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AUTONOMY vs. PATERNALISM

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In our society we place a rather high value on our freedom, independence and self-determination (Autonomy). At the same time we also pride ourselves on being a concerned and caring people always ready to help others in need -- sometimes to the point of thinking “we know best” (Paternalism). Autonomy and Paternalism are best viewed as at opposite ends of a continuum.

Paternalism <-----> Autonomy

When we seek to assist another person, we are challenged to strike a balance between protecting the right of the individual to be independent and self-determining (Autonomy) and our own sense of obligation to do what we think is best for the individual (Paternalism). This is the challenge for parents raising children, adult children caring for their now aged parents, health care professionals intervening with clients and even friends helping each other out.

Incapacity is perhaps the greatest threat to Autonomy. To the extent a person is incapacitated in some way, the person is then dependent on someone else. With this dependence comes an inequality, a loss of some Autonomy and a loss of power. The person may seek to neutralize this power differential in some other way. For a person with limited capacities, the only alternative may be the development of what are called “challenging behaviors”. Rather than combat these challenging behaviors with even more intrusive interventions (Paternalism), the more effective approach may be to provide the person with alternative opportunities for independence and increased influence and control (Autonomy).

For parents raising children, there is a need to transition from a posture of protection to control and then to support. Paternalism is gradually transitioned to Autonomy. When the transition does not proceed smoothly there are two potential and contrasting outcomes → an overly dependent adult child (stuck on Paternalism) or an estranged adult child (rebellious in pursuit of Autonomy).

Roles can be reversed when the adult child’s parents develop some serious medical problems and/or dementia syndrome. The adult child is then faced with the challenge of intervening with the parent → assisting the parent to remain as independent as possible (Autonomy) while also providing care to insure safety and welfare (Paternalism).

The incapacitated person is not the only one who necessarily has their Autonomy threatened. If a parent is in need of care, but pushes to remain independent, the Autonomy of the adult child is compromised by the necessity to provide that care on the parent's terms. Unresolved, a power struggle can ensue which can be a lose-lose situation for everyone.

The client seeking assistance from a health care professional maintains some level of Autonomy with the right to select the professional of choice and the right to refuse any recommended treatment. Informed Consent is required for any treatment.

Informed Consent includes 3 components - 1) relevant information must be provided, 2) the person must have the capacity to evaluate and appreciate the consequences of any alternative actions 3) the person's choice must be voluntary. The health care professional has some responsibility for all 3 components -- to provide understandable information to the client, to assess the ability of the client to use that information, to allow the client to make his/her own choice. If a client is suspected or determined to lack the capacity to use the information, then the right to self-determination (Autonomy) may need to be subjugated and an alternative source of consent sought (Paternalism).

The client is not the only person with Autonomy. The health care professional also has a source of independence and self-determination (Autonomy). If the client is uncooperative and/or in any way compromises the professional's ethics, he can choose to refuse to provide treatment. The private practice professional will usually have more such Autonomy (and therefore power) than the professional working for a government agency. The latter will need to seek other ways to neutralize this power differential -- perhaps the source of our stereotypes about governmental workers!!

These same issues regarding Autonomy and Paternalism also exist in the more casual case of one friend assisting another in some activity. Consider the case of 2 neighbors and friends -- one a carpenter and the other an accountant. The accountant asks the carpenter for help in building a deck on his house. With regard to building the deck, the accountant is dependent on the carpenter. The carpenter can take advantage of this dependency (and consequent power) to take over the project (Paternalistic) or he can just be willing to help as asked and thereby leave control with the accountant (Autonomy). Both the carpenter and the accountant maintain some ultimate Autonomy, i.e., the carpenter can decide he has no time, the accountant can decide to hire a contractor and give up on doing it himself.

We have been talking about two kinds of capacity here - the ability/skill to complete some task (e.g., build a deck) and "Decisional Capacity" (e.g., deciding to have a particular medical treatment). Typically, we use Decisional Capacity to compensate for skill incapacity. It is one of the 3 necessary components and a prerequisite to giving Informed Consent and allowing someone else to do something to or for us.

We have a special challenge when a person has the ability/skill to complete a task, but not the necessary related Decisional Capacity. There is the elderly person who can still write a check but might lack the ability to decide for what (or what not) to write it. There is the adolescent or person with mental retardation who has the physical ability/skill to engage in sexual activity, but might lack the capacity to make decisions about engaging (or not engaging) in it.

Decisional Capacity requires 3 abilities: 1) to understand and appreciate the consequences of one's potential choices, 2) to evaluate and make a choice 3) to communicate and/or execute that choice (whether you do it yourself or get someone else). All 3 components are critical. The person who lacks the ability to initiate and follow through on a decision (i.e., to communicate a decision by word or action) may be no less incapacitated than the person who lacks insight into the consequences of behavior due to some intellectual impairment.

It should be clear that capacity is not an all or none thing. We each have our own profile of abilities/skills. The accountant might need help with building a deck, but would be able to help the carpenter with doing his taxes. Decisional Capacity is also subject to variation depending on the nature and complexity of the decision to be made. Just about anyone can decide which cereal to have for breakfast. Appreciating the consequences and deciding between various approaches to treating cancer (e.g., medication, radiation, surgery), however, may be beyond some people's ability to comprehend. With some issues (e.g., sexuality), there are differences of opinion regarding just what consequences are critical and need to be appreciated in order to make a decision (health?, moral?, social? financial?, etc.)

Perhaps the most important and overriding capacity is the ability to assess one's own incapacity -- to be aware and recognize one's own need for help in certain other areas. Awareness of incapacity is what allows us to compensate, i.e., to ask someone else for help (e.g., to get an accountant to do our taxes). Lack of awareness exacerbates the potential consequence and danger of any of our incapacities (e.g., IRS auditing). Claiming incapacity and ignorance will be no excuse because of the assumption of the capacity to assess one's own incapacity (i.e., if you could not do it yourself, you should have gotten someone to do it for you!).

Everyone faces the potential of some increased incapacity (head trauma, health problem, dementia syndrome such as Alzheimer's Disease, etc.). While we still have capacity (and Autonomy), we are encouraged to plan for the possibility of such incapacity (and thereby minimize any Paternalism). President and Mrs. Clinton recently publicized the fact they were drafting "Living Wills". Forms for creating "Durable Powers of Attorney" are now readily available even in some supermarkets.

Setting up both a Living Will and/or a Durable Power of Attorney require that the person have capacity at the time they are developed. They are both acts of Autonomy. The person must be able to understand and appreciate the consequences of the action. A person with severe mental retardation or who already is in a later stage of Alzheimer's Disease undoubtedly would not meet the criterion of capacity to set up a Living Will or Durable Power of Attorney.

A Living Will maximizes Autonomy at the expense of Informed Consent. A Living Will requires the anticipation of some rather unforeseeable circumstances. The idea is to decide now (Autonomy) what you would want later when you might not be able to decide (and also not be able to change your mind!!).

A Durable Power of Attorney maximizes Informed Consent at the expense of Autonomy. A Durable Power of Attorney involves designating someone to execute decisions you make as long as you are still capable and allows the designee to start actually making the decisions for you in the event you become incapacitated.

Presumably the designated Power of Attorney is someone with whom you have shared your thoughts and values and is committed to making decisions as s/he believe you would if you could. At the cost of having this substitute decision maker (giving up Autonomy), the decisions can be made based on an understanding of the immediate and actual circumstances (Informed Consent). A complete Durable Power of Attorney should include specification of designee(s) and exactly what activities each is responsible for (e.g., financial, medical, placement).

The comparable option in the case of an already incapacitated individual would be the appointment of a Legal Guardian. This is an act of Paternalism. The Guardian is designated by the Court to serve on behalf of the person to oversee all or some designated part of his/her affairs and make decisions for the person when necessary.

Guardianship is still not a rationalization for extreme Paternalism. The Guardian should be expected to still allow the maximal Autonomy to the person. When a decision must be made by the Guardian, it should be made based on what the person would do if they had capacity, not what the Guardian would prefer or personally want to do.

Guardianships should be considered a last resort. They are only necessary in the most extreme case or when there is some unresolved conflict. Although they may meet the incapacity requirement for appointment of a Guardian, many people with mental retardation already have a sufficient level of support to make such an appointment unnecessary. The role of service providers is to maximize their capacities (Autonomy) and provide care and support to compensate for areas of incapacity (Paternalism).

Saying "the person was never adjudicated incompetent" is not an acceptable rationalization for not intervening when a person engages in a pattern of unsafe and irrational behavior. Parents, adult children, health care professionals and even friends/acquaintances bear responsibility for making ongoing evaluations of capacity. The parent evaluates and decides when to increase the child's responsibility. The adult child evaluates and decides when it is time to begin to reverse roles with the parent. The health care professional evaluates and decides what level of supports the client requires. The friend/acquaintance seeking a relationship must be concerned that the prospective partner is truly consenting.

The issues regarding Autonomy vs. Paternalism are clearly complex. Arguably, we all have rather limited decisional capacity in this area. Hopefully this article has shed some new light and perspective on the issues. And oh yes -- my area of expertise and capacity is Psychology, not Law. Consult an Attorney for additional information regarding Living Wills, Durable Power of Attorneys and Guardianships; and also Living Trusts !!! (added 11/04/94, GDC).

Reprinted from The Arc of Berks County Newsletter (December 1993). For subscription information call 610-603-0227 or e-mail berksarc@ptd.net.