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

BEYOND SERVICES TO CLIENTS:
Are we training staff to support self-determination and consumer decision making?

A Review of Staff Development Principles
and Practices Among State Agencies Serving
Persons with Disabilities in Connecticut

Dale Borman Fink, Ph.D.

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A Review of Staff Development Principles and Practices Among State Agencies Serving Persons with Disabilities in Connecticut

June 2004

Dale Borman Fink, Ph.D.

Submitted on behalf of the University of Connecticut,
A.J. Pappanikou Center for Excellence in Developmental Disabilities

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Introduction

The research for this report was carried out as a first step in achieving one of the objectives of the Connecticut Real Choice System Change grant[1]; namely, 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." As represented in the U.S. Supreme Court's 1999 Olmstead[2] decision, our nation's values and laws have moved to a point where states should be developing community supports and services with people, not for them. Yet many professionals were trained and agency protocols were set in motion in an earlier time period, when the current view was far from predominant.

Our aim was to learn to what extent several key state agencies and bureaus in Connecticut that serve citizens with disabilities have embedded into the orientation and professional development of their own personnel information, materials, and activities helping them to understand and promote self-determination among persons with disabilities served by these agencies. Are agency leaders helping their staff with the knowledge they need to take ownership of principles such as self-determination and practices such as building partnerships with families and empowering consumers to make their own choices and decisions? How are agency managers attempting to ensure that new staff, as well as veterans who came of age in a different time period, are given the necessary understanding and the supports to implement the

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[1] More information about the overall aims and activities of this grant are available from the A.J. Pappanikou Center website at http://www.uconnced.org/

[2] 1999 U.S. Supreme Court decision, "Olmstead v. L.C. and C.W. " L.C. and C.W. were confined in a Georgia state psychiatric hospital; Olmstead was Commissioner of Georgia's Department of Human Resources. On the basis of

practices that are currently viewed as respectful and empowering toward individuals who were once viewed primarily as "clients" or "dependents?"

The evolution of human service systems takes place on multiple levels and within an ecological framework. The most widely recognized description of this framework is that of Bronfenbrenner (1975)[3]. He postulated that we need to examine system change at four different levels. Applied to the present case, the <u>microsystem</u> is the interaction of a specific consumer with a specific agency. An <u>exosystem</u> is a setting the consumer does not enter but which may affect one or several microsystems (e.g., Centers for Medicare and Medicaid Services). A <u>mesosystem</u> is a system formed by the interaction between two microsystems. The present investigation can be seen largely as an exploration of the <u>macrosystem</u>, which is an ideology or set of values which encompasses all the other systems. What are the values that agencies are passing on to staff members who act in the name of the state of Connecticut to provide services or advocacy for persons with disabilities?

We anticipate that the findings of this report will generate discussion across the bureaus and agencies reviewed here as well as among leaders involved in training at state agencies that were not reviewed for this report. Furthermore, the findings can serve as the foundation for the design and development of future activities. By focusing on agencies which have done a great deal in this direction already, we can help to facilitate the further dissemination of the information, materials and approaches they have designed. To the extent that professional development activities at some state agencies have not been fully aligned with currently accepted

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the Americans with Disabilities Act, the opinion disallowed the state of Georgia (and indirectly all other states) from continuing to keep people in state institutions if they wished to live in the community.

[3] Bronfenbrenner, U. (1975). Reality and research in the ecology of human development. <u>Proceedings of the American Philosophical Society</u> <u>119</u>, 439-469.

principles, we hope that these findings—and the next phase of this project--can support the efforts of committed leaders within these agencies to improve their practices[4]. Equally important, the Real Choice System Change project hopes to work with these agencies to develop tools and techniques to ensure that any shift in values will ultimately not be confined to the macrosystem but will find itself embodied in the vast majority of microsystemic interactions involving consumers with disabilities across our state.

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[4] This investigation was confined to questions about how state agencies were training and preparing their employees to address persons with disabilities as recipients (directly or indirectly) of their services. We did not examine employment by state agencies of persons with disabilities.

State Agencies Selected for Review

Without exception, every state agency has dealings with citizens with disabilities. Limited resources and a short time frame necessitated that we select just a handful of state agencies to be the focus of the current review. Our sample of agencies was purposively drawn to include mostly agencies that targeted services to specific or general disability constituencies, and also a few others whose involvement with persons with disabilities was less direct or was in an advocacy role. Figure 1 displays the names of the nine agencies we studied[5]. The categories displayed here do not represent the way we thought about the taxonomy of agencies and their functions at the outset. Rather, we arrived at these categories only after sifting through our own findings.

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[5] Our initial sample included two other agencies: the Commission on the Deaf and Hearing Impaired (CDHI), and Department of Children and Families (DCF). We omitted these agencies from the report because we were not able to obtain sufficient information from them.

Figure 1: State agencies whose staff development policies we reviewed for this report

CATEGORY	AGENCY NAME
A. Agencies that target services to specific disability constituencies	1. Board of Education and Services for the Blind (BESB) 2. Department of Mental Health and Addiction Services (DMHAS) 3. Department of Mental Retardation (DMR)
B. Agencies that target services to constituencies with diverse disabilities	4. Vocational Rehabilitation Division, Bureau of Rehabilitation Services/Department of Social Services (BRS/DSS) 5. Bureau of Special Education, Connecticut State Department of Education (CSDE)
C. Agencies which have as their primary mission advocacy or the monitoring of compliance with laws or regulations	6. Connecticut Council on Developmental Disabilities (CCDD) 7. Office of Protection and Advocacy for Persons with Disabilities (P&A) 8. Division of Health Systems Regulation, Bureau of Health Care Systems /Department of Public Health (DPH)
D. Agency with oversight role	9. Office of Policy and Management (OPM)

Agencies that target specific disability constituencies

Three of the nine agencies provide direct services to constituencies with specific types of disabilities. The Board of Education and Services for the Blind (BESB) addresses both child and adult consumers who are legally blind or have conditions likely to lead to blindness. The Department of Mental Retardation (DMR) operates and supports a wide array of programs for Connecticut citizens who have intellectual disabilities. The Department of Mental Health and Addiction Services (DMHAS) addresses its supports and services to persons with needs related to mental health and the use and abuse of substances.

Agencies that target services to constituencies with diverse disabilities

Two of the selected agencies target services to broader constituencies with diverse disabilities. The Bureau of Rehabilitation Services/Department of Social Services (BRS/DSS) addresses vocational counseling and rehabilitation and a variety of other services related to independent living for consumers with a wide range of disabilities. The Bureau of Special Education of the Connecticut State Department of Education (CSDE) supports and monitors the local school districts in addressing the educational goals of students from ages three through twenty-one with all disabilities that are recognized under the federal Individuals with Disabilities Education Act (IDEA) as well as those that may arise under Section 504 of the Rehabilitation Act of 1973.

Agencies which have as their primary mission advocacy or the monitoring of compliance with laws or regulations

Three of the selected divisions or agencies support persons with disabilities through advocacy, enforcement of laws and regulations, and system change rather than through providing direct services. The Bureau of Health Care Systems, Division of Health Systems Regulation of the Department of Public Health (DPH) certifies residential facilities for persons with mental retardation[6]. The Connecticut Council on Developmental Disabilities (CCDD) promotes innovative practices and system change. The Office of Protection and Advocacy for Persons with Disabilities (P&A) provides legal and personal support to individuals and groups of persons

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[6] Many advocates nationally have stopped using the term “mental retardation,” viewing it as a socially constructed label devoid of functional meaning. Some Connecticut agencies have followed suit, including the CSDE which now has a special education category for “students with intellectual disabilities” in place of the previous lexicon. In this report we use the term “mental retardation” only when discussing agencies that continue to use that terminology to describe the consumers they serve.

with disabilities, and acts as the investigating agency for Connecticut's statute governing abuse and neglect of adults from ages 18 through 60 with mental retardation.

Agency with an oversight role

We also selected the Office of Policy and Management (OPM), because of its important oversight role within state government. The Office provides information and analysis that the Governor uses to formulate public policy goals for the State of Connecticut and assists State agencies and municipalities in implementing policy decisions. Their Policy Development and Planning Division informs public policy-making and implementation through research, analysis, and planning. It provides oversight to Federal and State grants such as Real Choice. We recognized that professional development activities geared for the staff of this agency would be of a different character, given that this agency provides no direct services to Connecticut citizens, with or without disabilities, nor is it involved in advocacy, training, or other related activities. Yet it seemed important to determine whether the leadership of an agency so central to the development of public policy was introducing its staff to current thinking about issues in serving persons with disabilities.

Method and Sources of Information for this Review

The research and writing of this report were carried out in six steps.

Step One. We informed each agency of the overall purpose of our study and requested from representatives of each agency copies of relevant published materials. We received and examined a wide variety of agency materials aimed at consumers, families, and the general public, as well as those aimed specifically at the training of agency personnel.

Step Two. Based on what we could glean from the printed materials, we put together a draft report which highlighted (to the extent we could discover it) how each agency incorporated currently understood principles such as self-determination and consumer decision making into their ongoing professional development activities.

Step Three. We made available to representatives of each agency the sections of the draft that were descriptive of their efforts, together with material from our introduction and conclusion, and requested their suggestions, corrections, and additions.

Step Four. We convened face-to-face meetings with representatives of each agency at a time and place of their convenience to receive their comments and suggestions in preparation for revising and generating our final draft.

Step Five. Incorporating many of the comments we received from the agency representatives, we drafted the current report.

Step Six. The Steering Committee of the Real Choice System Change project provided suggestions and comments and the current report reflects many of these.

Conclusions: Overview

1. Agencies use terminology which reflects their conceptual and legislative origins. Therefore they do not always share a common lexicon when it comes to discussing the principles that this report addresses. For example, "self determination" is a term favored by the CCDD and DMR. Others, such as BESB, BRS, and DMHAS more frequently use the lexicon of "consumer choice" and "consumer empowerment." P & A uses all the foregoing terms. The Bureau of Special Education speaks of "parents as full partners," "equal access" for students with disabilities, and "making informed life choices."
2. In spite of some disparities in the lexicon they use to describe their principles and values, the agencies seem to be converging on a common set of strategies. Increasingly, all these agencies speak of building "natural supports," "peer supports," and "person-centered" planning and services.
3. Each of the agencies we reviewed (except OPM) has at some point in the recent past adopted the key principles for which we were seeking evidence and infused them to varying degrees throughout their professional development efforts. There does not seem to be any need or role for the Real Choice System Change project, therefore, to offer guidance at the macrosystemic level to those who are charged with the orientation, training and professional development of staff. There could be a role for this project, however, in helping these agencies assess how well their efforts are succeeding in implementing these principles into day-to-day operations (i.e., in moving the principles from the macrosystem into the microsystems).

4. Nearly every agency we reviewed struggles to “do more with less,” as their vision for the training and professional development that is required exceeds the current resources that are available. Bureaus and agencies have to tailor their training plans to the fiscal realities. In some agencies, the training dollars are not equally available for all divisions, due to federal funds being available to support some areas of training and not others. The budget limitations are a hardship but they also engender a disposition toward reducing duplication and maximizing the impact of their efforts through collaboration with other agencies and with the Real Choice initiative.
5. Several interviewees indicated they would be interested in meeting with representatives of other agencies to share ideas across agencies regarding the activities, formats, and materials they use in professional development. The idea of meeting with persons with regional or national expertise in this domain also emerged from our discussions. This presents a potentially important window of opportunity for the Real Choice System Change project or the A. J. Pappanikou Center for Excellence in Developmental Disabilities.

Findings: A More Detailed View

Agencies that target services to specific disability constituencies

Among the three agencies that offered services to specific disability constituencies, we found among those in charge of professional development widespread and profound understanding of the principles and practices that were the focus of our investigation. BESB, DMR, and DMHAS all provided us with materials illustrating how they incorporate concepts such as self-determination and consumer decision making into the training of their staffs. (However, as indicated above, the term self-determination does not have currency at BESB. They speak of making choices and maximizing independent functioning.) We found that BESB makes some efforts in this direction, while the other two agencies have taken giant strides to infuse these concepts systematically into their training and practice.

BESB

The emphasis on community participation and independence is prominent in the literature of BESB. They define their mission as "to enable…clients to maintain their self-sufficiency and to maximize their participation in the community, at school, and in employment settings." To illustrate how they try to translate such goals to day-to-day operations, the agency shared excerpts from their Policy and Procedures Manual. For example, a section called "Informed Choice" reminds Vocational Rehabilitation counselors that the law requires consumer choice. It further requires that they document "how the consumer was informed about and involved in choosing among alternative goals, objectives, services, and methods used to provide or purchase such services."

DMR

The Department of Mental Retardation (DMR) appears to have made a major effort to embed the recommended principles and practices into its professional orientation and development. The agency implemented a "self-determination initiative" that was funded between 1997 and 2001 by the Robert Wood Johnson Foundation. This initiative was designed to introduce to DMR's leadership, case managers, providers, consumers, and families the underlying values and the practical applications of self-determination.

Since undertaking this initiative, DMR has sponsored and co-sponsored four annual conferences on the theme of self-determination and issued numerous fact sheets with titles that reflect the commitment to self-determination. (A few of the titles are as follows: *Hiring and Managing Your Own Supports*, *Person-Centered Planning*, *Self-Determination Orientation.)* They have produced and disseminated a series of documentary videotapes illustrating individual narratives (encompassing the successes and the unresolved challenges) of persons making the transition to a more independent, self-determined life. In DMR's Final Report submitted in 2001 to the funder, the agency stated that "during the course of the grant, the self-determination approach to service delivery grew from pilot project status to one of the core supports offered by the department.[7]"

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[7] Department of Mental Retardation, Final Grant Report, Self-determination Initiative, p. 11.

During the self-determination initiative (and continuing ever since), DMR re-deployed a number of their case managers and other staff into a newly created position called “support brokers.” These individuals have received training and technical assistance so that they can assist consumers to develop circles of support and make their own decisions about their aspirations and what kinds of help they need to achieve them.

Training on values and principles such as consumer decision making are not restricted to staff taking the new positions such as support brokers. A quick scan of the topics listed in the DMR New Employee Training Manual makes it clear that an understanding of historical trends and contemporary principles such as person-centered planning and self-determination have been prioritized as topics on which every employee will acquire knowledge.

Agency representatives report that in 2004 they are continuing to integrate the ideas and practices they began with this initiative. Their expectation is to make self-determination both implicit and explicit in every aspect of training. A series of half-day training opportunities offered in spring 2004 introduced participants to the department’s most recent innovation in supporting self-determination: the development of individual service agreements (ISAs) which allow DMR consumers to have greater control in deciding what services and supports they wish to purchase with the funding they have been allotted. One possible outcome of an ISA is that the consumer hires and manages her/his own staff, and this option is covered in one of the sessions.

DMR develops its training through a Staff Development Unit, a unit located within the Central Office Division of Strategic Leadership and Quality Management. The Staff Development Unit has had its personnel and training budget dramatically reduced in the past couple of years. It currently includes a Director of Staff Development and three training staff in the central office and three regional units each with three staff. In the aftermath of the budget cuts, they anticipate producing more training materials designed for self-study by individual employees in lieu of large-group training events.

DMHAS

DMHAS has engaged in what its leadership describes as a paradigm shift. They have publicly rejected the notion that clinical "experts" can or should design the treatment plans for clients or patients who are duly sorted according to their specific labeled pathologies. The department leadership has attempted to replace the deficit-oriented model with a new culture and a new way of framing their mission and services. The overall theme is "Recovery[8]'' which is meant to be person-centered, strength-based, and consumer-driven. It was formally inaugurated in a Policy Statement from the Commissioner of DMHAS in the fall of 2002. Representatives of the agency describe DMHAS as helping to lead the field toward self-determination principles both within Connecticut and nationally.

Reflective of the "recovery" theme, a substantial portion of the agency's training is organized under the rubric of the Recovery Institute. It is designed and conducted through an Education and Training Division. The targets of training are approximately 3000 individuals: the employees of about 200 contracted agencies as well as DMHAS employees. DMHAS offers professional development at three levels of intensity: (1) One-shot presentations or workshops; (2) Multi-session courses; (3) Centers of Excellence, which are individual agencies selected through a competitive application process to receive more intense training and technical

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[8] "'Recovery' is a process of restoring or developing a positive and meaningful sense of identity apart from one's condition and then rebuilding one's life despite, or within the limitations imposed by that condition." Commissioner's Policy Statement No. 83, Promoting a Recovery-Oriented Service System, September 16, 2002. Available on-line at http://www.dmhas.state.Connecticut.us/policies/policy83.htm.

assistance over a period of nine months in order to become models in one aspect or another of service delivery. (As of spring 2004, there are nine Centers of Excellence.)

At each of the three levels of intensity, one finds training content reflective of self-determination and consumer decision making. For instance, the spring 2004 training calendar includes a one-day session on "Introduction to the Recovery Model." At a greater level of intensity, there is a three-session course titled, "Working with Natural Support Systems."[9] At the most intensive level, two of the nine Centers for Excellence have been designated as models of training for person-centered planning.

Agencies that target services to constituencies with diverse disabilities

BRS Division of Vocational Rehabilitation

The Bureau includes two divisions. This review is centered on the Vocational Rehabilitation Division, which in the spring of 2004 included a staff of approximately 69 counselors spread across 3 regions. (The other is the Disability Determination Division.)

The opening sentence of the Policy Manual which BRS Vocational Rehabilitation counselors receive indicates that this agency wishes to provide each of them with the philosophical basis as well as the other dimensions for their duties. As one reads through the manual, one begins to understand just what philosophy is being promoted, and it turns out to be very consistent with the principles for which this investigation was searching. Among the guiding questions that counselors are urged to ask themselves in the opening pages of the Policy

Manual (as they support service recipients who are seeking work) is: "Are our consumers full partners in the rehabilitation process, and have we ensured that our consumers are given opportunities to make *informed choices*?" Another guiding question is, "Are we primarily looking at the person's capabilities and strengths, trying to develop a plan consistent with those abilities, or are we too focused on the deficits?" Later in the manual, there is an entire section regarding "informed choice," thoroughly defining the elements of that phrase. It stresses that counselors do not make decisions for consumers but try to ensure they have all the information about their options. Still later in the manual, counselors learn about the development of an "Employment Plan," and they are asked to examine any plan they are writing for its consistency with the consumer's employment goal, and with the consumer's "strengths, concerns, abilities, interests, priorities."

Another document that reinforces the values and practices identified in the Policy Manual is one called "Vocational Rehabilitation Counselor Competencies." There, "informed choice" is included in addition to other competencies such as "counseling skills" and "collaboration." Within the domain of "informed choice," counselors are expected to maintain case records that show "the data considered in making decisions," demonstrate "in counseling sessions and contact notes a range of choices for the consumer," and display such other performance behaviors as "can demonstrate…parameters for agency participation and the alternatives the consumer may pursue independently;" and "has a clear understanding of client's rights and responsibilities and recourse…and can explain this…utilizing language that can be understood by the consumer."

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[9] The course aims to teach participants how to work with "families, friends, roommates, partners and others who

The BRS currently has an Acting Training Coordinator and also has a system whereby each employee in every job class meets at least once a year with a supervisor to generate an Individual Staff Development Plan. This plan reflects individual training, education, and staff development needs for current positions and to enable individuals to prepare for future roles. Together with its documented attention to the principles and practices of self-determination and consumer decision making in its overall staff development and performance evaluation activities, this individualized planning for professional development would indicate that this agency is well poised to keep its work force current with respect to state-of-the-art approaches to working with persons with disabilities.

Bureau of Special Education, CSDE

Staff of the CSDE do not provide supervision or instruction directly to Connecticut's children; that responsibility falls to the local school districts. The 15 consultants at CSDE's Bureau of Special Education are responsible for guidance and policy development, ranging from monitoring, technical assistance, developing manuals, to mediation and deploying hearing officers for due process proceedings. Whenever the Bureau staff identify a need for training, the actual development and implementation of the training falls to an organization called SERC. SERC, located in Middletown, states on its web site that it is "a centralized resource for professionals, families, and community members regarding education and early intervention/prevention for all of Connecticut's children and youth and their families, particularly

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have a significant relationship with a person who has a severe and persistent mental illness."

children with special needs, at-risk learners, and diverse learners." CSDE has been contracting with SERC to fulfill this role since 1969[10].

The contents of current training sponsored by CSDE Bureau of Special Education and carried out by SERC are aligned with 12 outcomes identified in a Continuous Improvement Plan (CIP). These outcomes were chosen during a collaborative process that took place from 2001 through 2002 and are subdivided between four outcomes relating to IDEA Part C[11] (the responsibility of the Birth to Three System lodged within DMR) and eight others relating to IDEA Part B[12] which are the responsibility of CSDE. (There is one additional outcome that cuts across both sections of the law and both state agencies.)

Several of the outcomes are directly related to the principles and concepts that are the focus of this study. The expectation for "parent participation" is that "parents of students with disabilities…participate as full partners in the planning and implementation of their child's educational program." The expectation for "access and participation" is that "students with disabilities…will have equal access to and be active participants in their total school communities." The expectation for "community participation" is that students with disabilities will "develop and maintain healthy relationships and independent living skills to actively participate in their communities." A fourth intended outcome is "self-advocacy," which is spelled out as "identifying personal strengths, challenges, and interests and making informed life choices." With four of eight (Part B-related) outcomes framed in terms expressing the

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[10] The letters in the name used to be considered an abbreviation for Special Education Resource Center, but the organization now treats its name as a free-standing acronym.

[11] Part C of the Individuals with Disabilities Education Act sets down the parameters within which States define eligibility and early intervention services for children from birth to the third birthday.

[12] Part B of the Individuals with Disabilities Education Act sets down the parameters within which States define eligibility and special education services for students from age 3 to 22.

empowerment of students with disabilities and their families, we observe that at the macrosystemic level, this bureau has embraced many of the current understandings. The lexicon is somewhat different from what we find in other agencies, but that is explained by the function of the agency (education) and by the age of the service recipients (i.e., they are largely minors)[13].

There is no customized training of the Bureau staff. Rather, Bureau staff are frequently in attendance at SERC training events relevant to their areas of responsibility—events which they themselves have had a hand in bringing to life. In addition, Bureau staff participate in regional and national conferences of their professional disciplines. The educators who become staff of this Bureau are expected to be conversant from the time of their employment with the currently accepted principles and to take leadership in spreading those principles (as they apply within the educational system) to other constituencies.

Agencies which have as their primary mission advocacy or the monitoring of compliance with laws or regulations

Connecticut Council on Developmental Disabilities

We concluded the questions the CCDD faces related to staff training are quite different from those facing the agencies that provide direct services.

Asking the CCDD if they were training their staff to understand and promote consumer choice, self-determination, and other currently accepted principles was a "carrying coals to

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[13] Once students reach age 14, they are encouraged to participate in their own planning meetings (PPTs) and to take increasing responsibility for choices.

Newcastle[14]" moment. As they kindly noted, these principles have grown out of the same movement that gave rise to the Developmental Disabilities Councils across the country in the 1970s. Many of their efforts are designed (largely through their grant programs) to incubate system change that will positively impact persons with developmental disabilities in exactly the ways that the Real Choice System Change project is promoting[15].

The CCDD has only three full-time paid employees, all of whom are viewed as leaders within the wider world of service provision and consumer education. They are among those defining and articulating the vision and principles for which the current investigation is seeking evidence. To remain current, they attend conferences, build connections with other advocates, and get involved in discussions with their grantees.

They answer to a Council made up of gubernatorial appointees who are in large part constituents with disabilities or family members. A continuing challenge they face in the arena of staff development is what kind of orientation and education to provide to the Council members. They have to respond to the agenda and priorities of their Council while at the same time helping to shape that agenda and those priorities through the training they provide to them.

Office of Protection and Advocacy for Persons with Disabilities

P & A, with 43 employees, is a place to which persons with disabilities often turn when they believe state service systems have not lived up to their obligations. In this respect, it is by

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[14] Newcastle is a region in Great Britain known for generations for the production of coal. Thus the metaphor for an exercise in redundancy. The author has been advised by a reader of an earlier draft that this quaint old expression is no longer widely known and therefore offers this explanation.

[15] It is worth noting that the CCDD, the P & A, and the A.J. Pappanikou University Center for Excellence which houses the Real Choice initiative are "sister agencies" in that they are all funded by the federal Administration on Developmental Disabilities.

design not a part of the service system as a whole. An article that P & A shared with us to illustrate their efforts at professional development states that "while internal efforts to improve service quality are important, external safeguards such as advocacy must also be utilized." That is the spirit in which the agency orients and trains its personnel into the advocacy role: that they are part of the <u>external safeguards</u> for the people they represent rather than being a part of the service system.

P & A employees advocate for individuals with disabilities in their encounters with the health care system, in housing, employment, financial planning, and potentially any aspect of daily living. On occasion, their employees litigate against other agencies within the state service system. One of their divisions also investigates allegations of abuse or neglect of adults with mental retardation—including those taking place at institutions operated by other actors within the Connecticut state service delivery system.

On one hand, the values of consumer empowerment and self-determination underlie all of their activities. On the other hand, they are often cast in the role of "expert" rather than merely partner or facilitator in trying to assert the rights and needs of a person for whom they are advocating. The background "advocacy principles" the agency shared with us indicate that they recognize the tension in this role.

> When assuming the role of advocate, one must also accept the necessity of engaging in an ongoing process of rigorous values clarification. An advocate must be able to explore his or her own fundamental assumptions, values, attitudes, and beliefs about disability before he or she is prepared to question those of others. This learning process is never ending.

Although they acknowledge in the quote above that the learning process is "never ending," the agency has no training coordinator and no formal infrastructure for in-service training. They report that they explore person-centered philosophy from the time they first interview someone for a position, and they give each new hire a small packet of print materials (from which we selected the quotes above) reviewing basic values and principles. All new hires (and some veterans) are sent to national Protection and Advocacy conferences which offer additional education on self-determination and related issues. They are currently generating a new operations manual for advocates which will strongly emphasize the ways that advocates can respect and promote self-determination. Resource limitations have left them wishing they could do more in this arena.

Bureau of Health Care Systems, Division of Health Systems Regulation

The focus of the Division of Health Systems Regulation of the Bureau of Health Care Systems (of DPH), is very specific. It certifies Intermediate Care Facilities for Persons with mental retardation—known as ICF/MRs. It also regulates some other facilities and services. The professional development of the staff carrying out these functions (who are called surveyors) must closely track the federal standards which govern them. These federal standards have in the past decade become infused with the principles of self-determination and consumer choice. Here is an excerpt from one of the forms disseminated to the surveyors by the federal authorities:

> The field of DD [developmental disabilities] is increasingly emphasizing supporting individuals in their own homes and communities, rather than placing people in facilities. In addition services in virtually all States are placing increased emphasis on person-centered planning and person-centered services that focus on the preferences, goals, and aspirations of each individual and on supporting them in reaching their personal goals….This revised survey protocol gives [ICF/MR.] facilities broader latitude to develop the processes by which it implements active treatment services…The survey is to center on the fundamental requirements that produce outcomes for individuals. When those outcomes occur, review of additional supporting requirement of process and structure is not indicated.

In other words, the federal government has become less prescriptive about the precise processes that govern the operation of ICF/MR facilities and more focused on whether the residents of these institutions are having their dignity, aspirations, and needs respected and addressed. In order to confirm that operators of such facilities are in compliance, surveyors have to be trained to interview residents as well as family members, staff, and advocates, and to listen to the perspectives of persons with disabilities. The form the surveyors complete requires them not to be satisfied with platitudes but to take notes on such matters as whether service recipients are getting to choose they way they want to groom themselves and dress, the way they spend their leisure time, and even who controls the channel selection on the television. They also examine Individual Program Plans which specify the goals and activities to which the institution has committed itself during the current period.

Training to prepare the surveyors to carry out these responsibilities has been designed and implemented nationally by the Centers for Medicare and Medicaid Services (CMS). Every new hire attends a full week of mandatory CMS background training. Each administrator and surveyor then must receive additional training to become certified on specific types of facilities.

Here in Connecticut, the division also assigns a veteran surveyor to act as “preceptor” or mentor for each new surveyor. The division adds its own regular in-service training to the intensive preparation required by CMS, making use of teleconferencing in addition to face-to-face events. Many individuals are members of professional associations such as American Association on Mental Retardation, and they are encouraged to bring back current ideas and issues when they attend conferences and present them to colleagues as part of ongoing in-service.

It appears that at some point in the 1990s, this division, and those agencies governing its practices, were already asking the very questions the Real Choice System Change project is now posing. They appear to have created mechanisms for assuring that self-determination, consumer choice, and other related principles remain at the heart of their efforts.

Agency that Provides Oversight

The Office of Policy and Management (OPM) reported that information on disabilities imparted to OPM staff through formal training is related to general issues of respecting and protecting human rights, the Americans with Disabilities Act (ADA), and promoting diversity in the workplace.

Next Steps

Our review of the contents of staff orientation, training, and professional development activities at selected state agencies in Connecticut leads us to conclude that important changes in laws, values, and philosophy that have swept through our nation in the past two to three decades have not been ignored by those charged with providing services and advocating for persons with disabilities in our state. These agencies have made strong, specific, and public commitments to work with consumers and families as partners; to view the choosing of goals in various venues as primarily the province of the consumer, not the staff; and to move away from stigmatizing labels and deficit models toward strength-based approaches to children and adults with disabilities.

The conclusions we draw cannot yet reassure persons with disabilities and their families that every time they encounter someone working for one of these agencies, their experience will be one of empowerment and partnership in decision making centered on their own aspirations as they have defined them. But we can at least assure them that the upper managers of each of these agencies and those responsible for the professional development and evaluation of their work forces have made strong public commitments in this direction. Familiarity with some of the details of these public commitments should help consumers and their allies to press agencies to live up to the principles they espouse. Put another way, consumers may find it useful to invoke the promises made at the level of the macrosystem as they seek to redress problems they encounter in various microsystems.

Our findings regarding the agencies we reviewed do not permit us to make any assumptions about the principles and practices of other agencies within Connecticut state government. The agencies and bureaus we chose to examine—although we did not necessarily plan it this way—are very likely the ones which have expended the most effort and traveled the farthest on the road to incorporating current thinking about best practices regarding persons with disabilities. Now that we know that the agencies that serve the greatest numbers of persons with disabilities in Connecticut have set a high standard in this domain (at least at the level of the macrosystem), the Real Choice System Change project would like to take advantage of the evolution they have already encouraged within their own agencies. We would like to enlist them in helping us to look at the principles and practices of other agencies. Have other agencies—or even other bureaus within some of the same agencies--also embedded principles such as self-determination and consumer decision making and practices such as person-centered planning into their work? We are particularly eager to examine those agencies and bureaus which do not have service to persons with disabilities as a central part of their missions but which inevitably encounter consumers who have disabilities.

Representatives of nearly every agency we reviewed indicated that they would be interested in increasing the level of sharing of training experiences, materials, and perspectives across agencies. They appear to recognize the Real Choice System Change project and the University of Connecticut’s A.J. Pappanikou Center which houses the project as potentially worthy intermediaries.

We move to these next tasks with a spirit of optimism. We believe that among the Connecticut agencies and bureaus we have presently reviewed, there are an impressive number of professionals who share the values of the Real Choice System Change project. We hope the dissemination of this report will be viewed as a recognition of their efforts to date and an invitation to continue to work with us and with consumers with disabilities as well as other agency leaders on the unfinished tasks to which we have alluded here.