

A Comprehensive Guide to
**Intellectual &
Developmental
Disabilities**

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Paul H. Brookes Publishing Co.

Post Office Box 10624
Baltimore, Maryland 21285-0624

www.brookespublishing.com

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Typeset by Integrated Publishing Solutions, Grand Rapids, Michigan.
Manufactured in the United States of America by
The Maple-Vail Book Manufacturing Group, York, Pennsylvania.

Photographs in Chapters 12 and 17 kindly provided by MukiBaum Treatment Centres,
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Library of Congress Cataloging-in-Publication Data

A comprehensive guide to intellectual and developmental disabilities / edited by
Ivan Brown and Maire Percy.

p. cm.

Includes bibliographical references and index.

ISBN-13: 978-1-55766-700-7 (hardcover)

ISBN-10: 1-55766-700-4 (hardcover)

1. Developmentally disabled. 2. People with mental disabilities. 3. Developmental
disabilities. 4. Mental retardation. 5. Developmentally disabled—Services for.

6. People with mental disabilities—Services for. I. Brown, Ivan, 1947–

II. Percy, Maire Ede, 1939– III. Title.

HV1570.C66 2007

362.196'8—dc22

2006035713

British Library Cataloguing in Publication data are available from the British Library.

- Encouraging qualified professionals and frontline staff to enter and remain in the field
- Enhancing communication between medical and psychosocial professionals and among researchers, practitioners, and policy makers
- Finding helpful ways of obtaining and assigning a diagnosis
- Fostering community inclusion in new and additional ways
- Identifying and redressing gaps in the services and supports provided across the life span
- Improving supports for people with intellectual and developmental disabilities in educational systems
- Preventing disabilities (preventing biomedical, environmental, attitudinal, and social conditions that lead directly and indirectly to exclusionary lifestyles)
- Tackling underfunding at all levels in the field

A VISION FOR THE FUTURE

The previous sections of this chapter have outlined significant recent and expected changes in the field of intellectual and developmental disabilities. Readers will no doubt identify other changes in the course of their work and studies. The effects of current and future changes to our field need to be measured against a set of principles. This section sets out a vision of 10 principles for this purpose.

Our vision for the future is international in scope, recognizing that disability is part of every society. It is also universal in design, beginning with the belief that whatever a society has to offer should be offered to *all* of its citizens—laws, rights and privileges, freedoms, opportunities, education and services, and many more. The 10 principles in our vision support the view of a world where social orders extend their assets to people with intellectual and developmental disabilities as they do to people without disabilities and where the strengths of the world are used in positive ways for people with intellectual and developmental disabilities, their families, and those who support them in other ways. Our vision is detailed next and a summary is provided in Table 45.1.

1. The rights of people with intellectual and developmental disabilities are respected and acted upon

We envision a world where disability is no impediment to the full realization of the rights and entitlements that are available to all people of a society. For this to occur, it is recognized that special provisions, rights, and entitlements are required at several levels simultaneously. At the international level, a variety of conven-

Table 45.1. A vision for the future of people with intellectual and developmental disabilities

For social orders to extend their assets fully to people with intellectual and developmental disabilities, we envision a world where

1. The rights of people with intellectual and developmental disabilities are respected and acted upon
2. People with intellectual and developmental disabilities live among us with dignity and respect
3. People with intellectual and developmental disabilities have the education and supports they require
4. People with intellectual and developmental disabilities contribute to their societies in positive ways
5. People with intellectual and developmental disabilities enjoy the quality of life of their own determination

For the strengths of the world to be used in positive ways to help the field of intellectual and developmental disabilities, we envision a world where

6. National and international leadership in intellectual and developmental disabilities and other disabilities flourishes
7. Poor environmental conditions that contribute to intellectual and developmental disabilities and other disabilities are overcome
8. Medical and related knowledge is used to prevent intellectual and developmental disabilities and to enable people with intellectual and developmental disabilities
9. Emerging technology is used to assist, rather than segregate, people with intellectual and developmental disabilities
10. The professions and families that support people with intellectual and developmental disabilities are respected and honored in society

tions and agreements are already in place (see Chapters 5 and 6), and as of the date of publication of this book, a United Nations Convention on the Rights and Dignity of Persons with Disabilities is being developed. Some special groups of people with disabilities also have specific rights, such as refugees who have disabilities (United Nations Enable, 2006a). Within countries, but varying considerably from one country to another, constitutions, laws, and other policy documents set out the rights of people with disabilities, and often stipulate methods by which those rights should be acted upon. At the service system and individual levels, entitlement related to a wide variety of needs and ways to put them into practice are set out under a variety of funding agreements and service mandates for such things as residential care, employment support, inclusive education, adaptive devices, medications, and many other supports and services (see Herr & Weber, 1999).

2. People with intellectual and developmental disabilities live among us with dignity and respect

We envision a world where people with intellectual and developmental disabilities live freely among their family members, relatives, friends, neighbors, and acquaint-

tances. For children, such freedom is supported or limited somewhat by the influences of the family home, neighborhood, and school. For adults, it entails a degree of self-determination, following a variety of life experiences regarding the choice of living environment, personal habits, friends, family, daily activities, leisure activities, learning options, and life goals.

Whatever the life situations of children and adults may be, they will be fully recognized only if their human lives are accorded respect by others and if each person with a disability is treated by others in a dignified way that reflects the value of unique personalities within the larger social group. For the field of intellectual and developmental disabilities, it will be essential to continue to build on the foundations already in place for according respect and dignity to people with disabilities (see Display 45.1) and to provide leadership to the broader society for doing so.

3. People with intellectual and developmental disabilities have the education and supports they require

We envision a world where society acts on its responsibility for accommodating, including, and promoting people with disabilities by providing them with stimulating learning opportunities and the supports that enable them to take part in and enjoy life throughout their life spans. Stimulating learning opportunities include access to high-quality, close-to-home education throughout the childhood years that reflects individualized planning and instruction, and access to lifelong learning and training opportunities. Enabling supports include adequately trained and/or experienced personnel who help people with disabilities shape the overall direction and daily activities of their own lives in positive ways, as well as access to the resources (e.g., funding, community programs, human resources) and the services (e.g., housing, personal support, employment support) that make this possible.

4. People with intellectual and developmental disabilities contribute to their societies in positive ways

We envision a world where people with intellectual and developmental disabilities can accomplish their dreams and contribute to society in ways that are recognized and valued by all members of society. To achieve this, the field of intellectual and developmental disabilities will have to assume a considerable amount of responsibility for encouraging affected individuals to participate fully in society, for developing methods to assist them in delivering their contributions, and, perhaps most important, for taking leader-

Display 45.1

A wish for dignity and respect

I hope that when a child with a disability is born in Ukraine, he or she is greeted and welcomed into this world. I hope no parents will receive advice to abandon their child and hear bad things about their child. I also hope that early intervention programs will be available everywhere in my country, and that families will get the necessary support and intervention. I hope that the educational system will change in Ukraine, and that it will be possible for disabled children to be integrated into regular schools and preschools. I hope that attitudes of people towards persons with disabilities will change, so that persons with disabilities will have no experience with stigmatization, but will experience acceptance, friendship, and recognition of their gifts and talents. I hope in their adulthood, people with disabilities will have lots of possibilities to lead normal lives, with opportunities for realizing their human needs and their potential. I hope in their old age, people with disabilities can be in an environment that makes the experience of their aging and dying as human as it should be.

Source: Oleh Romanchuk, Dzhereho Children's Rehabilitation Center in Lviv, Ukraine; used by permission.

ship in helping people without disabilities to understand the value of these contributions and the importance to all humans for demonstrating that such contributions are valued. As shown by Philip's story (see Community Living Guelph Wellington, n.d.), these aspects of Vision Item 4 are indeed possible. We owe it to Philip and others like him to set examples and to provide confidence that such a vision can be attained.

5. People with intellectual and developmental disabilities enjoy the quality of life of their own determination

We envision a world where people with intellectual and developmental disabilities can determine and enjoy their own lives. To help achieve this, we need to begin by recognizing that people with intellectual and developmental disabilities, like people without disabilities, are best positioned to define and act on (within a range of opportunities available to them) the people, places, and things that add quality to their lives. Using such self-determination as a guide, our field's responsibility is then to try to enable quality of life improvement to occur. A critical aspect of providing such enablement is to remove physical, policy, practice, and attitudinal

barriers, especially by providing a strong and credible alternative to the view that limits to social worth and personal happiness are intrinsic to disability. This alternative will emphasize individualized definitions of quality that are recognized and valued by others and will provide ways for people with intellectual and developmental disabilities to move toward them.

6. National and international leadership in intellectual and developmental disabilities and other disabilities flourishes

We envision a world where the existing national and international leadership in intellectual and developmental disabilities joins with leaders in the broader disability field to take a prominent role in the direction of human affairs. People who are identified with disabilities make up between 10% and 25% of the general population (selection criteria differ somewhat among countries). For example, in the United States, 12% of working-age adults were reported as having a disability (Rehabilitation Research and Training Center on Disability Demographics and Statistics, 2004), and 23% of adults in Wales were reported to have a disability (National Statistics, 2006b). The United Kingdom reported that approximately 18% of children and youth younger than 20 years of age were identified as having a disability (National Statistics, 2006a). These prevalence rates represent such a significant proportion of the population of countries that virtually all human activities must accommodate disability. Strong national and international leadership is required to ensure that this occurs.

7. Poor environmental conditions that contribute to intellectual and developmental disabilities are overcome

We envision a world where the world's resources are used to enable people and to address problems that arise from the poor environmental conditions that contribute to intellectual and developmental disabilities. In all regions of the world, but to varying degrees, a great many people have intellectual and developmental disabilities that result from preventable causes such as malnutrition, deficiencies of certain minerals (e.g., iodine, iron), deficiencies of vitamins (e.g., folate), infections (e.g., measles) that can be prevented by immunization, and environmental hazards, including inadvertent exposure to teratogens and lead or mercury poisoning (Chapter 9). In addition, lack of good water, poor sanitation, and lack of medical care, including insufficient attention to HIV/AIDS (see Display 45.2), not only increase the prevalence of intellectual and developmental disabilities but also pose barriers to rehabilitation efforts. Finally, lack of physical

Display 45.2

Disability and HIV/AIDS

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is a serious problem everywhere and is an enormous problem in some parts of the world. In the intellectual and developmental disabilities literature, there is still insufficient attention to the risk of HIV infection and AIDS in people with intellectual and developmental disabilities (Groce, 2004). People with intellectual and developmental disabilities are sexually active and require education concerning risk of infection.

HIV infection adds to the intellectual and developmental disabilities rate. In vitro infection with HIV or postnatal HIV infection in children can result in significant intellectual and/or developmental disability, and HIV infection in adults is associated with cognitive impairment.

Practicing safer sex, safer handling of bodily fluids, and other precautions are important to containing and reducing the rate of HIV infection. Some treatments for HIV infection are now available, but prevention is still an uphill battle. Our vision for a future includes developing strategies for harnessing the increasing rate of HIV infection and the severity of HIV infection.

activity, poor social and cognitive stimulation, and physical and emotional neglect contribute significantly to disability. Unfortunately, many of these problems are more prevalent within minority or indigenous populations (see Display 45.3). The resources of the world should be actively channeled to address these issues.

8. Medical and related knowledge is used to enable people with intellectual and developmental disabilities

We envision a world where medical advances prevent intellectual and developmental disabilities where possible, and, where not possible, to enable people with intellectual and developmental disabilities to live in greater dignity and to attain higher levels of personal happiness. Knowledge is increasing about how to prevent intellectual and developmental disabilities, although methods of putting prevention knowledge into practice need to be strengthened. Since 1990, more has been learned about the brain and its relation to development and behavior than in all previous decades and even centuries. Brain imaging methods are particularly exciting, because they enable scientists to study the brain under different conditions. Information is

Display 45.3***Disability and indigenous peoples***

Some countries have citizens whose ancestors were indigenous to the lands that now form those countries. Some examples include the Aborigines in Australia, the Native Americans in the United States, First Nations peoples in Canada, the Maori of New Zealand, the Sami people living north of the Scandinavian border (Norway, Sweden, Finland, and Russia), and the Bedouins in Israel. India, Japan, the Philippines, and many other countries also have indigenous populations.

In spite of many positive steps forward for indigenous people since the 1990s in many countries (e.g., New Zealand, Australia, Canada, United States), these citizens often do not receive the same health, education, or social services as non-indigenous citizens. For children and adults with intellectual or developmental disabilities and their families, in particular, this is an important issue that needs ongoing redress.

exploding in the field of genetics, largely due to an extraordinary degree of international cooperation and collaboration among members of the scientific and medical communities who are contributing to the Human Genome Project.

We envision a world where there is similar international cooperation and collaboration among scientists who share the vision of preventing disabilities and enabling people with disabilities. In doing so, they might focus especially on emerging knowledge that is helping us to do the following (adapted with permission from the Association of University Centers on Disabilities, 2005):

- Prevent many types of intellectual and developmental disabilities by treating maternal infections and viruses transmitted to infants.
- Use brain imaging and genetic methods to better understand the causes of specific disabilities and suggest strategies for treatment.
- Develop gene therapies to prevent or reverse some of the symptoms of specific disabilities.
- Better understand the process of brain cell development and enrichment through studying the interplay of the brain's own chemistry with the child's experiences.
- Capitalize on the brain's natural "plasticity" to optimize brain development in children born with developmental disabilities through early intervention or by extending the period of brain development.
- Develop culturally competent psychological and

medical assessment and treatment procedures for children born into families from minority backgrounds.

- Prevent and treat atypical behavior among children and adults with disabilities who are especially prone to such difficulties, such as children with autism, fragile X syndrome, and Rett syndrome.
- Design learning environments so children have improved academic outcomes.
- Assist families in preparing their adult sons and daughters with disabilities for successful lives of their own.
- Prepare older people with disabilities for coping with the normal processes of aging.

9. Emerging technology is used to assist, rather than segregate, people with intellectual and developmental disabilities

We envision a world where current and future technology will be used to help people with intellectual and developmental disabilities lead successful lives. Two types of technology are particularly important for people with intellectual and developmental disabilities: assistive technology, and electronic and information technology. Assistive technology is any device that can increase, maintain, or improve functional capacities of individuals with disabilities.

Electronic and information technologies include such things as computers (to use for videoconferencing, looking at web sites, receiving e-mail, and so forth), telephones, bank machines, television and related technology, and the numerous fast-changing electronic devices for practical use and entertainment. Applications of these technologies include helping people with communication, mobility, management of their homes, activities of daily living, education, employment, and sports and recreation. However, not all people with disabilities can use technology in its current form, and already the term *e-divide* is used to describe the separation between those who use ever-changing electronic technology and those who do not. Cost, ongoing training, and ease of use are important challenges that need to be addressed for electronic and information technology to be helpful, not segregating. Social segregation resulting from technology that is too complex is a real and serious future danger for people with intellectual and developmental disabilities (Parmenter, 2003).

There is an enormous amount of technological expertise throughout the world, and we envision a world where this expertise focuses as much on ease of application as on innovation. The challenge is to make emerging technology as easy to use as turning on the lights or getting a radio to play music. If this challenge can be met, society will have gone a long way toward in-

cluding people with intellectual and developmental disabilities, as it has an obligation to do.

10. The professions and families that support people with intellectual and developmental disabilities are respected and honored in society

We envision a world where the professionals and family members who support people with intellectual and developmental disabilities are valued for the work they do. There is still a shortage of frontline workers and of knowledgeable professionals in many areas related to intellectual and developmental disabilities (see Chapter 27). The reasons for this are complex but are fairly well understood, and numerous strategies are available for addressing this problem (Larson et al., 1998). Primarily, though, the challenge for the field is to help ensure that the work of its professionals, paraprofessionals, other support personnel, and students is clearly understood by the wider society as essential and valued. To achieve this fully, leaders within the field will have to promote this view, both directly—by clearly stating the contribution of the field’s work and providing accompanying training—and indirectly—by advancing the other nine aspects of this vision.

SUMMARY

Significant changes have occurred in four core areas of the field of intellectual and developmental disabilities. There has been: 1) a shift in the concept of disability, 2) a broader understanding about the causes of disability, 3) change in public policy, and 4) a transition to a supports paradigm. Several other changes are also occurring, and all changes have some impact on others. It is not possible to predict precisely what changes may occur in the future, but we expect many changes—and these will help shape the nature of our field in the future.

Finally, our future vision is a world where people with intellectual and developmental disabilities are fully recognized as having rights that are respected and acted on, live among us with dignity and respect, have the education and supports they require, contribute to their societies in positive ways, and enjoy the quality of life of their own determination. We envision the strengths of the world being used in positive ways so that national and international leadership in disabilities flourishes, poor environmental conditions that contribute to disabilities are overcome, medical and related knowledge is used to prevent and enable people with disabilities, emerging technology is used to assist rather than segregate people with disabilities, and professions and families that support people with disabilities are respected and honored in society.

FOR FURTHER THOUGHT AND DISCUSSION

1. Identify two important policy changes and two important practice changes that have occurred in your geographic region during the past few years. Provide a rationale for why you consider each to be important.
2. Change occurs, but not without contributing factors. Some contributing factors are beyond your control and influence, but others are within your control and can be influenced. Think of three factors related to the field of intellectual and developmental disabilities that you and your colleagues might control or influence. For each, identify three or four specific actions that you might take to help exert control or influence, and discuss how you might ensure that these actions are successful.
3. Select 1 of the 10 areas of the vision provided in the final section of this chapter. List specific methods of making this part of the vision become a reality. For each method, consider which people should be involved, what they should do, and what success indicators should be used (i.e., how you will know that the goal has been achieved).
4. Talk with a person you know who has an intellectual or developmental disability. What is his or her personal vision for the future?

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