Chapter 2

The Mental Health Needs of Persons with Developmental Disabilities

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Learning Objectives

Readers will be able to:

1. Have an understanding of the mental health needs of persons with developmental disabilities from a developmental perspective
2. Be able to identify circumstances contributing to mental health disturbances in persons with developmental disabilities
3. Be able to identify circumstances contributing to optimal mental well being
4. Have an appreciation of how some mental health disturbances may be avoided

Introduction

We all have needs which, if met, serve to maintain optimal mental health. The mental health needs of the person with a developmental disability are fundamentally the same as for all other human beings. As humans, we are essentially social creatures; we are constantly seeking, and need shared experiences with others. This validates our own experience and daily reality, and is a necessary requirement in healthy growth, development and mental wellness across the lifespan. The person with a developmental disability may appear to be different from the non-disabled individual, behave differently, and communicate differently; as such, we find it more difficult to appreciate our shared human experience with that person. The difficulty of the non-disabled person in relating to the human experience and emotional expression of the disabled person has been a particular tragedy for persons with developmental disabilities. As a result, they have suffered, and continue to suffer greater disadvantage in many aspects of their lives (including health care) than might otherwise be the case. If we could better understand their perspective, and better understand their unique ways of communicating, whether this be about a physical illness, emotional distress, or some other upset in their daily environment, non-disabled people could respond more appropriately:

Mel relies on non-verbal behaviours to communicate the distressing experiences in his life (see case example 1 for An Introduction to Mel). To better understand his behaviour, it would be prudent to imagine what it is like to attempt to communicate his daily needs, frustrations, and discomforts from the limited vantage point of his world. His history, the nature of his developmental disability, and his medical conditions shed light on this. Without such perspective, we are at risk of seeing his behaviour as needing to be controlled or eliminated rather than as an attempt to communicate his needs to his caregivers.

The Case of Mel

Mel is a 29 year old man diagnosed with visual impairment and autism. Mel is not verbal, and communicates non verbally - which includes some gestures and a few signs. Mel lives in a group home, and while he has been assigned a day program, he is rarely able to attend. He has had the same support staff for many years, and maintains contact with his family. When he is doing well, he is generally pleasant, calm, affectionate and will participate in activities. However, if distressed he may scream, self-injure, strike out at others or cause destruction in his environment.

Mel has a history of many medical problems. Shortly after his birth, there was concern about his vision. Optic nerve damage was diagnosed; Mel now has no vision. He was reported very early to have indicators of autism, including stereotypies and unusual sensory behaviours, as well as communication and social impairments. Reports indicate that his sleep cycle has always been disturbed. He has a long history of rubbing his eyes aggressively, causing trauma to the surrounding tissue. He has many environmental allergies, and has been subject to frequent ear infections. He has also had grand mal seizures. Mel has been prescribed many oral and topical medications over the years for his various medical problems. Mel's history of self-injury, allergic reactions, and associated discomfort, seizures, and symptoms believed associated with an autistic disorder, and attempts to treat these have culminated in a cycle of distress. Those supporting Mel now feel it is beyond their resources to manage him. His *cycle begins with signs of allergic reaction after which Mel scratches or rubs the irritated area intensely, causing bleeding and bruising. During these periods, he will also bang his head with objects, or strike his head against walls.* **.** *Sedation and topical treatments are given at this time. The sedation is to calm him, while the ointments provide local relief and assist the healing process. Sometimes severe, self-injurious behaviour occurs before the sedation/topical treatments have been effective. Further, after healing has occurred, when medications are withdrawn, he has been known to have violent reactions which some have questioned may be withdrawal seizures.*

Development across the life span

All of us are born with a potential for further growth and further development. Fully realized, this potential is associated with the extent to which environments are nurturing and supportive, and offer opportunities and challenges to which we can comfortably respond. Persons with developmental disabilities may have suffered brain damage (see biological contributions to developmental disabilities under mental health vulnerabilities) may have been exposed to environments in their early lives which have been insufficiently nurturing or lacking in opportunities (see environmental and socioeconomic contributions to developmental disabilities). These early circumstances can limit the individual's potential, and delay and / or distort normal developmental pathways. However, we are now also aware that, regardless of the individual's unique potential, society's response to the person with a disability has a profound impact on the extent to which the person is disabled as an adult. See Box 1 for definitions and further understanding of impairments, disabilities and handicaps.

Box 1. Prevention of further disabilities and handicaps

In the context of health experience the World Health Organization (1980) has defined **impairment**, **disability** and **handicap** as:

impairment:	any loss or abnormality of psychological, physiological, or anatomical structure or function
disability:	any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being
handicap:	a disadvantage for a given individual resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual

An example of a **hearing impairment** would be loss of hearing, resulting from damage to the inner ear from infection. Many aspects of our daily existence have developed around the capacity to hear (e.g. communication - speech; entertainment - music; danger sign - sirens). Persons without hearing are not able to listen (they then suffer a **hearing disability**), and are thus excluded from activities that rely entirely on being able to hear (giving rise to a **hearing handicap**). If our social world was organized around vision (e.g. communication - signing, entertainment - visual, danger sign - flashing light) the hearing impaired person would not be disabled or handicapped in this visual world. If the hearing impaired person is provided hearing aid he or she may no longer have a hearing disability.

Impairments ➔ Disabilities ➔ Handicaps

In working with persons with developmental disabilities, the goal is to prevent and/ or minimize the impairments, disabilities, and handicaps.

For example, **hearing impairment** can be eliminated or reduced by identifying persons at risk, screening vulnerable groups, providing early intervention and treatment with antibiotics for ear infections. **Hearing disability** can be reduced by screening for hearing impairments, and providing hearing aids and augmentative communication aids. **Hearing handicap** can be reduced by adapting the external environment, and the social behaviour of hearing carers, to meet needs of the hearing impaired individual.

Developmental patterns and pathways across the lifespan

We are now beginning to understand some of the particular challenges that certain syndromes such as Down, Prader Willi, and fragile x syndrome present to the individual at different stages of life. This information is helpful in planning optimal educational opportunities, and in helping to avoid secondary disabilities and handicaps, and further damaging experiences. However, this research is relatively recent, and much still needs to be understood. In the meanwhile, it seems reasonable to consider that the person with a developmental disability passes through similar developmental stages as the person without such disabilities, even though this may be at a slower pace, and he/she may not reach the same end point.

There are two major areas in human development where an understanding of the usual sequence of events across the lifespan is particularly helpful in trying to provide optimal and appropriate supports for the person with a developmental disability.

(a) Cognitive development

Piaget (1896 - 1980), a Swiss biologist, has helped us understand normal cognitive development. He described four different types of thinking (cognitive structures), occurring at different stages of development: birth - 2 years; 2 - 7 years; 7 - 12 years; 12 years to adulthood. Humans pass through different thinking stages, each influencing the way the individual perceives and interacts with the world around him or her (See Box 2). An analogy might be made to the way some creatures such as amphibians pass though different stages requiring different supportive environments (e.g., tadpole with gills and limbs requiring aquatic environment; adult frog with lungs requiring air).

(b) Psychosocial and emotional development

Erikson (1902 - 1994), an American psychoanalyst and scholar with interests in cultural anthropology, child development, social psychology and the study of man in history, has helped us understand patterns of emotional experience across the life span. He described 8 stages of psychosocial development from birth to old age. In these stages, issues in the development of trust, independence, initiative, self esteem, identity, intimacy, isolation, despair and success are encountered, and may or may not be successfully resolved (see Box 2).

Both Piaget and Erikson have rooted their developmental stages relative to the chronological age of normally developing individuals. Of course, there will be some variation between individuals both in the tasks that are achieved by a certain age, and the sequence by which these tasks are achieved. But for the most part, most individuals will, by a certain age, have achieved success in the age related tasks appropriate for that age, and will have achieved success in all previous age related tasks. A person with a developmental disability lags behind his/her non disabled age peers in many aspects of mental development. While both are the same chronological age, the

Box 2. Developmental Stages of Piaget and Erikson

(adapted from Papalia, Olds, & Feldman, 1989)

Psychosocial Development (Erikson)

Basic Trust vs. Mistrust
(Birth - 12-18 mon.) Learns whether his (her) world is a place where he/she can trust others

Autonomy vs. Shame/Doubt
(1-3 yr.) Develops some independence from caretaker or experiences shame/self-doubt

Initiative vs. Guilt (3-6 yr.) Develops initiative through new experiences or feels failure

Industry vs. Inferiority (6 yr. - Puberty) Learns skills of culture or feels inferior to others

Identity vs. Role Confusion (Puberty - Yg. Adult) Develops self-identify or experiences confused sense of self

Intimacy vs. Isolation
(Yg. Adult) Develops relationships or feels isolated.

Generativity vs. Stagnation (Adult) Guides/supports the next generation

Integrity vs. Despair (Old Age) Accepts one's life and accomplishments or feels dissatisfied/despair.

Cognitive Development (Piaget)

Sensorimotor (Birth - 2yr.) Infant changes from primarily reflexive responses to learning about environment through senses and motor actions.

Preoperational (2-7 yr.) Develops a representational system: e.g. words, gestures.

Concrete operations (7-12 yr.) Logical problem solving on here/now issues.

Formal operations (12 yr. - adult) Thinking in abstract terms and being able to hypothesize.

person with a developmental disability is functioning at previous developmental stages. Cognitively, the person with a developmental disability may not progress through all types of thinking. However, socially and emotionally, he/she will confront the same issues. His/her cognitive limitations may in part inhibit resolution of these issues. It is important that caregivers recognize the developmental stages their client/relative has reached across the various domains of mental and emotional development. A clearer understanding of the client's actual level of functioning, and the meaning of his/her life experiences can guide the carer in assisting the client to gain more mastery in life skills within his/her ability, and to develop a belief in his/her own competence. These latter experiences will, for the client, dispel the disquieting fear/anxiety of not being adequate.

How can an understanding of cognitive and emotional development help us to respond more optimally to Mel and provide him with more appropriate supports?

Mel has severe/profound developmental disability (as defined by APA, 1994). In addition, he has visual impairment or mental retardation, and has a diagnosis of autism. These three circumstances will impact on his ability to function, and will combine to limit his ability to be aware of, and to process information about his environment. Applying Piaget's understanding, he is functioning in the Early Pre-operational stage (see Box 2), with some behaviours still in evidence from the Sensorimotor stage.

Mel is able to understand and respond to verbal information/requests from others. He has been able to learn some sign language which he uses to make his needs known. These are indicators of a representational system, and are skills indicative of having reached the Pre-operational stage in some cognitive areas. He shows an understanding of concepts that would have developed in the Sensorimotor stage: he can lead people to places to show what he wants, such as to the kitchen to get cookies (an indication of "object permanence"). He knows how some items in the house function/turn on and off (an indicator of "operational causality"). However, Mel still responds with many reflexive responses (e.g., oversensitivity to sounds/ touch), and engages in sensory-based activities (e.g., rocking or self injury in response to discomfort), at a level one would expect of someone still in the Sensorimotor stage.

Emotionally, Mel is in Erikson's second stage: Autonomy vs Shame and Doubt. He has developed some sense of the social world, and enjoys interactions with others. He does initiate in a limited way his own actions, such as going to lie down during the day, requesting food, or requesting an outing. However, he is still dependent on others for his basic needs, and often others are unable to respect or follow through with choices he makes for himself. He is not at the point of initiating new, unlearned acts.

The Case of Sam

Sam is a man in his thirties who has a mild developmental disability. His parents are high achieving professionals as are his older brother and sister. The family's lifestyle has allowed Sam to have many opportunities to which other persons with a developmental disability may not have had access. He has traveled extensively, enjoys recreational activities such as skiing, horseback riding, going to concerts and theaters. He is currently living in an apartment with a roommate and receives support from an agency staff. He attends a sheltered workshop part time, and programs offering training in daily living skills and recreational opportunities part time. He has a special female friend, but has no close male friends. His primary support, both for his needs and his socialization, continues to be *family. Sam takes medication because he hears voices and reacts overtly to them. These are not believed to be due to a psychotic disorder, but due to anxiety based in developmental experiences as outlined below.*

Sam developed speech late, and was not talking when he started school. He was teased by classmates who called him "retard". Sam's family arranged activities for him, and tried to ensure he had stimulation and social interaction. Sam reports that many adults were also rude to him during his childhood. The most difficult period for him seemed to be adolescence when same-aged classmates were going to parties and on dates, and he was excluded. His older brother and sister were socially active, and this reinforced for Sam that he was different. Sam has vivid memories of a party his brother had, and when his brother was not in the room, the teenagers there taunted Sam and made rude comments to him.

Sam was an overachiever in school, having a good memory and being able to read beyond most of his peers with a comparable delay. His family encouraged him. Sam, striving not to be handicapped, seems to have pushed himself beyond his limits. He was accepted into an early childhood education program at a community college, and during that year had a "breakdown". He began to present as depressed, engaged in self-talk, and reported hearing voices. Usually, the voices told him he was "stupid" or "no good". The family wanted him diagnosed with a label and prescribed a cure. Those professionals supporting Sam, however, believed that he had pushed himself past his limits, and had recognized he could not achieve what he had been attempting. He was responding to voices from the past that had told him he was stupid and no good. He experienced high anxiety, and his self esteem was very low during this period. He has been treated with medication and individual therapy for about three years. Sam goes through long periods where he *appears to experience few distressing symptoms. He goes through other periods where the voices become stronger. He responds overtly to them, and he has difficulty continuing his daily activities. There appear to be some events that trigger the anxiety and voices including: school beginning in the fall; visits from his siblings; parties/social events with unfamiliar people.*

Sam's early experiences, including labeling, name calling and other negative social feedback seem to have had a profound and damaging influence on him, even though he has had a supportive family and many opportunities which other persons in his situation do not have. The memories which are triggered present much like a flashback does to people who have been traumatized. Many individuals we have worked with who have had negative social experiences, do have intrusive memories that have an impact on their vocational, social and daily lives. They are misunderstood by their friends, professionals and their caregivers.

Sam functions in the mild range of developmental disability (or mental retardation as defined by APA, 1994). Applying Piaget's understanding, he is functioning at the Concrete Operations stage.

Sam can read, write, do basic arithmetic, care for his daily hygiene, do some household chores/cooking, hold a job, take public transportation, and can solve basic problems if they are focused on the here and now (i.e., are concrete). He dates, shops with friends and attends social activities. Sam may not always be able to project into the future, so may not weigh the consequences of an action before he engages in it. Issues which are complex, such as legal and medical decisions with potential problems and implications require explanation.

Emotionally, Sam is in Erikson's sixth stage: Intimacy vs Isolation. He has not achieved resolution of all the issues at this stage. Many of his relationships have been arranged by family/care providers. These relationships come to a natural end, which leaves him feeling loss and rejection. Those which are naturally occurring relationships, such as that with his girlfriend, are few. Although he has reached this stage, he has not achieved full resolution of issues at previous stages – i.e., the fourth, Industry vs Inferiority. He is aware he is different from his family members, and can never achieve what they do, and he feels inferior because of this. As well, issues from Erikson's fifth state (Identity vs. Role Confusion) carry forward: his awareness of being different from others, his attempts to figure out where he fits, and his attempts to come to terms with himself and accept his own limitations.

What needs to be in place to help Mel and Sam reach their potential?

For Mel and Sam to reach their potential, those supporting them must understand the developmental stages and have awareness of where Mel and Sam are along that developmental path. Mel and Sam must be encouraged to take the next developmental steps without making huge leaps that place unrealistic expectations on them. For example, for Mel, it may be important to have more material/activities available, and to teach him how they are used so he can engage in independent activity. It may also mean providing him with a better communication system with which to express himself. For Sam, it may mean counseling to help him come to terms with his limitations, and to help him in recognizing the strengths he has, and the positive relationships he has been able to develop on his own. Identifying what is at the next developmental step, providing opportunities to learn tasks at that step, and providing reinforcement for success and encouragement when success is not quite achieved, will be most helpful in moving them toward their potential. Care-providers must also understand that there will eventually be limits to what each individual can achieve, and they should respect that rather than push the individual past that point.

Mental health: Vulnerability

We are now beginning to understand some of the factors that may leave some of us more **vulnerable** to mental health disturbances and psychiatric disorders. For example (1) loss of a primary caregiver (usually the mother) before the age of eleven may result in an increased risk for developing depression as an adult; (2) having a family history of anxiety or mood disorders may provide an increased risk for developing such disorders.

However, we are also beginning to understand what factors help to protect us from developing such disturbances. The same individual at risk for depression may develop **resilience** to depression by developing a supportive social network, by having a close relationship and satisfying partnerships with a spouse. Likewise, the individual with a genetic vulnerability to psychiatric disorder may become more resilient to the onset or impact of such disorder by identifying environmental stressors, becoming sensitive to the early development of symptoms, and being able to access preventive interventions as required, such as lifestyle changes, counseling, psychotherapy and medication.

There are many additional circumstances which predispose persons with developmental disabilities to mental health disturbances; this predisposition also leaves them more vulnerable to the negative impact of normal life events. In addition, having a developmental disability predisposes the person to more negative life experiences and traumas; for example, persons with developmental disabilities are at greater risk than peers without such disabilities for physical and sexual abuses.

The biological, psychological and social circumstances that contribute vulnerability to mental health disturbances in persons with developmental disabilities are described below (see Box 3).

Box 3. Vulnerabilities - Check List

Circumstances causing or contributing to mental health and behavioural disturbances in persons with developmental disabilities:

Biological
Brain Damage; Dementia; Epilepsy; Sensory (e.g., vision, hearing) impairments; Sensory (e.g., visual , auditory) processing problems; Physical illnesses other medical treatments

Psychological
Distorted personality development; Separations / losses; Deprivation / abuse / trauma; Other life events; Positive / negative learning experiences; Self-insight / self-esteem; Communication difficulties; Language disorders; Psychological impact of the above biological factors on the individual

Social
Attitudes - negative social feedback; Labeling; Rejection; Infantilization; Victimization; Unrealistic expectations; Few / limited repertoire of coping strategies;
Inadequate supports / relationships; Inappropriate environments / services; Under-/ overstimulation; Valued / stigmatized roles; Financial / legal disadvantage

Family
Diagnostic and bereavement issues; Life cycle transitions / crises; "Letting go"; Psychiatric and emotional disorders in immediate family members;
Stress / adaption to disabilities; Relationships / resources (financial, emotional, supports)

(a) Biological

In persons without developmental disabilities, brain damage, epilepsy and dementia are all associated with an increased prevalence of behavioural disturbance and/or psychiatric disorder. As a group, persons with developmental disabilities have an increased prevalence of brain damage and seizure disorders. At least 25% of all cases of mental retardation are known to be caused by biological abnormalities which affect the brain (and often other body systems). Seizure disorders are increased proportionately as the level of cognitive disability becomes more severe (one in two individuals with profound developmental disability may have a seizure disorder). Dementia appears to be more prevalent in some conditions associated with developmental disability (e.g., most persons with Down Syndrome over the age of forty show the neuropathological changes of Alzheimer's dementia, and some go on to develop the disease at an earlier age than the population without developmental disability).

Some syndromes associated with developmental disability appear to be associated with an increased risk for certain psychiatric disorders (e.g., mood and anxiety disorders in persons with Autism and Down Syndrome). Some syndromes run in families (e.g., fragile x). In the general population, there is a genetic predisposition to certain psychiatric disorders (e.g., some mood and anxiety disorders are more prevalent in some families). A person with a developmental disability with a family history of psychiatric disorder may also, therefore, be at increased risk for such disorder.

As a group, there is a greater prevalence of physical illnesses, such as ear, nose, mouth problems, congenital heart disease and gastrointestinal disorders, physical disabilities such as Cerebral Palsy and sensory impairments and unusual physical appearance. Any illness, physical disability or unusual appearance usually has associated psychological consequences for the individual as he/she comes to terms with the loss or absence of a fully functioning sense of self. The addition of these problems, and others' reactions to these problems, may add to the negative self image and low self esteem experienced by many persons with developmental disabilities.

Persons with developmental disabilities as a group are less able to share their inner experiences and describe their experience of pain and bodily discomforts. As such, they are at greater risk for medical misdiagnoses (e.g., misattributing oesophageal reflux induced sleep disturbance to the behaviour of someone with a developmental disability, otherwise referred to as “diagnostic overshadowing”), and negative outcomes from therapeutic interventions (e.g., side effects from medications). These latter "iatrogenic" biological factors can also contribute to mental health and behavioural disturbances.

It is very important to identify an individual's biological vulnerabilities. It offers the opportunity to design and implement interventions that will serve to increase resilience associated with these vulnerabilities. For example, in recent years, there has been an explosion of knowledge in understanding certain syndromes associated with developmental disability, such as Down, Prader Willi, fragile x, and 22 Deletion Syndromes. Proactive health guidelines are now available for many of these syndromes.

(b) Psychological

All of us express our temperament early in infancy. That is, we will have differences in activity level, mood and how we adapt to changes in the environment. Throughout the developmental period, temperament will influence how people respond to us and how we respond to others. The experiences we have in our social environment, influenced by our temperament, are said to result in our own unique personality. Our personality is made up of characteristics others see in us such as introversion/extroversion, and which allow others and ourselves to anticipate how we will act in a certain situation. For example, the introvert is shy and withdrawn, and tends to focus on his internal world; the extrovert is comfortable in social situations, and seeks out others.

When a person has a developmental disability, his/her personality will develop in that same manner as it does for the rest of us. However, there are often some differences in the developmental experiences of persons with developmental disabilities. These atypical experiences during development have allowed researchers to predict how this will affect the personality of the person with a developmental disability. For example, a person with a developmental disability is often excluded from activities (e.g., minor sports, teenage parties). He/she may have to endure stigmatizing perceptions and negative social reactions and comments. He/she often begins early in childhood by requiring more assistance than others would in physical, communication and learning areas. People may become accustomed to helping him/her, and he/she may become accustomed to being helped, so that the experience of managing with less assistance is not developed. Personality characteristics often seen in persons with developmental disabilities include over-dependence, lack of confidence, poor self-identity, or low self-esteem. These characteristics may also decrease the person's development of good ways to cope with psychological, social and biological experiences the person may encounter, and may increase his/her vulnerability for psychological/emotional difficulties. When the person with a developmental disability encounters life events such as separation/loss, personal or family milestones, or experiences requiring learning and/or insight, illness of self or others, or extreme events such as deprivation, abuse or trauma, the individual may have poor coping strategies, and may be more vulnerable to a range of mood and anxiety disorders.

(c) Social

Individuals with developmental disabilities are often socially isolated or have social networks that are made up of primarily family members and "artificial" friendships. While some people with developmental disabilities may have more normal friendships or play relationships early in childhood, their differences separate them from same-age others as they reach adolescence and on into adulthood. Usually persons with developmental disabilities are not included in the activities of their classmates, and are in fact, often overtly shunned. Family tends to arrange social activities for them. This may include bowling or swimming for persons with disabilities, special needs workers or volunteers to take the person out and to assist in teaching social and adaptive skills. Other social engagements tend to be with family or with the friends of the parents. When the person with a developmental disability reaches an age where he/she may leave home, usually an agency or family decides where the person will live, and who he/she will live with. If the person doesn't get along with roommates, he/she is often identified as having behavioral problems. He/she may have few, if any, naturally developing relationships; and thus start to identify staff as friends. This can be problematic because staff leave and the individual may feel repeatedly rejected.

The individual with a developmental disability is easily victimized. He or she may have poorly developed social boundaries because of a lack of experience in social situations, may be easily intimidated or coerced because (s)he's been taught to comply, and may appreciate attention paid, even if its inappropriate attention. Therefore, the person with a developmental disability is prone to be exploited sexually, financially and in many other ways.

If an individual has been encouraged and given the opportunity to develop a good social network, has had access to realistic role models, and has been taught to value him/herself, he/she will feel included and achieve some degree of social success/

happiness. However, if the individual has not achieved a positive social network, and has poor self-identify/low self-esteem, the individual may strive to belong or be accepted without always having appropriate or realistic role models from whom to base expectations of him/herself. Television and movies portray beautiful and successful people, and put high value on relationships. The person with a developmental disability who has poor self-perception or low self-esteem may have a life that, by comparison to successful siblings or TV soap stars, may feel unhappy and unsuccessful. He or she may express anxiety behaviours, changes in mood or other behavioral disturbances, including those which may be misinterpreted as psychosis, such as an active fantasy life or self-talk.

In what way might Mel (Case Example 1) or Sam (Case Example 2) be vulnerable to mental health disturbances?

Mel is unable to communicate his needs apart from a few non specific gestures and a few learned signs. This leaves him unable to communicate pain (resulting in medical conditions and bodily discomforts remaining unrecognized), anger, frustration, happiness, and many of his feelings outside of behaviours which reflect or express these in some way. Mel is dependent on others to identify the causes of his upset behaviours. He is dependent on others to take him places, and to provide his basic needs. This means he must place a great deal of trust in people. Because he cannot communicate things that frighten him, or relate experiences of his past that may have been terrible for him, those care providers may inadvertently put him in a situation which is daunting to him. This inability to express his experiences of pain and bodily discomforts, his needs and feelings, the need to trust when venturing into the unknown, and the possible occurrence of being retraumatized without others knowing, make Mel vulnerable to mental health disturbances.

Sam has many skills and abilities. However, he is aware he is never going to be able to accomplish the same things as those to whom he is closest. Therefore, he is in a constant state of feeling different/inferior. As Sam grew up, others pointed out his differences, and said things to him which he has held in his memory and has not resolved, often because it reflected what he found was true – he **was** different. Sam has limited ability to problem solve, or project into the future. Therefore, he feels stuck in a situation that he finds difficult, and he has no way to plan how to change that. His feeling of inferiority, which has been reinforced by events in his life, and his inability to find a positive path for himself, makes him vulnerable to mental health problems. His difficulty in communicating his inner experiences to his doctor adds to difficulties in the treatment of his depression.

Resilience and Optimal Supports

As caregivers, we can help our clients become more resilient to the vulnerabilities previously discussed Resilience is a characteristic in some individuals which is protective, or which lessens the negative impact of stressors for them. Resilience is thought to be an aspect of the personality, and some features of a person's environment may increase a person's resilience. These include:

- early emotional support from one's family of origin
- few risk factors in one's environment (examples of such risk factors would be exposure to financial distress, disruption in the family structure, abusive relationships)

- encouragement to learn independent problem solving
- supportive environments outside of the home
- development of positive self image.

If we think of persons who have developmental disabilities, as individuals who have experienced negative social feedback, have poor self-images, or have not been able to cope with experiences without mediation, then we would assume that these individuals will enter adulthood without much resilience. Considered in other terms, they have less protection against the negative impact of stressors, and are therefore more vulnerable to mental health problems.

An individual's protection against life stressors can be increased by developing optimal supports. These supports would aim to increase competence, and increase self-esteem and better regulation of mood. Optimal supports would also decrease an individual's anxiety by decreasing stressful circumstances in the person's life, and by providing support to develop positive ways to cope with unavoidable stressors (See Box 4).

Emotional, psychiatric and behavioral disorders (dual diagnosis)

People who have developmental disabilities can have any of the same physical, psychiatric or emotional difficulties as any other person. However, because of the experiences described earlier, they are more likely to develop emotional or mental health problems. Often, these disturbances are first recognized by others because of changes in the person's behaviour. It is important to remember that a behaviour is not an isolated event - it results from one or a combination of developmental, social, family, medical, psychological/emotional, or environmental circumstances that impact on the individual. When a behaviour occurs, it is communicating something about the person, either in terms of something that has happened to him/her, something he/she needs or wants, or some internal experience such as feelings or bodily discomfort. Individuals who have developmental disabilities often have difficulty sharing verbally such experiences and for some individuals, a change in non verbal behaviour is the **only** way they can communicate to others that something is amiss. For individuals without developmental disabilities, bizarre or unusual behaviour is often the first indication that a psychiatric disorder is present. Health care personnel unfamiliar in working with persons with developmental disabilities, and in particular, unfamiliar with their ways of communicating distress or their emotional responses, may automatically conclude that such changes in behaviour reflect an underlying psychiatric disorder, and frequently antipsychotic medication is prescribed. The opportunity to conduct a full functional analysis as to what the behaviour change may truly be communicating is lost, and because of the sedative and other side effects of the medication, individuals are often left less able to effectively communicate what may be causing their distress. Under these circumstances, behaviour often escalates. At this point, the medication may be increased or further medication added without a clear understanding of what is being treated; the individuals are effectively "gagged", and doomed to continue suffering in silence. In any psychiatric evaluation of someone with a developmental disability, the primary goal is to understand what any change in verbal or non verbal behaviour is communicating for that individual. This requires a comprehensive assessment by health care staff experienced in working with individuals across the spectrum of disability from mild to profound developmental disability (or

Box 4. Resilience and Optimal Supports Check List

The onset of anxiety and mood disorders for example, in persons with developmental disabilities, can be prevented and /or their impact minimized by:

Decreasing Stress in the environment and Helping the Individual feel more Competent:

- Increase opportunities for success in work / leisure
- Increase opportunities for satisfying social/ life experiences
- Ensure ability to communicate and make choices
- Offer medical intervention / therapy when appropriate
- Offer information / education on how to cope with frustration, issues of sexuality, loss
- Redefine person / situation to allow for new approaches (i.e., externalize the problem so the person does not see it as part of himself)
- Encourage expression of and validation of emotions
- Assist individual in developing supportive social networks
- Ensure social and other supports sufficient to meet individual's health and emotional needs

Attention to the above contributes to:

- Increased emotional and social supports available to client

And client experiences:

- Increased coping skills
- Increased self esteem
- Fewer stressful life events
- Decreased anxiety
- Greater ability to regulate mood

mental retardation as defined by APA, 1994) (see Box 5).

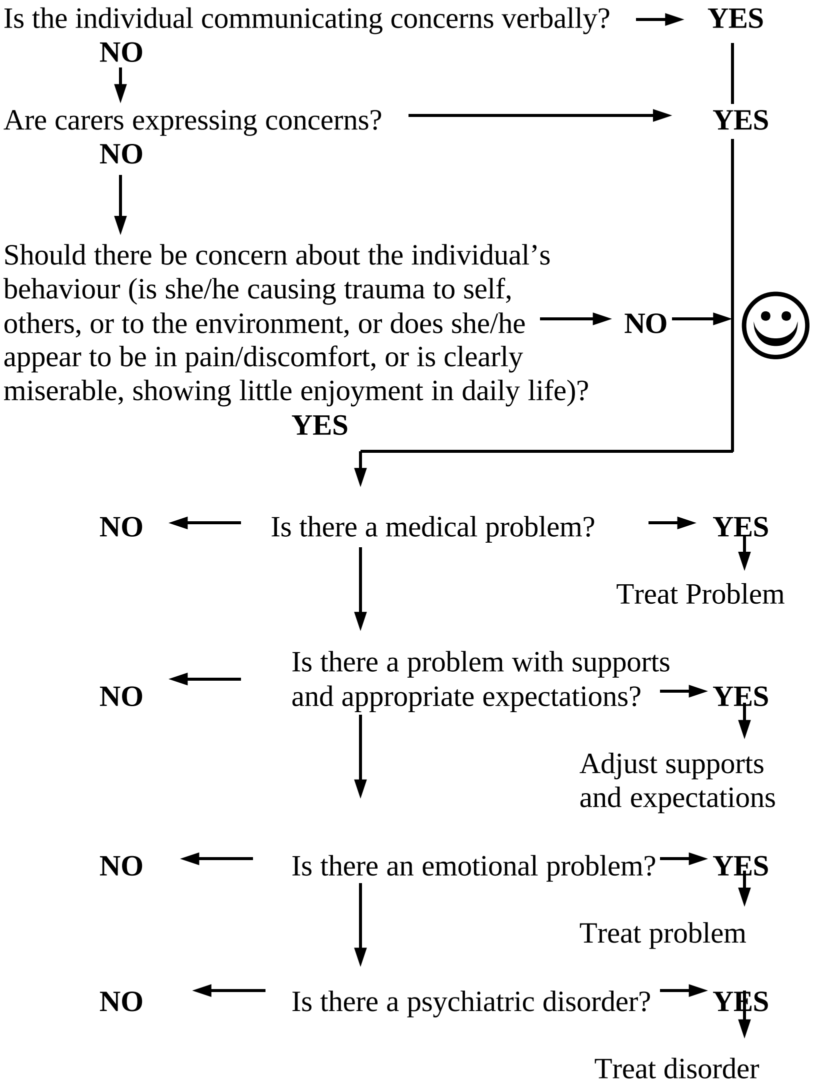
The Impact of Systems on Mental Health, Vulnerability, Resilience and Optimal Supports

Persons with developmental disabilities and their carers live within larger systems that can impact positively or negatively on mental well-being. In many industrialized countries such as North America and Europe, people with developmental disabilities used to be admitted to institutions when they were very young, and essentially lived lives separated from same-age peers without such disabilities. In the 1960s, there were increasing concerns being expressed about the negative physical and social conditions in these institutions. Subsequently, in the 1970s and 1980s, many families, activists and politicians began taking action to keep those with developmental disabilities with their families, or in their communities and to move those in institutions back to their home communities. Below we describe support systems currently in place in Ontario.

(a) Community supports

In Ontario, the Ministry of Community and Social Services is the branch of government that funds institutions, agencies with vocational and residential opportunities for persons with developmental disabilities, assessment and treatment centres which offer services to those with developmental disabilities, and pensions for person with disabilities who cannot work, or who form of independent income. Originally, funds were transferred from the Ministry to agencies to plan and provide residential (group home/supported independent living) situations and vocational opportunities (life skill training workshops have no other supported employment) for individuals. We are now in a transition period where, while this model is still in

Box 5. Mental Health Assessment- Decision Tree



(Bradley & Summers, 1999) Reprinted with permission from *Developmental Disabilities in Ontario*, p. 414, Toronto, Canada: Front Porch.

effect, new resources are not being put into this model.

Instead, families are meeting with agencies to develop a plan for their adult son or daughter who has a developmental disability, and families are more active in determining what services are needed, as well as finding such services. More individuals with developmental disabilities are living in independent settings, and are expected to find competitive employment. At one time, people who had developmental disabilities could receive a disability pension through the province. It has been our clinical experience that recent changes in the system have made it more difficult for the persons with developmental disabilities to get such financial support. These same individuals may not have families who can support them, may not be able to find competitive employment (or do the work without support even if they did find it). Assistance may also be needed to apply for financial support if the individual cannot work. Again individuals with developmental disabilities may not have access to or know how to access this type of assistance. We have worked with individuals with developmental disabilities, who often have mental health problems, who live on the street, who frequent shelters, or who live in poorly maintained lodging homes. These individuals are destined to poverty, social isolation, poor physical and mental health support, and are vulnerable to a high degree of risk of violence in their daily lives.

(b) Access to medical and psychiatric care

About thirty years ago in Ontario, plans were drawn up to discharge persons with developmental disabilities from institutions, and to support all persons with developmental disabilities in community settings. It was assumed that such persons would access health care in the same manner as persons without such disabilities. In principle, persons with developmental disabilities continue to have *equal* access to health care (equal rights for all Canadians are protected under the Canadian Charter of Rights and Freedoms). However, many studies have now substantiated that persons with developmental disabilities do not have *equity* of access to health care (Beange, 1996; Gelinas & Ross-Greenside, 1993; Gitta, 1993; Turner & Moss, 1996). In other words, often, they do not receive either the same level or the same quality of health care enjoyed by non disabled persons. As a consequence, even some basic health needs remain unmet. The reasons for these unmet needs include:

- persons with developmental disabilities are not "typical" patients. They are often unable to communicate their concerns verbally, and health care personnel are not trained to understand their atypical ways of communicating pain and discomfort. Misdiagnoses, and consequently inappropriate interventions and treatments are common.
- health care personnel often have negative stereotypes of persons with disabilities which interfere with the services they may be able to provide.
- in the health care arena there is a general lack of knowledge and recognition of specific health vulnerabilities associated with developmental disabilities.
- persons with developmental disabilities often take longer to assess and treat; for example, it is necessary to meet with families and caregivers, review medical records and past assessments, consult with other colleagues involved in the client's care, as well as to provide direct clinical care to the client. Generic services are rarely resourced to provide the time necessary for all these activities.

- routine tests and procedures often need to be adapted if they are to be accessed by the person with a developmental disability.
- preventative information is not offered in a format which is easily accessed/understood by those who have a developmental disability.

As a consequence of these barriers, persons with developmental disabilities often receive poor and inadequate health care. The same picture prevails for psychiatric care. Frequently, we encounter clinical situations where the psychiatric crises and distress suffered by the client has been made worse by system deficits as outlined above. See the MATCH Project (1996) for further consideration of these concerns.

Evidence indicates that the model of "access to generic health care" for persons with developmental disabilities is not sufficient on its own to meet their health needs, particularly in the absence of training in developmental disabilities of health care personnel in these generic settings. See Aspray, Frances, Tyrera, and Quilliam, 1999 for recent editorial.

The Needs of Families and Caregivers

It has been pointed out that when a child is born with an obvious disability, the typical celebration and congratulations at birth are restrained or non-existent. Parents may blame themselves for contributing to the disability, even if the cause is unknown or outside of their control. If a disability becomes apparent later in childhood, families often “shop” for new assessments and answers to determine what went wrong. Interventions begin early to try to “correct” the problem to whatever extent is possible. Therefore, the child, from the time of the first recognition of his disability, is thought of with some sense of not being fully able and needing help. As families seek help and interventions, the child and the family will have the perception of this “difference” reinforced. The family may seek help, experience guilt, and must learn about the “systems” that can offer support.

In traditional families, mothers have most often been thought of as the parent who provides both physical care and nurturing. When a child is born who has a disability, there are additional special needs for care. One parent may have to give up a career in order to become a full time care provider, meeting the special needs of the individual, and acting as an advocate for service. This person is most often the mother. At the same time, she must continue to address the needs of the rest of the family. The time and energy involved in care provision may make her less able to attend to her own needs, and to those of the rest of the family. In the role of advocate, if she is not persistent, she may not get services. If she is persistent, she may be viewed by the system as a problem.

There are high rates of dissolution of marriages following the birth of a child with a disability. Fathers of children with disabilities more often experience depression, have less enjoyment in their children, and have lower self-esteem than fathers of non-disabled children. Siblings of children with disabilities are also affected. They may have to assist with provision of care, or may have less access to their parents’ time and energy than other children do. As the person with a developmental disability ages, the siblings are often expected to replace the parents in offering support to the disabled person, and arrange appropriate service provision.

Support systems providing services to persons with developmental disabilities tend to be too few, not well-linked and not well advertised. When services are found, the resources available are often not adequate to meet the needs, whether, these are medical, social, educational or supportive. Service providers overextend themselves to provide services; yet, families and individuals with disabilities tend to be on long waiting lists, or to receive incomplete services. Therefore, everyone within the system is under stress. The search for appropriate services is often frustrating, and families often have to rely on other families to tell them how to navigate the system. While such family linkages may be supportive, the need to be constantly seeking advice or giving advice takes further time and energy away from the family unit.

Summary

There is a recognized increased prevalence of behavioural, emotional and psychiatric disorders in persons with developmental disabilities compared to the general population. In this chapter, we have tried to outline the broad spectrum of circumstances that can contribute to the vulnerability of persons with developmental disabilities to mental health disorders. However, the fact that someone is vulnerable does not mean (s)he will go on to develop such a disorder. By identifying certain vulnerabilities, and by understanding the nature of resilience to mental health disturbances, and how to promote such resilience in persons with developmental disabilities, we can both prevent some of these disorders from occurring, **and** lessen the impact of those that do develop. Biological, psychological, social, cultural, and political circumstances, and particular philosophies of care and support, combine in complex and intricate ways. They determine how vulnerable the person with a developmental disability may be to mental health disorders, and whether such disorders develop. When someone with a developmental disability presents with a significant change in usual behaviour, or with behavioural disturbance, clinical assessment involves evaluating the relative contributions of each of these circumstances in contributing to or maintaining the client’s mental distress. From such an assessment, an appropriate treatment program is formulated. Invariably, given the complexity of circumstances contributing to mental health disturbances in persons with developmental disabilities, such treatment programs usually require the active participation of both the client and his/her direct caregivers Frequently, caregivers also have to act as advocates in helping to make the environmental and system changes necessary to promote healing and maintain optimal mental health.

Do You Know?

1. How may understanding of an individual's emotional and cognitive development contribute to an understanding of his/her disturbed behaviour? How may this understanding affect the treatment plan?
2. Describe some of the medical, emotional, psychological and psychiatric disorders that contribute to behaviour disturbance in individuals with developmental disabilities.
3. Optimal mental well-being is related to optimal physical health, optimal psychological functioning, and optimal treatment of psychiatric illness. Describe how you would promote optimal well being in your client.
4. Many mental health disturbances (emotional, behavioural and psychiatric) can be avoided. Describe how mental health disturbances arise. Select two examples and describe how these might be avoided.

Resources

Developmental Disabilities Program. http://www.psychiatry.med.uwo.ca/ddp/. For access to a range of Developmental Disability Web Sites and resources.

References

American Psychiatric Association, American Psychiatric Association, & Task Force on DSM-IV. (1994). *Diagnostic and statistical manual of mental disorders DSM-IV.* (4th ed.). Washington, DC: American Psychiatric Association.

Aspray, T. J., Francis, R. M., Tyrer, S. P., & Quilliam, S. J. (1999). Patients with learning disability in the community. *British Medial Journal, 318*, 476-477.

Beange, H.P. (1996). Caring for a vulnerable population: Who will take responsibility for those getting a raw deal from the health care system. *Medical Journal of Australia, 164*, 159-160.

Bradley, E. A., & Summers, J. (1999). Developmental disability and behavioural, emotional and psychiatric disturbances. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (pp. 409-428). Toronto: Front Porch Publishing.

Brown, I. & Percy, M. (Eds.). (1999). *Developmental disabilities in Ontario*. Toronto: Front Porch Publishing.

Gelinas, K. M. & Ross-Greenside, J. (1993). The health care coordination project: Interim report and future concerns. *Clinical Bulletin of the Developmental Disabilities Program 4(1*), 1-3.

Gitta, M. (1993). Community health issues in Southwestern Ontario 1992-1993. *Clinical Bulletin of the Developmental Disabilities Program, 4(3)*, 1-2.

Papalia, D.E., Olds, S.W., &.Feldman, R.D. (1989). *Human* *development (4th ed.)* New York, NY: McGraw Hill Books.

The MATCH Project. (1996). *Creating a continuum of supports and services: A resource document*. Toronto: MATCH.

Turner, S. & Moss, S. (1996). The health needs of adults with learning disabilities and the Health of the Nation strategy. *Journal of Intellectual Disability Research, 40*, 438-350.

World Health Organization. (1980). *International Classification of Impairments, Disabilities and Handicaps.* Geneva. Author.