CHAPTER 43

Developmental Disability and Behavioural, Emotional and Psychiatric Disturbances

Elspeth Bradley & Jane Summers

WHAT YOU WILL LEARN

- People with developmental disability experience similar kinds of mental health problems as their non-disabled peers but are relatively more prone to emotional and psychiatric disorders
- Emotional and psychiatric disturbances often present as behavioural disturbance
- Left untreated, emotional and psychiatric disturbances may become crippling chronic disorders, adding further to the existing disability
- Many of the emotional disturbances can be prevented, and both emotional and psychiatric disorders are significantly diminished with appropriate intervention and treatment

The view that people with developmental disability experience the same types of mental health problems that similarly affect the general population was not popularized in North America until fairly recently. For many years, the term "dual diagnosis" was applied almost exclusively to individuals with psychiatric disorders and concurrent addictions. This is no longer the case, as dual diagnosis is now more generally accepted as referring to people with a developmental disability and a mental health (psychiatric, emotional and/or behavioural) problem. In this chapter, we will review key issues relating to the assessment and treatment of mental health problems in people with developmental disability. Wherever possible, we will try to focus on the Ontario perspective by referring to provincial policies, relevant statistics and clinical practices. We will also try to identify factors that impact on the provision of mental health services for this population and offer suggestions to overcome some of the difficulties that occur.

PREVALENCE OF MENTAL HEALTH PROBLEMS

There is mounting evidence that people with developmental disability are at greater risk of developing a mental health problem than their non-disabled peers. Prevalence estimates vary widely, ranging from approximately 14% to 67% of the developmental disability population (Corbett, 1979; Einfeld & Tonge, 1996;

Rutter, Tizard & Whitmore, 1970; for reviews see Borthwick-Duffy, 1994; Campbell & Malone, 1991). These statistics are often confusing but may be understood more easily if one recognizes that higher prevalence rates of behavioural and psychiatric disturbance appear to be associated with the following three factors: (1) the use of a broad definition of mental health problems that includes emotional and behavioural disturbances in addition to psychiatric disorders; (2) the group being studied being composed primarily of verbal individuals who are better able to communicate their distress and therefore more likely to be referred to mental health services; and (3) the populations examined being those still living in institutional settings or clinical populations referred for mental health services.

According to one estimate, there are approximately 227,000 people in Ontario with developmental disabilities, of whom upwards of 85,000 are expected to have behavioural, emotional, or psychiatric problems (Yu & Atkinson, 1993). These statistics are based on a 2.25% prevalence rate for developmental disability within the general population and an estimated 38% prevalence rate for psychiatric problems in people with developmental disability. Within the broader population of people with developmental disability, certain sub-groups may be especially prone to disturbance. The findings of a recent Niagara-based study of adolescents and young adults with developmental disability indicate that individuals with autism are more than twice as likely to have a concurrent psychiatric disorder than those without autism (Bradley & Bryson, 1998).

Types of mental health problems

People with developmental disability experience the same kinds of emotional and psychiatric disorders that occur among the general population (Benson, 1985; Rutter et al.,1970). Some of the more common psychiatric conditions include mood and anxiety disorders, adjustment problems, personality disorders, and attention deficit hyperactivity disorder (American Association on Mental Retardation, 1992; King, DeAntonio, McCracken, Forness & Ackerland, 1994). Behaviour disturbances, which are generally captured under these categories, include verbal and physical aggression, self-injury, hyperactivity, attentional problems, and oppositional behaviour (e.g., Jacobson, 1982). Some conditions, such as autism and stereotypies, are seen more frequently in people with developmental disability than in the general population.

Basis of mental health problems

Organic, psychosocial and environmental factors play a major role in the occurrence of mental health problems in people with developmental disability. Organic factors, which include genetic influences, brain injury, trauma, disease or infection, may directly underlie both the developmental disability and the mental health problem (Jakab, 1982; Rutter et al., 1970). In terms of environmental and psychosocial influences on mental health problems, many people with developmental disability live in impoverished environments, lack meaningful employment opportunities and strong support systems, do not have control over many aspects of their lives, and feel isolated from the mainstream of society (Stark, Kiernan & Goldbury, 1988). They may also have poor or inadequate social and coping skills, and, when these conditions occur on top of the cognitive and communication deficits, feelings of frustration, sense of failure and an awareness of being "different" can be further heightened.

Clinical challenges

A number of challenges exist in correctly diagnosing mental health disturbances in individuals with developmental disability. *Diagnostic overshadowing* refers to the tendency of professionals to underestimate signs of psychiatric or emotional disturbance in people with developmental disability (Reiss, Levitan & Szysko, 1982). This occurs when aberrant behaviours are viewed as an inherent part of the person's developmental disability; hence, they are less likely to be seen as evidence of possible underlying mental health problems. Another phenomenon that poses a challenge to diagnosing mental health problems is known as *behavioural highlighting*, where severe or intense behaviour problems may make the detection of underlying problems more difficult (Sovner & Hurley, 1986).

Other diagnostic challenges are related to *personal characteristics*, such as severe communication and cognitive impairments that make it difficult to articulate the nature and source of their distress (Reid, 1982). In these situations, it is necessary to rely more heavily on information that is provided by caregivers than on self-reports. With increasing disability, it becomes more difficult to detect distinctive clinical patterns to assist with diagnosis as the behavioural presentation can be *non-specific* (e.g., when aggression or self-injury is the main referral problem) or even *atypical* in individuals with these more severe impairments.

Co-morbidity, which is the co-existence of another medical or psychiatric condition, can further complicate the clinical picture. For instance, sensory impairments (vision and hearing problems), seizure disorders, and medical disorders (e.g., cardiovascular problems or abnormal thyroid functioning) can produce changes in behaviour that can be mistaken for symptoms of psychiatric disorders.

ASSESSMENT AND TREATMENT

Overview of Issues

As a group, people with developmental disability are over-medicated and undertreated (Reiss & Aman, 1998). Cognitive and language impairments often limit their capacity to reflect on their own internal mental and feeling states, and to communicate this subjective experience to others. With increasing disability in these areas, they are more reliant on immediate carers to be sensitive to the pattern of their daily lives, and to understand the impact of daily events, such as changes in daily routines or inappropriate expectations, on their emotional responses and capacity to cope. If carers are unfamiliar with the usual responses of the individual, or are unaware of particular life events that may have occurred for that person, emotional and psychiatric disorders may be missed and remain untreated. For example, withdrawn behaviour and loss of interest may not be noticed, or, if observed, may be incorrectly attributed to being a feature of the person's developmental disability *(diagnostic overshadowing)*.

Those engaging in behaviours that are disruptive or causing damage to themselves or to others may be referred to mental health services or to the emergency medical services. Service providers (e.g., physicians, nurses) unfamiliar with the needs of people with developmental disability may also attribute this disturbed or unusual behaviour to the developmental disability and thus the behaviour may be managed with medication or other behavioural interventions, leaving the underlying problems undiagnosed and untreated. Emotional upsets, difficulties in coping with situations, frustrations with daily circumstances, physical illnesses and psychiatric disorders most frequently present to emergency

Box 1: Clinical Scenario 1

Background

Michelle, aged 29, was referred because of severe self injurious behaviours (SIB) which had been present from an early age. Michelle was mostly non verbal and functional skills were around an 18-24 month level. During her life, in response to severe escalations of the SIB, she had been seen by many specialists including medical, neurological, behavioural, and psychological. She was diagnosed as having autistic behaviours, and was being treated for an underactive thyroid. Various interventions were tried, including high doses of medication and behavioural strategies, but met with limited success. At the time of referral she had been in the same group home for a number of years, with a stable group of carers committed to ensuring optimum quality of life for their client. Carers were experienced in supporting persons with developmental disability and had an excellent working relationship with a consulting behaviour therapist; together they were able to provide Michelle with an environment that understood her developmental level, was emotionally nurturing and had appropriate expectations of her, both in her day and residential settings. However, there continued to be concern about the excessive medication Michelle was taking (Michelle went on to develop a sudden abdominal obstruction requiring a piece of her bowel to be removed. This was likely related to the long term use of medication used to "manage" her SIB behaviour). Carers had managed to secure a psychiatric consultation and a medication change was recommended, but no psychiatric follow up was available. This medication change was carefully followed by the family doctor and carers, but Michelle's behaviour started to escalate and she was immediately reinstated on the original medication – but at higher doses!

Comment

SIB arises out of many circumstances, but can only begin to be adequately assessed in a continuous and stable setting where carers and involved health care staff share an understanding of the behaviours and emotional responses of the developmentally disabled person (particularly when in distress or medically ill), and have a shared vision of possible outcomes. Michelle's care was continuous and stable as long as she remained within her day and residential settings, and as long as she had no medical problems or behavioural escalations requiring emergency medical or psychiatric intervention. The assessment of SIB often requires trials of interventions, some of which may cause behavioural escalations. From the outset it is necessary, therefore, to map out the continuum of services that is required in order to allow an adequate assessment, and in particular to map out responses to crises that may arise so as to ensure continuity of assessment and treatment between in patient and out patient settings. In Michelle's case, the following local services became partners in her care over the ensuing two years: Michelle's immediate care team (residential and day counsellors, supervisors and managers), consulting behaviour therapist, family physician, community psychiatrist and specialist assessment services, local pharmacist, emergency hospital services, inpatient psychiatric services, specialist medical services (e.g., neurology, surgical), community nursing, and the Office of the Official Guardian and Public Trustee (Michelle was unable to consent to her treatment and had no family). Regular meetings occurred to review Michelle's progress and to ensure all partners in her care were informed as required. The anxiety was taken out of the crises. There was no longer the fear that Michelle's medication would be changed without adequate consultation with carers, and inpatient services no longer feared that Michelle would become a long term patient. As the crises abated for Michelle and for the systems of support, Michelle's behaviour stabilized, and a pattern of cycles emerged. She was treated with a mood stabilizing medication and her antipsychotic medication was reduced. There has been significant improvement in her quality of life and SIB rarely occurs.

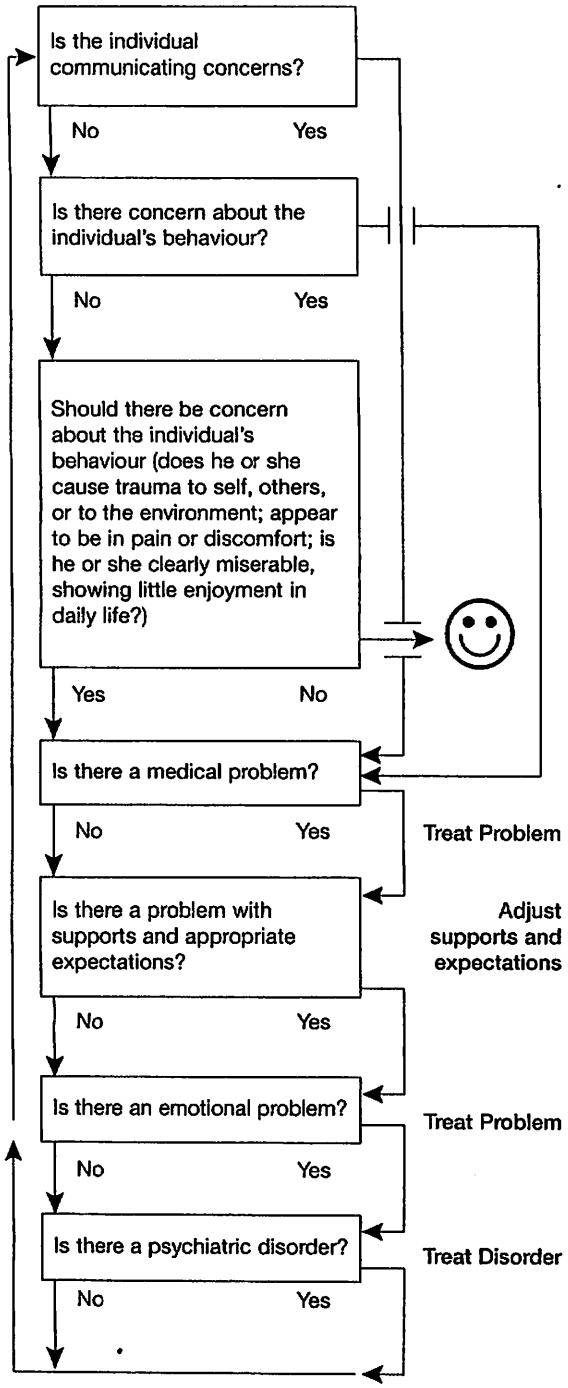

Figure 1: Mental Health Assessment Decision Tree

and mental health services as non-specific behaviour disturbance. The challenge for these service providers is, therefore, to understand what these disturbed or unusual behaviours "really mean" (or what these behaviours are "communicating"). Teasing these issues apart requires coordinated teamwork involving the person with disabilities, his or her immediate carers, and access to specialists who have experience working both in the field of mental health and developmental disability and who are aware of the medical and mental health vulnerabilities of this population. In some jurisdictions, such as the United Kingdom, there are teams of professionals in each health locality (called Community Learning Disability Teams) who provide specialist support to people with developmental disability and mental health problems and assist in coordinating access to the local generic health and mental health services. Formal training of mental health professionals is provided through university and college programs. However, in Ontario, as in much of Canada, the training of mental health professionals in developmental disability has been greatly neglected (see Lunsky & Bradley, 2001 re: physician training). Services and systems have evolved somewhat differently, and not infrequently, specialized support, if such is available, is developed around each individual only after recurrent failures of the generic services to provide appropriate care (see clinical scenario, Box 1).

In Ontario, there are few formal training programs available for mental health professionals in the area of health and developmental disability, and, not infrequently, access to generic medical, and particularly psychiatric services, is problematic as service providers may consider they do not have the expertise to deal with the individual with developmental disability. A more comprehensive discussion of

Table 1: Psychiatric Assessment and Treatment Formulation

Concerns*

What are the concerns, who is concerned, why the concern?

History of concerns

What has been tried, for how long, what worked, what did not work, who was involved?

When was client last at his/her best, how was a typical day spent then, how is the day spent now, what has changed?

Background information – client*

**Developmental level. *Reports of psychological and adaptive functioning, communication assessments, school reports, developmental/pediatric assessments*

**Communication skills. *Verbal and non verbal, including how he/she communicates pain, bodily discomfort, emotional distress*

Social circumstances in past. *Family and social supports, institutional care, losses, major life events, trauma, abuse, school, work, occupation, and leisure*

Recent changes/life events. *Are these linked to onset of concern?*

Medical. *Hearing or visual impairments, cerebral palsy, seizures, biological cause of developmental disability, presence of a syndrome, other medical disorders, medications past and present*

Family history. *Medical conditions, developmental disability, psychiatric disorders and responses to treatments*

Emotional and coping responses. *Past response to stressors, life events*

Psychiatric history and pre-existing behaviours. *Baseline behaviours (e.g., tics, self injury, obsessions) before concerns*

Background information – supports

- *The understanding carers have of the developmental disability*
- *Social, emotional, physical (environmental), residential and day supports*
- *The structures and organization within which carers and staff work*
- *The appropriateness of services and expectations on clients*
- *Support for carers and staff*

Examination

Client:

- *Physical (e.g., medical condition, is a syndrome present?)*
- *Interview/mental state*
- *Review of behavioural data*

Support System:

- *Are the physical and emotional environments optimally supportive?*
- *Are attitudes and expectations appropriate?*

Formulation

- *What is the problem?*
- *Where is the problem located?*

  Individual. *e.g., psychiatric or physical illness*

  Carers. *e.g., inappropriate expectations, staffing structure*

  Support System. *e.g., lack of appropriate service*

  Philosophy of care. *e.g., insistence on chronological, rather than developmental, age-appropriate behaviours*
- *What further information or data is required?*
- *What further investigations are required? (e.g., medical)*
- *What intervention or treatment is needed?*
- *For individual? carers? system?*

* *Before gathering information, identify a reliable and knowledgeable informant*

** *Prior to, and since, outset of concerns*

mental health services in Ontario will follow in a later section.

Assessment of psychiatric disturbances

When identifying whether behavioural disturbance is due to a psychiatric disorder, it is necessary to explore systematically all those areas that may give rise to behavioural disturbance. A brief outline of this process is provided in Figure 1 (decision tree for a mental health assessment) and Table 1 (psychiatric assessment and treatment formulation).

In many instances, non-specific behaviour disturbance may be the final outcome of more than one related or unrelated cause, such as disruptive behaviour associated with a mood disorder, but made worse by toothache. People with a mild or moderate developmental disability will usually be able to assist in this exploration and will be able to share some of their inner discomforts, although time is usually required for them to feel comfortable with the interviewers, and for both to understand how the other communicates. Independent information from someone who knows the person well (an informant) should also be sought as the individual may not fully appreciate the larger context within which he/she feels distressed (e.g., the distress may be associated with an external event such as a bereavement). For the individual with little or no language, the assessment rests primarily in understanding the behavioural changes and in making inferences about internal feeling states from the characteristics and patterns of these changes in behaviour. Here, informants who know the individual well are key to a good assessment in terms of providing information on how the person usually communicates frustrations, emotions, physical pains, and so on. It is always helpful to meet with the referred persons in settings where they normally live and spend their work and leisure time. Knowing and observing whether the behaviours of concern change in different settings provides clues to their underlying cause.

Circumstances giving rise to behavioural disturbance

Physical health and medical issues. Individuals with mild developmental disability may be less able than their non-handicapped peers to articulate or comment on their physical discomforts and pains, and often do not do so spontaneously. If a problem is suspected, it may be necessary to ask specific questions and to help the individual communicate his/her discomfort and pinpoint where the pain is located. Those individuals with more severe disability may be totally unable to communicate a pain or localize a discomfort either verbally or even by gesture. Chronic disorders (such as constipation), fluctuating pain (such as toothache) or side effects of medication may present to the carer and clinician as disruptive or irritable behaviours. As a group, people with developmental disability suffer a higher prevalence of other disabilities (such as visual and hearing impairments) and medical conditions (such as neurological impairments including seizures and cerebral palsy). Those individuals with identifiable genetic or metabolic disorders, which may occur in up to 45% of those with severe developmental disability (for reviews see Curry et al., 1997; Raynham, Gibbons, Flint & Higgs, 1996), frequently have associated physical and medical disorders and these can give rise to painful conditions (e.g., arthritis in adults with Down syndrome). Other problems, such as orthopaedic, gastrointestinal, nutritional, feeding, pulmonary, cardiac, endocrine, urological, gynaecological, dermatological, and

dental problems may also give rise to pain and distress. Some syndromes (e.g., Autism, Fragile X, Williams, Prader-Willi) are associated with particular medical conditions and specific psychological and behavioural patterns. Identifying such syndromes and, where possible, the cause of the developmental disability is an important part of the assessment, as this may direct attention to medical disorders and painful conditions that might otherwise remain hidden.

Expectations and support needs. Developmental disability encompasses significant impairments in cognitive and adaptive functioning. The latter involves deficits in communication and social skills, as well as skills in areas of self care, home and community living, self-direction, health and safety, leisure and work, and functional academics. Each person with developmental disability is unique in his/her blend of adaptive abilities and skills, and he/she may demonstrate considerable strengths in some areas and considerable weaknesses in others. Some strengths may hide or mask weakness in other areas and give rise to unreasonable expectations of the individual, which in turn can lead to emotional and psychiatric disturbance. For instance, good conversational and social skills may mask severe difficulties in understanding (as in Williams syndrome). Assessment of behavioural disturbance therefore includes an assessment of the person's psychological profile, including adaptive functioning, and an assessment of the environment supporting that person, including the expectations of carers (and including teachers if the individual is still at school).

Emotional Disorders. Persons with developmental disability experience circumstances that might be expected to predispose or give rise to emotional disturbances. Any associated disability, such as language and communication disorder, sensory impairment, seizures, neurological impairment (including cerebral palsy), or pain and discomforts from physical disorders, has to be managed and accommodated. Early experiences may have interfered with early bonding and personality development, adversely affecting the person's response to stress, coping strategies, and capacities to develop social supports and friendships. People with developmental disability are generally at risk of stigmatization, rejection and teasing by peers. They often develop poor self-esteem and self-image in a society that values achievement, independence and conformity. Opportunities for satisfactory work and leisure pursuits and for intimate relationships are often greatly limited. Most have experienced disadvantaged environments and some have lived in abusive situations. Not surprisingly, behaviour disturbance that is associated with emotional problems is often as severe as that associated with serious mental illness. Distinguishing between these two disorders, however, is often difficult as they frequently co-exist.

Identifying a psychiatric disorder

In jurisdictions where there is no network of specialist psychiatric services for persons with developmental disability (as is the case in Ontario), individuals with psychiatric illnesses most frequently present in crisis to their family doctor or to local emergency services. At these times, an appropriate immediate response is often to stabilize the situation with medication. However, medication should be reviewed at the earliest opportunity and a more comprehensive assessment begun so as to identify whether a psychiatric disorder is indeed present or whether the problems are related to the other considerations outlined in the previous sections (i.e., physical health and medical issues, expec-

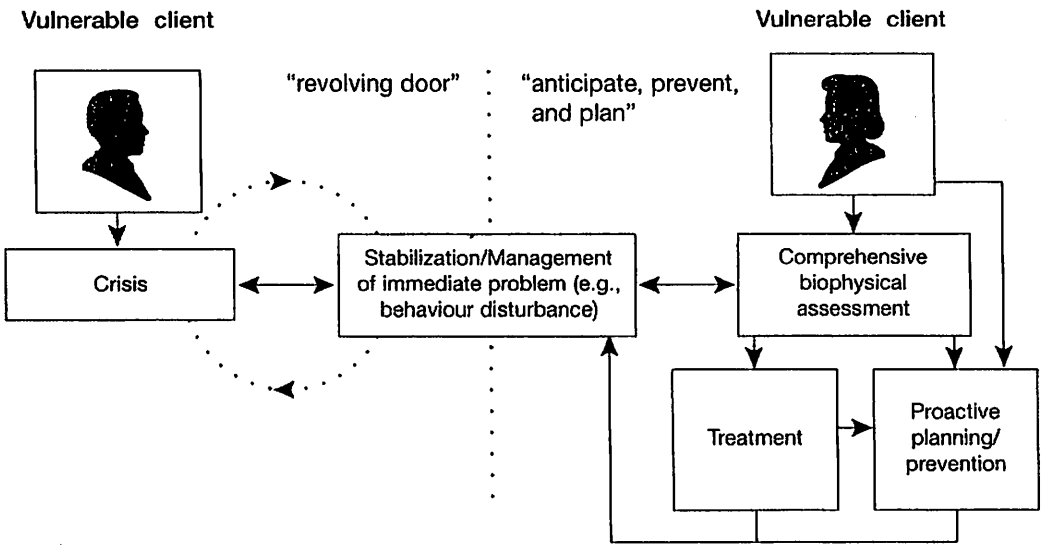

Figure 2: Reactive versus Proactive Responses to Psychiatric/Behavioural Disturbance in Vulnerable Individuals

Crisis/reactive "management" of behaviour disturbance associated with "revolving door" phenomenon, which adds further to disability

Proactive and preventative assessment and treatment minimizes further disability

tations and support needs, and emotional responses). A decrease in behavioural disturbance in response to medications (most often antipsychotics) that are used at a time of crisis does not imply that a psychiatric disorder is present. Indeed, such medications are known to mask some conditions (for a review see Crabbe, 1989) – most will contribute further to the developmental disability by impairing or slowing down the person's ability to focus and think clearly, and many result in side effects. In people who have difficulty already communicating bodily discomforts, these side effects may give rise to further behavioural disturbance. It is prudent, therefore, to distinguish clearly between managing the behaviour disturbance and treating the underlying cause giving rise to this disturbance (see Figure 2).

Some syndromes are associated with a vulnerability to particular disorders. For example, Alzheimers dementia is associated with Down syndrome, mood disorder with autism, and anxiety disorders with Williams syndrome. Co-existing psychiatric disorders *(co-morbidity)*, such as autism, attention deficit hyperactivity disorder (ADHD), stereotypies, anxiety, obsessive compulsive disorder (OCD), phobias and fears, and tics, should be systematically identified where present (see Caron & Rutter, 1991). The clinical presentation of new onset disorders, such as mood and psychotic disorders, may be distorted by these pre-existing disorders, and, unless the latter are identified as background behaviours, misdiagnoses may be made. For example, an increase in "bizarre" self talk in someone with autistic disorder can easily be mistaken for schiz-

ophrenia or an escalation of behaviour disturbance in someone with ADHD and limited verbal skills can be mistaken for mania. A good psychiatric assessment, therefore, requires a detailed description of "baseline" or usual behaviours prior to the onset of the new dis-turbance Changes in behaviour are examined to identify whether they meet standard diagnostic criteria, using classification systems such as DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization, 1992) for psychiatric disorder. Changes in behaviour can be used as markers (or "target behaviours") in monitoring the effectiveness of the treatment offered.

The goal of the psychiatric assessment is to identify and diagnose any psychiatric disorder and to treat it, optimally without further adding either to the developmental disability or to any physical problem. A further goal is to identify stressors and other circumstances that contribute to, or precipitate, the psychiatric or behaviour disturbance so that further crises and relapses can be prevented.

Not infrequently, because of the complexity in diagnosing psychiatric disorders in this population, there remains uncertainty as to the precise diagnosis. When this occurs, the steps to follow are:

- Generate the best clinical diagnostic hypothesis using information currently available.
- Collect data to confirm or refute this hypothesis.
- Review this data along with the results of the assessments in other areas (e.g., psychological, communication, environmental, expectations).

By following this approach, it should be possible to minimize the potential for inappropriate treatment, particularly with psychotropic medication (see clinical scenario in Box 2).

The comprehensive psychiatric assessment of the person with a developmental disability is usually an ongoing and dynamic process that may take several months. It requires a coordinated approach across all the settings where the individual spends time, including in-patient and out-patient settings if hospital admission is required.

Assessing and correctly diagnosing psychiatric disorders in people with developmental disability requires an understanding and experience of developmental disability and of psychiatric disorders. Assessment is best done within an interdisciplinary team context, working closely with carers who know the individual best. During the process of an assessment specialist input may be required from many perspectives, including medicine (developmental pediatrics, genetics, psychiatry, neurology, family medicine, audiology, ophthalmology), nursing, psychology, speech and language pathology, behaviour therapy, and occupational and/or physiotherapy.

An effective team will have developed a systematic approach to assessment and treatment, will be using valid and reliable instruments and procedures, and team members, experienced in working with individuals with developmental disability, will be able to adapt their usual clinical approaches appropriately to the broad spectrum of functioning levels seen in this group. Such a team should be able to focus the assessment in appropriate areas, be able to coordinate the assessment findings in a meaningful manner and also be able to provide a balanced formulation on which treatment recommendations should be based. Fragmented or incomplete assessments and those conducted by professionals who are unfamiliar with the emotional responses of persons with developmental disability unfortunately contribute to

Box 2: Clinical Scenario 2

Background

Dave, age 22, was referred by his community psychiatrist who felt "out of his depth" treating someone with a developmental disability. Despite knowing Dave over many years and helping him through two periods of distress during adolescence, the underlying psychiatrist's diagnosis remained unclear and Dave was not responding to conventional treatment approaches.

Dave was the middle child of an academic family. He was identified as having a mild mental retardation at an early age but this had largely been ignored. Dave himself had internalized expectations of academic success and despite some success in other aspects of his life, was unable to enjoy these. Feelings of worth and self esteem were closely tied to academic achievement. High school was a very difficult time for Dave; he struggled to keep up, he identified with the students heading towards university and felt very rejected when he was not accepted into their friendship groups. Dave succeeded in graduating from a modified high school program through hard work, good attendance and an "understanding school principal." After school he enrolled in college but had to leave because it was too stressful. Two years after school, Dave started to hear voices. He described people calling him "retard," he was tearful, agitated, lethargic and expressing feelings of not wanting to live. At this time, Dave had also experienced a number of recent life events, including a rejection from a girlfriend and his friends going off and living together without including him. Physical examination and routine laboratory investigations were normal. He was started on an antidepressant and supportive psychotherapy. His mood improved but the voices remained. An antipsychotic was started, resulting in fewer experiences of voices most of the time. However, any attempt to reduce the antipsychotic medication resulted in a return of the voices, requiring reinstating of the medication at higher doses. Even with the antipsychotic medication, Dave continued to hear voices at times of high anxiety (e.g., when his program was too stressful, when he was out in crowds, when he was seeking the attention of peers). They were always derogatory, calling him names like "retard", and they were associated with ideas of reference having their origin in persons present in his immediate environment, although usually some distance away.

Dave refused to talk about the voices when they were most bothersome and was reluctant to discuss them outside of these times. With his therapist, Dave started to share his intense and painful experiences of being teased and called names at school.

Comment

The underlying disorder giving rise to Dave's behaviour and mental experiences is not clear at this point. When well, his developmental disability and concreteness limit his capacity to share, or to see the relevance of sharing, these experiences with this psychiatrist, yet when hearing the voices, he becomes hostile and paranoid, and refuses to discuss them (perhaps because of cognitive confusion and fear). Yet determining the psychiatric diagnosis requires more information about these experiences. From the information available, a number of psychiatric disorders should be considered: psychotic disorder, including schizophrenia, major depressive disorder, anxiety disorder (including social phobia), and post traumatic stress disorder (flash backs from experiences in school). A "clinical diagnosis hypothesis" as to the psychiatric diagnosis, considered within a biopsychosocial perspective, and taking account of the impact of the developmental disability on the clinical picture, can be generated (rather than making a more definitive "diagnosis" on less than adequate information). Based on this, an intervention or treatment plan can be formulated, including a procedure to identify and collect further information that would help to support (or refute) the working hypothesis. The intervention/treatment plan should include a process to review the working diagnosis to determine whether the latter needs to be modified given the further information available and given Dave's responses to the intervention/treatment.

misdiagnoses and inappropriate and sometimes harmful treatments.

Treatment

Initially, treatment may be more focussed on the management of the behavioural disturbance until a clearer understanding of the cause of these behaviours is available. A comprehensive assessment will indicate the presence (or absence) of a psychiatric disorder and will provide information not only on those circumstances that may be underlying the behavioural disturbances, but also information on those circumstances that exacerbate or maintain these and other behaviours (even after the initial cause is no longer present). During the assessment period, various "crisis" interventions (most often medication or behavioural) may be tried in response to the need to manage serious or dangerous behaviours. The responses of the individual to these interventions should also be monitored and documented carefully, as they may provide further insights into the underlying cause of the disturbance and may be relevant to future treatment recommendations (e.g., if the individual was restrained, how did he/she respond to this?). As a clearer understanding of the underlying disorder becomes available, treatment becomes more focussed and individualized (see Boxes 3 and 4).

After a diagnosis, medication is required only to the extent that it is recommended for the optimal treatment of a clearly defined psychiatric disorder. Effective treatment will involve educating the person with disabilities and carers about the disorder, about treatment options, and about strategies to minimize relapses and promote mental well-being. It is important to map out a proactive response to crisis or relapse, with a clear outline of the involvement of community and emergency and inpatient services. This will help to stabilize the system supporting the individual and consolidate the treatment plan, will minimize anxiety and the escalation of distress in both the person with disabilities and his/her carers, and most importantly, will help ensure continuity of care and specialized treatment (an example of this approach is outlined in Box 1).

Box 3: Treatment Principles

Decrease organic/biological contribution and prevent the occurrence of secondary disabilities and handicaps:

- *attention to sensory impairments*
- *attention to physical impairments*
- *treatment of seizures*
- *treatment of other medical disorders,*
- *treatment of psychiatric disorders and/or symptoms that respond to psychotropic medication*

Decrease stress:

- *appropriate environments*
- *appropriate expectations*
- *appropriate supports to match level of functioning and adaptive skills*

Increase competence:

- *increase coping skills*
- *increase self esteem*
- *increase social support systems*

Coordinated system approach:

- *continuity of care (e.g. inpatient to outpatient)*
- *Identify spectrum of supports (e.g. physicians, nursing, behaviour support, case manager)*
- *proactive crises management*

Box 4: Treatment Approaches

Counselling

Psychotherapy
(individual, family, group, cognitive etc.)

Behavioural support

Communication assistance

Environmental alteration

Psychopharmacology

Education about developmental disability and mental health

System interventions

Carer and staff support

With counselling or psychotherapy, individuals can be helped to develop alternative coping strategies, learn to modulate their emotional responses and manage frustration and stress more effectively. However, carers have a key role in managing the amount of stress in the individual's environment (e.g., noisy work environments when the person has a hearing impairment, inappropriate expectations given the individual's developmental level) and in helping them to gain access to lifestyles that promote physical and emotional well-being (e.g., attention to physical health and medical disorders, friendships, inclusion in work and recreational activities; see Box 4).

Research into the psychological and behavioural aspects of various syndromes has gained prominence in recent years (for a review of syndromes and behavioural phenotypes see Dykens, Hodapp & Finucane, 2000, and O'Brien & Yule, 1996). This new knowledge, coupled with autobiographical accounts by some of the more able individuals with these syndromes (for example, see Kingsley & Levitz, 1994 for Down syndrome; Lenhoff, Wang, Greenberg & Bellugi, 1997 for Williams syndrome; and Grandin & Scariano, 1986; Williams, 1992 and 1994 for autism) offers an opportunity to design environments and supports that are more sensitive to the disabilities and handicaps experienced by these individuals. Persons with autism, for example, are at greater risk for psychiatric disorders than developmentally disabled persons without autism, and often present with severe behaviour disturbance. A broader understanding of the experience of the autistic individual and of the disabilities associated with autism allows a greater appreciation of, for example, how confusing and stressful their daily pattern of social life can be. These broader perspectives encourage the development of services that can optimally support the autistic individual and, in particular, minimize the stress they experience.

People with developmental disability and psychiatric disorder require regular follow-up and careful monitoring of their mediation. Shared care involving the psychiatrist, nurse, and family doctor with access to specialist services (such as psychology, behaviour management and counselling/psychotherapy) can work well. In some jurisdictions (e.g., the United Kingdom and some services in the United States), community psychiatric nurses are core members of the treatment team and play a crucial role in ensuring access to appropriate health care. In Ontario, however, the nursing role in supporting individuals with developmental disability and mental health problems remains largely unrecognized, and few nurses are trained to practice in this area. In some localities, generic ("non-specialized") community nurses may become involved with specific people for a limited time. Generally speaking, though, the relative roles of the nurse,

psychiatrist, and family doctor at any time during treatment will be determined by the needs of the individual, the service context within which each of these professionals works, and the comfort level of each in working with people with developmental disability.

THE MENTAL HEALTH SERVICE SYSTEM IN ONTARIO

Historical perspective

In the past two decades a number of socio-political factors have helped shape the mental health services now available to people with developmental disability residing in Ontario (see Table 2a, b).

In 1971, a report commissioned by the government of Ontario, the "Williston Report," recommended the downsizing of facilities for people with developmental disability and the establishment of community-based services to enable them to be supported in their local communities. In 1974, the Developmental Services Act came into effect. This act enabled responsibility for children and adults with developmental disability to be transferred from the Ministry of Health to the Ministry of Community and Social Services. This shift in government policy mirrored the increasingly popular view that a system that was based primarily on a medical model was not appropriate for the majority of people with developmental disability. Unfortunately, the decision to divest responsibility, instead of adopting a joint approach, may have set the stage for the gradual erosion and fragmentation of medical and mental health services for people with developmental disabilities, as the Ministry of Community and Social Services lacked the infrastructure and cross-sector linkages to provide or co-ordinate these types of services.

Another significant development occurred in 1987, when the government released a strategic plan for community living in a policy document entitled *Challenges and Opportunities: Community Living for People with Developmental Handicaps*. This document outlined a multi-year plan for the phasing out and eventual closure of provincial institutions for people with developmental disability. The infrastructure that had developed within the institutions to respond to the medical and mental health needs of people with developmental disability was starting to be dismantled, despite the lack of a co-ordinated plan to set up a comparable system of community-based care. Implicit in these policy changes was the notion that people with developmental disability would have their health care needs met by accessing generic services. However, many studies have now highlighted the specialist health care needs of this population which, if not met, will result in them not having access to the same standard of health care enjoyed by their non-disabled peers (Beange, 1996; Lennox, Diggens & Ugoni, 1997; Lennox & Kerr, 1997). In addition, over time, the realization took hold that people with developmental disability were even more vulnerable to mental health problems than their non-disabled peers, yet had greater difficulty accessing appropriate services. Recent government strategies to address some of these issues relating to mental health services have consisted of joint ministerial (Ministries of Health and Community and Social Services) funding to stimulate cross-sector activities and the development of policy guidelines to encourage greater equity of access to generic mental services (see Table 1).

Current services

When mental health problems arise, the family physician is usually the first point of contact

Table 2a: The Ontario Perspective: Policies Affecting the Lives and Mental Well-Being of People with Developmental Disability

Year	*Name of Discussion Paper, Policy Document or Bill*	*Ministry/Ministries Responsible*	*Key Elements*
1971	*Present Arrangements for the Care and Supervision of Mentally RetardedPersons in Ontario ("Williston Report")*	*Health*	*Called for the development of comprehensivecommunity-based services for people withdevelopmental disability*
1974	*Developmental Services Act*	*MCSS*	*Responsibility for people with developmental disability was transferred from Ministry of Health to Ministry of Community and Social Services*
1980	*Bill 82*	*Education*	*Stipulated that school-age children with exceptional needs would receive appropriate special education services and programs*
1987	*Challenges and Opportunities*	*MCSS*	*Multi-year strategic plan for the phasing out and closure of provincial institutions for the developmentally disabled* *Called for comprehensive community-based service system to be established*
1988	*Building Community Support for People: A Plan for Mental Health in Ontario ("Graham Report")*	*Health*	*People with a dual diagnosis were identified under special target groups as being susceptible to mental health problems and disadvantaged in terms of obtaining needed services*
1990	*Interministerial Initiative on Dual Diagnosis*	*Health and MCSS*	*Demonstration projects were funded to generate innovative ideas and improved cooperation among service providers to improve the health status and community integration of people with a dual diagnosis*
1993	*Putting People First (Mental Health Reform)*	*Health*	*Policy framework to reform mental health services in Ontario. Recommendation to develop programs to provide comprehensive services for those with severe mental illness and unique needs* *People with developmental disability are included as a "first priority population"*

*MCSS = Ministry of Community and Social Services

Table 2b: The Ontario Perspective: Policies Affecting the Lives and Mental Well-Being of People with Developmental Disability *continued*

Year	Name of Discussion Paper, Policy Document or Bill	Ministry/ Ministries Responsible	Key Elements
1995	Developmental Services Framework: Draft Paper	MCSS	Strategic plan for promoting integration of people with developmental disability into community supports and services
1997	Making Services Work for People	MCSS	Framework for reshaping services for people with developmental disability
1997	Policy Guidelines for the Provision of Services for Persons with a Dual Diagnosis	MCSS and Health	Policy direction for the planning,delivery and coordination of cross-sector services for people with a dual diagnosis
1997	Reinvestment Strategy for Children and Youth;	MCSS	Strategies to prevent or reduce the need for essential and long-term government supports, and increase the use of investment supports/services
1998	Reinvestment Strategy for Adults with a Developmental Disability	MCSS	Approach to enhancing accountability and individualized approachesto services and supports in the developmental services sector
1999	Individual Support Agreements for People with Developmental Disabilities	Health and Long Term Care	Framework for and implementation plan to improve the delivery of services and supports through the mental health reform process
	Making It Happen: Implementation Plan for the Reformed Mental Health System and Operational Framework for the Delivery of Mental Health Services and Supports		Individuals with a dual diagnosis (developmental disability with psychiatric disorder) are identified as one of the target populations who qualify for specialized services

*MCSS = Ministry of Community and Social Services

and is the most common source for help ("primary level" health care). Depending on the nature and severity of the problem, the family physician has several options in terms of referring to more specialized services, such as an independent practice psychiatrist, community mental health program, or general hospital outpatient or inpatient service ("secondary level" health care). Individuals in acute crisis may be referred to the nearest emergency department

able to provide a psychiatric service. Those with severe, intractable, and/or chronic disorders, have, in the past, tended to receive service from the nearest Provincial Psychiatric Hospital ("tertiary level" health care). In the 1980s, there were 10 Provincial Psychiatric Hospitals (PPHs) covering the province (Penetanguishine; Brockville, Kingston, Lakehead, Thunder Bay, North Bay, Toronto (Queens Street Mental Health Centre), Whitby, Hamilton, and London/St Thomas). Many of these hospitals had dual diagnosis programs (i.e., they had a service specifically for people with developmental disability and psychiatric disorders) and/or wards specifically for persons with developmental disability, offering long term outpatient support and immediate access to inpatient beds at times of crises. With the mental health restructuring of recent years (Ontario Ministry of Health, 1999a, 1999b), these hospitals have been, or are, in the process of being divested; in this process, the PPHs acquire public hospital status and their governance changes accordingly. Many have entered into agreements with existing public hospitals offering psychiatric services in their locality (previously the "secondary level" of health care). Services offered by the PPH on the day of divestment are protected in this process but these services are now delivered under the new governance. Tertiary level health care is still catchmented: in terms of persons with dual diagnosis, this implies that each region/locality has to attend to the specialist needs of these individuals either by offering services directly or, if such services are not directly available in that locality, by arranging service from some other locality with appropriate transfer of funds and resources. Psychiatric services within general hospitals and community mental health programs generally have not in the past serviced specific catchment areas and have sometimes restricted their services to particular groups of individuals; for example, admitting only those with known, or suspected, mood or anxiety disorders and excluding those who do not meet their admission criteria (e.g., specifically excluding those with developmental disability). There is the potential for this recent mental health restructuring to provide new opportunities for persons with developmental disabilities and mental health disorders to gain better and greater access to mental health programs in the locality in which they live; however, the history of mental health services for persons with developmental disabilities is one of exclusion. Unless the process of restructuring includes specific educational programs aimed at providing a greater understanding of the needs of persons with developmental disabilities for mental health professionals working in generic settings (including access to a range of generic and specialist services), people with developmental disability are likely to continue to be denied appropriate mental health care.

Regardless of whether inpatient care is, or has been, delivered in a PPH or psychiatric ward of a public hospital, in general, inpatient and outpatient services are not linked closely; this can lead to fragmented, discontinuous care and can result in the client with a dual diagnosis being held "captive" in a systems crisis which is often mistaken as a client crisis. A tenacious and committed effort to pursue coordinated and collaborative assessment, treatment, and discharge planning is fundamental to the provision of adequate mental health services for this population.

Barriers and bridges

Although people with developmental disability have, in principle, access to the full spectrum of services available to the citizens of

Ontario, there are significant barriers that impede obtaining and benefiting from these services. For this population it is relevant, therefore, to differentiate between *access in principle* and *access in practice* (sometimes referred to as *equity* of access).

For many years, it has been consistently observed that people with developmental disability and mental health needs tend to "fall through the cracks" for services. This may be traced in part to the relatively separate operation of mental health and developmental service sectors. There has been comparatively little joint planning and activity between the two sectors, and professionals and caregivers receive little or no training or experience with "cross-over" issues. Some additional factors that impact on the provision of mental health services include the following:

- Exclusionary criteria for services, which result in many people with developmental disability being denied access to generic services.
- The need to utilize the expertise offered by different disciplines (e.g., psychiatry, family medicine, psychology, behaviour therapy, speech-language pathology, neurology, developmental pediatrics, genetics, occupational therapy, physiotherapy, nursing) in complex cases; this may be difficult to arrange due to a lack of professionals with relevant training and experience and problems co-ordinating this type of input.
- The need for professional staff to modify traditional procedures and approaches due to differences among people with developmental disabilities in cognitive and communicative functioning. For example, it takes approximately four times as long to assess and treat the individual with a developmental disability and mental health problem as it does for the person without such disability (Piachaud, 1989). The existing generic system is not easily able to accommodate this additional time requirement.
- Reimbursement schedules that do not permit physicians, and other health care providers, to be appropriately compensated for the amount of time many of these cases require.
- The fact that the individual with developmental disability does not always behave as a "typical" patient, which can leave staff feeling bewildered, deskilled and sometimes angry and terrified if their best treatments and intentions only result in further escalation of disruptive behaviours. Professionals may feel "out of their depth" due to lack of training or experience. This can all lead to negative stereotyping of people with developmental disability and avoidance of getting involved in the future.
- Budget cuts that threaten existing services and place individuals with developmental disabilities at even further disadvantage in trying to access appropriate services.
- The lack of an infrastructure and clear lines of responsibility and accountability within which to address gaps in the provision and co-ordination of services.

Developing an Ontario vision of a mental health service sensitive to the needs of people with developmental disabilities

In reviewing the literature on service development and provision in this area (Bouras, 1995; Dosen, 1993, 1995), certain requirements stand out as being particularly pertinent in the planning and delivery of mental health services sensitive to the needs of people with developmental disability. These include:

- Recognition of the greater prevalence of

health related problems experienced by people with developmental disability so that a) resources can be targeted to those most at risk, and b) problems can be anticipated and prevented.

- A sustained commitment to, and support for, developing a more integrated mental health system for people with developmental disability.
- The development of a spectrum of mental health and health-related services that are organized into a co-ordinated and cohesive network including: primary (e.g., family medicine), secondary (e.g., crisis and emergency services, community psychiatric services and access to general psychiatric inpatient services), and tertiary level services (e.g., consultation, assessment and treatment of more complex problems and access to professionals with special expertise in developmental disability and mental health problems); at each level staff are needed who are experienced and comfortable working with people with developmental disability.
- The need for professionals and caregivers from relevant service sectors (e.g., Health and Family and Children's Services) to enhance their knowledge of mental health issues and their knowledge of the range of the available community resources and supports. In recognition of the cross-sectoral education and training issues that affect the provision of services to people with developmental disability, the Habilitative Mental Health Resource Network was awarded funding from both Ministries to develop an introductory dual diagnosis training curriculum (Griffiths, Stavrakaki & Summers, in press). The book and training material will be distributed at no cost to a diverse group of caregivers from across Ontario.
- The need to integrate broad-based resources (including case management, respite, home-based services, employment options, social and leisure supports, education and housing) into the mental health service system so as to address people's needs from a holistic perspective.
- The need to promote clinical and service excellence and innovation by working in partnership with Academic Health Science Centres to develop training, education and research activities that focus on the needs of people with developmental disability. McCreary (1998) recommended the creation of a national plan to address the shortage of psychiatrists trained to respond to the mental health needs of persons with developmental disability. The plan was based on program outlines submitted to the Canadian Psychiatric Association from the various medical schools in Canada that offered postgraduate education in psychiatry, which would serve as the basis for a "blue print" for the initiative. The outlines would address the manner in which each academic Department of Psychiatry would support the training of psychiatrists. Although letters of intent were submitted by 15 of 16 medical schools across Canada, including all five Academic Health Science Centres in Ontario, federal and provincial funding for the initiative has not been secured.
- The need to develop a process to bring together service providers from relevant service systems to identify common issues and promote joint "ownership" through collaborative problem-solving efforts.

An appreciation of the concept of *critical mass* also appears to be crucial to the successful and effective development and delivery of mental

health services for people with developmental disability and for training professionals. Relative to their non-handicapped peers, individuals with developmental disability are few in number but have significantly greater health care needs. Thus, health care professionals need to be exposed to a sufficiently large number of people with developmental disability in order to develop knowledge, understanding and expertise in the assessment and treatment of psychiatric and behavioural disturbance. Another critical mass issue is related to population size. A report of the ENCOR program in Nebraska, a service model well known for its exemplary support of people with developmental disability, concludes that:

> for human services providing a range of programs from speciality to generic (for example, in mental health, mental retardation and special education) the most desirable population size for regional services is in the 50,000 to 150,000 range. Population size must be large enough to support efficient services to persons with infrequently occurring needs. With 50,000 people as a minimum, the upper limits to size are determined by breakdown in management, which seem to occur as systems approach populations of 200,000 and again at 500,000. (Casey, McGee, Stark & Menolascino, 1985, pp. 106-107)

The ENCOR service provides specialist support to people with developmental disability and behavioural and psychiatric disturbances through its affiliation with the University of Nebraska Medical Center, thus ensuring that health professionals have adequate exposure to persons with developmental disability in well supported social programs; this linkage in turn ensures good quality medical care. In the United Kingdom, the unit of service is the Community Learning Disability Team (core membership of these teams includes nursing andsocial worker with access to specialist services such as psychiatry, psychology, speech and language). These teams are often affiliated with the nearest University Medical Centre and many of the latter have now established academic departments in developmental disability.

These critical mass issues must be addressed at the most meaningful administrative level, where the larger picture of needed services and supports can be appreciated, and where there is the capacity to implement change. For example, in Canada, a decision to develop mental health services within defined catchment areas would take place at the provincial level. However, issues relating to the education and training of professional staff may only be effectively addressed at a national level where, for example, professional colleges and National Examining Boards are better placed to ensure the development and maintenance of best clinical practices.

People with developmental disability and mental health problems present service challenges that can only be embraced by a truly biopsychosocial approach. Their needs span traditional administrative boundaries of health, social services and education. Interministerial initiatives and joint funding provide the solid bedrock on which integrated services develop.

SUMMARY

In this chapter, we have presented key issues in the assessment and treatment of mental health problems in people with developmental disability and on how service systems impact on optimal assessment, treatment, and mental health support. In recent years, there has been an explosion of knowledge in the biological and neurosciences and in clinical genetics. This knowledge already

Box 5: Recent Initiatives in Ontario

The Area Resource Team, Chedoke Child and Family Centre, Hamilton Health Sciences Centre, Hamilton

This tertiary service, operating out of the Hamilton Health Sciences complex (but funded by the Ministry of Community and Social Services), provides mental health consultation, assessment, treatment and support to persons with developmental disability living in the catchment area, a total population of around 1 million, located within 3 regions. Through its interdisciplinary clinical and teaching activities, the team supports the further development of primary (family doctors) and secondary (local hospitals) services' understanding of the mental health needs of persons with developmental disability. Staff on the team have affiliations with the Faculty of Health Sciences at McMaster University and are involved in teaching medical students, residents, fellows and other health-related disciplines, including psychology and nursing. The service has developed specific links with mental health professionals (such as psychiatrists, psychologists and nurses) and other developmental disability services (such as behavioural support teams) in each of the regions of the catchment area, thus ensuring continuity of support and care for persons referred to this tertiary service (Summers et al., 1995).

The Griffin Community Support Network, Toronto

This offers support and short term residential placement options for dually diagnosed adults 16 years and upwards, living within the community of Toronto (population around 4 million). The network had identified 7 beds located throughout the city (in a mix of settings funded from a variety of sources). Supporting these beds, agreements have been negotiated with 7 hospital settings, 8 day centres, 14 agencies providing assessment, consultation and direct support, 20 agencies providing short and long term case coordination and case management, and 3 mobile crises teams, so as to provide responsive and flexible services to individuals admitted to these beds; a clinical facilitator coordinates the activities and supports, identified as necessary to meet the clients' mental health needs (Griffin Centre,1999).

has relevance for our understanding of developmental disability and for our understanding (and therefore the assessment and treatment) of those individuals who have a developmental disability and additional emotional problems, behavioural disturbances or psychiatric disorders. If individuals with developmental disability are to benefit from this explosion of knowledge in a timely manner it is imperative that effective research, academic (education and training) and clinical links are developed alongside the service systems responsible for the care and support of this vulnerable population (see Moss, Emerson, Bouras & Holland, 1997 for further exploration of these issues).

ACKNOWLEDGEMENT

The authors greatly appreciate the contribution of Marika Korossy in the development of this chapter.

FOR FURTHER THOUGHT AND DISCUSSION

1. A friend has recently moved into your neighbourhood. She is worried about her teenage daughter Sophie who has started "to stay up late at night and has become oppositional and stubborn." Sophie has Down syndrome. What might be going on, what assistance is required and how would you help your friend access appropriate services in your area?
2. Consider the origins of negative attitudes towards people with developmental disability. How do such attitudes affect access to good health care?
3. What is meant by a "proactive/preventive" and "crisis/reactive" health care service? Why is a proactive/preventive approach preferable to a crisis/reactive approach in the support of people with developmental disability?

MORE RESOURCES

Autism Resources
Website: www.unc.edu/~cory/autism-info

The Integrated Network of Disability Information and Education
Website: www.indie.ca/

Developmental Disabilities Program at the University of Western Ontario
The University of Western Ontario
Health Sciences Addition
1393 Western Road, Main Floor
London, Ontario N6A 5B9
Website: www.uwo.ca/psychiatry/ddp.html
Telephone: 519 661-3804 Fax: 519 661-3487
Email: ddp@uwo.ca

Habilitative Mental Health Resource Network (Ontario Chapter of the National Association for the Dually Diagnosed)
c/o Plaza 69 Postal Outlet
1935 Paris Street, Box 21020
Sudbury, Ontario P3E 6G6
Website: www.nbpsych.on.ca/HMHRN.HTM
Telephone: 905 891 1790 Fax: 905 891 0908

National Association for the Dually Diagnosed Mental Illness/Mental Retardation
132 Fair St. Kingston, NY 12401-4802
Website: www.thenadd.org
Telephone: 845 331-4336 Fax: 845 331-4569
Email: thenadd@aol.com

Mental Health Aspects of Developmental Disabilities
Psych-Media, Inc. P.O. Box 57, Bear Creek, NC., USA, 27207
Telephone: 336581-3700 Fax: 336 581-3766
Email: mhaspectsofdd.com.

Society for the Study of Behavioural Phenotypes
Website: www.psychiatry.cam.ac.uk/ssbp

Ministry Documents

Ontario Ministry of Community and Social Services (1987). *Challenges and opportunities.* Toronto, ON: Queen's Printer.

Provincial Community Mental Health Committee (July, 1988). *Building community support for people: A plan for mental health in Ontario (The Graham Report).* Toronto, ON: Queen's Printer.

Ontario Ministries of Health and Community and Social Services (July, 1990). *Policy guideline for the provision of services for persons with a dual diagnosis (developmental disability/mental health needs).* Toronto, ON: Queen's Printer.

Ontario Ministry of Community and Social Services and Ministry of Health (1991). *Initiatives for persons with developmental disability and mental illness.* Toronto, ON: Queen's Printer.

Ontario Ministy of Health (1993). *Putting people first: Reform of the mental health services in Ontario.* Toronto, ON: Queen's Printer.

Ontario Ministry of Community and Social Services (March, 1995). *Developmental services: Draft paper.* Toronto, ON: Queen's Printer.

Ontario Ministry of Community and Social Services (1997). *Making services work for people.* Toronto, ON: Queen's Printer.

Ontario Ministry of Community and Social Services (October, 1997). *Reinvestment strategy for children and youth.* Toronto, ON: Queen's Printer.

Ontario Ministry of Community and Social Services (December, 1997). *Reinvestment strategy for adults with a developmental disability.* Toronto, ON: Queen's Printer.

Ontario Ministry of Community and Social Services (1998). *Individual Support Agreements for People with Developmental Disabilities.* Toronto, ON: Queen's Printer.

Ontario Ministry of Health (1999a). *Making it happen: Operational framework for the delivery of mental health services and supports.* Toronto, ON: Queen's Printer.

Ontario Ministry of Health (1999b). *Making it happen: Implementation plan for the reformed mental health system.* Toronto, ON: Queen's Printer.

Statutes

Education Act of 1974, R.S.O 1980 (Bill 82).

General Reading

Bouras, N. (Ed.). (1994). *Mental health and mental retardation.* Cambridge: Cambridge University Press.

Fletcher, J. R., & Dosen, A. (Eds.). (1993). *Mental health aspects of mental retardation: Progress in assessment and treatment.* Toronto, ON: Lexington Books, Maxwell Macmillan Canada.

Fletcher, J. R., & Menolascino, F. (Eds.). (1989). *Mental retardation and mental illness, assessment, treatment, and service for the dually diagnosed.* Toronto, ON: Lexington Books, Maxwell Macmillan Canada.

Russell, O. (Ed.). (1997). *Seminars in the psychiatry of learning disabilities.* London: The Royal College of Psychiatrists, Gaskell.

REFERENCES

American Association on Mental Retardation (1992). *Mental retardation: Definition, classification, and systems of support* (special 3rd ed.). Washington, DC: Author.

American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Beange, H. P., (1996). *Caring for a vulnerable population. Medical Journal of Australia, 164,* 159-160.

Benson, B. A. (1985). Behavior disorders and mental retardation: Associations with age, sex and level of functioning in an outpatient clinic sample. *Applied Research in Mental Retardation, 6,* 79-85.

Bradley, E., & Bryson, S. (1998). *Psychiatric illness in mentally handicapped adolescents (and young adults) with autistic disability.* Report to the National Health Research and Development Program. Ottawa, ON: Health Canada.

Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 17-27.

Bouras, N. (1995). The Frank Menolascino lecture: Dual diagnosis towards the year 2000. *The NADD Newsletter, 12*(2), 1-4.

Campbell, M., & Malone, R. P. (1991). Mental retardation and psychiatric disorders. *Hospital and Community Psychiatry, 42,* 374-379.

Caron, C., & Rutter, M. (1991). Comorbidity in child psychopathology: Concepts, issues and research strategies. *Journal of Child Psychology and Psychiatry, 32,* 1063-1080.

Casey, K., McGee, J., Stark, J., & Menolascino, F. (1985). *A community-based system for the mentally retarded: The ENCOR experience.* Lincoln, NE: University of Nebraska Press.

Corbett, J. (1979). Psychiatric morbidity and mental retardation. In F. E. James, & R. P. Snaith (Eds.), *Psychiatric illness and mental handicap* (pp. 11-25). London: Gaskell.

Crabbe, H. F. (1989). *A guidebook for the use of psychotropic medication in persons with mental illness and mental retardation.* State of Connecticut, Department of Mental Retardation.

Curry, C. J., Stevenson, R. E., Aughton, D., Byrne, J., Carey, J. C., & Cassidy, S. (1997). Evaluation of mental retardation: Recommendations of a consensus conference. *American Journal of Medical Genetics, 72,* 468-477.

Dosen, A. (1993). Development for mental health care for persons with handicaps in Europe. *The NADD Newsletter, 10*(6), 1-4.

Dosen, A. (1995). Mental health in mental retardation: A path to normalisation. *The NADD Newsletter, 12*(6), 1-4.

Dykens, E. M., Hodapp, R. M., & Finucane, B. M. (2000). *Genetics and mental retardation syndromes: A new look at behavioural interventions.* Baltimore: Brookes Publishing Co.

Einfeld, S. L., & Tonge, B. J. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: II Epidemiological findings. *Journal of Intellectual Disability Research, 40*(2), 99-109.

Grandin, T., & Scariano, M. (1986). *Emergence: Labelled autistic.* Navato, CA: Arena Press.

Griffiths, D., Stavrakaki, C., & Summers, J. (Eds.). (in press). *An introduction to the mental health needs of persons with developmental disabilities. Habilitative Mental Health Resource Network.*

Jacobson, J. W. (1982). Problem behavior and psychiatric impairment within a developmentally disabled population I: Behavior frequency. *Applied Research in Mental Retardation, 3,* 121-139.

Jakab, I. (1982). Psychiatric disorders in mental retardation. In I. Jakab (Ed.), *Mental retardation* (pp. 270-326). Basel, Switzerland: Karger.

King, B. H., DeAntonio, C., McCracken, J. T., Forness, S. R., & Ackerland, V. (1994). Psychiatric consultation in severe and profound mental retardation. *American Journal of Psychiatry, 151,* 1802-1808.

Kingsley, J., & Levitz, M. (1994). *Count us in: Growing up with Down syndrome.* New York: Harcourt Brace & Co.

Lenhoff, H. M., Wang, P. P., Greenberg, F., & Bellugi, V. (1997). Williams syndrome and the brain. *Scientific American, 277,* 68-73.

Lennox, N. G., Diggens, J. N., & Ugoni, A. M. (1997). The general practice care of people with intellectual disability: Barriers and solutions. *Journal of Intellectual Disability Research, 41,* 380-390.

Lennox, N. G., & Kerr, M. P. (1997). Primary care and people with an intellectual disability: The evidence base. *Journal of Intellectual Disability Research, 41,* 365-372.

Lunsky, Y., & Bradley, E. A. (2001). Developmental disability training in Canadian psychiatry residency programs. *Canadian Journal of Psychiatry, 46,* 63-67.

McCreary, B. D. (1998). Educating Canadian psychiatrists for professional responsibilities in the field of developmental disabilities. Discussion paper prepared for the Educational Council of the Canadian Psychiatric Association, Department of Psychiatry, Queen's University, Kingston, ON.

Moss, S., Emerson, E., Bouras, N., & Holland, A. (1997). Mental disorders and problematic behaviours in people with intellectual disability: Future direction for research. *Journal of Intellectual Disability Research, 41,* 440-447.

O'Brien, G., & Yule, W. (Eds.). (1996). Behavioural phenotypes. *Clinics in Developmental Medicine (No. 138).* Cambridge, UK: McKeith Press.

Piachaud, J. (1989). Calculating the medical time required in the psychiatry of mental handicap. *Psychiatric Bulletin, 13,* 486-489.

Raynham, H., Gibbons, R., Flint, J., & Higgs, D. (1996). The genetic basis for mental retardation. *Quarterly Journal of Medicine, 89,* 169-175.

Reid, A. H. (1982). *The psychiatry of mental handicap.* London: Blackwell Scientific Publications.

Reiss, S., & Aman, M. G. (1998). *Psychotropic medication and developmental disabilities: The international consensus handbook.* Columbus, OH: Ohio State University Nisonger Center.

Reiss, S., Levitan, G. W., & Szysko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency, 86,* 567-574.

Rutter, M., Tizard, J., & Whitmore, K. (1970). *Education, health and behaviour.* London: Longman.

Sovner, R., & Hurley, A. D. (1986). Managing aggressive behavior: A psychiatric approach. *Psychiatric Aspects of Mental Retardation Reviews, 5,* 16-21.

Stark, J. A., Kiernan, W. E., & Goldbury, T. (1988). In J. A. Stark, F. J. Menolascino, M. H. Albarelli, & V. C. Gray (Eds.), *Mental retardation and mental health: Classification, diagnosis, treatment and services* (pp. 300-312). New York: Springer-Verlag.

Summers, J., Wyngaarden, P., Adamson, J., Honeyman, S., Tweedie, G., & Bergen, D. (1995). The Area Resource Team of Southern Ontario: Attempting to bridge the gap between the developmental service and mental health care system. *Proceedings of the National Association for the Dually Diagnosed, 12,* 75-76.

Williston, W. B. (1971). Present arrangement for the care and supervision of mentally retarded persons in Ontario. Report to the Ontario Minister of Health. Toronto, ON: Ontario Department of Health.

Williams, D. (1992). *Nobody nowhere: The extraordinary autiography of an autistic.* New York: Avon Books, Inc.

Williams, D. (1994). *Somebody somewhere: Breaking free from the world of autism.* New York: Times Books, Random House.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders. Clinical descriptions and diagnostic guidelines.* Geneva, Switzerland: Author.

Yu, D., & Atkinson, L. (1993). Developmental disability with and without psychiatric involvement: Prevalence estimates for Ontario. *Journal on Developmental Disabilities, 2*(1), 92-99.

J Primary Prevent (2007) 28:375–388
DOI 10.1007/s10935-007-0100-1

ORIGINAL PAPER

Cognitive Impairments and the Prevention of Homelessness: Research and Practice Review

Thomas Earl Backer · Elizabeth A. Howard

Published online: 5 June 2007
© Springer Science+Business Media, LLC 2007

Abstract Cognitive impairments can increase significantly a person's level of risk for becoming or remaining homeless. Five topics are explored that address these impairments in preventing homelessness: (1) the nature and estimated prevalence of cognitive impairments among people who are homeless, especially those with vulnerabilities like mental illness or substance abuse; (2) the multiple origins of these impairments; (3) how these impairments impact services for people at risk for homelessness; (4) good practice approaches to handling cognitive impairments in homeless shelters, supported housing programs, and other service systems for people at risk for homelessness; and, (5) important research and practice issues requiring further action.

Keywords Cognitive impairments · Homelessness · Prevention · Assessment · Intervention

Introduction

Cognitive impairments can significantly affect an individual's ability to obtain and maintain stable housing, and to benefit from supportive services. Deficits in a person's memory, perception, judgment, planning, and speech can result in poor problem-solving and social skills, and in his/her inability to make sound decisions. The behaviors resulting from cognitive impairments are largely unintentional, but they are often poorly understood by providers and others, and are sometimes mistaken for noncompliance. For example, landlords sometimes deny housing to people with cognitive impairments because their behaviors may be difficult to understand. Frequently behaviors that occur as a result of cognitive impairments are misinterpreted as being intentionally antisocial or disruptive. People with

T. E. Backer (✉) · E. A. Howard
Human Interaction Research Institute, 5435 Balboa Boulevard, Suite 115, Encino, CA 91316, USA
e-mail: hirila@aol.com

cognitive impairments who do obtain housing often lose it through eviction, because these impairments leave them unable to figure out how to pay for rent and utilities, or how to maintain their residences appropriately (HCH Clinicians' Network 2003).

The nature, prevalence, and origins of cognitive impairments are relevant to the prevention of homelessness for all three levels of ''prevention'' as classically defined. Primary prevention refers to preventing people who are at risk but not yet homeless from becoming so, and might involve providing cognitive remediation or other services more widely. Secondary prevention and tertiary prevention activities focus on helping people who already are homeless (especially the core population of chronically homeless people) find permanent and stable housing. The good practices presented here for assessing and intervening with cognitive impairments are specific to secondary or tertiary prevention services provided through homeless shelters, supported housing programs, and other service programs for people who already have had some experience with homelessness.

At present only a limited research and practice literature is available to support families and mental health care workers in finding solutions for people with cognitive impairments at risk for homelessness (Spence et al. 2004). In many communities, ''neuropsychological assessments, diagnosis and treatment for homeless people tend to be inadequate or altogether lacking'' (Solliday-McRoy et al. 2004, p 471). This review examines five questions related to these challenges: (1) What are cognitive impairments and how many homeless people are cognitively impaired? (2) What are the origins of these cognitive impairments? (3) How do cognitive impairments impact services for people at risk for homelessness? (4) What are some good practice approaches to handling cognitive impairments in homeless shelters, supported housing programs, and other service systems for people at risk for homelessness? and (5) What research and practice issues require further action?

Gladwell (2006) describes the high costs of homelessness for people who are extremely vulnerable. Costs might be reduced by using a ''power law'' approach, increasing impact of services and cost-effectiveness by giving priority to the most severely disabled people. If the presence of significant cognitive impairments is understood to be ''severe,'' people with these severe disabilities would be candidates for enhanced services under a ''power law''-type policy. This approach is controversial because it tends to pit subgroups of people who are homeless against each other. However, this is a policy option requiring consideration, given tight resources.

The National Alliance to End Homelessness believes that ending chronic homelessness is well within the nation's grasp and could be accomplished within 10 years given public will and funding support (National Alliance to End Homelessness 2000). Recently, the Department of Housing and Urban Development announced $1.2 billion in funding for homeless assistance (National Alliance to End Homelessness 2005). This funding underscores a growing commitment among funders, communities, advocates, and service providers to deal more systemically with chronic homelessness. Addressing cognitive impairments among people at risk for homelessness can enhance the larger systems change effort, as well as individual person-focused efforts to prevent homelessness.

What are Cognitive Impairments and How Many Homeless People are Cognitively Impaired?

At least 20 million Americans suffer from some type of mild to severe cognitive impairment. These impairments result from brain disease or injury and compromise ''perception, information processing or formulation of a verbal or motor response'' (HCH Clinicians' Network 2003). They affect attention, memory, and language; they have impact on visual and spatial functioning, the ability to perform unfamiliar tasks, overall awareness, and the ability to organize and regulate behavior (Filley 2002).

It is difficult to estimate precisely the number of people with cognitive impairments in the homeless population. People in shelters are infrequently assessed for cognitive impairments. Even when they are, they are often treated only for other conditions, such as severe and persistent mental illness or substance abuse. For people on the streets, the ability to assess cognitive impairments may be compromised by more temporary conditions, such as inebriation or recent drug use.

Spence et al. (2004) reviewed published work to assess evidence of cognitive dysfunction among adults who are homeless. Despite liberal inclusion criteria, they identified only 17 studies, conducted mainly in the U.S. with about 3,300 subjects in all. These studies indicate that there is a considerable burden of cognitive dysfunction among homeless people, although existing research does not directly establish a causal connection.

Solliday-McRoy et al. (2004) estimate that the prevalence of cognitive impairment among people who are homeless may be as high as 80%. Douyon and colleagues (1998) found that homeless veterans displayed higher levels of cognitive impairments than non-homeless individuals. They also showed higher levels of hostility, prior criminal activity, and family history of psychiatric illnesses, but lower levels of depression. This study identified practical consequences of leaving cognitive impairments undiagnosed and untreated. For instance, if higher hostility is common among homeless people with cognitive impairments, it can affect their ability to access and sustain service involvement.

What are the Origins of These Cognitive Impairments?

Cognitive impairments arise from a number of sources—including schizophrenia, substance abuse, traumatic, or acquired brain injury, progressive neurological disorders, and developmental disabilities. For many homeless people, their impairments may come from more than one source, and the pattern of their cognitive problems may shift over time. Each of these sources is discussed below.

Cognitive impairment is a core feature of *schizophrenia*, affecting at least 85% of this population (Gopal and Variend 2005; Keefe and Hawkins 2005), with resulting negative impact on the ability to maintain stable housing and otherwise function effectively in the community. These difficulties can be significantly reduced with appropriate medication, in concert with cognitive remediation therapy (Gopal and Variend 2005; Wexler and Bell 2005), which is discussed below.

Poor attention is an early cognitive symptom, but difficulties with memory and visual motor speed may also be present, even before the onset of psychotic symptoms (Medalia and Revheim 2002). People with schizophrenia also seem unable to maintain voluntary control over the maintenance and manipulation of information (Goldberg and Green 2002), so they may have difficulty formulating plans, implementing them, and then flexibly changing to a new strategy once an old one no longer works. Research typically shows abnormalities in both the frontal and temporal lobes of their brains, controlling respectively the executive/attentional systems and memory systems (Rains et al. 1995). In severe cases, people who have such impairments often cannot complete daily activities without assistance (Rains et al. 1995; Turetsky et al. 2002).

Prolonged *substance abuse* may result in more temporary and reversible cognitive impairments. Delirium often results from severe intoxication, and impairments from abuse of drugs such as cocaine also are common (Osher 2006, personal communication). Because many people at risk for homelessness are substance abusers, interventions that reduce substance use can also reduce these temporary cognitive impairments, and sometimes the more enduring ones described below. This in turn can play a significant role in efforts to prevent homelessness (National Alliance to End Homelessness 2000).

Traumatic brain injury resulting in cognitive impairments is seen more frequently in people who are homeless than in the general population (Gonzalez et al. 2001; HCH Clinicians' Network 2003). Traumatic brain injury may be caused by auto accidents, falls, accidental poisonings, assaults, or gunshot wounds. Homeless individuals bear a disproportionate risk for severe head injury, at least partly because they are more likely to be victimized by assaults, have higher propensity for risk taking, and have a higher prevalence of antisocial personality disorder (Silver and Felix 1999).

Acquired brain injury most often occurs among people who are homeless as a result of chronic substance abuse, strokes, post-traumatic stress disorder (particularly likely among the many homeless people who are veterans), and infections or malnutrition (Silver and Felix 1999). All these types of injuries may have been acquired as a consequence of being homeless.

Other cognitive impairments are associated with progressive *neurological disorders*. These include multiple sclerosis, Parkinson's, and Alzheimer's disease or dementia due to aging (HCH Clinicians' Network 2003).

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments, resulting in problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age, and usually last throughout a person's lifetime. They are attributable to such conditions as mental retardation, cerebral palsy, or autism, and typically involve some degree of cognitive impairment. Nearly four million of the estimated 20 million Americans with cognitive impairments have a developmental disability (U.S. Department of Health and Human Services 2000). Because developmental disabilities are typically diagnosed early in childhood, many assessment and treatment protocols for these impairments are offered as part of

special education programs. Early intervention services are designed to meet developmental needs of an infant or toddler, and then lead to special education programs for school-age children (National Dissemination Center for Children with Disabilities 2003).

Other sub-types of developmental disabilities, typically diagnosed in very young children, are the various conditions covered by the umbrella term Fetal Alcohol Spectrum Disorder (FASD), all resulting from a mother's alcohol abuse during pregnancy. Over half of all children diagnosed with these conditions are clinically defined as having attention deficits, resulting in significant impact on their daily lives, as children and later as adults (Lockhart 2001).

As many as 35% of people with a developmental disability also have a mental illness. Prevalence rates for this kind of dual diagnosis are unreliable because individuals diagnosed with developmental disabilities usually are not assessed for mental illness. People with co-occurring mental illness and developmental disabilities rarely receive appropriate assessment and care for both disorders. As a result, they may be at increased risk for long-term institutionalization and homelessness (National Association of State Mental Health Program Directors 2004).

People with developmental disabilities are more vulnerable to becoming homeless at two critical junctures. The first occurs when a young person ages out of the care system designed for children (including, in many cases, foster care). Special education and other in-school programs can no longer offer services, and adult supports may not be accessible (National Dissemination Center for Children with Disabilities 2003). Unless the individual has strong family ties, they are at high risk of becoming homeless. The second juncture occurs when parents of a developmentally disabled person are no longer living. If plans for support and stable housing are not in place before the death of the parents, the individual is more likely to become homeless.

How do Cognitive Impairments Impact Services for People at Risk for Homelessness?

Assessing cognitive impairments

Various instruments are available for assessing the presence and severity of cognitive impairments. For example, in a review conducted by Spence et al. (2004), 10 of the 18 agencies studied employed the Mini-Mental Status Examination (MMSE) to assess cognitive functioning – a widely-used but relatively non-specific assessment tool (Gonzalez et al. 2001). The Cognitive Impairment Assessment Education Series (Weaverdyck 2006), like the MMSE, provides questions in a format that service agency staff who are not mental health professionals can use to assess cognitive functioning. Instruments commonly used by mental health professionals also include the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) and the Brief Assessment of Cognition in Schizophrenia (BACS) (Keefe and Hawkins 2005).

Inspite of the availability of assessment instruments, cognitive impairments of people who are homeless often are not assessed, (Osher 2006; Solliday-McRoy et al. 2004). Service workers are often focused on addressing pressing survival needs of people who are homeless, such as food, shelter, and medical attention (HCH Clinicians' Network 2003). Furthermore, shelter staff and others serving people who are homeless are often untrained in assessment.

When assessments are conducted, they can be quite challenging (Eberlein 2000). Individuals with cognitive impairments may be unable to participate fully in assessment because of their inability to communicate their thoughts, experiences, and feelings (Fodero n.d.). According to Eberlein (2000), cognitively impaired individuals often find it difficult to undergo formal neuropsychological assessment, and sometimes may be reluctant to do so, even though it may provide helpful diagnostic information. Later, as they receive services, people with cognitive impairments may be unable to discuss their discomfort with service protocols (sometimes severe enough to cause them to reject services), rules for living in a shelter or supported housing program, or difficulties such as medication side effects (Benson and Wilkerson 2000).

Misdiagnosis may also be a problem, especially due to the multiple causes of cognitive impairments. For example, people with severe cognitive impairments that are not related to a mental illness such as schizophrenia are still sometimes diagnosed only as mentally ill, resulting in incomplete or inappropriate services (HCH Clinicians' Network 2003). For example, antipsychotic medications will only ameliorate cognitive impairments that were caused by schizophrenia.

Other health issues may complicate assessment of cognitive impairments. Symptoms of some diseases can mimic organic brain disorders. For example, cognitive impairment in a homeless person with HIV may indicate AIDS-related dementia, but it can also indicate prolonged depression, opportunistic infection, side effects from medication, or self-medication with psychoactive substances. Confusion, incoherence, and distorted speech can indicate cognitive impairment, but it may be related to untreated diabetes; people with pre-lingual deafness are sometimes diagnosed as psychotic or mentally retarded (HCH Clinicians' Network 2003).

The reason for undertaking assessment is not to attach a label, but rather to identify areas of need and services required if cognitive impairments are present (Benson and Wilkerson 2000). In practical terms, however, a diagnostic label may be useful if it allows the individual to qualify for needed services. For instance, full neuropsychological testing may reveal that an individual qualifies for services from the adult developmental disabilities system (Osher 2006), or for SSI/SSDI benefits.

Serving People with Cognitive Impairments

People with major cognitive impairments are often among the most challenging to serve in programs that focus on people at risk for homelessness, such as shelters or supported housing programs (HCH Clinicians' Network 2003). Cognitive impairments may be experienced in many different ways; they may impact an individual's

ability to function in one area, but not in others. Some people can appear high functioning when engaged in social or casual conversation, but are nevertheless impaired to an extent that increases their risk for becoming or remaining homeless (Medalia and Ravjeo 2002).

Cognitively impaired people may be erroneously considered ''non-compliant'' or ''in denial'' because their impairments preclude their full participation in the service process (Gonzalez et al. 2001). Sometimes they are banned from service settings due to impairment-related disruptive behavior or failure to comply with prescribed treatments (HCH Clinician's Network 2003). Folk and Fernandez (n.d.) give the example of a woman with undiagnosed mild mental retardation who was constantly in danger of being kicked out of a shelter because she did not do her chore of vacuuming the floor at night. She always would agree to the task when asked by staff, but then did not follow through. This led them to assume she was manipulative and resistant. An advocate who suspected she might be cognitively impaired discovered that she did not know how to operate a vacuum cleaner—but agreed to do so when asked to please the shelter workers.

Cognitively impaired people may reject services, sometimes rebuffing even the most basic interactions with service staff. This may happen because they are unable to comprehend what is being asked, or the benefit from their participation. Such people also may resist services because they have fixed and inaccurate ideas about the service system. This situation is only made more complicated by cognitive impairments that affect their ability to judge and understand. In some cases, the best providers can do is to keep these individuals from leaving the service system altogether, and significantly worsening their life situations (HCH Clinicians' Network 2003). Whenever the service system seems to be ''failing'' someone, service staff can check again to determine whether an undiagnosed cognitive impairment is contributing to the individual's difficulties.

People with cognitive impairments also may be more vulnerable to substance abuse because of an inability to regulate their behavior (Price 2005). These individuals often lack protective and resiliency factors (e.g., feelings of self-competence, self-control, and personal power) that can protect against the temptation to abuse substances. They may self-medicate against feelings of loss and frustration specific to their cognitive functioning. Using drugs or alcohol in a social context may also help to reduce the social isolation resulting from their impairment.

Moreover, people with co-occurring cognitive impairments and substance abuse are often unable to benefit from or participate in traditional substance abuse treatment programs. Some programs move too quickly, or require a level of intellectual participation cognitively impaired people may find difficult (such as some aspects of 12-step programs). If the impairment is severe, the person may not understand the effects of substance abuse, or the workings of a particular program, but counselors may interpret this as denial (HCH Clinicians' Network 2003). Counselors may lack the skills to respond to people with cognitive impairments and make needed adjustments in the service process.

For instance, motivational interviewing is an evidence-based practice designed for engaging ambivalent or resistant people (Squires and Moyers 2001). It relies

heavily on an individual's ability to participate in an open exchange with others. It assumes a level of self-sufficiency and judgment that simply is not present in many people with substantial cognitive impairments. Thus, despite its powerful evidence base, providers may need to find alternatives to motivational interviewing when they have concerns about a person's level of cognitive impairment.

Many juveniles and adults with cognitive impairments become involved with the criminal justice system, but their disabilities may not be easily recognized by intake personnel. Arrestees may not understand their rights, and frequently waive them. Once in jail or prison, other inmates often victimize people with cognitive impairments. They may spend long periods in segregation because they have difficulty understanding jail and prison rules, or orders from guards. Because they often are not identified as cognitively impaired, and because there are few specialized programs for reintegrating people with these disabilities after they are released, they often are discharged to homelessness, and thus enter ''revolving door cycles'' like prison to parole and back to prison (Petersilia 2000). In addition, they may be refused housing because of their criminal records.

Services also need to respond to ethnic and cultural differences in conceptualizing cognitive impairments, as well as to people's abilities to understand and participate in their service programs (National Association of State Mental Health Program Directors 2004). To deal with these challenges in the Seattle area, the Arc of King County's program for homeless people who have developmental disabilities (described below) offers cultural competency training for both service recipients and professionals (The Arc of King County 2006).

What are Some Good Practice Approaches to Handling Cognitive Impairments in Homeless Shelters, Supported Housing Programs, and Service Systems for People who are Homeless or at Risk for Homelessness?

Strategies for handling cognitive impairments among people at risk for homelessness exist, but are not well-integrated into standard practice because they come from varied settings and disciplines. Space does not permit a more detailed examination of these approaches, but listed below are some representative good practices. They include (a) general strategies for providing services, (b) services that target people with identified cognitive impairments, and (c) methods for training service providers or family members.

Solliday-McRoy et al. (2004) analyzed research- and practice-based strategies for modifying assessment, treatment, or shelter/supported housing services to reflect the special needs of people with significant cognitive impairments. They suggest the following general strategies, and claim they can be useful regardless of the source of the impairment:

- Use service modalities that are not cognitively demanding,
- Set well-defined goals for all services,
- Repeat all basic concepts and instructions,
- Provide concrete explanations of actions to be taken,

- Offer continual behavioral reinforcement,
- Use memory enhancement approaches,
- Use cognitive rehabilitation approaches when feasible, and
- Use structured skill learning as part of services.

When working with people with cognitive impairments, it is important to use very clear, concise, and specific language, avoiding abstractions and unnecessary detail. Information should be provided slowly, with opportunity for questions. Goals can be broken down to one-at-a-time, instead of presenting the person with a *set* of goals they may find overwhelming. Although adults with cognitive impairments may at time appear childish, they *are* adults and should be treated as such. It may be necessary to repeat instructions frequently, use diagrams or demonstrations, and ask the person to repeat instructions (HCH Clinicians Network 2003).

Programs offered by a shelter or other service agency can serve people with cognitive impairments more effectively by adapting one or more of the above general approaches. For example, medication management programs can be custom-fitted for people in supported housing programs who have cognitive impairments. This may include increasing the time allotted for explanations or using photographs or pictures from journals or magazines to illustrate instructions (Osher 2006).

Some service programs by their nature are more amenable to such custom-fitting. For instance, many homeless health care clinics use intensive case management approaches based on Assertive Community Treatment (ACT), an evidence-based approach to intensive services (Lehman et al. 1999). The person is fully engaged in treatment from the beginning, and sets goals such as stable housing, employment, and self-sufficiency. Under these conditions, cognitive impairments, even if not formally diagnosed, are more likely to be recognized and can be dealt with in the service process.

Velligan and colleagues (2006) promote custom-fitting of another type. Considerable research shows that ''cognitive adaptation training'' with individually-tailored environmental supports (signs, alarms, special medication containers, etc.) can help people with medication compliance and other adaptive behaviors. However, in a controlled study Velligan et al. (2006) found that such supports are not likely to be used unless they are customized to meet the needs of individuals, and set up in their own home environments.

''Errorless learning,'' used successfully in teaching entry-level job tasks, also is effective in teaching social problem-solving skills to people with schizophrenia (Kern et al. 2005). This approach, which breaks down task performance into smaller, more-easily-mastered subunits, may have potential for application to other kinds of learning needs for people with cognitive impairments, whether arising from schizophrenia or not.

Harvey et al. (2005) suggest that since cognitive impairment is a major determinant of functional outcome in schizophrenia, treatment of cognitive impairment at the time of the first psychotic episode might have the potential to change functional outcomes of the illness. Their study examined changes in cognitive functioning associated with treatment with risperidone compared with

haloperidol. Treatment with risperidone at the time of the first episode of schizophrenia is associated with wide-ranging improvements in cognitive functioning; overall improvement is significantly greater with risperidone than with haloperidol. Thus, treatment decisions related to a primary diagnosis of schizophrenia can have an impact on reducing cognitive impairments, in cases where mental illness was the primary source of the impairment.

Cognitive remediation is an intervention for improving cognitive function, which has shown large and lasting improvements in cognition for people with schizophrenia (Wexler and Bell 2005); it may also have potential for handling cognitive impairments of all types. Exercises to improve attention, memory and executive function are performed in either individual or group settings, sometimes with computerized exercises or manualized programs. Growing evidence suggests that cognitive remediation improves real-world functioning as well (Gaddes and Edgell 1994; Medalia and Richardson 2005).

Comprehensive service programs have been developed to address the needs of people with cognitive impairments who are at risk for homelessness. For instance, the Arc of King County Survival Services Program (The Arc of King County 2006) has since 1989 provided services specifically for people who are homeless with developmental disabilities. Survival Services helps people secure and maintain public assistance, locate affordable housing, and provides crisis intervention on an ongoing basis. The aim is to teach people the skills necessary to achieve the highest possible level of personal responsibility.

The Homeless Case Management Program in Silver Spring, Maryland, published a resource document for providers serving people who are homeless and have developmental disabilities (Folk and Fernandez n.d.). The Maryland Developmental Disabilities Administration (2006) provides an array of services to individuals in crisis, including those at high risk for homelessness. Services help adults deal better with their cognitive impairments, and continue living in their own homes or with their families, or in a residential service setting. Many other states have similar programs, such as the New York Office of Mental Retardation and Developmental Disabilities (2006) and its Options for People Through Services (OPTS) program.

Service programs can be enhanced by bringing together agencies and professionals from mental retardation/developmental disabilities and mental health to design programs and treatment protocols that will address *both* cognitive impairment and mental illness (as well as substance abuse, when needed). This is particularly important because public services often are organized as though individuals have only one disability, e.g., mental illness *or* developmental disability, whereas in fact they may have several (Shriver 2001). In a report on a conference bringing together these two systems, the National Association of State Mental Health Program Directors (2004) provide a number of suggestions for how a more integrated approach could be developed, with resulting improvements in services for people who are homeless.

In many service settings, staff are not trained to detect or respond to cognitive impairments in people who are homeless, often because of limited financial resources, or simply because training is not available. The need is particularly acute

for training to serve people with multiple challenges (mental illness, substance abuse, developmental disabilities, etc). The Ohio Coordinating Center of Excellence (CCOE) in Dual Diagnosis trains professionals in mental health/mental retardation/developmental disabilities and related service systems (including but not limited to those focused on people at risk for homelessness). It also provides clinical and organizational consultation across Ohio. CCOE developed regional training programs where systems change and clinical best practices are presented, and provided mini-grants to foster local collaboration, as well as offer individual consultation to clinicians (Benson and Wilkerson 2000).

Medalia and Revheim (2002) assembled a handbook for families and friends of individuals with psychiatric disorders, to help them understand and respond to cognitive impairments of these individuals. It discusses the impact of cognitive impairment on daily functioning and outlines various treatment and service options. The manual also discusses things family members can do to help the individual improve his/her cognitive functioning.

What Research and Practice Issues Require Further Action?

More research is needed to document the prevalence of cognitive impairment among people who are homeless and at risk for homelessness, about the origins and severity of their impairments, and about the consequences of these impairments for the effectiveness of the service process. Study also is needed about how to economically and accurately assess cognitive impairments. For instance, considerable empirical evidence indicates that cognitive impairments, when properly assessed, are among the most important predictors of long-term disability in schizophrenia. The MATRICS project, funded by the National Institute of Mental Health, is developing more rigorous assessment methods, along with pharmacological approaches to cognitive impairments among people with schizophrenia, and ways to encourage the pharmaceutical industry to develop promising drugs for this purpose (MATRICS Project 2006).

Controlled studies are essential to determine more precisely the effectiveness of innovative methods or service programs that address cognitive impairments among people in service systems, including supportive housing and homeless shelters. Of particular value would be research showing that cost savings are likely when cognitive impairments are addressed more systematically among people who are homeless, as well as studies about how to use these approaches in primary prevention of homelessness – among populations with cognitive impairments who are not yet homeless.

Re-shaping of public policy might be possible based on good cost-benefit data. Also, more research is needed on newer types of preventive interventions, such as drugs that reduce the disabling effects of cognitive impairment (Filley 2002). Neurosurgical techniques have advanced, and may lead to helpful interventions in the future. There is some hope that gene therapies may be created that can help treat some of these impairments. Also, the University of Colorado's Coleman Institute

for Cognitive Disabilities (2006) is pioneering the development of technology to help individuals residing in community living environments. When more widely implemented, these technologies may reduce the risk of homelessness. All of these approaches are still in the early stages of development.

At the practice level, mental health, substance abuse and mental retardation/developmental disability professionals need to continue working together to develop integrated assessment and service programs. Medical professionals might be included, as well, since homeless people are at high risk for injury, and for diseases such as HIV/AIDS, which can also result in cognitive impairments. The National Association of State Mental Health Program Directors conference report (2004) provides a number of concrete recommendations for such service and systems integration.

Stigma remains an issue for many people in the homeless service system—many people will not come into the service system because they fear the negative effects of stigma. Misconceptions and prejudices of providers about people with cognitive impairments are part of the challenge. Professional as well as public education is needed, to promote greater awareness of the special challenges faced by people with cognitive impairments who are homeless or at risk for homelessness. In general, more resources are needed to support training of staff and improvement of service systems so they can better respond to the needs of people with cognitive impairments.

Lastly, a Federal interagency task force needs to be assembled to examine the complex issues of cognitive impairments and prevention of homelessness. This task force could include representatives from various Federal agencies concerned with mental illness and substance abuse, as well as those concerned with homelessness. It could include researchers, providers, foundation representatives, policymakers, and people at risk for homelessness and their family members. Such a task force could spearhead development of a toolkit on assessment and treatment of cognitive impairments for people who are at risk of or experiencing homelessness. Such a toolkit could then be disseminated widely, as part of a national plan for workforce development on this subject.

Action on all of the issues just outlined will be needed to answer the five questions that framed this review of research and practice on cognitive impairments. These challenges are a fact of life for many people who are homeless or at risk for homelessness, and for service providers, their families, and the community at large. The difficulty of creating good practices is increased because these impairments have multiple origins, and they are not easy to diagnose or treat. However, progress on the several fronts discussed here is essential, if we hope to end chronic homelessness in the United States within the next ten years.

Acknowledgments The authors acknowledge with gratitude the input provided by Dr. Deborah Stone, Center for Mental Health Services; and Dr. Mary Anne Myers, Westat. Useful input also was provided by Dr. Fred Osher, University of Maryland; William Compton, Project Return, Los Angeles; Dr. Alex Kopelowicz, San Fernando Mental Health Services; Dr. Timothy Kuehnel, research psychologist; and Daryl Washington, Vanessa Heim and Temma Allen, all of the Fairfax County Community Services Board. Preparation of this paper was supported by the Knowledge Application Program Project, Center for Mental Health Services Task Order 270-03-6005.

References

The Arc of King County. (2006). *Survival services program*. Seattle, WA: Author.

Benson, B., & Wilkerson, D. (2000). *Report and recommendations: Clinical best practices for serving people with developmental disabilities and mental illness*. Columbus, OH: Department of Mental Health/Depertment of Mental Retardation and Developmental Disabilities Advisory Committee.

Coleman Institute for Cognitive Disabilities. (2006). *Coleman Institute sponsored projects*. University of Colorado, Retrieved February 12, 2007, from http://www.colemaninstitute.org.

Douyon, R., Guzman, P., Romain, G., Ireland, S. J., Mendoza, L., Lopez-Blanco, M., et al. (1998). Subtle neurological deficits and psychopathological findings in substance-abusing homeless and non-homeless veterans. *Journal of Neuropsychiatry and Clinical Neurosciences*, *10*, 210–215.

Eberlein, L. (2000). Guidelines for the evaluation of persons dually diagnosed with mental retardation and mental illness. In B. Benson & D. Wilkerson (Co-Chairs) *Report and recommendations: Clinical best practices for serving people with developmental disabilities and mental illness* (pp. 6–12). Columbus, OH: Ohio Department of Mental Health/Ohio Development of Mental Retardation and Developmental Disabilities Advisory Committee.

Filley, C. M. (2002). *Cognitive disorders: The state of the science*. Coleman Institute for Cognitive Disabilities, University of Colorado School of Medicine, Unpublished manuscript.

Folk, L., & Fernandez, C. B. (Eds.) (no date). Helping homeless people with developmental disabilities: A guide for providers. Rockville/Silver Spring, MD: Affiliated Sante Group and The Lt. Joseph P. Kennedy Institute.

Fodero, J. (no date). *Forgotten: The other dually diagnosed*. Retrieved February 12, 2007, from http://intotem.buffnet.net/mhw/30jf.html.

Gaddes, W. H., & Edgell, D. (1994). *Learning disabilities and brain function: A neuropsychological approach*. (3rd ed.) New York: Springer-Verlag.

Gladwell, M. (2006, February 13 & 20). Million-dollar Murray. *The New Yorker*, 96–107.

Goldberg, T. E., & Green, M. F. (2002). Neurocognitive functioning in patients with schizophrenia: An overview. In K. L. Davis, D. Charney, J. T. Coyle & C. Nemeroff (Eds.), *Neuropsychopharmacoogy: The fifth generation of progress* (pp. 657–670). Nashville, TN: American College of Neuropsychopharmacology.

Gonzalez, E. A., Dieter, J. N., Natalie, R. A., & Tanner, S. L. (2001). Neuropsychological evaluation of higher-functioning homeless persons: A comparison of an abbreviated test battery to the Mini-Mental State Exam. *The Journal of Nervous and Mental Disease*, *189*(3), 176–181.

Gopal, Y. V., & Variend, H. (2005). First-episode schizophrenia: Review of cognitive deficits and cognitive remediation. *Advances in Psychiatric Treatment*, *11*, 38–44.

HCH Clinicians' Network. (2003). *Dealing with disability: Cognitive impairments & homelessness*. Nashville, TN: HCH Clinicians' Network.

Harvey, P. D., Rabinowitz, J., Eerdekens, M., & Davidson, M. (2005). Treatment of cognitive impairment in early psychosis: A comparison of risperidone and haloperidol in a large long-term trial. *American Journal of Psychiatry, 162*, 1888–1895.

Kern, R. S., Green, M. F., Mitchell, S., Kopelowicz, A., Mintz, J., & Liberman, R. P. (2005). Extensions of errorless learning for social problem-solving deficits in schizophrenia. *American Journal of Psychiatry*, *162*, 513–519.

Keefe, R., & Hawkins, K. (2005). Assessing and treating cognitive deficits. *Psychiatric Times*, *23*(3), 1–4.

Lehman, A. F., Dixon, L., Hoch, J. S., Deforge, B., Kernan, E., & Frank, R. (1999). Cost-effectiveness of assertive community treatment for homeless persons with severe mental illness. *British Journal of Psychiatry*, *174*, 346–352.

Lockhart, P. J. (2001). Fetal alcohol spectrum disorders for mental health professionals: A brief review. *Current Opinions in Psychiatry*, *14*, 463–469.

Maryland Developmental Disabilities Administration. (2006). *Services provided by DDA*. Retrieved February 12, 2007, from http://www.ddamaryland.org.

MATRICS Project (2006). *Overview*. Retrieved February 12, 2007, from http://www.matrics.ucla.edu.

Medalia, A., & Revheim, N. (2002). *Dealing with cognitive dysfunction associated with psychiatric disabilities: A handbook for families and friends of individuals with psychiatric disorders*. Albany, NY: New York State Office of Mental Health.

Medalia, A., & Richardson, R. (2005). What predicts a good response to cognitive remediation interventions? *Schizophrenia Bulletin*, *31*(4), 942–953.

National Alliance to End Homelessness. (2005). *Comparing proposals for HUD McKinney-Vento funding*. Washington, DC: National Alliance to End Homelessness.

National Alliance to End Homelessness. (2000). *A plan not a dream: How to end homelessness in ten years*. Washington, DC: National Alliance to End Homelessness.

National Association of State Mental Health Program Directors. (2004). *Serving individuals with co-occurring developmental disabilities and mental illnesses: Systems barriers and strategies for reform*. Alexandria, VA: National Association of State Mental Health Program Directors.

National Dissemination Center for Children with Disabilities. (2003). *Pervasive developmental disorders: Fact sheet 20 (updated from 1998)*. Washington, DC: National Dissemination Center for Children with Disabilities.

New York Office of Mental Retardation and Developmental Disabilities. (2006). *Options for people through services: General information brochure*. Retrieved February 20, 2007, from http://www.omr.state.ny.us.

Petersilia, J. (2000). Doing justice? Criminal offenders with developmental disabilities. *California Policy Research Center Brief Series*, *12*(4), 1–62.

Price, A. (Ed.) (2005). The intersection of developmental disabilities, substance abuse and parenthood: Challenge and response. *The Source*, *14*(2), pp. 1–4.

Rains, G. D., Sauer, K., & Kant, C. (1995). Cognitive impairment consistent with left frontal-temporal abnormality in schizophrenia patients. *Journal of the International Neuropsychological Society, 1*(2), 133.

Shriver, E. (2001). Presentation on behalf of the Joseph P. Kennedy Foundation (no title) to workshop convened by the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development, the National Institute of Mental Health, the National Institute of Health Office of Rare Diseases and the Joseph P. Kennedy Foundation.

Silver, J. M., & Felix, A. (1999). Neuropsychiatry and the homeless. In F. Ovsiew (Ed.), *Neuropsychiatry and mental health services* (pp. 319–333). Washington, DC: American Psychiatric Press.

Solliday-McRoy, C., Campbell, T. C., Melchert, T. P., Young, T. J., & Cisler, R. A. (2004). Neuropsychological functioning of homeless men. *Journal of Nervous and Mental Disease*, *192*(7), 471–478.

Spence, S., Stevens, R., & Parks, R. (2004). Cognitive dysfunction in homeless adults: A systematic review. *Journal of the Royal Society of Medicine*, *97*, 375–379.

Squires, D. D., & Moyers, T. B. (2001). *Motivational interviewing: A guideline developed for the Behavioral Health Recovery Management Project*. Springfield, IL: Illinois Department of Human Services, Office of Alcoholism and Substance Abuse.

Turetsky, M. D., Moberg, P. J., Mozley, L. H., Moelter, S. T., Agrin, R. N., Gur, R. C., et al. (2002). Memory-delineated subtypes of schizophrenia: Relationship to clinical, neuroanatomical, and neurophysiological measures. *Neuropsychology, 16*(4), 481–490.

U.S. Department of Health, Human Services, Administration for Children and Families (2000). *Federal developmental disabilities programs*. Washington, DC: U.S. Department of Health and Human Services, Administration for Children and Families.

Velligan, D. I., Mueller, J., Wang, M., DiCocco, M., Diamond, P., Maples, N. J., & Davis, B. (2006). Use of environmental supports among patients with schizophrenia. *Psychiatric Services*, *57*, 219–224.

Wexler, B., & Bell, M. D. (2005). Cognitive remediation and vocational rehabilitation for schizophrenia. *Schizophrenia Bulletin*, *31*(4), 931–941.

Weaverdyck, S. E. (2006). *Assessing cognition of the person with cognitive impairment: Questions to ask. Cognitive Impairment Assessment Education Series, Session 2*. Ann Arbor, MI: Michigan Alzheimer's Disease Research Center, University of Michigan.

What Is Recovery? A Conceptual Model and Explication

Nora Jacobson, Ph.D.
Dianne Greenley, M.S.W., J.D.

This paper describes a conceptual model of recovery from mental illness developed to aid the state of Wisconsin in moving toward its goal of developing a "recovery-oriented" mental health system. In the model, recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery—hope, healing, empowerment, and connection—and external conditions that facilitate recovery—implementation of the principle of human rights, a positive culture of healing, and recovery-oriented services. The aim of the model is to link the abstract concepts that define recovery with specific strategies that systems, agencies, and individuals can use to facilitate it. (*Psychiatric Services* 52:482–485, 2001)

The current notion of recovery from mental illness dates back to the 1980s, with the publication of a major study that demonstrated that the course of severe mental illness was not an inevitable deterioration (1) and of several first-person accounts by consumers who described their experiences with a diagnosed mental illness and how they had managed to emerge intact or recover (2–4). Mental health professionals drew on such accounts to formulate theoretical and practical models of recovery that could be adapted for use in psychosocial rehabilitation and other mental health services (5–9). In the 1990s, as states were faced with the challenge of reconfiguring their publicly funded mental health services according to the principles of managed care (10), recovery became a tool for guiding system reform in both policy and practice (11).

The use of the term "recovery" in these different arenas—outcomes research, personal narrative, services design and provision, and system reform—has led to confusion. Recovery is variously described as something that individuals experience, that services promote, and that systems facilitate, yet the specifics of exactly what is to be experienced, promoted, or facilitated—and how—are often not well understood either by the consumers who are expected to recover or by the professionals and policy makers who are expected to help them.

The conceptual model of recovery described in this paper was designed for the purposes of education and self-assessment (12). It was developed by the first author under the aegis of the State of Wisconsin's recovery implementation task force, an advisory body composed of consumers, providers, advocates, and policy makers that has been charged with moving the state toward its goal of developing a "recovery-oriented" mental health system (13). The model aims to link the abstract concepts that define recovery with the specific strategies that systems, agencies, and individuals can use to facilitate it.

***Dr. Jacobson** is an associate scientist with the University of Wisconsin School of Nursing in Madison, K6/316 Clinical Science Center, 600 Highland Avenue, Madison, Wisconsin 53792 (e-mail, najacobson@facstaff.wisc.edu). **Ms. Greenley** is a supervising attorney at the Wisconsin Coalition for Advocacy and co–principal investigator with the women and mental health study site at the University of Wisconsin School of Social Work.*

The model

In our model, the word recovery refers both to internal conditions—the attitudes, experiences, and processes of change of individuals who are recovering—and external conditions—the circumstances, events, policies, and practices that may facilitate recovery. Together, internal and external conditions produce the process called recovery. These conditions have a reciprocal effect, and the process of recovery, once realized, can itself become a factor that further transforms both internal and external conditions.

Internal conditions

An analysis of numerous accounts by consumers of mental health services who describe themselves as "being in recovery" or "on a journey of recovery" suggests that the key conditions in this process are hope, healing, empowerment, and connection.

Hope. The hope that leads to recovery is, at its most basic level, the individual's belief that recovery is possible. The attitudinal components of hope are recognizing and accepting that there is a problem, committing to change, focusing on strengths rather than on weaknesses or the possibility of failure, looking forward rather than ruminating on the past, celebrating small steps rather than expecting seismic shifts in a short time, reordering priorities, and cultivating optimism. Gaining hope has about it something of the transcendent. "A tiny, fragile spark of hope appeared and promised that there could be something more than all of this darkness. . . . This is

the mystery. This is the grace. . . . All of the polemic and technology of psychiatry, psychology, social work, and science cannot account for this phenomenon of hope. But those of us who have recovered know that this grace is real. We lived it. It is our shared secret" (3).

The source of this grace is different for each individual. For one it will be the entity he or she knows as God. For another, it might be a spiritual connection with nature. Individuals not drawn to spirituality may find their grace in other sources, such as making art or contemplating philosophical issues. Hope sustains, even during periods of relapse. It creates its own possibilities. Hope is a frame of mind that colors every perception. By expanding the realm of the possible, hope lays the groundwork for healing to begin.

Healing. Consumers and professionals who accept the dictionary definition of recovery—to regain normal health, poise, or status—may resist the very possibility of recovery because they see it as an unrealistic expectation. However, it is important to remember that recovery is not synonymous with cure. Recovery is distinguished both by its endpoint—which is not necessarily a return to "normal" health and functioning—and by its emphasis on the individual's active participation in self-help activities. The concept of recovery is better captured by the notion of healing, a process that has two main components: defining a self apart from illness, and control.

As Estroff (14) has noted, people who have psychiatric disabilities often find that they lose their "selves" inside mental illness. Recovery is in part the process of "recovering" the self by reconceptualizing illness as only a part of the self, not as a definition of the whole. As consumers reconnect with their selves, they begin to experience a sense of self-esteem and self-respect that allows them to confront and overcome the stigma against persons with mental illness that they may have internalized, thus allowing further connection with the self.

The second healing process is control—that is, finding ways to relieve the symptoms of the illness or reduce the social and psychological effects of stress. For some consumers, medication is a successful strategy for effecting control. Another strategy is learning to reduce the occurrence and severity of symptoms and the effects of stress through self-care practices, such as adopting a wellness lifestyle or using symptom monitoring and response techniques (15,16)

The word "control" has a double meaning. In one sense it refers to the outcome of managing symptoms or stress. The second meaning, however, refers to the locus of control, or who has control. In recovery it is the consumer who has taken control, who has become an active agent in his or her own life. Control is an important factor in the next internal condition, empowerment.

An analysis of numerous accounts by consumers who describe themselves as "being in recovery" suggests that the key conditions in this process are hope, empowerment, healing, and connection.

Empowerment. In its simplest sense, empowerment may be understood as a corrective for the lack of control, sense of helplessness, and dependency that many consumers develop after long-term interactions with the mental health system. A sense of empowerment emerges from inside one's self—although it may be facilitated by external conditions—and it has three components. The first is autonomy, or the ability to act as an independent agent. The tools needed to act autonomously include knowledge, self-confidence, and the availability of meaningful choices. The second is courage—a willingness to take risks, to speak in one's own voice, and to step outside of safe routines. The third is responsibility, a concept that speaks to the consumer's obligations.

In the recovery model, the aim is to have consumers assume more and more responsibility for themselves. Their particular responsibilities include developing goals, working with providers and others—for example, family and friends—to make plans for reaching these goals, taking on decision-making tasks, and engaging in self-care. In addition, responsibility is a factor in making choices and taking risks; full empowerment requires that consumers live with the consequences of their choices.

Connection. Recovery is a profoundly social process. As consumers' accounts make clear, much of what is being recovered is a way of being in the company of others. The internal condition called connection captures the aspect of recovery that has to do with rejoining the social world—what some have called "getting a life." The ability to forge connections with others is both a result of hope, healing, and empowerment and a way to make these internal conditions possible.

To connect is to find roles to play in the world. These roles may involve activities, relationship status, or occupation. Many consumers report that the most powerful form of connection is helping others who are also living with mental illness. For some consumers, this means becoming a mental health provider or advocate; for others, it means bearing witness, or telling their own stories in public arenas. In all of these capacities, consumers increase the general understanding of what it is like to live with a mental illness. They find ways to validate and reconcile their own experiences, and by standing as living exemplars of the possibility of recovery, they serve as role models for others.

In yet another sense, connection is the bridge between internal and external conditions, allowing reciprocal action between the two.

External conditions

The external conditions that define recovery are human rights, "a positive culture of healing" (17), and recovery-oriented services. On the surface, these three conditions seem quite different. Human rights denotes a broad, societal condition; a positive culture of healing refers to the cultural milieu in which services are offered; and recovery-oriented services are the actual services provided. It is important to recognize, however, that these three conditions are simply different foci viewed through the same lens. That is, implementation of the principles of human rights in an organization results in a positive culture of healing, and recovery-oriented services are services that emerge from such a culture.

Human rights. In its broadest sense, a human rights agenda lays out a vision of a society in which power and resources are distributed equitably. When applied to mental illness, human rights emphasizes reducing and then eliminating stigma and discrimination against persons with psychiatric disabilities; promoting and protecting the rights of persons in the service system; providing equal opportunities for consumers in education, employment, and housing; and ensuring that consumers have access to needed resources, including those necessary for sustaining life (adequate food and shelter) as well as the social and health services that can aid recovery (physical, dental, and mental health services; job training; supported housing; and employment programs).

This human rights agenda allows for different perspectives and different types of activism. It can be used to advocate for the reduction and ultimately the elimination of involuntary commitment and other forced treatment, which many view as violations of human rights, or it can be used to campaign for parity legislation and universal health coverage. In this formulation, equal opportunity is promoted through expanded access to care and services that might otherwise be restricted by poverty, stigma, or the law itself.

A positive culture of healing. Fisher (17) has written of the need to "build a coherent social faith and order" as a way to promote recovery. He described this new order as "a positive culture of healing . . . a culture of inclusion, caring, cooperation, dreaming, humility, empowerment, hope, humor, dignity, respect, trust, and love." When applied to the culture of a human services organization, this vision of a positive culture of healing begins with an environment characterized by tolerance, listening, empathy, compassion, respect, safety, trust, diversity, and cultural competence. A healing culture is oriented toward human rights for all individuals and groups. Consumers' rights are incorporated into all decisions, and informed consent is part of the bedrock of daily practice.

The external conditions that define recovery are human rights, "a positive culture of healing," and recovery-oriented services.

In a positive culture of healing, professionals as well as consumers are empowered and engaged. For providers, empowerment means first believing that they can make a difference and then making a commitment to changing the way they conceptualize the course of mental illness and the way they practice. Providers must embrace the belief that every consumer can achieve hope, healing, empowerment, and connection, no matter what his or her current status. This belief must lead them to focus on the person, not the illness, and on his or her strengths and goals.

A key component of a positive culture of healing is the development of collaborative relationships between consumers and providers. In contrast to a hierarchical model of service provision, the collaborative model allows consumers and providers to work together to plan, negotiate, and make decisions about the services and activities the consumer will use to support his or her recovery. Collaboration implies that the consumer is an active participant, that he or she is presented with a range of options and given the opportunity to choose from among them, and that providers allow the consumer to take some risks with these choices. Consumers have the opportunity to make choices other than those the provider might have made for them.

Finally, a true collaborative relationship is one in which both consumer and provider come to see each other as human beings. For providers, this means learning to see beyond the diagnostic—or racial, ethnic, and socioeconomic—categories they have been trained to use and rethinking "boundary issues" so they can allow themselves to relate to consumers on a human level.

Recovery-oriented services. The Boston University Center for Psychiatric Rehabilitation has developed a model for designing recovery-oriented services (5,7). The model delineates four major consequences of severe mental illness—impairment, dysfunction, disability, and disadvantage. Recovery-oriented services address the range of these features and include services directed at symptom relief, crisis intervention, case management, rehabilitation, enrichment, rights protection, basic support, and self-help.

A second model, developed by the Ohio Department of Mental Health (18), describes the best practices to be implemented by consumers, clinicians, and community supports at four different stages of the mental health recovery process. The practices encompass clinical care, peer and family support, work, power and

control, stigma, community involvement, access to resources, and education. A third model (19) offers practice guidance within "a framework for designing, implementing, and evaluating behavior healthcare services that facilitate individual recovery and personal outcomes." Using the overarching metaphor of "a healing culture," this model addresses such issues as language, dignity and respect, empowerment and personal responsibility, consumer and family involvement, challenging stigma and discrimination, reflective practice and continuous improvement, cultural sensitivity and safety, and spirituality and personal meaning.

Each of these models integrates services provided by professionals, services provided by consumers, and services provided in collaboration. Services provided by professionals include medication, psychiatric rehabilitation, and traditional support services such as therapy and case management. The recovery orientation in these services lies in the attitudes of the professionals who provide them. For example, decisions about medication are worked out in a partnership between the provider and the consumer, rather than being dictated by the provider.

Consumer-run services are planned, implemented, and provided by consumers for consumers. Examples include advocacy, peer support programs, hospitalization alternatives, hotlines or "warm lines," and programming that provides opportunities for role modeling and mentoring.

Collaborative services are provided by and for both consumers and professionals as well as family members, friends, and members of the larger community and emphasize their diverse but complementary strengths. Examples include recovery education and training, clubhouse organizations, crisis planning, the development of recovery and treatment plans, community integration, and consumer rights education.

Although many of these services may sound similar to services currently being offered in many mental health systems, it is important to recognize that no service is recovery-oriented unless it incorporates the attitude that recovery is possible and has the goal of promoting hope, healing, empowerment, and connection.

Conclusions

The reciprocal relationship between the internal and the external conditions of recovery has been implicit in the presentation of this model. For example, reducing social stigma will help reduce the internalized stigma that restricts the ability of some consumers to define a self apart from their diagnosis. Access to appropriate mental health services, including education, will provide consumers with the knowledge, skills, and strategies that can help them relieve symptoms and control the effects of stress. Collaborative relationships between providers and consumers will empower both parties, allowing meaningful power sharing and a more mutual assumption of responsibility. Peer support provides opportunities for bearing witness, a practice that allows the speaker and the listeners to establish new connections and validates the idea that recovery is possible.

Similarly, as more consumers recover, and as recovery becomes more firmly entrenched in policy and practice, internal and external conditions will be transformed. More consumers in recovery will provide more models of what hope, healing, empowerment, and connection might look like. More experience with and evaluation of recovery-oriented services will determine which of these services has the greatest influence on recovery. ♦

Acknowledgment

Dr. Jacobson's work on the conceptual model and on this paper was supported by the Wisconsin Coalition for Advocacy.

References

1. Harding CM, Brooks GW, Ashikaga T, et al: The Vermont longitudinal study of persons with severe mental illness: II. long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. American Journal of Psychiatry 144:727–735, 1987
2. Houghton JF: First-person account: maintaining mental health in a turbulent world. Schizophrenia Bulletin 8:548–552, 1982
3. Deegan PE: Recovery: the lived experience of rehabilitation. Psychosocial Rehabilitation Journal 11(4):11–19, 1988
4. Unzicker R: On my own: a personal journey through madness and re-emergence. Psychosocial Rehabilitation Journal 13(1):71–77, 1989
5. Anthony W: Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. Psychosocial Rehabilitation Journal 16(4):11–23, 1993
6. Hatfield AB, Lefley HP: Surviving Mental Illness: Stress, Coping, and Adaptation. New York, Guilford, 1993
7. Spaniol L, Koehler M, Hutchinson D: The Recovery Workbook: Practical Coping and Empowerment Strategies for People With Psychiatric Disability. Boston, Boston University Center for Psychiatric Rehabilitation, 1994
8. Fisher DB: Health care reform based on an empowerment model of recovery by people with psychiatric disabilities. Hospital and Community Psychiatry 45:913–915, 1994
9. Davidson L, Strauss JS: Beyond the biopsychosocial model: integrating disorder, health, and recovery. Psychiatry 58:44–55, 1995
10. Mechanic D: Emerging trends in mental health policy and practice. Health Affairs 17(6):82–98, 1998
11. Jacobson N, Curtis L: Recovery as policy in mental health services: strategies emerging from the states. Psychiatric Rehabilitation Journal 23(4):333–341, 2000
12. Jacobson N: A Conceptual Model of Recovery. Madison, Wis, Wisconsin Coalition for Advocacy, 2000
13. The Blue Ribbon Commission on Mental Health: Final Report. Madison, Wis, 1997
14. Estroff SE: Self, identity, and subjective experiences of schizophrenia: in search of the subject. Schizophrenia Bulletin 15:189–196, 1989
15. Copeland ME: WRAP: Wellness Recovery Action Plan. Brattleboro, Vt, Peach Press, 1997
16. Crowley K: The Power of Procovery in Healing Mental Illness. San Francisco, Kennedy-Carlisle, 2000
17. Fishe DB: Towards a positive culture of healing, in The DMH Core Curriculum: Consumer Empowerment and Recovery, Part I. Boston, Commonwealth of Massachusetts Department of Mental Health, 1993
18. Townsend W, Boyd S, Griffin G, et al: Emerging best practices in mental health recovery. Columbus, Ohio Department of Mental Health, undated
19. Curtis LC: Practice guidance for recovery-oriented behavioral healthcare for adults with serious mental illnesses, in Personal Outcome Measures in Consumer-Directed Behavioral Health. Towson, Md, Council on Quality and Leadership for Persons With Disabilities, 2000

45

Family Life and Developmental Disability

Patricia Minnes and Julie Burbidge

What you will learn:

- The changing roles of parents and professionals
- The parent as advocate, therapist/mediator, educator, and caregiver
- Aging parents and changing roles
- The roles of other family members
- Evolving roles for parents in the 21st century

With the closure of the last institution for individuals with developmental disabilities in 2009, all individuals with disabilities are now accommodated in the community. As a result, increasing numbers of persons with disabilities are being integrated into community activities, into the educational mainstream, and into supported employment. Although such changes in philosophical orientation have had many beneficial effects for persons with disabilities over the past 50 years, they also have had major implications for families.

The Changing Roles of Parents and Professionals

For the first half of the 20th century, services for persons with developmental disabilities were guided primarily by the *medical model* and people with developmental disabilities were viewed as patients with diseases or organically based disorders. Physicians and disability professionals were viewed as experts, and parents often had relatively little involvement in the treatment and care of their children with disabilities. However, in the late 1960s and 1970s, with the introduction of behavioural techniques based on operant conditioning, there was a gradual shift from the medical model to a more *developmental model*, which focussed on education and training for people with developmental disabilities. Greater parental involvement was encouraged and parents and caregivers were trained to carry out programs with their children. This approach, known as the *mediator model*, was widely adopted.

Such changes, although beneficial for people with

developmental disabilities in a variety of ways, added to the responsibilities and burden of care for families. Compared to the 1970s, when the move to community-based services began, the last two decades have been times of considerable financial restraint that limit the expansion of supports for families caring for an individual with a disability in the community. Although the mediator model continues today, reduced funding has sometimes meant that there is a greater reliance upon pharmaceutical interventions to manage difficult behaviours.

In addition, with many new developments in genetic, physical health, and pharmaceutical knowledge, *biological models* may be gaining increasing acceptance. In many instances, interventions based on these models can be helpful in conjunction with behavioural strategies, especially with individuals whose behaviours are particularly challenging in the community. Well-controlled research is needed, however, to determine the relative effectiveness of behavioural and pharmaceutical interventions and the impact of such treatments upon the quality of life of persons with developmental disabilities and their families (see also Chapter 34).

Since the 1970s, parents have become increasingly active, advocating for the rights of their children and lobbying governments to improve services and supports. At first, many parents who were disillusioned with professionals took matters into their own hands but, in recent years, parents and professionals alike have begun to work toward developing more collaborative relationships and partnerships. The Ontario government has responded over the years to the needs of individuals with developmental disabilities and their families through legislation and a series of policy documents. In 1974, the Ontario government committed to a major change in services for people with developmental disabilities, shifting the focus from institution-based care to community-based services. This shift was partly in response to the apparent failure of the institutional system, and partly because many parents indicated the wish to care for their children with developmental disabilities at home but required assistance.

In 1987, the Ontario Ministry of Community and Social Services released a document entitled *Challenges and Opportunities: Community Living for People with Developmental Handicaps*, which outlined new service goals resulting from consultations with consumer and interest groups and agencies offering programs to individuals with disabilities and their families. In addition to its major long-term goal to establish a comprehensive community service system that would provide support to individuals with developmental disabilities in their home communities, the report described initiatives designed to strengthen supports for families caring for children with developmental disabilities at home and to develop new supported independent living arrangements for adults. Services such as special day care programs, respite care services, and Handicapped Children's Benefits under the Special Services at Home Program were introduced. Such changes were clearly designed to provide additional support for persons with developmental disabilities and their families. What was not clear — and is still not clear today — was how parents learn about such programs and how much additional burden parents experience if they need to connect with new agency personnel, learn about the application process, and complete an application for support. In some parts of Ontario, language is a major barrier, especially for immigrant families who do not speak English well or are unfamiliar with our service systems. Evaluation of these processes, their impact on parents, and factors contributing to successful outcomes are topics that have received very little attention in the literature to date.

In 1997, a new initiative titled *Making Services Work for People* outlined the Ontario government's plans to update the social service system and strategies not only to alter the services offered to families but also to improve the delivery of such services. The Ministry of Community and Social Services (then called Ministry of Community, Family and Children's Services) set out nine goals for reshaping social services in Ontario, including a commitment to ensure the maintenance of essential supports, greater integration of services, earlier and better provision of services for families and individuals with disabilities, and more consistent provision of core services across the province.

As described in the *Making Services Work for People* document, these changes included four shifts in direction: 1) a shift from services that respond only to entrenched problems to services that anticipate problems, respond earlier and reduce the need for future services; 2) a shift from services organized by agencies to services organized to respond to the needs of individuals and families in general; 3) a shift in emphasis from viewing increased funding as the major impetus for change to the view that service delivery can be improved using existing resources; and 4) a shift from government responsibility to shared responsibility. The impact of these changes for family members and the success of these initiatives have yet to be fully evaluated.

In 2008, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* was passed in the Ontario legislature. As of 2011, the Ministry of Community and Social Services was developing policy directives and regulations required before the Act can become law (*www.ontario.ca/community*). This legislation replaces the *Developmental Services Act* (1974). Changes to the new Act include new criteria regarding eligibility for government funding, more flexibility regarding the types of support and who can provide them, and providing more choices for services and supports (e.g., person-directed planning; direct funding to permit individuals to manage their supports and make their own decisions rather than working through community agencies). To date, it is not clear what impact such changes will have on parents and community agencies. The process of implementation of such legislation often takes several years and critical issues related to evaluation of outcomes may be overlooked until several years after the programs have been in place.

The Multiple Roles of Parents

The role of parents as advocates

In order to face the challenges involved in raising a child with a developmental disability, parents often take on the role of "advocate." Munro (1991) defined effective advocacy as "a non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction and contribute creative solutions to problems existing in human service systems" (p. 1). In order to become advocates, parents need to expand their function as parent and caregiver to include the jobs of information seeker, problem solver, committee member, public educator, political activist and, most importantly, spokesperson for the needs of a child who may be unable to communicate his or her own needs to those in power. In order to advocate effectively, parents need to be aware of their social, economic, and political environments and become aware of changing service philosophies, legislation, and budgetary issues.

A parent of an individual with a developmental disability may advocate in a variety of different situations and in many different ways. Parents can be advocates individually or as part of a group. They can write letters, make phone calls, and enlist the help of the media in furthering their cause. They may focus on their own child or the needs of all children with developmental disabilities. Their actions may occur at the community, national, or international level. A parent may view advocacy as a necessary evil, as something that just needs to be done, or as a full-time career. For parents to be successful advocates within a service delivery system — health, education, or social services — there needs to be a sense of partnership between the professional and caregiver, and they must learn to cooperate as equals. Unfortunately, the parent-professional partnership is an ideal notion that may be complicated by reality. While some parents have been able to immerse themselves in the role of collaborator, some professionals may be unprepared to deal with the "parent-as-expert." A sense of resentment may build in situations where parents are unable to discriminate between "what is legally their right and what privileges go beyond the scope of their power" (Nelson, Howard, & McLaughlin, 1993, p. 64). Open communication, mutual respect and trust, shared decision making, and parental empowerment, as well as recognition of the knowledge and skills of both parents and professionals, have been found to be important components of successful parent-professional partnerships (Davies & Hall; 2005; Minnes &

Box 1

Mary Ann is the mother of two children. Eric is 10 and has an intellectual disability due to unknown cause and epilepsy. Eric's younger brother Robbie has joined Cub Scouts and Mary Ann would like Eric to be able to attend as well. During a discussion with the Cub Scout pack leader, it became clear to Mary Ann that inclusion of Eric would be problematic. He would need someone to assist him in activities and the leader had safety concerns due to the severity of Eric's seizures. He also was concerned that he and others would need training to deal with the seizures. The leader reluctantly said that they would not be able to take Eric into the Cub Scout troop until these issues were addressed. Since Mary Ann is a single mother with limited finances, she was not able to hire someone to go to Cubs with Eric and she did not want to limit Robbie's activities by giving him extra responsibilities for his brother. Mary Ann also did not want to wait until she could find suitable supports. As a result, Mary Ann and a friend decided to set up their own Cub Scout group at home so that Eric could participate. Robbie and some of his friends have joined this new cub scout group and other children have expressed an interest. This initiative has provided new opportunities for Eric to interact with typically developing children.

Steiner, 2009).

A qualitative study by Nachshen and Jamieson (2000) explored the outcome of the role of advocacy, in relation to parents' sense of well-being. It was found that six factors contributed significantly to the perception of advocacy as a positive or negative experience. The first factor, *the role of advocacy*, referred to the parents' own sense that their advocacy role was a strategy to achieve change and not just an extra struggle. *The outcome of advocacy* related to the parents' belief that their actions would exert a positive effect on their environment. A third important factor was *the role of professionals*, which focused on professionals' negative or supportive response to the parents' efforts. Whether the parents were advocating for things to come or past injustices was the basis of the fourth factor, *the focus of advocacy*. The fifth factor, *the effect on personal life* emphasized the need for advocacy actions to create interpersonal links, rather than to destroy them. As well, parents spoke of the need to balance the need for advocacy with other personal needs, such as time, money, and relaxation. Personal *emotional issues* was the final factor, accentuating the relevance of parents' own emotional response. Advocacy could inspire feelings of confidence and empowerment, or depression, guilt, and anxiety.

In recent years, parents of children with autism have become particularly strong advocates, pressuring governments for funding to support early intensive behavioural intervention for their children. Parents have argued that failure to fund such programs is an infringement of their children's equality rights under the *Canada Health Act*. Such efforts, however, have had mixed results. For example, in 2002 the British Columbia Court of Appeal ruled that: "It is discriminatory under the Canadian Charter of Rights and the United Nations Convention on the Rights of the Child to not provide universal access to intensive behavioural intervention (IBI) for children with autism." The judgement concluded that "IBI is the most effective known therapy for children with autism and that it is a medically necessary intervention without which prognosis is poor" (Couper, 2004, p. 559). However, in a British Columbia government appeal, the Supreme Court of Canada refused to order the provincial government to fund IBI treatment (The Globe and Mail, November 20, 2004). Similarly, in Ontario a class action suit filed in 2004 by parents seeking assurances that their children with autism would have access to IBI in school was unsuccessful and in 2008, the Supreme Court rejected their application to appeal the decision (*http://www.autismontario.com/client/aso/ao.nsf*). Nevertheless, Boards of Education in Ontario and advocacy groups such as Autism Ontario subsequently began to work together on this issue. For example, Public Policy Memo 140 has been developed to provide guidance and support to school boards in the use of applied behaviour analysis (ABA) with students with autism spectrum disorders.

Box 2

Joanna and her husband Rick have twin boys. Both have been diagnosed with autism and they are on a waiting list for publically funded IBI. As an Occupational Therapist, Joanna is very eager for her boys to have IBI as soon as possible. She has done training courses and has been trying to work on skills with the boys but both she and her husband need to work. They also have an older daughter who needs their time and attention. Joanna has a friend who works at a local community college where there is a training program for behaviour therapists. Joanna and her friend developed a creative idea whereby a practicum placement would be set up in Joanna's home and students would work under supervision with her boys. This is just an interim measure while Joanna waits for funding and she is concerned that there will be gaps when the students are writing exams or on holidays. However, this is one example of an innovative approach and a win-win situation for the children, the parents and for the students who will gain valuable training and experience.

The role of parents as mediators/therapists

The mediator model is based on family involvement, enlisting family members as therapists to implement treatment programs. This model allows more families to be served by a small number of trained professionals. The professional meets with the family several times at the beginning of the intervention to do an assessment, formulate a treatment plan and train the family in carrying out the intervention. Following this, the family carries out the intervention in the home. The professional then collects and analyzes the data from the family and provides ongoing feedback. The ability of the family to carry out the intervention on a day-to-day basis allows the trained professional to work with many families at the same time.

An important advantage of this model is that it involves families in the process of change. The family's expertise and knowledge of their family member with a disability are an integral part of the assessment and critical to the implementation of the intervention. This collaboration between professionals and family members should result in the family feeling a sense of ownership of the process. However, many parents who are in need of services delivered in this fashion do not have the time, energy, or personal resources to be able to carry out the role of mediator. Often, these families are at the end of their own resources when they contact agencies for support. The expectation that the family can take on the extra burden of carrying out the intervention may not be realistic in many cases, and may be setting up the intervention and the family to fail. Some families are not good candidates to be mediators because of their own physical, cognitive, or emotional challenges. In the mediator model, a family member takes on the role of home therapist. To take on this role, the family member must be highly motivated, follow through consistently, and carry out the dual roles of caregiver and therapist. These blurred boundaries between professional and personal roles can make it difficult for the family member to serve as a good mediator and can put stress on the family system. When services are only offered in terms of the mediator model, many families are placed in a no-win situation where either they cannot engage the services and carry on as is when they need more support or they become engaged in a process that they are unable to carry out successfully. Such situations put added pressure on a family system that is already heavily burdened.

Despite the absence of research evidence supporting the importance of family involvement, the mediator model has been used extensively in a wide variety of interventions. One of the best known is the involvement of parents of children with autism spectrum disorders in the implementation of intensive behavioural interventions (IBI; Solish & Perry, 2008). Recent research focussing on factors contributing to parent involvement has highlighted parental self-efficacy or confidence in their ability as a significant predictor of parental involvement. Parental knowledge and belief in IBI were found to be correlated with involvement; however, they did not emerge as predictors of involvement. Although

Box 3

Bruce, who is 32 and has Down syndrome, was diagnosed last year with depression. For a time, doctors thought that Bruce was showing signs of early dementia (e.g., confusion, withdrawal, irritability, loss of skills). His mother, Barbara, researched the topic and found that diagnostic overshadowing (i.e., attributing symptoms to intellectual disability) can often lead to misdiagnosis. Once Bruce was referred to a dual diagnosis team, his problems were recognized as being related to depression but also to hypothyroidism, which is common in people with Down syndrome. Bruce was given medication to address these issues. Barbara and her son have since become involved in the Clinical Learning Centre at the local university. They regularly participate in education sessions for medical students about developmental disabilities, and Bruce has become a standardized patient helping medical students to improve their interviewing and communication skills.

the mediator model continues to be viewed as a useful and important model of service delivery in the field of developmental disabilities, further research is needed to evaluate its effectiveness.

The role of parents as educators

Ignorance is often cited by parents of a child with special needs as being one of the major challenges they face. In addition to parents becoming increasingly involved in programs designed to facilitate their child's development, many parents find themselves taking on the role of educator with professionals as well as with the public at large. Many parents feel that they have no choice but to try to meet their child's needs, first by informing themselves and then by passing on the information to others. Parents and professionals alike have highlighted the need for more education about developmental disabilities (Minnes, Lauckner, & Recoskie, 2007; Minnes & Steiner, 2009; Phillips, Morrison, & Davis, 2004). Parents also have suggested that they are better equipped to deal with professionals if they are well informed. One parent wrote, *"I have had good success with my doctors. I tell my doctors things they didn't know about Down syndrome"* (Nachshen, 1996). Educating others about their child's disability also helps many parents to deal with those around them. A parent explained: *"Most of the time when I name the syndrome, people have never heard of it and want to know more about this syndrome because it's so uncommon. I have had great experiences with explaining her condition. People have really accepted her."* Other suggestions from parents include the development of readily available and understandable information for the general public, grandparents and friends. Research is needed to explore the role of the media in providing such information. For example, television programs such as *Life Goes On*, have been shown to have potential in educating the public and changing attitudes about developmental disabilities (Hall & Minnes, 1999). Although many parents appreciate their role as educator, it is important to note that this may also be an added burden for parents. Many parents cope with the challenges they face in dealing with the public by trusting their own judgement. One parent wrote, *"We just do what we have to for our son, and if other people can't understand that, then we don't waste our time on them."* Another parent offered this advice: *"Ignore those who disapprove."*

The role of parents as caregivers

Despite the pressures on parents of individuals with developmental disabilities to be therapists and advocates, the main role of these parents, as with most parents, is that of caregiver. When a child with a developmental disability is born into a family, much of the family's energy is spent caring for their child with special needs. Families face a variety of challenges across the lifespan. Some of these are related to developmental transitions that take place in all families, including the child's progression through early developmental stages such as learning to walk and talk and later transitions such as starting school, puberty, developing friendships, and making plans for the future. Other challenges are related to events that are not experienced by par-

ents of nondisabled children, including disability-related issues such as diagnosis, having to deal with problem behaviours, and making plans for future accommodation and guardianship.

The stress experienced by parents of children with disabilities has been well documented in the research literature (e.g., Schneider, Wedgewood, Llewellyn, & McConnell, 2006). Some studies support a "wear-and-tear" hypothesis suggesting that family stress increases over time. Ongoing concerns may accumulate and contribute to chronic stress across the child's lifespan (Webster, Majnemer, Platt, & Shevell, 2008). In contrast to the view that stress in parents of children with developmental disabilities is chronic, many parents indicate intermittent periods of emotional distress corresponding to significant transition periods and stages in their child's development (Minnes & Woodford, 2004; Wikler, 1986). For example, parents are often concerned about their children meeting developmental milestones (e.g., walking, talking, puberty, leaving school). Moreover, differences between children with and without developmental disabilities are often highlighted during these periods and present unique challenges for families with children with disabilities.

Caregiver stress has been found to vary according to a number of factors, such as the age of the child (Baker, Blacher, Crnic, & Edelbrock, 2002), the type and degree of disability, and behavioural challenges (Hastings & Johnson, 2001; Nachshen, Garcin, & Minnes, 2005). Differences in parental stress may not only be the result of differences in the child's temperament, social responsiveness, and behaviour, but also the availability of support services. Although greater caregiving stress frequently is found with greater dependency and management needs and more severe degrees of disability, some researchers have found that parents of children with milder disabilities report more caregiving stress. The behaviour and appearance of children with milder disabilities may be closer to what is perceived as normal or typical and, as a result, parents may develop unrealistic expectations for their child, whereas parents of children with more severe disabilities may be less able to deny or overlook problems (Minnes, 1988b).

In a study conducted in Ontario (Nachshen, 1996), parents of children with developmental disabilities, including fragile X syndrome, Down syndrome or developmental disability due to other causes, indicated that the diagnosis of their child as having a developmental disability was a major issue for their family. Qualitative studies (Minnes, Laukner, & Recoskie, 2007; Minnes & Steiner, 2009) also have highlighted challenges associated with the diagnostic process, particularly for parents of children with fragile X syndrome and autism. Parents often sense that something is not right about their child's development but these concerns may not be taken seriously by professionals. Parents of children with fragile X syndrome found physicians' lack of interest in learning about the condition and a series of misdiagnoses to be major challenges. Parents of children with autism spoke of the difficulty of obtaining a timely diagnosis in order to access services. In such cases, a number of parents resorted to paying privately rather than waiting for public diagnostic services (Minnes et al., 2008; Minnes & Steiner, 2009).

Other issues of parental concern include: explaining to others about their child's disability; dealing with professionals in general; creating and/or finding opportunities for their child to make friends and participate in activities; meeting their own personal needs; choosing the best level of integration for their child; dealing with teachers and the education system; and dealing with their feelings about the cause of their child's disability (Nachshen, 1996).

Positive outcomes

A theme within the literature on parenting and families has been the considerable stress experienced by parents of children with developmental disabilities compared to parents of children without disabilities. There has been some concern, however, that too much emphasis on this tends to pathologize parents (Glidden, 1993) and, as a consequence, the focus of research has shifted in the past decade. Research has shown that many such families often cope well, and may not be distinguishable from families that do not have a child with disabilities (Perry, Harris, & Minnes, 2004). Indeed, many parents report positive impacts of having a child with a disability (Hastings & Taunt, 2002), including oppor-

tunities for personal growth, improved relations with others, and changes in philosophical or spiritual values (Scorgie & Sobsey, 2000), satisfaction with providing care (Rapanaro, Bartu, & Lee, 2008), and empowerment (Nachshen & Minnes, 2005). Reported positive impacts have also been shown to vary across cultural groups (Blacher & Baker, 2007).

Factors That Help Parents in Their Role as Caregiver

The stress associated with caring for a child with a developmental disability can be buffered by a number of individual and family resources. Four of the most important are highlighted below.

Family resources

Family adjustment and adaptation to change or stress have been associated with a number of resources that contribute to resiliency (McCubbin & McCubbin, 1996). In addition to personal resources and coping strategies used by individuals within a family, family system resources such as cohesiveness, communication, organization, control, and flexibility can often assist families under stress. Family cohesion or unity refers to the amount of bonding, trust, respect, and support in a family (McCubbin & McCubbin, 1996). Families that are cohesive tend to be encouraging, use listening skills, negotiate to avoid conflict, and foster a sense of belonging (Spina, Ziviani, & Nixon, 2005). Open communication patterns, use of organizational skills, and flexibility have also been found to contribute to family adaptation (McCubbin & McCubbin, 1996). The degree to which a family can find a balance between cohesiveness and independence, and between organization, control, and flexibility contributes to adaptation (Minnes, 1988a).

Financial resources are a critical factor for all families, but families of children with developmental disabilities are more likely to have lower socioeconomic status (Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006; Lopes, 2008). Being of lower socioeconomic status and having additional expenses associated with the costs of raising a child with a disability can impose increased stress on the family (Lopes, 2008). Poverty can also be associated with poor parental health, a decreased sense of well-being, and poorer parenting practices, all of which can have adverse effects on children (Emerson, 2004).

Social support

Informal social support networks also can have a positive impact on family quality of life (Flynt, Wood, & Scott, 1992; Minnes et al., 1989; Trivette & Dunst, 1992). In addition, informal support has been found to be strongly related to confidence in parenting and optimism (Bailey, Nelson, Hebbeler, & Spiker, 2007). On the other hand, there is evidence to suggest that some, but not all, families of children with disabilities become socially isolated. Informal support from extended family, friends, and neighbours can be helpful, although parents frequently indicate that people beyond their immediate family do not understand their situations (Renwick & Brown, 1998).

An Ontario study (Nachshen, 1996) highlighted the support needs of parents. One mother spoke of her need for informal support stating, *"I felt ignored by my family and friends while in the hospital. Only one friend came to visit, and only because I didn't tell her the circumstances. People in general didn't know how to react, and [were] likely uncomfortable so they stayed away. I desperately needed people around me to support me and maybe say congratulations."* Parents also reported that ignorance and insensitivity in the general public are frequent challenges. When describing her experiences with people in the neighbourhood, one parent said, *"People who barely know us make comments on our situation and our child's condition or behaviour. I don't like being put on the spot, even if people 'mean well' with their remarks."*

Despite the challenges, parents still indicate that family life can be enjoyable and that other people in their lives can be supportive. This was one theme in a compilation of thoughtful reflections by professionals who were also parents of children with developmental disabilities in the United States (Turnbull & Turnbull, 1985), and was highlighted in a Toronto-based qualitative study of family quality of life (Renwick & Brown, 1998). One parent in the

Nachshen study (1996) stated that her spouse was optimistic about their son's capabilities and was very understanding about their child's needs: *"There are times when we need a break, (but) our family and friends are there."*

Professional support

Although formal services are often assumed to provide support, and thus reduce family stress, this is not always the case. Families who use more services may have higher levels of stress and thus higher needs for services, or they may have lower levels of stress due to service-related assistance. Services can also potentially increase stress if the nature of service delivery is not effective (Blacher, Neece, & Paczkowski, 2005) or is not sufficiently family-centred (Trute, Hiebert-Murphy, & Wright, 2007). Furthermore, due to the changing availability of services at different ages (i.e., services for children and adults are often funded by different government Ministries), parents often need to seek out new services at transition points, which can add to already elevated stress levels.

Although it is generally assumed that more formal support from professionals and service agencies is beneficial for families of children with developmental disabilities, interactions with professionals have often been reported to contribute to parental distress rather than reducing it (Baxter, 1987). Many parents feel that professionals can be an important resource, but parents also describe problems when dealing with professionals (Nachshen, 1996). One parent noted at the time she was told of her son's diagnosis, *"It was very disappointing because two strange doctors brought my son to me and described what his condition was. It was not my own doctor."* Another parent discovered her child's condition when she read the newborn's chart, which had accidentally been left open. Often, however, parents feel that the diagnosis of their child was made easier because of professionals who were thoughtful and caring, and had a positive attitude.

Physicians have often been criticized for being uninformed about developmental disabilities. *"They make important decisions for our children, but they are not as informed as they should be."* Interestingly, many parents feel that some professionals also lack information on their child's disability (Minnes & Steiner, 2009). One parent wrote, *"I find many times I'm more of an expert on Down syndrome, and particularly my son, than the so-called professionals."* Efforts to educate professionals are not always met with success, as one parent pointed out: *"...all the literature I have given [my doctor] has been tucked away. He as much as told me he doesn't have time to read it"* (Nachshen, 1996). Older parents also have expressed concerns in this regard: *"[The doctors] won't do what you want them to do. It is difficult for medical people to accept ideas that come from parents."* Another parent suggested that *"there needs to be increased understanding, education, and flexibility within the medical profession."* In response to some of the concerns expressed by parents and others, Canadian guidelines for primary health care of individuals with developmental disabilities (Sullivan, Heng, Cameron, Lunsky, Cheetham, et al., 2006) have recently been developed in an effort to help family physicians better meet the needs of patients with developmental disabilities and their families.

In addition to feeling that others are ignorant of their child's condition, many parents feel that they do not have enough information themselves to deal adequately with the challenges that they face. One parent wrote, *"Not having enough information about fragile X makes it difficult to explain."* In making decisions concerning integration in school, one respondent felt that it was *"difficult to get information [about the] successes and problems of full integration."* This lack of information has also been highlighted by those dealing with their child's sexuality: *"We would like to know what others do about this. We are totally ignorant about how to handle this and it worries us very, very much!"*

Parents have indicated that teachers can be an important source of support. *"Her first kindergarten teacher was great and talked to me about her all the time — for example, her accomplishments, friends, hardships, etc. It made us feel good about her and her life around her."* However, teachers frequently are also criticized for creating difficulties for the family. *"A teacher centred us out by speaking loudly about our son amongst other parents and children.*

She should have been discreet and spoken privately to me" (Nachshen, 1996). All families are different and have different needs. However, one common complaint is that schools and community organizations are not flexible enough to meet those needs. Most parents seek full integration in the school system. Although some achieve success in that respect (often after years of struggling), many remain unsatisfied, feeling that the schools are reluctant to integrate and modify programs. One parent who felt more strongly about this issue, stated that *"forced integration [is a] farce — [there's] no such thing."* Another parent whose children were fully integrated was not satisfied for a different reason: *"I don't think integration into normal classrooms helps with our kids' social lives. Yes, they are well liked as a rule, but not invited to things by normal kids. They need opportunities to be with their peers — they seem to make the best friends with people like themselves."* Many parents feel that schools are not equipped to deal with their children appropriately, complaining of untrained teachers and a lack of one-on-one teaching for their child (Nachshen, 1996).

Support groups

Growing numbers of parents are participating in support groups in person or online. Research with parents of children with developmental disabilities has reported that parents involved in a support group report significant positive changes in their perceptions of their child compared to parents in a wait-list control group (Singer et al., 1999). Mandell & Salzer (2007) found that 66% of parents of children with autism spectrum disorders had participated in support groups. Potential benefits of such groups include providing emotional support, coping strategies, role models, a sense of belonging, and a sense of mastery or control (Solomon, Pistrang, & Barker, 2001). Online groups can be relatively cost-effective, include families in rural and remote areas, and reduce the need for travel and child care (Clifford & Minnes, 2010). Parents report that online support groups can be helpful for seeking information, connecting with other parents, and promoting advocacy, although parents also report frustration with confusing, unreliable, or overwhelmingly negative information (Carter, 2009).

Opportunities to talk with other parents of children with similar challenges can be very helpful for parents. In the Nachshen (1996) study, the diagnosis of their child as having a developmental disability was made easier for one parent when *"a professional parent having experience with her own child with Down syndrome visited us and asked if we would like any information. We readily accepted and I started reading information before I left the hospital."* The same parent suggested that a list of parents who are interested in offering support to new parents of disabled children at the hospital for anyone who would like support would help to make the experience of the diagnosis easier for others in a similar situation. A support group would be extremely helpful to one parent who said, *"Most people do not want to hear about any difficulties or problems you're having."* Parents also have suggested that support groups for their nondisabled children would be helpful.

Coping with Caregiving Across the Lifespan

Some of the most commonly cited coping strategies for managing stress are problem-focused, emotion-focused, and appraisal or perception-focused coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Parents who use problem-focused coping (i.e., attempting to alter the problem or situation), as opposed to emotion-focused coping strategies (i.e., attempting to reduce the emotional distress caused by the situation), have been found to report less stress and greater well-being (Glidden, Kiphart, Willoughby, & Bush, 1993; Shapiro, Blacher, & Lopez, 1998). Furthermore, parents with a greater internal locus of control, who rely on themselves rather than others, have been found to report less depression than those who report high external locus of control.

Cognitive appraisals (i.e., perception-focused coping) have also been found to contribute to parental adaptation (Hastings & Brown, 2002; Plant & Sanders, 2007). For example, older parents' perceptions of aging and stress have been found to mediate the relationship between parent health and depression (Minnes, Woodford, & Passey, 2007).

Table 1: Issues of Concern to Older Parents

Issue	Percent Rating Issue as Stressful	Mean Stress Score of Parents who Rated this Issue as Stressful (0-4)
Long-term planning for accommodation	*83%*	*3.11*
Planning for emotional and social support	*68%*	*2.63*
Creating opportunities	*56%*	*2.53*
Meeting your own personal needs	*55%*	*2.16*
Decision about accommodation in the home or in the community	*54%*	*2.91*
Time apart from offspring	*51%*	*2.41*
Planning for wills, trusts and guardianships	*50%*	*2.68*
Dealing with health professionals	*50%*	*2.03*
Transportation	*48%*	*2.79*
Financial issues	*48%*	*2.55*
Employment for child	*46%*	*2.46*
Diagnosis of disability	*44%*	*2.43*
Feelings about the cause of disability	*39%*	*2.42*
Explaining to others about the disability	*39%*	*1.98*
Level of integration	*38%*	*2.5*
Assistance with day to day care	*38%*	*2.23*
Meeting the needs of spouse	*36%*	*2.14*
Meeting the needs of other children	*34%*	*2.3*
Dealing with people day to day	*33%*	*2*
Maintaining satisfying friendships for self	*31%*	*2.04*
Dealing with child's sexuality	*30%*	*2.33*
Dealing with legal professionals	*23%*	*2.59*

Adapted with permission from Minnes & Woodford (2004); Minnes, Woodford, & Passey (2007).

Table 2: Service and Support Use and Needs of Older Parents for their Children

Services and Support for Offspring	Service Use	Service Need	t	p
Social/Recreational Activities	*48%*	*76%*	*4.34*	*0.0001**
Case Management	*63%*	*69%*	*2.06*	*0.044*
Respite Care	*44%*	*63%*	*4.28*	*0.0001**
Supported Employment	*29%*	*63%*	*4.9*	*0.0001**
Day Program	*32%*	*58%*	*5.31*	*0.0001**
Residential Placement	*15%*	*53%*	*6.89*	*0.0001**
Special Medical	*36%*	*37%*	*1.43*	*0.159*
In-home Support	*22%*	*36%*	*3.03*	*0.004**
Speech Language Therapy	*9%*	*36%*	*4.49*	*0.0001**
Counselling	*11%*	*28%*	*3.62*	*0.0001**
Social Work	*16%*	*25%*	*2.32*	*0.024*
Assistive Devices	*22%*	*22%*	-	-
Behaviour Management	*6%*	*22%*	*3.74*	*.0001**
Physical Therapy	*11%*	*14%*	*1.76*	*0.083*
Occupational Therapy	*5%*	*13%*	*2.06*	*0.044*
Psychology	*7%*	*13%*	*1.35*	*0.182*

**p<.01* *Adapted with permission from Minnes & Woodford (2004); Minnes, Woodford, & Passey (2007).*

Other cognitive appraisals associated with positive adaptation in mothers include: 1) a sense of meaning in their experiences as parents of a child with special needs, 2) a sense of mastery and control, 3) an optimistic outlook and trust in others who care (Affleck & Tennen, 1993), 4) focussing on the positive or reframing (Hastings, Allen, McDermott, & Still, 2002), 5) persistence, and 6) information seeking (Nachshen, 1996). Although spirituality or religiosity have received limited attention in the literature, there is some evidence indicating that they also can be a resource. Parents may gain social support from other

members of the spiritual or religious community and spiritual or religious beliefs may contribute to a sense of meaning or empowerment (Speraw, 2006).

The Changing Roles of Aging Parents

Improvements in lifestyles, environments, and health care have led to increased numbers of people with developmental disabilities living into their 50s, 60s and beyond. For many of these people, parents and other family members continue to provide care at home. The burden of care is very often greater at this stage, however, because of aging parents' declining health, strength, and patience, and because of age-related changes in the health, ability, and behaviour of older individuals with developmental disabilities.

The well-being of older parents of adults with developmental disabilities has been studied in relation to stresses associated with both caregiving responsibilities and their own aging (Minnes & Woodford, 2004; Minnes, Woodford, & Passey, 2007; see Table 1). Long-term planning for accommodation for individuals with developmental disabilities is a primary concern of older parents. For example, Minnes & Woodford (2000) found that 83% of parents rated this issue as stressful. One parent explained: *"Our family was on a waiting list for five years and only moved from 87th to 85th place. As older parents, that's just not acceptable or realistic"* (Minnes & Woodford, 2000, p. 39). Accommodation is not the only concern, however. Even parents who have found accommodation for their child express concern about ensuring that the child's ongoing emotional and social support needs will be met: *"It is very difficult to plan for an adult. I am trying to think of what is best for [my son]. Caregivers must consider the unique needs of the individual"* (Minnes & Woodford, 2000, p. 50). Another parent commented: "*Will they have the time to do little things for our son that we do now?...Is there enough time to look after the little...nice things in life...take him for a walk, or to a movie or to town?*" (Minnes & Woodford, 2000, p. 39). Transportation is also a major concern for older parents: *"I have to do it all myself if my son is going to do anything. I spend $400/month on taxis. The only other option is that my son sits at home and does nothing"* (Minnes & Woodford, 2000, p. 52).

Although the older parents in this study rated their life satisfaction as high, they also indicated that they had many unmet service and support needs, particularly in terms of productive activities for their adult children, parent relief services, and residential placements (see Table 2).

Older parents expressed concerns about finding accommodation. They reported dissatisfaction with the range of accommodation options, concerns for their child's feelings about moving away from the family home, and concerns about the adequacy of care. In addition to their concerns, however, parents also made the following recommendations about how to improve their lives (Minnes & Woodford, 2000, p. 68):

1. Assist older parents to plan for alternative accommodation, while providing ongoing emotional and social support for their sons and daughters with developmental disabilities; in addition, assist with wills, trusts, and guardianship with:
   i. more readily available and detailed information about options,
   ii. parent support groups and educational packages to facilitate information exchange,
   iii. more training for lawyers, doctors and health professionals about developmental disabilities, and
   iv. a change in legislation to allow parents to leave their homes to their child without it affecting their disability pensions.
2. Ease concerns of older parents regarding the nature of alternative accommodation through:
   i. development of permanent homes for less than four individuals, and
   ii. improvements to community residences, including more family-like environments (less structure), a better standard of living, and greater continuity of staff and care.
3. Ease the burden of care experienced by parents of adults with developmental disabilities and ease the transition from home to community by providing:

i. more day programs for senior citizens with developmental disabilities, and
ii. more readily available respite care.

4. Ease problems associated with transportation by providing:
   i. funding for specialized transportation for persons with developmental disabilities and/or an allowance to help pay for taxis or to hire someone to accompany their offspring on public transport.

The Roles of Other Family Members

Although the presence of a child with a disability in the family can be particularly challenging for parents, the impact is often felt by other members of the family as well. Parents often face challenges in meeting the needs of the other children in the family (Minnes & Nachshen, 1997). Some families feel that their nondisabled children are forced to grow up too fast. As one parent stated, *"Having a handicapped little brother, at times, has created stress for my daughter and son. He doesn't learn as quickly as a non-handicapped child. Often, he makes messes and gets into mischief. Sometimes the older two are frustrated because we depend on them so much to help us with their little brother. I sometimes feel guilty for robbing them of their childhood."* Other parents feel that their nondisabled children receive less attention than they deserve.

Studies of in-home interactions, activities of older and younger children with developmental disabilities and their nondisabled siblings indicate that the role of siblings is often important (Stoneman, Brody, Davis, Crapps, & Malone, 1991). Relationships between disabled and nondisabled siblings are frequently different in that the responsibility for caregiving and the role of teacher are assumed by siblings, especially sisters. These differences have been found to increase with age and with greater language and adaptive skill deficits in the younger sibling. Similar patterns of role relationships have been found between younger siblings of older children with developmental disabilities where younger siblings commonly assumed roles normally held by the oldest children in the family. In contrast to older siblings of nondisabled children, who tended to assume the dominant role, the younger siblings of disabled children were found to be more involved in teaching and behaviour management. However, contrary to expectation, older siblings with developmental disabilities were also found to adopt teacher and helper roles more frequently than nondisabled older siblings. This behaviour may have been learned through modelling of the younger sibling's helping behaviour (Brody, Stoneman, Davis, & Crapps, 1991).

In adulthood, many nondisabled siblings maintain high levels of contact with their brother or sister with a disability (Seltzer, Greenberg, Orsmond, & Lounds, 2005). On average, siblings make up about one-quarter of the social network of disabled adults (Krauss, Seltzer, & Goodman, 1992). Gender plays a role in sibling involvement, with sisters typically providing more emotional and instrumental support to their disabled siblings than brothers (Orsmond & Seltzer, 2000). Additionally, sisters are more likely to expect future caregiving roles and to expect to co-reside with their disabled sibling when parents are no longer able to provide support (Greenberg, Seltzer, Orsmond, & Krauss, 1999). In a meta-analysis of sibling research, Heller and Keileing Arnold (2010) concluded that, despite mixed results, the psychosocial outcomes for siblings are generally positive.

Many parents of disabled adult children have not completed future planning for their sons and daughters, including making decisions about guardianship, caregiving, and residential needs (Heller & Kramer, 2009). Additionally, parents are often hesitant to involve their nondisabled children in planning for the future of their disabled son or daughter (Heller & Caldwell, 2006). Siblings are most likely to be involved in residential planning and identifying a future caregiver, and they are less often involved in more formal matters, such as establishing powers of attorney and creating letters of intent (Heller & Kramer, 2009).

Despite the expectations of co-residence held by many siblings, longitudinal research shows that most adults with disabilities do not co-reside with their siblings after transitioning out of their parents' homes (Freedman, Krauss, & Seltzer, 1997). However, many siblings still do play an active role

Box 4

Sandra is a 51-year-old woman who lives with her husband and her two teenage sons. She works part-time as a nurse and her husband owns a small business. Sandra's younger brother Gerald has Down syndrome, and he lives with their mother. Their father passed away 3 years ago. Sandra and Gerald's mother is 82 years old, and she is experiencing increased difficulty with living independently and acting as Gerald's caregiver. Sandra recently spoke to her mother about moving to an assisted living facility and finding a home in the community for Gerald; her mother is reluctant to have Gerald live with someone other than a family member. Sandra and Gerald have a good relationship, and they see each other weekly. Sandra is concerned about Gerald's future and she wants to be involved in his life; however, she does not believe that she has the time or resources to become Gerald's full time caregiver. It is possible for Gerald to move into the assisted living facility with their mother; however, Sandra believes that living in a facility designed for seniors would limit Gerald's ability to spend time with friends his own age. Sandra and her mother worked with Gerald's case manager to develop a solution. Through a community agency, they found an associate family for Gerald to live with full time. This will allow Gerald to live in a safe, family environment within the community where he can continue to work at his part-time job and spend time with his friends while still having regular visits with his mother.

in the lives of disabled individuals after the transition out of parental care. Most commonly, siblings are involved in making important life decisions, managing finances, and advocating for services for their disabled sister or brother. In addition, adult siblings may be involved in monitoring service provisions, managing medical care, coordinating social contacts, fulfilling legal roles (e.g., legal guardian), providing primary care, and providing support to others who provide primary care (Bigby, 1997).

While struggling to meet the needs of their nondisabled children, many parents also feel that they have been unable to fully meet the needs of their spouse or partner (Renwick & Brown, 1998). A lack of free time to spend alone together is often given as the main reason for this difficulty. A lack of time may also make it difficult for parents to meet their own needs.

Grandparents are often overlooked as people who sometimes play an important role in families of children with developmental disabilities. In some instances, grandparents can help to relieve some of the burden of parenting borne by their children by acting as extra caregivers for their grandchildren with or without a disability. In other families, however, where parents are unable to care for their children, grandparents become the primary caregivers. As a result, grandparents also may need information and support. Curricula have been developed specifically to help grandparents. Such programs provide up-to-date information on a variety of topics related to developmental disability and help to prevent additional family stress caused by grandparents who may give their children inaccurate or outdated advice about what they should do to help their grandchild (Meyer & Vadasy, 1986).

Meeting the Needs of Families in the 21st Century

The primary role of families continues to be care for their family member with a disability. However, with the shift from institutional to community-based care, caregiving responsibilities have extended across the lifespan. Unfortunately, service provision tends to focus primarily on the needs of the identified person and the needs of family members may be overlooked. Although disability services and supports frequently focus on the needs of parents of young children with disabilities, experience and recent research are now helping us to understand that the needs of families are ongoing and that a variety of services is required for all members of families at different stages of the development of the child with a disability.

Although community-based accommodation and services for persons with developmental disabilities have been the preferred approach for at least

Box 5

Marion and her daughter Sue live in a rural area. Sue has an intellectual disability but has many independent living skills and was a great help when her father was terminally ill. Marion and her husband have run a business in the small town where they live for many years and Marion decided to continue after her husband's death. Sue would like to enroll in a continuing education program at a community college in the city, but there is no public transport available and her mother is not able to take the time for the 90 minute drive. Sue also would like to participate in other activities such as Special Olympics, not offered in her area. Marion contacted the Association for Community Living in the city and they were able to find accommodation for Sue during the week with an associate family. Sue has become more independent since her move to the city. She has learned to use public transport, she enjoys helping her associate family with their young children and has made new friends through her college program and Special Olympics activities.

the past 40 years, and parents now routinely keep their children at home, there is an ongoing need for out-of-home placements. The decision to house a child outside the family home is often an extremely difficult one for parents. Research regarding such decisions indicates that placement decisions depend upon a complex combination of factors, including the availability and use of formal support services as well as parental thoughts and feelings (Bromley & Blacher, 1989). Higher placement rates have been related to the child's level of dependency and maladaptive behaviour, day-to-day stressful events, disruption in family relations, and family mental health problems (Black, Molaison, & Smull, 1990). Parents' feelings of attachment to the child and guilt, as well as the availability of formal support services, helped to delay placement (Bromley & Blacher, 1991). Respite care is often considered to be a factor preventing out-of-home placement, although research by Perry and Black (1997) suggested that use of respite care may indeed reflect a transitional stage between the child living at home and the child being placed in the community.

Respite care and out-of-home placement are critical supports for many older parents. Still, older parents are frequently more reluctant than younger parents to use such services. They often continue to care for their child with a disability for as long as possible due to the interdependence with the child, the sense of purpose derived from caregiving, and concern over the lack of acceptable services (Heller & Factor, 1991). In one study, 40% of younger caregivers were found to use residential services, compared to only 8% of older caregivers (Rinck & Calkins, 1995).

In Ontario, finding appropriate community placements for adult children with developmental disabilities can be extremely difficult for older parents. Research has shown that older parents find long term planning to be very stressful (Minnes & Woodford, 2004; Smith, Majesky, & McClenny, 1996) and long waiting lists add to the problem. As a result, residential placement of adults with developmental disabilities who have lived at home often does not occur until after the death of the parent (Heller, 1995).

Clearly there is a need for a range of respite care and accommodation services to address the needs of families across the lifespan. Furthermore, introducing parents early to the importance of future planning and discussion of options across the lifespan could be very helpful to parents and individuals with developmental disabilities.

Evolving family and professional roles: directions for the future

Turnbull & Turnbull (1986) documented how much the roles of parents have changed since the 1950s. Parents originally were seen as clients, and in many cases as "the problem." In more recent years, parents have taken on the role of educators and advocates, and often the most important sources of care and support. Professionals are also sometimes seen as advocates, but at other times they are viewed as adversarial or obstructionist, not helpful, and not understanding. Accounts in the literature have indicated strong parental dissatisfaction with professionals and services, and point to the need for

professional services to carefully evaluate what they are doing (Baxter, 1989; Brown, 2010).

The development of parent/professional partnerships is an important goal for clinicians, parents, and researchers alike. Recent efforts to adopt more family-centred approaches to service delivery and efforts to evaluate the positive outcomes for families (Trute et al., 2008) are important developments that merit greater attention in research and practice. The quality of life of individuals with developmental disabilities and their families rests in the balance.

Summary

In the past 40 years, the roles of parents and families and the roles of professionals in relation to families have changed within a changing socio-political context. With the move to community-based care, the need for more parent-professional partnerships has become clear. As with coping and adjustment to other unexpected, non-normative events with long-term consequences for families, the adjustment of parents of children with developmental disabilities depends upon a number of factors, including the characteristics of the child, the resources available within and beyond the immediate family, individual perceptions and coping strategies, and the ability to develop and change over time. Research with families indicates that parents do not always feel heard or respected by professionals and caregivers. Moreover, research has provided some important insights into the experiences of family members and the factors that contribute to coping and adjustment. In light of this, the following are a few guidelines to consider when helping families:

1. Recognize transition periods and acknowledge that such times can be stressful for families.
2. Consider and anticipate new and changing roles that may occur at such times.
3. Listen carefully to parents and respect their priorities, which may not be the same as yours.
4. Take an individualized approach that incorporates the specific wishes of the family. Remember to consider the needs of all family members.
5. Be flexible and be prepared to learn.

For Further Thought and Discussion

1. What are your assumptions about the impact of having a person with a disability in the family?
2. How can we as professionals, paid caregivers, or volunteers be more supportive of families?
3. When working with families of children with developmental disabilities:
   a. Are we asking too much of families or too little, given their levels of stress and resources?
   b. Are we giving too much or too little?
   c. Are our suggestions consistent with the family's priorities?
   d. Are our priorities consistent with the family's stage in the life cycle?

More Resources

G. Allen Roeher Institute

http://indie.ca/roeher

The Roeher Institute is a source of research information focussing on factors promoting the equality, participation, and self-determination of people with intellectual and other disabilities with a view to reducing societal barriers that limit the well-being of people with disabilities.

Ontario Association for Community Living

www.communitylivingontario.ca/

The Ontario Association for Community Living mandate includes advocacy and promotion of full inclusion for people who have an intellectual disability in all aspects of community life.

Family Village

http://www.familyvillage.wisc.edu/

Family Village provides web-based information and resources, and communication opportunities for persons with intellectual and other disabilities, for their families, and for service providers.

The Beach Center on Disability

http://www.beachcenter.org/
http://www.lsi.ukans.edu/beach/beachhp.htm

The Beach Center on Disability located on the University of Kansas campus. Their website provides extensive resources for parents, including guides on a wide range of topics such as: parent to parent support, transition into school, care coordination. It

also provides relevant journal articles, research, and policy information.

Children's Disabilities Information
http://www.childrensdisabilities.info
This website provides articles and resources with a view to empowering parents of children with disabilities and special needs.

Association for Birth Defect Children, Inc. (ABDC)
http://www.birthdefects.org
Birth Defect Research for Children, Inc. (BDRC) provides parents with information about birth defects and support services for their children. BDRC has a parent-matching program that helps families of children with birth defects to communicate with similar families. BDRC also sponsors the National Birth Defect Registry, which supports research investigating links between birth defects and exposure to environmental toxins.

Miriam Foundation
http://www.miriamfoundation.ca
The Miram Foundation provides funding in support of rehabilitation, and vocational services and residential accommodation for individuals with intellectual disabilities or Autism Spectrum Disorders. In addition to promoting increased socialization and community integration, the Miriam Foundation, through the Abe Gold Learning & Research Centre, supports research and educational initiatives and publishes and publishes Exceptional Family, a magazine for parents and caregivers of children with disabilities.

Exceptional Parent Magazine & The Family Education Network
http://www.families.com/sr.asp?ch_no=20
This organization focuses on all disabilities.

The Autism Treatment Network – Toronto
http://www.autismspeaks.org/science/programs/atn/
The ATN is a network of treatment and research centres dedicated to improving medical care for children and adolescents with autism.

The Canadian Down Syndrome Society
http://www.cdss.ca
The Canadian Down Syndrome Society provides information and education about Down syndrome to parents, individuals with Down syndrome and families across the lifespan.

Autism Ontario (formerly Autism Society Ontario)
autismontario.com
Autism Ontario provides information and education, supports research, and advocates for programs and services for individuals with autism spectrum disorders and their families and caregivers.

Links to Learning
Linkstolearning.ca
This website was developed by parents to provide resources for parents and families.

Autism Spectrum Disorders Canadian-American Research Consortium
www.autismresearch.ca
ASD-CARC is a multi-disciplinary team of researchers and clinicians working with families in Canada and internationally.

Autism Connects
www.asdcarc.com
Autism Connects provides opportunities for participation in research, updates on resources and events.

Sibling Support Project
http://www.siblingsupport.org/
This website focuses on increasing awareness of the needs and contributions of siblings of individuals with disabilities. It also provides information on developing workshops, listserves, and websites for young and adult siblings.

Association for Children with a Disability
http://www.acd.org.au/siblings/index.htm
This website provides web resources for parents and siblings in Australia.

Chromosome Deletion Outreach (CDO)
http://members.aol.com:80/cdousa/cdo.htm
This organization focuses on chromosome deletions, inversions, and additions.

References

Affleck, G., & Tennen, H. (1993). Cognitive adaptation to adversity: Insights from parents of medically fragile infants. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families and disability* (pp. 135-150). Baltimore: Paul H. Brookes.

Bailey, Jr., D. B., Nelson, L., Hebbeler, K., & Spiker, D. (2007). Modeling the impact of formal and

informal supports for young children with disabilities and their families. *Pediatrics, 120*, e992-e1001.

Baker, B., & Blacher, J., Crnic, K., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three year old children with and without developmental delays. *American Journal on Mental Retardation, 107*, 433-444.

Baxter, C. (1987). Professional services as support: Perceptions of parents. *Australia and New Zealand Journal of Developmental Disabilities, 13*, 243-253.

Baxter, C. (1989). Parent-perceived attitudes of professionals: Implications for service providers. *Disability, Handicap & Society, 4*, 259-269.

Bigby, C. (1997). Parental substitutes? The role of siblings in the lives of older people with intellectual disability. *Journal of Gerontological Social Work, 29*, 3-21.

Blacher, J., & Baker, B. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation, 112*, 330-348.

Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry, 18* (5), 507-513.

Black, M. M., Molaison, V. A., & Smull, M. W. (1990). Families caring for a young adult with mental retardation: Service needs and urgency of community living requests. *American Journal on Mental Retardation, 95*, 32-39.

Brody, G. H., Stoneman, Z., Davis, C. H., & Crapps. J. M. (1991). Observations of the role relations and behavior between older children with mental retardation and their younger siblings. *American Journal on Mental Retardation, 95*, 527–536.

Bromley, B., & Blacher, J. (1991). Parental reasons for out-of-home placement of children with severe handicaps. *Mental Retardation, 29*, 275-280.

Brown, I. (2010). Family quality of life: A comparison of trends in eight countries. In. V. P. Prasher (Ed.), *Comtempory issues in intellectual disabilities* (pp. 255-264). New York: Nova Publishers.

Carter, I. (2009). Positive and negative experiences of parents involved in online self-help groups for Autism. *Journal on Developmental Disabilities, 15*, 44-52.

Clifford, T., & Minnes, P. (2010). *Developing an online support group for parents of children with Autism Spectrum Disorders: Lessons learned.* Poster presented at the Ontario Association on Developmental Disabilities Research Special Interest Group conference. Toronto, March 31, 2010.

Couper, J. (2004). Who should pay for intensive behavioural intervention in autism? A parent's view. *Journal of Paediatric Child Health, 40*, 559–561.

Davies, S., & Hall, D. (2005). Contact a family: Professionals and parents in partnership. *Archives of Diseases in Children, 90*, 1053–1057.

Emerson, E. (2004). Poverty and children with intellectual disabilities in the world's richer countries. *Journal of Intellectual & Developmental Disability, 29*, 319-338.

Emerson, E., Hatton, C., Llewellyn, G., Blacher, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 50, 862-873.

Flynt, S. W., Wood, T. A., & Scott, R. L. (1992). Social support of mothers of children with mental retardation. *American Journal of Mental Retardation, 4*, 233-236.

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. (1986). The dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology, 50*, 992-1003.

Freedman, R., Krauss, M., & Seltzer, M. (1997). Aging parents' residential plans for adults with mental retardation. *Mental Retardation, 35*, 114-135.

Glidden, L. M. (1993). What we do not know about families with children who have developmental disabilities: Questionnaire on Resources and Stress as a case study. *American Journal on Mental Retardation, 97*, 481-495.

Glidden, L. M., Kiphart, M. J., Willoughby, J. C., & Bush, B. A. (1993). Family functioning when rearing children with developmental disabilities. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families and disability* (pp. 183-194). Baltimore: Paul H. Brookes.

Greenberg, J. S., Seltzer, M. M., Orsmond, C. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services, 5*, 1214-1219.

Hall, H., & Minnes, P. (1999). Attitudes toward persons with Down syndrome: The impact of television. *Journal of Developmental and Physical Disabilities, 11*, 61-76.

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 269-275.

Hastings, R. P., & Brown T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107*, 222-232.

Hastings, R., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural interventions for their young child with autism. *Journal of Autism and Developmental Disorders, 31*(3), 327-336.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.

Hastings, R. P., & Taunt H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*, 116-127.

Heller, T. (1995). Aging caregivers of persons with disabilities: Changes in burden and placement desire. In K. A. Roberto (Ed.), *The elderly caregiver: Caring for adults with developmental disabilities* (pp. 21-38). Thousand Oaks, CA: Sage Publications.

Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation, 44*(3), 189-202.

Heller, T., & Factor, A. (1991). Permanency planning for adults with mental retardation living with family caregivers. *American Journal on Mental Retardation, 96*, 163-176.

Heller, T., & Keiling Arnold, C. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*, 16-25.

Heller, T., & Kramer, J. (2009). Involvement of adult siblings of people with developmental disabilities in future planning. *Intellectual and Developmental Disabilities, 47*, 208-219.

Krauss, M. W., Seltzer, M. M., & Goodman, S. J. (1992). Social support networks of adults with retardation who live at home. *American Journal on Mental Retardation, 96*, 432-441.

Lopes, V. (2008). *Factors contributing to the successful transition of preschoolers with and without developmental delay into school.* Unpublished master's thesis, Queen's University, Kingston, ON.

Mandell, D. S., & Salzer, M .S. (2007). Who joins support groups among parents of children with autism? *Autism, 11*, 111-122.

McCubbin, M. A., & McCubbin, H. I. (1996). Resiliency in families: A conceptual model of family adjustment in response to stress and crises. In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (Eds.), *Family assessment: Resiliency, coping and adaptation — Inventories for research and practice* (pp. 1–64). Madison, WI: University of Wisconsin.

Meyer, D., & Vadasy, P. (1986). *Grandparents workshops: How to organize workshops for grandparents of children with handicaps.* Seattle, WA: University of Washington Press.

Minnes, P. (1988a). Family resources and stress associated with a mentally retarded child. *American Journal on Mental Retardation, 93*, 184-192.

Minnes, P. (1988b). Family stress associated with a developmentally handicapped child. In N. Ellis & N. Bray (Eds.), *International review of research in mental retardation, vol. 15* (pp. 195-226). New York: Academic Press.

Minnes, P., Lauckner, H., & Recoskie, K. (2007). Healthcare concerns of parents of individuals with fragile X syndrome: Preliminary results from qualitative analyses. *Journal on Developmental Disabilities, 13*, 119-132.

Minnes, P., McShane, J., Forkes, S., Green, S., Clement, B., & Card, L. (1989). Coping resources of parents of developmentally handicapped chil-

dren living in rural communities. *Australia and New Zealand Journal of Developmental Disabilities, 15*, 109-118.

Minnes, P. M., & Nachshen, J. S. (1997). The Family Stress and Support Questionnaire: Focussing on the needs of parents. *Journal on Developmental Disabilities, 5*, 67-77.

Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of healthcare for their children with Fragile X syndrome, Autism or Down syndrome. *Child Care, Health & Development, 35*(2), 250–256.

Minnes, P., & Woodford, L. (2000). *Well-being of older caregivers of adults with developmental disabilities*. Unpublished report to the Ontario Ministry of Community and Social Services, Developmental Services Branch.

Minnes, P., & Woodford, L. (2004). Well-being in aging parents caring for an adult with a developmental disability. *Journal on Developmental Disabilities, 11*, 47-66.

Minnes, P., Woodford, L., & Passey, J. (2007). Mediators of well-being in aging family caregivers of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disability, 20*, 539-552.

Munro, J. D. (1991). Training families in the "step approach model" for effective advocacy. *Canada's Mental Health, 39*, 1-6.

Nachshen, J. S. (1996). *Parental stress in families of children with developmental disabilities: A pilot study using the Family Stress and Support Questionnaire*. Unpublished B.A. Honours thesis. Department of Psychology, Queen's University at Kingston, Canada.

Nachshen, J. S., Garcin, N., & Minnes, P. (2005). Problem behaviour in children with intellectual disabilities: Parenting stress, empowerment, and school services. *Mental Health Aspects of Developmental Disabilities, 8*, 105-114.

Nachshen, J. S., & Jamieson, J. (2000). Advocacy, stress and quality of life in parents of children with developmental disabilities. *Developmental Disabilities Bulletin, 28*, 39-55.

Nachshen, J. S., & Minnes P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research, 49*, 889-904.

Nelson, D., Howard, V. F., & McLaughlin, T. F. (1993). Empowering parents to become advocates for their own children with disabilities. *B.C. Journal of Special Education, 17*, 62-72.

Orsmond, G. I., & Seltzer, M. (2000). Brothers and sisters with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation, 105*, 486-508.

Perry, A., & Black, A. (1997). A prospective study of out-of-home placement tendency in families of children with autism. *Journal on Developmental Disabilities, 5*, 1-23.

Perry, A., Harris, K., & Minnes, P. (2004). Family environments and family harmony: An exploration across severity, age, and type of developmental disability. *Journal on Developmental Disability, 11*, 15-24.

Phillips, A., Morrison, J., & Davis, R. W. (2004). General practitioners' educational needs in intellectual disability health. *Journal of Intellectual Disability Research, 48*, 142-149.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*(2), 109-124.

Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities, 21*, 34-47.

Renwick, R., & Brown, I. (1998). *The family quality of life project*. Report to Developmental Services Branch, Ontario Ministry of Community and Social Services, Toronto, Ontario.

Rinck, C., & Calkins, C. (1995). Family satisfaction with case management and service provision: Rural and urban perspectives for older families of persons with developmental disabilities. In K. A. Roberto (Ed.), *The elderly caregiver: Caring for adults with developmental disabilities* (pp. 125-145). Thousand Oaks, CA: Sage Publications.

Schneider, J., Wedgwood, N., Llewellyn, G., & McConnell D. (2006). Families challenged by and

accommodating to the adolescent years. *Journal of Intellectual Disability Research, 50*, 926-936.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have cisabilities. *Mental Retardation, 38*, 195-206.

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation, 43*, 354-359.

Shapiro, J., Blacher, J., & Lopez, S. R. (1998). Maternal reactions to children with mental retardation. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 606-636). Cambridge, MA: Cambridge University Press.

Singer,G. H. S.,Marquis,J.,Powers,L. K.,Blanchard, L., Divenere, N., Santelli, B., Ainbinder, J., & Sharp, M.(1999). A multi-site evaluation of parent to parents programs for parents of children with disabilities. *Journal of Early Intervention, 22*, 217-229.

Smith, G. C., Majeski, R. A., & McClenny, B. (1996). Psychoeducational support groups for aging parents: Development and preliminary outcomes. *Mental Retardation, 34*, 172-181.

Solish, A., & Perry, A. (2008). Parents' involvement in their children's behavioural intervention programs: Parent and therapist perspectives, *Research in Autism Spectrum Disorders 2*, 728-738.

Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology, 29*, 113-132.

Sperow, S. (2006), Spiritual experiences of parents and caregivers who have children with disabilities or special needs. *Issues in Mental Health Nursing, 27*, 213–230.

Spina, S., Ziviani, J., & Nixon, J. (2005). Children, brain injury and the resiliency model of family adaptation. *Brain Impairment, 6*, 33–44.

Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M., & Malone, D. M. (1991). Ascribed role relations between children with mental retardation and their younger siblings. *American Journal on Mental Retardation, 95*, 537-550.

Sullivan, W. F., Heng, J., Cameron, D., Lunsky, Y., Cheetham, T., Hennen, B., Bradley, E. A., Berg, J. M., Korossy, M., Forster-Gibson, C., Gitta, M., Stavrakaki, C., McCreary, B., & Swift, I. (2006). Consensus guidelines for primary health care of adults with developmental disabilities. *Canadian Family Physician, 52*, 1410-1418.

Trivette, C. M., & Dunst, C. J. (1992). Characteristics and influences of role division and social support among mothers of preschool children with disabilities. *Topics in Early Childhood Special Education, 12*, 367-385.

Trute, B., Hiebert-Murphy, D., & Wright, A. (2008). Family-centred service coordination in childhood health and disability services: The search for meaningful service outcome measures. *Child: Care, Health and Development, 34*(3), 367-372.

Turnbull, H. R., & Turnbull, A. P. (1985). *Parent speak out: Then and now.* Columbus, OH: C. E. Merrill.

Turnbull, H. R., & Turnbull, A. P. (1986). *Families, professionals and exceptionality: A special partnership*. Columbus, OH: Merrill Publishing.

Webster, R. I., Majnemer, A., Platt, R. W., & Shevell, M. I. (2008). Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *Journal of Child Neurology, 23*(1), 32-38.

Wikler, L. M. (1986). Periodic stresses in families of children with mental retardation. *American Journal of Mental Deficiency, 90*, 703-706.