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A Series of Topical Papers on Developmental Disabilities

Current Trends and
Future Issues

by Jane Belau

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on the
Future

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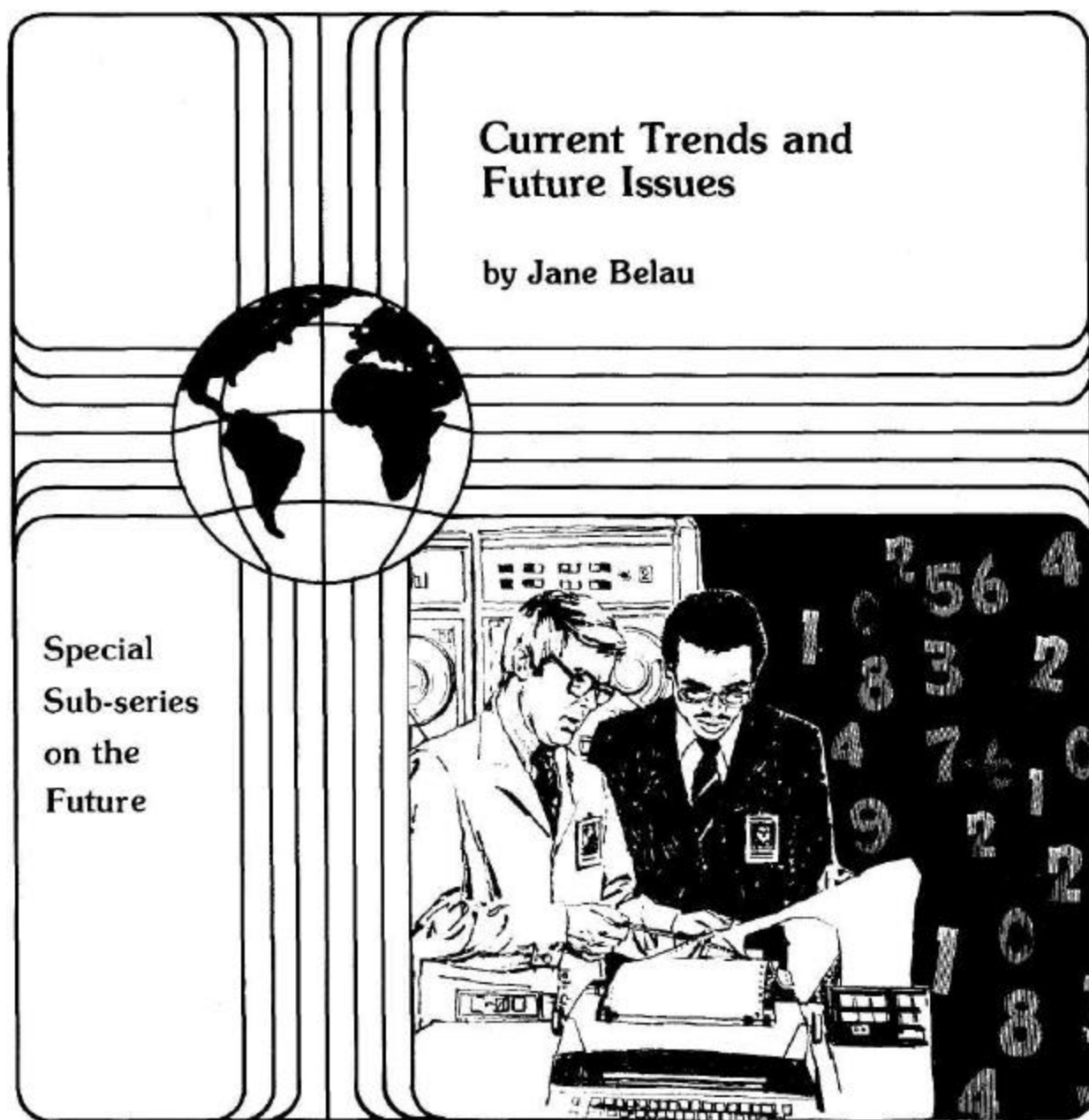
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Current Trends and Future Issues

by Jane Belau

Is the future important? We can best answer that question with another: why do we plan? We plan in order to manage our future. And it is imperative that we identify trends of today, assess the implications of those trends and that we carefully plan strategies in order to achieve our goals and fulfill our missions during times of change.

As persons participating in activities of advocacy, planning and delivery of services as well as in education and training, our goals and mission center around assuring that the needs of developmentally disabled individuals are met and that their rights are protected, that services are appropriately delivered in the appropriate environments with assurance of quality, and that persons with developmental disabilities, their parents and/or guardians achieve full participation in decision-making and in influencing the events that have an impact on their lives.

Thus, we must think about future issues likely to effect the quality of life for developmentally disabled individuals and their families. We must bring together persons who are developmentally disabled, their parents and guardians, service providers, public policy influencers, decision-makers, advocates and futurists for a meaningful discussion and analysis of future issues. Through these explorations we can define and prioritize major areas of concern, and then begin the process of developing alternative strategies for addressing the problems identified. Our ideas must be shared and contributed to the literature and public discussion in order that we can generate and continue on-going dialogue.

Forecasting is an approach to considering the future. Forecasting takes many forms from the assessment of the past, to observations of present trends, to the writing of a scenario or description of a future along with a description of how to get there. Presented here are observations of current trends made and collected over a long period of time. There are obvious major implications as well as subtle influences that, should these trends continue in the same manner, will affect not only advocacy and services for developmentally disabled persons but other publicly funded services as well. Interruption, intervention in or management of these trends would change the possible outcomes; however, the first steps are simply to share observations, report current trends, and identify some potential issues. One would not expect agree-

ment in all of the observations but, rather, would hope to generate debate, promote discussion and illumination of the need to seriously consider the future *now.*

No current trend or future issue exists in isolation or within cleanly defined categories, but there is a need to bring some order to a long list of random but related observations. There seem to be four observable environments of the future: the systems and organizational environment, the socio-political environment, the technological environment, and the economic environment. Again, this caveat: this is not intended to be an exhaustive list of currents or a definitive categorization. It is intended to prompt thought, discussion and debate.

The Systems and Organizational Environment

Included in this set of observations are systems, components of systems, programs and organized groups of persons who influence, participate in, comprise systems or parts of systems.

Discontinuity of programs and systems. Programs must be given time enough to develop integrity, credibility and the ability to respond adequately to the needs for which they were developed. Fickleness in program design and initiative contributes to failure; a continuing proliferation of new programs, new initiatives, new labels, designs, definitions of services and those to be served only confuses the recipients, the providers and the public. A lack of sufficient time to establish a program, a lack of adequate resources, little or no chance to evaluate and fine-tune predestines it to failure. The developmental disabilities movement serves as an excellent example. The concept was established in legislation less than a decade ago; it embodied principles of planning, coordination of similar services to persons with similar needs and established councils, one for each state and territory, made up of providers of services, public members and consumers in order that the planning process have the maximum opportunity for effectiveness. In a recent article, Dr. Elizabeth Boggs comments on the specified representation for councils and their strength in saying,

> These are people with diverse interests, people
> whose pieces of power can be used either competi-
> tively or cooperatively. In the ordinary course of
> events, many of these individuals, even those in
> government would not be brought face-to-face.

Boggs goes on to quote Dr. Donald Stedman on the consumer role in the council membership:

> The involvement of consumers, especially the
> handicapped, is an absolute necessity to improve the
> quality, timeliness and propriety of the service
> needed as well as to guarantee that an appropriate

and objective evaluation can be derived in the face
of mounting service program costs.

With the unique strength that the developmental disabilities concept with its planning councils could provide in terms of planning, coordination, maximizing limited resources, eliminating duplication and filling gaps in services, one would expect that the concept would be strengthened both fiscally and continuity-wise making it a force to reckon with rather than one that can be "waited out" until it goes away. Instead of being able to move forward from a position of strength and confidence, the program continues to struggle for a meaningful existence. There has been, at both the state and federal levels, uncertainty regarding responsibility, authority, definition, regulations, reporting requirements, administrative placement and a year to year anxiety about the legislative future of the Developmental Disabilities concept. The expansion of the definition continues to challenge fragility of the coalition supporting the program.

The early anti-poverty programs are given as another example of programs where at first there was aggressive leadership, ample financial support, eager recruits, sympathetic media and no visible antagonists. Time passed and funds became scarce, projects competed, local interest groups developed strong counter movements and organizations had to use their resources and energy in defending their program rather than moving forward.

Discontinuity of programs occurs in part because legislatures and the Congress respond to *new* issues and pressures. This is also true with other program designers as well as funding sources. It has been shown many times that it is easier to capture the imagination with new and innovative program ideas than to sustain that interest in maintenance, monitoring and strengthening an on-going initiative.

Those granting funds and establishing public policy from a federal level as well as from other sources change major directions from year to year. There is rarely a thoughtful, well-developed long range plan for follow-through on a major initiative for a period of years. When there is an abundance of money, this is creative and stimulates new areas of service. But when there is increasing competition for those dollars and a smaller money supply, it becomes more important to support those successful initiatives already started.

Difficulty in creating change in systems. Competing interest groups and established systems of providers sometimes are barriers to change. In *Organizations and Social Change,* Charles Grosser quotes from Machiavelli's *The Prince:*

> There is nothing more difficult to arrange, more
> doubtful of success, and more dangerous to carry
> through than initiating changes in a state's consti-
> tution. The innovator makes enemies of all those
> who prospered under the old order, and only luke-

warm support is forthcoming from those who
would prosper under the new.

The growth of complex, social systems. SRI in a study for the National Science Founda-
tion, identified limits to the management of large, complex systems as one of the six (out of a
total 41) future problems identified for in-depth study. Sixteen possible manifestations of ex-
treme levels of scale in social system size are defined by Elgin and Bushnell in *The Futurist*
magazine. Among them are included the diminishing ability of an individual to comprehend
the system, diminishing public participation in making decisions, declining public access to de-
cision makers with more experts involved in decision making, dehumanized interactions with
increasing alienation, growth in costs of coordination and control. Growth, rigidity, vulnera-
bility, performance decline and ultimately deterioration of the system are possible manifesta-
tions of large, complex systems.

We can all understand the frustration of not knowing how to thread one's way through a
maze of programs, offices and individuals, the frustration that results from trying to impact an
institution whose size promotes anonymity. The challenges to one's patience and endurance
are great; disenchantment is more readily found and easily understood. Avoidance of the
system or the process often results; disinterest and apathy conclude the range of attitudes that
may begin with energy and an eargerness to solve a personal or public problem.

Increasing systems of information. In an attempt to evaluate and monitor programs, to
manage cases, to track individuals and dollars, and for countless other reasons, information is
being collected in an ever-increasing number of ways. The collection, storage, access, retrieval
and use of data raises questions concerning the need for protection of information and privacy.
Information systems need uniform data collected in uniform ways with the issue of *who* will
have access and *how much* being weighed against how much access can be allowed and not
threaten one's right to privacy and confidentiality? What is the usefulness of the stored infor-
mation if it cannot be accessible to those who need it?

Systems growth and decreasing personalization. The larger the system becomes, the
more depersonalized the service becomes, and the process is accompanied by a growing sense
of powerlessness on the part of the recipient as well as the system participant.

*Increasing amounts of time, manpower and dollars contribute to systems growth and are
consumed by the system.* The descriptive plans, information of all kinds, evaluation, reporting
and feedback accompanying a growth in programs and large systems amounts to substantial
cost in time, personnel and money. In times of limited resources, trade-offs must be made.

The Socio-Political Environment

Changing attitudes and a reported decline in altruism. Rising costs of all goods and ser-
vices without a corresponding rise in spendable income affects all persons. People become
more concerned about themselves, their personal needs and goals and, thus, less about others.

And there are other reasons for these changing attitudes:

Changing nature of traditional institutions like the family. Families have changed from the extended family to the nuclear family to the variety of family forms existing today. The growing lack of commitment to families and other institutions challenges a wide range of traditional values based on the nuclear family of parents and children. Attitudes are reflected in responsibility expressed toward other related family members, our aged and disabled persons as well as to those around us. Much has been written about the changing nature of how individuals in today's society perceive others in the same society. Ellen Goodman, Boston Globe columnist syndicated by the Washington Writers Group, recently wrote of the new hostility between adults and children and warns that something has gone wrong in the relationship between the community of adults and children. Defensive, inward adults, Goodman says, have become "human signposts of the erosion, bit by bit, of a wider sense of responsibility and connection between generations.'

High mobility of families and individuals. Increasing mobility of families and individuals has contributed to the decreasing outreach outside of one's own immediate grouping. Stress on individuals without support of a larger family or community group on a more permanent basis, and an increasing unwillingness to commit emotional energies toward others outside one's personal environment are other manifestations of high mobility.

The current emphasis on success and physical perfection. Society's current activities, as well as its best seller list, center on power, success, winning, beauty makeovers, how to dress, how to run. Magazines feature articles on the physical elite emphasizing perfection. Our values are reflected in what we do with our time, what we read, and what we buy; it is clear that success has become our model.

Diminishing participation in organized religion. As participation declines, fewer people will be practicing the traditional church philosophies with their emphasis on caring for others.

Individuals are yielding their "brother's keeper" roles to the public sector. It has happened unconsciously, but a new generation has grown up with government as the primary provider of fiscal reimbursements for care of persons in need. It has seemingly become accepted as the way things are done.

Individual sense of powerlessness. As mentioned in the section on systems, one result from confronting those systems is frustration which turns into and is vented on service providers, the amount of money spent on services and, finally, on those most vulnerable, the recipients themselves.

The continually reinforced trend toward instant gratification. Messages from our culture say patience is no longer a virtue. We don't "save for rainy days", anymore, because inflation will eat up all the money. We don't buy on lay-away with a down payment anymore because it is easier to charge it to a bank card. We don't save for our old age, anymore, because we have

pension plans, or the government will provide support or we probably won't be able to afford what's waiting, anyway. Marriage is reported to have changed in its perceptions from the time of "til death do us part" to "as long as we both shall love." We seek instant money with cards and a machine, fast food, electronic machines reading grocery boxes. The faster the better is becoming a rule. What is the message for us when the people with and for whom we work require great patience....and where our concerns for the developmentally disabled are long term concerns and where progress is made slowly?

In addition to the changing attitudes, there are other significant trends observable in the socio-political environment.

A climate of organizational or movement backlash. The recent reference by Andrew Young to the new "negativism" regarding civil rights, the prolonged controversy and debate surrounding the ratification and the time extension for ratification of the equal rights amendment for women, and voter repeal of other human rights ordinances clearly demonstrate what others are calling a backlash phenomenon. Emerging resistance to directed change and reluctance to pay for changes relating to rights of handicapped individuals indicates an area of growing challenge where the resistance must be confronted in an effort to preserve gains made in P.L. 94-142, the 504 regulations of the Rehabilitation Act and provisions for protection and advocacy.

Devaluing of volunteerism as an activity. The concept that says all people should be paid a meaningful wage for their work has tended to devalue volunteer activity. This is a particular problem especially now when what we need is an *increased* involvement of the private sector in services, a resurgence, if you will, of volunteerism when dollar cut-backs will reduce paid staff in some programs.

The influence of media. A force to be reckoned with is the tremendous influence of the electronic media on us as a people, its influence on our attitudes toward others, our expectations for ourselves and its emphasis on youth, beauty, mobility, affluence and exciting, rewarding lifestyles. Ultimately, it affects our attitude, behavior and willingness to care for others who are not young, beautiful, mobile, affluent and exciting.

Further, we are not learning skills of communication while passively viewing activities through television. If we cannot argue, constructively disagree, achieve consensus or convince each other of a point of view, we cannot successfully communicate or relate to one another or on behalf of one another. The National Science Foundation report by SRI details the socio-cultural impact of media:

> Rather than direct experience in the real
> world, an increasing proportion of people's life
> experiences are vicarious through the media.
> Consequently, their perception of social
> reality may be distorted and their judg-

ment may be more susceptible to intentional and
unintentional manipulation. They may
also tend to withdraw from direct political
and social participation.[q]

We are an aging population. Statistics show that, as the years pass, fewer in America will work to support more. This becomes not only an issue for the working and worked-for, but becomes an issue of available dollars as well. The well publicized problems of the Social Security system and pension funds in other sectors become examples of where part of this issue will focus. Developmentally Disabled persons in need of services and long term care will compete with increasing demands from a larger population of older persons for resources.

Fluctuating unemployment and underemployment. This creates corresponding difficulty for disabled persons to get jobs—particularly, appropriate jobs with in-service training and opportunities for upward mobility.

The "decline of liberalism" or the "new conservatism." These two phrases have been mentioned regularly in the media recently. The exact extent of the changing philosophy is unknown; it varies in different areas of the country, and there are a wide variety of opinions to explain just what the two phrases mean. However, what is always implied by those phrases is a growing reluctance to pay for publicly supported human services.

There is a decrease in public advocacy for programs of service. Perhaps much of this is due to the current economic climate, but few, if any, persons are running for office in the upcoming elections on a platform of *more* programs or *increased* funding.

Increasingly complex ethical issues. Technological advances have generated a series of complex ethical issues and interest groups seeking to affect decisions involving those issues will draw a great deal of public attention to them. Biological advances, life extension, genetic engineering, cloning, "test tube" babies, abortion policies, euthanasia, and a number of other issues will be thrust into the public forum. Questions of access, selection, circumstance, and who will decide are among those that must be discussed. Underlying decisions will be value statements important to us as a society.

The world food crisis. In many areas of the world a food crisis already exists. In other areas malnutrition exists despite relative affluence because of poor quality food and poor eating habits. One of the causes of deficiences, both congenital and developmental, is malnutrition.

Competition with major national and international issues. Major world crises in a number of areas can make disability related services seem unimportant in terms of competing for the attention of the public and the decision makers. The potential for conflict in parts of the world (either directly or indirectly involving us), energy, the world money market and the continuing fluctuation in the value of the dollar, rebellion of the nation's food producers, pol-

lution of our air and water, conflicts over land use and between public good and private rights, strikes by workers and urban violence are among those competing issues.

The Technological Environment

This may be an area in which the change will be the most dramatic because of the potential for "break-throughs." Overnight, research of many decades might pay off and massive change result. The point in considering technology, though, is to assure us that we manage the technology and that it does not control us. Challenges in this area include:

*How to just "keep up" with technology-related information and advances.

*The effects of technology on human thinking and behavior.

*The dehumanizing effects of increasing use of technologies. Where will people fit? What will this do to us as individuals and as a society?

*How to use technology in the most constructive way, so it directly benefits individuals.

* Increasing use of technology with risks in safety, loss of privacy or information, or accidental interruption of activity through malfunction.

*The possible destructive capacity of surveillance and weapons technology. Questions of use by whom, on whom, and who will decide are critical issues.

Communications technology will create uneven access to information. As more information is held in sophisticated computers, accessing information will require a higher level of skill and education. The SRI study for the National Science Foundation describes a "growing subculture of the information-poor" and the growing gap between those who will have information and those who will not.

The Economic Environment

The recently expressed and apparently increasing taxpayer sensitivity to government spending will have a definite impact on public and private funding for services. While the focused expression of this attitude occurred in the California vote on Proposition 13 reducing revenues for California's local governments, it is already clear that the sentiment expressed by California voters is being expressed elsewhere with anticipatory action being taken by the Congress and other elected officials. While this environment may have an impact on our future, other economic trends will also effect publicly funded services:

Inflation. Inflation is identified in many parts of the country as our number one problem. It is especially difficult for individuals on fixed incomes as many developmentally disabled persons are. It is also difficult for publicly funded services when costs of serving continue

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to rise and sources of funds are becoming restricted. Inflation is linked to many of the socio-political trends discussed previously.

The emphasis in the government and the private sector on economy and efficiency. Most persons recognize the difficulty in effectively demonstrating cost/benefit ratios in human services. The SRI study acknowledged this in describing the need for better socio-economic models and observed that the "management technology appears to have grown faster than design capabilities for social science systems."[11]

The trend toward integration and consolidation of human services. Consolidation of services has been proposed or implemented at all levels of government for different reasons. Systems persons feel it is a better way to organize the delivery of a number of services. Those who provide funds see integration of services as a way to cut costs and provide administrative efficiency. The concomittant problems of tracking people and dollars through a totally integrated system may be outweighed by improvement in that system. If the integration and consolidation occurs as a cost-cutting measure without a goal of improving service delivery, then it requires thorough consideration and review of the possible effects on services to individuals with disabilities.

Growing local costs. Resistance to major public policy directions from upper levels of government is developing at the local levels of government where officials are most accessible to the voters. Local officials are now looking at "seed money" and "start-up funds" with a wary eye and ask, what will it cost *us* in a year or two? The costs accompanying major initiatives continue to emerge at the local level. These are often not projected in initial discussions because many of the hidden costs are unknown. The cumulative costs at the state and local levels of legislative and administrative directions without accompanying funds are of growing concern.

Growing competition for the same dollars. An increasing number and variety of programs are competing for the Title XX Social Services money, for example. Facilities and services for the developmentally disabled are facing growing competition from correctional programs, chemical dependency programs, shelters for battered women, programs for mentally ill persons, all developing the full spectrum of services and, where possible, facilities. These are but a few examples of the programs accompanying emerging movements as those advocates sharpen their lobbying skills and skills of program development.

Continuing need for research in areas of economic support and funding reimbursement mechanisms. Whether in the area of a rational, adequate program of economic support for individuals with disabilities or whether in the area of home health care, attendant care or other support services, it remains necessary for attention to be directed at the issue of financing and human need.

Potential decrease in voluntary sector support giving. As individuals' real income grows more slowly or decreases, so may voluntary giving. As with the decrease in volunteerism, the

decrease in financial support given the voluntary sector occurs at a time when an increase in private sector support will be needed.

The possible extension of cost containment measures. Cost containment is a recent strategy for putting a lid on the cost of health care. In an economic climate where there are more demands than dollars, the extension of cost containment to human services becomes a possibility. There is an excellent opportunity here for the planning and coordination of services provided in the developmental disabilities legislation to demonstrate the value of that planning and overview.

Looking to the Future

Let's look at these and other current trends. Let's ask, how do these trends and the listed potential problems affect our mission of service? Take the list of future issues and add some. Change some. But seriously consider the future. Then decide how to manage it. Develop a strategy.

As a beginning, we must:

*Sharpen our communications skills and communicate needs to the appropriate audiences.

* Develop a management approach to the provision of services with understandable goals, reasonable goals and quantifiable goals.

* Recognize the need for strengthening planning, participation in setting and resetting priorities and allocations of funds while recognizing the limits to resources.

*Not be divided by resource limitations like competitors but, rather, we must work together with others sharing our needs in meeting those needs in the best possible way.

We must encourage commitment to people; rediscover caring and compassion as well as dedication to the provision of services, protection of rights, advocacy, and full participation by disabled persons and families in public policy setting. It is a time to become better planners, be better managers and more effective influencers. It is a time to support good people in government who have been "broad-brushed" into "big government." It is a time to assess our own opportunities to cut costs if possible, to set our own priorities and, all the while, make sure needs are being met with quality and adequate resources.

It is a time to view future issues. It's our move!

Footnotes

Stephen P. Hencley and James R. Yates, *Futurism in Education* (Berkeley, CA: Mc-Cutchan Publishing Corp. 1974) pp. 12-26.

²Dr. Elizabeth Boggs, "Mental Disabilities: The State Role" in *State Government* (Lexington, KY: Council of State Governments) p. 242-243.

³*Ibid.* p. 243.

Charles F. Grosser, *New Directions in Community Organization,* (New York: Praeger Publishers) pp. 121-122.

⁵*Ibid.* p. 119.

"SRI International, "Assessment of Future National and International Problem Areas", project abstract (Washington, D.C.: National Science Foundation).

'Duane S. Elgin and Robert A. Bushnell, "The Limits of Complexity: Are Bureaucracies Becoming Unmanageable" in *The Futurist,* December 1977.

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11 *Ibid.*

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