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Interacting with People who have Severe Communication Problems: ethical considerations

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ABSTRACT *People who have severe speech and communication problems have difficulties making themselves "heard" both in everyday communications and society at large. In spite of the positive results which have followed the development of non-vocal intervention strategies, this group of people is at risk for being left out of the social common and being alienated. It is important to realise that one cannot do in the technical what one cannot do in the ethical. Unless both social interaction and intervention with people who have severe communication impairments are based on ethical reflection, the moral standards that are applied to this group may be lower than for other people. True communicative interaction depends on the acceptance that the other partner has something of value to communicate, even if the means for expressive communication are limited and the messages are vague and difficult to understand. A moral requirement for autonomy, that is, an equal footing or right to expression, places an ethical imperative on the more competent communication partner to strive to overcome the asymmetrical relationship and help the disabled person create authentic messages. Ethics is awareness based on the reflection on moral phenomena, grounded in the norms and values of the society and typically the result of discourse and co-constructive reflection, in the form of everyday discussions as well as of public philosophical scrutiny. Communication is a vehicle of reflection and discourse may be regarded as joined reflection. Thus, time for discourse in professional work may be a prerequisite for ethical practice.*

Ethical issues related to people with disabilities have received growing attention within the fields of medicine and law. In the medical literature, there is an emphasis on questions related to survival and death, and prevention and termination (Ashley & O'Rourke, 1994; Darr, 1991; Dehan, 1994; Graham, 1994; Matthews, Meier, & Bartholome, 1990). Within law and other professions, questions regarding life and death have also been central, as well as issues related to life quality and

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rights to intervention and compensatory measures to create equal opportunity in spite of differences in abilities (Brown, 1995; Elkins & Anderson, 1992; Kentsmith, Salladay, & Miya, 1986; Leahy & Szymanski, 1995; Syse & Eskeland, 1992).

The present paper is concerned with people who have severe speech and communication problems, and who therefore have difficulties making themselves "heard." This group is at-risk for being left out of social interactions and thus being alienated. Unless both social interaction and intervention with people who have severe communication impairments are based on ethical reflection, the moral standards that are applied to communication with this group may be lower than for other people, not only in social interaction and intervention but in all aspects of life.

Communication Impairment

The focus here is people who do not speak or for whom speech is not sufficient to fulfil all communicative functions, including people with motor impairment, intellectual impairment, and autism. They may rely mainly on their limited speech or use augmentative and alternative communication systems to supplement or replace speech. Both interacting with and working for this group of people pose problems which warrant ethical consideration. These problems are not in the person with a disability or in the professional, but in their relationship. However, as communication partners they are not on an equal footing—for the disabled partner, the possibility for expression is reduced, and for the speaking partner the possibility to receive what the disabled partner intends to communicate is negatively influenced. This complementarity creates a relationship with an uneven distribution of power. This asymmetry has implications for professional practice as well as for communication interactions (*cf.*, von Tetzchner & Jensen, 1996; von Tetzchner & Martinsen, 1992).

Ethical Questions and Professional Practice

Terms are the tools of reflection. Following Aristotle, Skjervheim (1964) distinguishes between primary and secondary ethics, which correspond to Aristotle's terms praxis and poiesis. *Praxis* are everyday acts; acts which involve interaction with other human beings, both in private and elsewhere. They are not valued according to the results they produce, but whether they are performed according to the cultural standard, habit, and tradition. These are matters regarding how one should conduct one's life and relate to those who are near to one, as well as to strangers, including such matters as making laws and governing a state. Praxis is also a matter of honesty, of acting truthfully. *Poiesis* are acts which have a meaning outside themselves, that is, are goal directed. They are valued according to their intention as well as the final result. The right poiesis acts are those that lead to the desired state, what matters is being able to perform in a professional sense.

According to Skjervheim (1964), it is the primary morality or praxis which

makes secondary morality or poiesis possible, and thus is the basis of professional practice.

> What I have termed *primary morality* concerns the basic human praxis. The *secondary ethics* or *morality* concerns the question of which goals one should set, where the means to obtain the goals can be found by rational calculation. (p. 77)

The fact that secondary morality depends on primary morality implies that it is the *praxis* of the person that determines the moral status of the situation and, through reflection, the ethics and the intervention to be performed. However, Skjervheim (1964) expresses concern that this relationship is being overlooked and that poiesis has become primary in education. Arguing against the utilitarian tradition following from John Stuart Mill (see MacIntyre, 1967), he emphasises that one cannot do in the technical what one cannot do in the ethical. This is illustrated in his view on developmental psychology and upbringing:

> To act technically means to act on the basis of a calculation of what will happen if one does this or that ... Upbringing belongs to the more general human praxis, where the attitude behind the acts is more important than choosing the right means. But where the attitude is decisive, it is not primarily a question of psychology, but of ethics. (Skjervheim, 1964, pp. 79–80)

According to Skjervheim (1964), goals of "intervention" (secondary ethics) can only be achieved if they are based on primary moral acts. A similar view was proposed by Durkheim at a much earlier time (Miedema, 1994). However, in discussions of ethics related to disability from a psychological and educational perspective, the *praxis* perspective may be difficult to detect. Focus is typically on the quality of the work being done by professionals from a technical perspective, for example, whether they have selected an appropriate vocabulary or provided the right kind of communication aid (e.g., Cockerill, 1994). The discussions differ little from technical-professional discussion in general. All professional questions are basically ethical, but if the focus is solely on technical aspects, ethical dilemmas may be hidden behind questions related to form and execution.

A related distinction is put forward by Tranøy (1994), who distinguishes between *morals* and *ethics*, where morals concern what is good and bad, and right and wrong, in everyday acts of life. Ethics comprises a more explicit, systematic and elaborated treatment of moral issues. Implicit in this distinction is the fact that ethics is related to consciousness, that is, to an awareness which is based on reflection on moral phenomena. These phenomena are part of the living of everyday life, as well as of professional practice. Professional ethics are reflections on the moral implications of professional practice. One may in fact say that ethics in this sense is a bridge between the two aspects of being a professional person: the professional side with its technology or *poiesos* on the one hand, and the everyday-life experiences or *praxis* on the other.

Moral Duty and Moral Consequence

There is thus an important distinction between moral duty and the quest for the best for as many people as possible. From the point of view of work and profession, it is easy to argue for the best for all instead of the dignity of the individual (*cf.*, Coyte, 1992). Moreover, because priority is inherent in political decisions far away from the people they concern, as well as in all kinds of intervention and every-day interactions, it may easily be concluded that one person's life is more important, or worth giving priority, than another. For example, a severely communication impaired person may not be able to contribute to the common good in such obvious ways as a teacher, a carpenter, or a doctor. The quality of life of the person with a disability may be considered to be less than that of people without such impairments. This is, of course, related to the society's and the individual's perceptions of a good life.

It may here be noted that moral acts transcend the rights of the individual. Laws are only necessary precautions against the lack of moral and ethical reflection in society. Acting ethically does not merely imply following a legal rule, but rather a human duty, where *respect* for the individual is added to the acknowledgement of the law. Most important in this is the ability to see a person with a disability as a person instead of as an expression of impairment. For the professional, transcending the values rather than the laws of society is the essence of advocacy.

From Object to Subject

The primary reflection on moral acts would be the question of whether the individual with a disability is treated as a person. In the professional literature within medicine, education, and psychology, ethical considerations are primarily related to the roles of the professionals. People with a disability are mainly mentioned as "patients" or "subjects" of research—really meaning "objects." The literature rarely addresses people with a disability as communication partners or the fact that basic human values determine the professional decisions, thus disregarding the fact that professional acts should not only reflect "best practice" but also the general morals of the society, including the implicit rules that govern human interaction.

The transformation from object to partner implies seeing the individual with a disability as a person, not as a set of symptoms of a particular impairment, and at the same time accepting the limitations and differences in ways of functioning that the impairment implies. Of particular importance is the fact that the focus now is on the relation to a "stranger." For the professional, the person with a disability is not family or another person with whom they belong, a fact that makes a significant difference in the relationship, compared to family and other people who are close to the person with a disability.

There are two ways in which to obtain a false picture of the situation of a person with a disability. Firstly, the professional may keep distance and see the situation from a narrow technical-professional perspective. The other way is to focus on one's own feelings. Many professionals' perception of people with a disability seems to be based on the fear they experience when they think of how it would be like to be in

a similar situation (see e.g., Tomkiewicz, 1996). This may create a false belief of empathy and of being able to evaluate what a good life is for that other person. This false belief increases the probability that the professional's own views will be attributed to people with a disability as if they did not have their own life. It is necessary for the professional to take an outside perspective in order to see both the person with a disability *and* him/herself as equal partners in the relationship. Both these ways have in common that they do not imply communication, the professional has not listened to the person with a disability or looked for the details in his or her life world. Only through experience and seeing people with a disability as individuals who are as different as all others, is it possible to obtain an authentic impression of their situation.

Authentic Communication

A truly moral professional practice depends among other things on the acceptance of the person with a disability's expression as authentic—as is any other person's. This means that it is perceived as an actual expression of the individual's thoughts (Habermas, 1983, 1984, 1987). To acknowledge another person's communication as authentic also implies an acknowledgement of what the other person says as having value and worth taking into consideration, not only in order to achieve a particular goal, but to reach a shared understanding. For Habermas, agreement is an important hypothetical result of the ideal communicative relationship. Henriksen (1997) raises doubts about this and suggests that well-founded disagreement is an equally likely result. However, he proposes that Habermasian discourse, with its acknowledgement of the other person's communication as authentic, may contribute to people developing the ability to be empathic and listen to viewpoints other than their own, an ability he regards as decisive for a moral actor in a pluralistic society. Henriksen makes these points in relation to present-day multicultural societies in general, but his considerations are equally valid for reflections concerning the standing of people with a disability in society. For people with severe communication impairments it is not agreement that is vital, but to be "heard" and taken seriously by other people. For individuals who use non-vocal alternatives or supplements to speech when expressing themselves, the communication form itself makes it difficult to attain this goal.

The communication processes of conversations between impaired and normally speaking people are in several ways substantially different from those taking place in dialogues involving normally speaking or signing partners. In addition to being an *interlocutor* who expresses his or her own views and negotiates topic and meaning as in face-to-face interactions where both partners are able to speak normally, the speaking communication partner may have to be a *message formulator* who articulates the message of the speaker with an impairment. This is done on the basis of single words and incomplete and fragmented sentences produced with orthographic script or manual or graphic signs, which serve as cues for the partner's interpretation (in addition to gestures and other nonverbal means of communication). The following

dialogue, taken from von Tetzchner and Martinsen (1996, p. 75) serves as an example.

George (G; aged 7 years 4 months) communicates with eye pointing and dependent scanning. His communication aid is a book containing 845 PIC signs, drawings, and photographs. He and his father (F) were going to start playing, but the father saw from George's expression that something was wrong.

F: *Here?* (Turning pages, asking for each page).
G: *BODY.* (Gaze).
F: *Body. Body?* (Turns pages).
G: Vocalises and gets tense in the body.
F: *Hm? Was it not the body? What was it? Was it this one.*
G: "No" (eye movements).
F: *This one?* (Points at *CLOTHES).*
G: "Yes" (eye movements).
F: *Clothes.* (Indicates domain. The father turns the pages to the clothes pages). *And here?*
G: "Yes" (eye movement).
F: *What?*
G: *SWEATER* (gaze).
F: *Is it something with the sweater?*
G: "Yes" (eye movement).
F: *What?*
G: "Yes" (eye movement, probably prompts guessing).
F: *Are the sleeves too long?*
G: "Yes" (eye movement).
F: *Oh, they are. Yes.*
(Time elapsed, 2:0).

One implication of this is that one communication partner is significantly more adept in adapting than the other. The basic features of the interaction and the inherent asymmetrical relationship that usually exists between speaking and non-speaking partners (see Collins, 1996; Marková, 1995), puts the responsibility for interpretation on the speaking partner (von Tetzchner, 1996). One may say that the speaking partner is in some respects responsible for both sides of co-construction, which places an ethical duty—in a Kantian sense—on him or her to "speak" for the other. At the same time, the speaking partner's double role as interlocutor and message formulator necessitates ethical reflection on his or her own contribution in order to ensure authentic communication on behalf of the communicator with a disability. The speaking partner may fail to fulfil this function, as in this dialogue between Joey (J) and a helper (H) from Silverman, Kates, and McNaughton (1978, p. 407):

H: *When's the holiday?*
J: (Points at the communication board containing Blissymbols) MONTH Ω.
H: *Month O? I don't get you, Joey.*

H: *Try to form a sentence with it.*
J: (Pounds three times on the letter) O. O. O.
H: *Does the month begin with an O?*
J: Yes
H: *October?*
J: Yes
H: *So. A holiday in October. Uh, let's see. Oh, I know. Thanksgiving (Canadian).*
Do you like Turkey as much as I do?
J: (Points at the board) H.
H: *H? I don't understand. What does H have to do with Thanksgiving?*
J: (Does not answer)
H: *Do you know why we celebrate Thanksgiving? About the pilgrims and Plymouth Rock and all of that?*
J: (Expresses frustration)

The ability to receive is a prerequisite for sharing, in particular in dialogues where one of the partners has limited expressive means. In such circumstances it may be difficult to apprehend what the other person is trying to communicate, sometimes even to know whether the person is trying to communicate anything at all. Still, although the nonspeaking person in the dialogue above, Joey, was known to have a good comprehension of spoken language, the speaking partner, H, did not seem to acknowledge that Joey had anything valuable to say (Joey meant Halloween). H did not attribute authenticity to what Joey said. Instead, he took on an educational role—out of turn, so to speak—and thus became a technique-oriented "school teacher." It may be the case that H actually was Joey's teacher, but even so, his answers implied lack of sensitivity and respect for Joey as a person. Outside the teacher–student setting, the communicative consequences of the communication partner's lack of an ethical stance are devastating, and contribute to extend the asymmetric relationship beyond the communicative act itself.

A somewhat similar—but different in significant ways—example involving a 42-year-old woman with intellectual disability and limited comprehension of speech and means of expression is presented by Møller and von Tetzchner (1996, p. 264):

> One Monday in June 1995, Bodil told her teacher about a fishing trip she had been on the day before. She found the PCS sign *FISHING-TRIP* and glued it into the right day (Sunday) in her calendar. She also told the teacher who had been there and that they had coffee and cakes. This conversation took more than half an hour.
>
> A little later, Bodil and the teacher went to her home (sheltered housing) for video recording a conversation between Bodil and one of the staff members. Bodil immediately pointed to *FISHING-TRIP* and began to tell about the trip. The staff member, however, began talking about a fishing trip they were planning for the following Tuesday. He also mentioned different people and said they were going to have juice and cakes. But while he stuck to his story, Bodil did not. She was the first to realise that they

> were actually communicating about two different trips. She began to smile, manually signed FUN and pointed to the Tuesday in the calendar, indicating that she was looking forward to the trip.

It was immediately assumed that Bodil was wrong and that she spoke about a future event instead of one that had taken place. Considering her intellectual impairment, this was not an unreasonable assumption. However, instead of disregarding her opinion completely, the staff member tried to convince her that she was wrong. He articulated in speech what she expressed with her graphic and manual signs, took his own dialogue turns, and even pointed at the board 14 times, something both he and Bodil's other communication partners rarely did. He became in fact an exemplary communication partner. The pointing indicates that he took the matter seriously and wanted to convince her that she was wrong, and thereby accepted the authenticity of her expression—as she had acknowledged his. He disagreed—as he might have done with any communication partner, but he regarded her point of view as authentic and worth arguing about. In spite of the inequality in language competence, he managed to forget his position and did not reduce the issue to a matter of paternalistic care.

Also in this example from Soro, Basil, and von Tetzchner (1992) a speaking participant shows respect for the message produced by an aided speaker:

> A girl and a boy, both using communication aids and a few manual signs, were sitting together with their teacher, who was functioning as a sort of mediator between them. The girl was listing the children she wanted for her birthday, but did not mention the boy, who eagerly indicated that he wanted to come. The teacher relayed the request. The girl indicated *NO* and the teacher relayed this message to the boy without interfering, that is, without attempting to make her change her answer.

It happens that conversation partners fail to "listen" or take what is to be communicated for granted, attributing limited or incorrect content to the expressions of people with a disability. One reason may be that the communication partners do not have their attention on the same focus, that is, have different contextual frames, as in this example from Krivohlavy (1996):

> One terminally ill woman managed to whisper *water*, but when a glass of water was brought to her, she did not want to drink. She was asked whether she had said *water* and confirmed this. Only when the communication partner went to her side in order to follow her gaze did he understand the meaning of the utterance: she was looking at a flower. When the water in the glass was poured into the vase of the flower, she smiled her acknowledgement.

In order to understand the woman, it was necessary—as in all true communication—to take her perspective.

A more difficult problem of attributing authenticity is when a profoundly impaired person is without any evident communicative expressions. Accepting the person

implies the attribution of meaning and decision to all his or her acts while at the same time acknowledging the person's inability to express meaning in an ordinary manner, and sometimes not even in an unconventional way. This creates a serious danger of unwarily attributing wishes and ideas that the person does not actually have, and thus a need for the normally communicating partner to see him/herself and the possible influence she/he may have on the interpretation of the person with a disability's behaviour.

It may be noted, however, that *conscious* overinterpretation is a different matter, as applied in the intervention method "structured overinterpretation" (von Tetzchner, 1996). In the use of this strategy, interventionist reflection is implied. An ethical stance requires that one is fully aware of the implications of what one is doing—and of the problems of not taking persons with a disability seriously.

Reflection and Discourse

The final point goes back to ethical reflection. Morals, even if applied to the individual, are basically social, reflecting the norms and values of the society. Moral development is not conceivable outside a community of some kind. It is, however, not enough to follow the habits and traditions of the society, it is these that the individual has to take a stand on and transcend. It is possible to reflect on ethics in solitude, but ethics can only be cultivated in a social room and through discourse. Communication is a vehicle of reflection and discourse joined to reflection (Jensen, 1992). To ensure ethical intervention, discourse should be facilitated between various professionals, family, and other significant persons in the communication impaired individual's life. Communication with severely and profoundly communication impaired people, even if their communicative means are limited, must also be part of this process.

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