The Value of the Incompetent: Application of Social Work Values

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The Code of Ethics of the National Association of Social Workers provides a framework for practice, including policy formation. This article explores the ethical principle, “Social workers respect the inherent dignity and worth of the person.” The ethical principle is applied to practice at the macro-level, in a unique exploration of policy formulation through the inclusion of persons with intellectual and developmental disabilities, with persons under corporate guardianship in the state of Wisconsin.

The Value of the Incompetent: Application of Social Work Values Andrea B. Bauman Sponsored by Professor Sharon Keigher University of Wisconsin-Milwaukee Journal of Social Work Values and Ethics, Volume 4, Number 2 (2007) Copyright © 2007, White Hat Communications This text may be freely shared among individuals, but it may not be republished in any medium without express written consent from the authors and advance notification of White Hat Communications. Keywords: ethics, self-determination, policy, incompetent, guardianship

Abstract The Code of Ethics of the National Association of Social Workers provides a framework for practice, including policy formation. This article explores the ethical principle, “Social workers respect the inherent dignity and worth of the person.” The ethical principle is applied to practice at the macro-level, in a unique exploration of policy formulation through the inclusion of persons with intellectual and developmental disabilities, with persons under corporate guardianship in the state of Wisconsin.

1. Introduction

Social workers are expected to practice within the framework provided by the Code of Ethics of the National Association of Social Workers (1996) (the Code). The framework includes a set of core values and ethical principles along with ethical standards that provide guidance for their implementation. The core value of Dignity and Worth of the Person is defined in the Code as follows:

> Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients’ socially responsible self-determination. Social workers seek to enhance clients’ capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients’ interests and the broader society’s interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession. (NASW, 1996)

This article seeks to explore what this principle looks like in action, applied to practice with persons under corporate guardianship1 in the state of Wisconsin.

2. Background

As a graduate student, I interned at Wisconsin’s federally mandated protection and advocacy agency for persons with disabilities (such agencies receive authority under P.L. 99-319), where I was exposed to macro practice in a variety of venues. One such area was revision of Wisconsin’s Administrative Code HFS85, which provides the rules for nonprofit corporate guardianship agencies in the state.

Wisconsin administrative code HFS 85 was initially promulgated in 1983. In September of 2006, the Department of Health and Family Services (DHFS) issued a statement of scope2 to revise the code for the first time since its original promulgation. In the statement of scope, DHFS stated the following:

> Policy Analysis Chapter HFS 85 establishes criteria by which the Department of Health and Family Services finds a non-profit corporation suitable to serve as guardian of persons who are determined by a court to be incompetent. Criteria include the number of wards a corporation is authorized to assume for guardianship, the number of staff needed to carry out the responsibilities of a guardian, staff qualifications, either by training or by experience, proof of financial stability, conflict of interest standards and the frequency of personal contact with wards. The rule also contains provisions for the Department to withdraw its finding of suitability if the corporate guardian no longer meets the eligibility criteria, and the rule provides appeal rights for any party adversely affected by this action. The Department proposes to revise Chapter HFS 85 for the following reasons. A. To reflect current standards of practice for corporate guardianships in the areas of staff qualification and training, caregiver background checks, adequacy of staff, contacts with wards and conflicts of interest standards. B. To include requirements for corporate guardians to maintain agency policies in the areas of abuse and neglect prevention, complaint and grievance investigations, and advance directives. C. To reflect the increase in the number of adults in need of guardianship and the increase in their acuity level. D. To incorporate recent changes to 2005 Wisconsin Act 387 to ch. 880, Stats., relating to the limitation on the number of wards of a corporate guardian. (State of Wisconsin Department of Health and Family Services, 2006)

The statement of scope recognized a need to bring the rule governing corporate guardianship in line with current practices and changes to other Wisconsin statutes related to guardianship.

As an intern, I had been involved in discussions regarding corporate guardianship with DHFS-Division of Quality Assurance (DQA) prior to the issuance of the statement of scope. This relationship afforded me an initial seat at the table when DHFS began planning an advisory committee to review and make recommendations for the new rule, and I continued in this role as an independent student after my placement concluded.

One of the first tasks the committee established was to develop a survey of the corporate guardianship agencies in the state. As one of 23 advisory committee members, I worked with other members to create a survey that was then sent to all of the corporate guardianship agencies operating in the state. The survey was developed to learn more about the practices that were taking place within the corporate guardianship agencies and to inform the advisory committee as it moved forward with the rule revision. The tool was designed to be used as a voice for the corporate guardianship agencies that would be affected by the rule revision. The survey asked for a breakdown of the populations served, the staff employed by such agencies, duties provided by the agency, and operational structure related to agency policies, procedures, and case files.

The advisory committee began meetings in January 2007. Representatives from DHFS, county probate offices, corporate guardianship agencies, county representatives, and disability advocates were present. The first meeting was an introduction for committee members and a brainstorming session to identify areas within the rule that committee members believed were in need of considerable revision. After reviewing the rule revision process, focusing on the stakeholders involved, a key participant group appeared to be missing—persons under

guardianship. As a social work student and committee member, I felt that if I did not bring this matter to the committee’s attention, I would be in conflict with my professional responsibilities to the wards that would be affected by changes to the rule. After speaking to members of the advisory committee regarding this concern, DHFS-DQA staff agreed to develop a series of listening sessions to gather the input of current wards, a group that would be vitally affected by revisions. This article focuses on the application of the Code’s ethical principle of Dignity and Worth of the Person to the ward listening sessions. 3. Application of the Code to Practice Within the Code’s ethical principle of “Social workers respect the inherent dignity and worth of the person,” social workers are called to “...promote clients’ socially responsible self-determination,” and to “...resolve conflicts between clients’ interests and the broader society’s interests in a socially responsible manner...” Reviewing the Code further, the following ethical standards appeared to apply to my practice and goal of gathering input from the wards who would be most affected by HFS 85 rule revisions: (1.02) self-determination, (1.14) clients who lack decision-making capacity, (6.02) public participation, and (6.04) social and political action: 1.02 Self-Determination Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients’ right to self-determination when, in the social workers’ professional judgment, clients’ actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others. (NASW, 1996) Self-determination recognizes the dignity and worth of a person. Mental health advocates define self-determination as: ...clients’ rights to be free from all involuntary treatment; to direct their own services; to be involved in all decisions concerning their health and well-being; and to have meaningful leadership roles in the design, delivery, and evaluation of services and supports. (Cook, 2002) When analyzing the lack of ward input in the rule revision process, I recognized that advocate groups and corporate guardianship agencies could present information and concerns on behalf of the wards; however, they did not have the first hand experience of living under guardianship. My thought was that the wards might be able to shed light on how the rule affected their lives, as well as any areas of the rule that might be of concern to them. Johnson (1999) purports that there has been a tendency of those in leadership roles to act in ways that conflict with this value and states, “...serious concerns have been raised in the disability community over discrepancies among public statements made by federal disability policy leaders in support of the self-determination of people with disabilities and their actual behavior, decisions, and actions.” This statement clearly cautions policymakers to examine the ways in which they carry out their duties, and to be cognizant of their intent and action. The HFS 85 rule revision presented an opportunity to redefine how the policy formulation process proceeded. In this case, DHFS recognized the importance of including the voice of the wards in the rulemaking process. 1.14 Clients Who Lack Decision-Making Capacity When social workers act on behalf of clients who lack the capacity to make informed decisions, social workers should take reasonable steps to safeguard the interests and rights of those clients. (NASW, 1996) and, 6.02 Public Participation Social workers should facilitate informed participation by the public in shaping social policies and institutions. (NASW, 1996) In this case, although wards are considered incompetent, they retain their right to participate in decisions that will affect their care. Froemming & Abramson state: Even though a person is under guardianship, he or she retains the right to communicate with government officials about his or her treatment and to seek legal advice or court review concerning the need for guardianship, the guardian's actions, or any orders for protective placement or services. (Wisconsin Department of Health and Family Services Division of Supportive Living, 2000). The inclusion of current wards under corporate guardianship was justified because the rule directly affects the practices of corporate guardianship agencies in relation to the care of the ward. To obstruct or disregard this right could result in an unintended omission or oversight within the rule that could have a detrimental impact on the ward. An example of the disconnect experienced between providers and consumers can be seen in Shumway’s (1999) dialogue regarding an “open microphone” meeting with consumers that was used to inform policy revisions for person-centered care: Individuals stated their dreams and desires and compared them to their current circumstances. Increasingly, individuals were expressing where they wanted to live and the relationships they wanted to have. The discrepancy in satisfying individuals, in addition to the realization of the clarity of many individual’s visions, were jarring for agency staff. The consumers impacted by the policy did not share the same feelings as the agency staff, and this would not have been communicated if the consumers had not been invited to share their thoughts. 6.04 Social and Political Action (a) Social workers should engage in social and political action that seeks to ensure that all people have equal access to the resources, employment, services, and opportunities they require to meet their basic human needs and to develop fully. Social workers should be aware of the impact of the political arena on practice and should advocate for changes in policy and legislation to improve social conditions in order to meet basic human needs and promote social justice. (b) Social workers should act to expand choice and opportunity for all people, with special regard for vulnerable, disadvantaged, oppressed, and exploited people and groups... (d) Social workers should act to prevent and eliminate domination of, exploitation of, and discrimination against any person, group, or class on the basis of race, ethnicity, national origin, color, sex, sexual orientation, age, marital status, political belief, religion, or mental or physical disability. (NASW, 1996) Because persons who are most affected in their daily life by HFS 85 are persons who have been declared incompetent, and have no family member or friend willing or able to be guardian, I believe that this group represents one of the most vulnerable and disadvantaged groups in our society. As a result, I offered to work with DHFS-DQA to establish and facilitate the ward listening sessions to further inform the rule making process. 4. Method A questionnaire was developed to guide the sessions and included questions in the following areas: Experience under guardianship, participation in decision-making, complaint and grievance processes, and contact with the corporate guardian. Three ward listening sessions were held between March and April 2007. Attendance averaged 10 wards per session. A total of 31 wards were interviewed. All wards were over the age of 18. All participants appeared to be of European descent. Participants reported various lengths of service provided by corporate guardians, from a few months to many years. Two of the sessions were held at workshops

where the wards were employed, and one session was held at a community drop-in center. All three locations were in rural counties of the state. Personal attendants and a few service providers sat in on the sessions as well. The facilitator presented opening remarks about the reason for the session and how the information would be used to develop HFS 85 during its revision. Participants met as a group, where the facilitator went through the questionnaire with the group and proceeded to prompt each participant individually for his or her response. For wards that were able to read, the facilitator copied the questions onto a flipchart, and participants were informed of its availability during the session. Each session averaged one and a half hours in length. A DHFS-DQA staff member recorded participant comments to each question by hand. Audio and visual recording devices were not used to record responses.

5. Results The comments of the wards were grouped into the four key areas that the questionnaire addressed: 1) experience under guardianship; 2) participation in decision-making; 3) complaint and grievance processes; and 4) contact with the corporate guardian. 5.1 Experience under guardianship This area focused on general experiences under corporate guardianship and asked for input on what was working well and what could be improved. Most of the wards reported that they liked having a corporate guardian and that their life had improved as a result. Some of the wards said they did not see their guardian often. A few stated they didn’t know who their guardian was because the guardian was newly appointed and they had not met their guardian yet, and others stated they could not remember the last time they saw the guardian. 5.2 Participation in decision-making Participation was discussed with an emphasis on how the ward participated in decisions related to their living arrangements, choice of doctor, day programming or work, and choice of worship. Many of the wards reported that they were satisfied with their current role in the decision-making; however, a few wards did have specific wishes for different living situations and stated a preference for more inclusion in the decision making process. One ward explained: “I’m 32 years old....I would like to live closer to my brother...I should not have to live with children...I’d like to visit my grandparents (who live in a neighboring state).” Another ward stated the residence she was at would not allow her children or parents to visit after 6 p.m. and this interfered with her being able to see them. One ward expressed an interest in moving to another state. Another ward stated she was told how many gifts her children could have, but that she wanted to buy them more. 5.3 Complaint and grievance processes Participants were asked how they handled complaints or grievances about their living arrangement, doctor, or their daily activities. Participants were also asked whether they talk about these complaints with their guardian, and who else they contact if their guardian was not able to assist them. As a whole, wards seemed unaware of any right to question decisions made by their guardians. A few wards stated they would call their guardian if they had a complaint; however, most of the wards did not express any knowledge of how to handle such a conflict. 5.4 Contact with the corporate guardian. Finally, respondents were asked how often their guardian contacted them face to face or by phone and how often the ward contacted their guardian. Responses to these questions varied widely, with many wards reporting weekly and monthly visits or phone contacts, while a comparable portion reported bi-monthly, quarterly, or less frequent contact. 6. Analysis The facilitator and DHFS-DQA staff met briefly after each session to discuss the listening sessions. After all the sessions were completed, the results were compiled into a document to be presented to the advisory committee. The document outlined the sessions and included information on how the data would be used during the rule revision process. Additionally, DHFS-DQA offered a statement on the usefulness of holding the sessions. The document states the following: 1. What common themes emerged from the Listening Sessions?

- Rights and grievances – Some wards did not know their rights and expressed wanting more information regarding their rights and how to follow up on a grievance.
- Contact with guardian – Some wards said they wanted more face to face visits at their residence with their guardian.
- Decision making – Some wards did not know why some decisions were made, such as where they live, and wanted to be involved in the decision making process.

2. How will the Division of Quality Assurance use the information obtained from the Listening Sessions in the rule development process? The information obtained from wards who attended the Listening Sessions will be shared with the Advisory Committee at the next HFS 85 Rule Revision Committee meeting. Their views will be given the same consideration as the views expressed by other members of the Advisory Committee when drafting rule language. For example, comments by wards related to frequency and location of visits with their guardian, notification of rights and grievance procedure, involvement of wards in decision making and any other areas identified by the committee in which wards expressed comment, will be considered when drafting proposed rules. 3. How have the Listening Sessions helped the Division of Quality Assurance? The Division stresses the importance of involving all persons who are affected by the rule in the rule making process. Wards are personally affected by the rule making, and it is important to obtain their comments and incorporate their ideas, to the extent possible, in any proposed changes to the rule. In addition, the lessons learned by including wards directly in the rule making process for HFS 85 can be used when the Division revises other administrative codes by including residents, clients, patients, and family members to obtain their perspective of the rule. (State of Wisconsin Department of Health and Family Services, 2007) 7. Discussion The three listening sessions with wards provided a venue for the voice of the wards likely to be affected by revisions to HFS 85. Their comments, while generally positive, did reflect some concerns in areas related to rights and grievances, contact with the guardian, and involvement in the decision making process. DHFS has recognized these problematic areas and plans to review sections of the code that can address these issues.

8. Limitations The information gathered from the listening sessions is specific to Wisconsin and were most representative of the rural counties within. An effort was made to hold similar sessions in urban areas; however these sessions did not occur because of scheduling conflicts and time constraints. The results must be reviewed carefully because of this concern, as urban area corporate guardianship agencies may operate differently than those in rural areas. Some of the participants may have had difficulty understanding or answering the questions, and this may have

biased the responses. Additionally, some of the responses may have been affected by comments from peers or the influence of personal attendants or service providers in attendance. Lastly, all of the wards who appeared at the sessions were of European descent, and may not hold the same views as wards of other ethnicities. It is difficult to ascertain whether this was due to the location of the sessions or some other reason. 9. Conclusion The process described above provides an example of the application of the Code’s core value of “Dignity and Worth of the Person” to practice. By applying the ethical standards presented in the Code, I was able to assess the need for input from the wards as well as develop a method of including them. Further, I was able to work with policymakers to ensure that the information gathered from the wards would be used to inform the rule making process. By including the wards in the policy formulation process, Wisconsin has made an affirmative statement that wards, although deemed incompetent, continue to retain dignity and worth as individual persons. Social workers should continue to look for ways to involve their clients at the macro level of practice, to ensure that policies include the input of all stakeholders—including those who are vulnerable or oppressed. Notes 1 Corporate guardianship is considered a guardianship of last resort in Wisconsin. Persons who receive services from a corporate guardian have no family member, friend, volunteer, or other party that is interested or able to serve as their guardian. Many states utilize provide public guardianship, where the state acts as guardian for such persons. Corporate guardianship differs from public guardianship in that it relies on non-profit corporations to provide the guardianship services. 2 The statement of scope is the first step in opening an existing rule up for revision. The statement of scope announces to the public the intent to revise the rule. The statement includes an analysis of the rule, statutory authority for the rule, an estimate of the time it will take to develop the rule, entities that may be affected by the rule, and comparable federal regulations if any. References Cook, J., and Jonikas, J. (2002). Self-determination among mental health consumers/survivors: Using lessons from the past to guide the future. Journal of Disability Policy Studies, 13(2), 87-95. Johnson, J.R. (1999). Leadership and self-determination. Focus on Autism and other Developmental Disabilities, 14(1), 4-16. National Association of Social Workers (1996). Code of ethics of the National Association of Social Workers. Washington, DC: NASW Press. Shumway, D.L. (1999). Freedom, support, authority, and responsibility: The Robert Wood Johnson Foundation national program on self-determination. Focus on Autism and other Developmental Disabilities, 14(1), 28-35. State of Wisconsin Department of Health and Family Services. (2006). Administrative rules statement of scope for proposed rules. (Doc. EXS-261, HFS 85, issued September 19, 2006). Wisconsin: Office of Legal Counsel. State of Wisconsin Department of Health and Family Services. (2007). Wisconsin administrative code HFS 85:Results from listening sessions with wards. (issued April 26, 2007) Wisconsin: Division of Quality Assurance. Wisconsin Department of Health and Family Services Division of Supportive Living. (2000). Guardianship of adults: A decision-making guide for family members, friends and advocates. Madison, WI: Author.