is “the model for consumer involvement.” Their own Council has usually contained more than half self-advocates (i.e., persons with disabilities). They detailed their current Council membership as including 7 self-advocates and 5 parents of children or adults with disabilities out of a total membership of 19. They emphasized that the Council is not an advisory body to a staff-run agency but is the policy making body to which the staff report.

In order to assure that membership on the Council can be meaningfully carried out, the CCDD reimburses for transportation, personal assistants, and “whatever it takes,” and also pays a stipend for meeting attendance. They have engaged outside consultants to help design meetings in which self-advocates are able to participate more readily. The design issues have included different seating plans and the color-coding of printed materials.

Beyond their own Council, the CCDD engages with the broader constituency of persons with developmental disabilities by convening public forums (six in 2003-4). They also use their grant funds to support projects and organizations started and/or operated by persons with disabilities.

OPA (Office of Protection and Advocacy)

The staff of Connecticut’s OPA has not analyzed the comments it has received from consumers in a manner that lends itself to public reporting. However, they described several ongoing mechanisms for seeking input and to learn about the level of satisfaction of consumers with their activities. Starting at the most general level, self help booklets they disseminate to acquaint citizens with the agency include a page that allows the reader to provide input and/or request materials. The agency also participates in and sponsors public forums at which they seek public and consumer input. For those unable to attend these forums, they have sometimes convened focus groups. Paper surveys are distributed to participants in these forums and focus groups for those that wish to provide additional feedback in writing. also provided to attendees for their use and anyone wishing to provide feedback/commentary.

More targeted efforts at collecting feedback are made with individuals who have initiated more formal contact with the agency. They mail a postcard-sized survey to a random sample of individuals who contact the agency for any kind of support or information. To a smaller subset of individuals whose involvement with the agency is of a more extended nature, they mail a survey once they have completed their advocacy efforts (i.e., "closed the case"). The OPA staff acknowledged that they do not get very good rates of return on the surveys to either of these constituencies. They do use the feedback they receive to address unresolved issues or dissatisfactions either individually, through changes in agency practices, or both.

CONCLUSIONS

The following conclusions are drawn from our review of data from the six agencies that have made the greatest efforts to access the perspectives of consumers of their services. Although we are critical in our discussion below of some of their efforts, we wish to emphasize that they are still several steps ahead of many other agencies that have not yet begun to make a serious effort to tap the opinions of citizens with disabilities or their families.

1. Connecticut agencies have begun asking consumers about their satisfaction with the process of service delivery.

In the "new paradigm" model of service delivery, agencies recognize recipients of their services as partners in decision making, rather than clients who are totally dependent on the expertise provided by agency professionals. In that context, it is important to find out whether consumers are content with the process by which services are selected and delivered and the roles and relationships they take on vis-à-vis agency staff. What we learned is that the six agencies that have made a systematic effort to reach consumers are asking consumers about these processes and roles.

For instance, a survey of BRS clients asked respondents to rate the importance of “feeling like a full partner,” and “involving you in decisions.” Their survey then followed up by asking if their experience had matched their hopes in these areas. Another survey asked how BRS respondents felt about “the degree of control and involvement” they had in their V.R. experience. The survey also asked, “How satisfied were you with the kind and amount of information you were given about the choices you had?”

A BESB survey asked how satisfied respondents were with their counselor’s assistance in helping them understand their rights and responsibilities within the vocational rehabilitation system, how satisfied respondents were with the way their counselor helped them to identify career goals and services needed to achieve the goals, and the extent to which the services they received have met their expectations. A survey of parents of infants and toddlers served by BESB asked their opinions on whether the “BESB teacher values their [parents’ or guardians’] opinions and input,”

CSDE asked parents of students receiving special education services if the school “listens to my suggestions and ideas when developing my child’s IEP,” and also whether “I feel I am an equal partner…when we plan my child’s program.”

DMHAS service recipients were asked to indicate if they agreed with this statement: “I, not the staff, decided my treatment goals.” They were also asked if they felt they were treated with respect.

DMR consumers who have been selected for the NCI interview sample have been asked (for instance) if individuals wishing to enter their homes or their bedrooms respect their privacy, what level of input they have had in deciding where to live, and whether they can spend their own money as they choose. DMR families have been asked (to cite a few of many possible examples) if their choices and opinions are respected by those working with their family member, and if they have had input into choosing the provider agencies with which they work. They have also been asked about their role in understanding and controlling budgets and in the hiring and management of staff.

2. **Some Connecticut agencies are doing better than others in thoughtful design and construction of surveys.**

Among the data and survey instruments we reviewed that were locally developed for Connecticut agencies, those designed on behalf of BRS and DMHAS stood out as well designed. In addition, we would cite as exemplary the multi-state survey in which both BRS and BESB participated and the nationally developed NCI surveys in which DMR participates annually.

In contrast, we were unimpressed with a CSDE survey of families of all students potentially affected by the "P.J." settlement. First, the agency enclosed information about the case in the same mailing in which they asked respondents whether they had received information about the case. This confounded any effort to determine how many families knew something about the case prior to the dissemination of the survey.

There were other problems of an even more fundamental nature with the "P.J." survey. They asked whether children of respondents were enrolled in regular classrooms and "home schools" but not whether this had changed since the P.J. settlement. Thus there was no way to assess whether the litigation may have influenced changes in placement at the district level. A question about whether respondents “agreed with” the settlement (a substantial proportion did not) failed to define or illustrate in practical terms what agreeing or disagreeing with the settlement meant. Did those who disagreed prefer segregated classes and denial of access to extra-curricular activities? Did they feel the court didn’t go far enough in promoting inclusion? Did they believe that the settlement was fine on paper but had not yet yielded any tangible fruits for their own child? The survey results leave readers guessing.

A question on the same survey asked about extra-curricular activities in the future tense: “My child will participate in school-sponsored extracurricular activities this year.” The usefulness of survey responses is always limited by the inherent subjectivity of the respondents. Asking respondents to record their future hopes rather than reporting on something that has already occurred unnecessarily multiplies the subjectivity factor. Also, the menu of replies offered no way for a respondent to indicate discrepant reasons why children with disabilities might not be participating (e.g., early childhood and young primary-aged students are not ordinarily offered many opportunities to participate in school-sponsored extra-curricular activities).

A BESB Birth to Three survey illustrates the challenges of survey design when agencies are interested in both family and child outcomes. Respondents were asked how satisfied they were with their “level of community involvement.” The survey then provided as examples of community involvement the following: play groups, library story hours, and talking with other parents. More than one-quarter (28%) of respondents did not answer this question. It may have been in part because the survey failed to distinguish between two separate activities: parent involvement (represented by “talking with other parents”) and child involvement (represented by “play groups, library story hours”). How would parents answer this question if, for example, they have a sufficient level of involvement in the community but feel that their children with disabilities do not? If an agency wishes to know the answer to both questions (Do parents feel sufficiently involved? Do they believe their children are sufficiently involved?) then they need to ask about these issues separately.

In comparing two generally well-designed surveys[10] of BRS vocational rehabilitation clients (one from the CSRA in Connecticut and the other a multi-state survey from a Maine-based evaluator), one can gain insights from noting an important difference. The CSRA survey confined itself to questions about the experience with the agency and did not solicit information about the respondents’ employment status. The multi-state survey asked whether respondents were working over or under 35 hours per week, whether they were seeking employment, receiving job training, and so forth. They also asked those who were employed to indicate how satisfied they were with their jobs. Although the focus of our analysis is on what these surveys reveal about the process of receiving services rather than on the quality, efficacy, or outcomes of service, this example alerts us to the fact that the collection of some outcome data may be required in order to place the “process” data into a richer, more meaningful context. One’s feeling of living a self-determined life (in the vocational sphere) must derive not only from one’s

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[10] We mean “well-designed” from the point of view of asking meaningful questions related to processes, roles, relationships, and self-determination. Aside from that focus, we are not attempting to critique the survey instruments.

role and relationships vis-à-vis a state agency that provides vocational assistance but also from one's real-world experience in finding and keeping gainful employment.

3. Some agencies have overlooked opportunities to seek data regarding empowerment and self-determination.

The BESB Birth to Three survey posed its questions about community involvement in such a way that the responses could not illuminate the agency's role in supporting community participation. They asked (in a confusing way, as discussed above) if parents were satisfied with their (and their children's) level of community involvement. But their level of satisfaction may or may not be influenced by agency practices. Why not ask more pointed questions. For instance: Did BESB bring early intervention services and supports into natural settings such as play groups, gym and swim for toddlers, nursery schools, and childcare? Did BESB staff ever provide training or consultation to community-based settings the child or family frequented? Did any agency activities help the parent/respondents in their networking efforts with other similarly situated parents? Even if these weren't the kinds of services the child or family ultimately received (or desired), the survey could produce useful data by asking if respondents recalled that such options for services and supports were ever discussed.

In an otherwise nicely designed CDSE survey of students who exited special education (and left high school) in 2000, questions related to empowerment or self-determination were omitted. The survey could have asked, for example, whether the respondents' high school programs had prepared them to make decisions and choices or to advocate for their own needs. The survey could have asked whether these young adults were satisfied with their current levels of community involvement, or with the degree to which they were currently making decisions and choices for themselves. Several respondents touched on these issues in response to an open-ended question at the end. This indicated that a few questions targeted to these topics could have yielded important data.

4. **Consumers are giving mostly favorable responses —but with room for improvement\--when asked about state agency practices with respect to empowerment and self-determination.**

An impressive 77% of BRS survey respondents rated their counselors with the highest possible “very good” score (10 on a scale of 1 to 10) on “involving you in decisions.” Large but not overwhelming majorities gave high marks in “feeling like a full partner” and “developing a plan which reflected your talents.”

Over half (51%) of BRS respondents were “very satisfied” at the agency’s efforts to support them in “feeling like a full partner.” A slightly lower 45% pronounced themselves “very satisfied” with staff support in “developing a plan which reflected your talents.” Fully 83% of respondents to another BRS survey strongly agreed that staff treated them with dignity and respect, and another 12% agreed,

Yet the response to the question, “Were you offered a selection of choices as your Employment Plan was developed?” indicates there is still room for improvement. While nearly 50% said yes, one out of four (24.5%) said no, and others were not sure.

Among BESB adult service recipients, a plurality of respondents who gave answers were very satisfied with the help they received in understanding their rights (44%), the help they received in identifying career goals (44%), and with the match between services received and the plans developed (45%). (The remainder mostly “did not know.") In another survey of BESB clients, 88% of respondents rated their counselor positively in "helping them to understand their Rights and Responsibilities as a vocational rehabilitation client," and 81% were either very satisfied or satisfied with their "control and involvement."

Among families responding to a survey concerning BESB's Birth to Three services, 100% were very satisfied that BESB teachers respected the target child and 94% were very satisfied with how much the BESB staff valued parental input.

Among parents of special education students from the ACES region responding to a CSDE survey, 83% stated the school "listens to my suggestions and ideas when developing my child's IEP," and 81% reported feeling like "an equal partner" in planning their child's program.

Among DMHAS clients, nearly two-thirds (65%) agreed with the statement, "I, not the staff, decided my treatment goals." A higher proportion (77%) agreed they were treated with respect.

Among DMR consumers and families, three out of four felt that the staff respected their choices and opinions all or most of the time. When it comes to approaches that have only been introduced in the past few years, there is a greater divergence between what is desired and what exists. For example, 56% would like to have control over the hiring and management of support workers while only half as many (28%) reported they usually or always have significant input or control. This is not surprising in a service system that has recently embraced a new paradigm that is a radical departure from the old one. Just a decade ago, the idea that consumers and families could and should have significant control over such items as hiring and budgets was a flicker in the eye of a few visionaries.

5. **There remains a sizable minority among consumers and families that do not appear to embrace the principles of inclusion and self-determination.**

Responses to the CSRA survey of BRS consumers are a very good barometer as to what percent of persons with disabilities are embracing the concept of self-determination. Someone who identifies with this concept would <u>strongly agree</u> that they want to be a full partner in the development of their employment plan. Majorities of respondents did agree strongly with this point, but a close look at the data reveals that there were marked differences among age groups and by ethnicity. While 85% of those between 25 and 44 placed great importance on being a full partner, the percentages were considerably lower among clients under 25 (64%) and over 44 (59%). Also, African-Americans (72%) and Latinos (85%) were more likely than Whites (59%) to state that feeling like a full partner was very important. By any measure, this leaves a substantial number of service recipients who do not (yet) view being a partner in decision making as a high priority.

Some of the data that emerged from the survey of “P.J.” families by the CSDE raises similar questions with regard to the identification with the philosophy and practice of inclusion. Why did such a large proportion (nearly half) state that they did not agree with the P.J. settlement? As indicated in our earlier discussion, the construction of the survey does not lead us to any firm conclusions. But the numbers not embracing the settlement are a red flag that calls for further investigation. Local school districts and the CSDE need the support of the vast majority of families of children with intellectual disabilities if they are truly going to move forward with plans to end the segregated schooling of this group of children and also break down barriers to their participation in the full life of the schools (i.e., extra-curricular activities.)

Finally, the data from the NCI tell us that not all DMR families are embracing the new plans for consumer decision making that the agency is implementing along with its partners across the country. One out of six respondents (17%) reported that they preferred not to have input or control on the budget of the person receiving services.

Persons with disabilities and their families and guardians are as widely variable as the population of Connecticut as a whole. We should not be surprised that individuals approach our state service systems with a wide range of needs, preferences, and understandings. Some may continue to be more comfortable with a system that is driven by experts and treats them as clients and dependents. Advocates of consumer involvement, empowerment, and self-determination are in the ascendancy within the federal and state bureaucracies; the Real Choice System Change project is a product of that ascendancy and embraces those principles. However, it would be a mistake to imagine that the entire "disability community" has achieved a common consciousness. These data can help us to go forward, fully mindful of the diversity of the constituencies we aim to serve.