Wellness and Quality of Life

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Some Key Elements of Wellness and Quality of Life

• Wellbeing
• Emotional Wellbeing
• Lifelong learning
• Leisure pursuits
• Natural connections
• Empowerment and self-determination
• Social inclusion
• Self esteem

Element One is Wellbeing

Wellbeing=Integrity of physical and mental health

Health
Fitness
Nutrition
Freedom from disease
Mental Wellness
Free from symptoms
Absence of undue stressors

Holistic approach

Learning from the Masters:
Robert Sovner & Bill Gardner
Integrated Biopsychosocial influences on Dual Diagnosis
The Human Genome Project

Story of John

- John was referred as a sexual problem-insertion of objects up his rectum, frotteurism, and what they called “aggressive hugging”, although this is less as he gets older. He also has engaged in some stripping of clothes.

I asked

- How is his vision? his hearing? his skin? his sleep?
- Any seizures? Prolonged outbursts?
- Is he engaging, endearing, humorous and always wanting to please?
- Does he crave for attention and is he competitive with others over that attention?
- When he gets excited does he do a little upper body squeezing thing and facial grimacing?
- Does he have an unusual walk and a deep hoarse voice?

SMITH-MAGENIS SYNDROME

Benefits of syndrome identification (Griffiths & Watson, 2004)

- Understand the reality of the individual
  - The persons strengths and skills
  - Possible medical vulnerabilities
  - Associated mental health risks or resiliency
- Leads to increased support for families, care-providers and the individual
- Assists in communication between professionals
- Allows us to learn more about the syndrome and it’s biopsychosocial influences

MEDICAL ISSUES

- Angelman
- Down
- Fragile x
- PKU
- Prader Willi
- Rett
- Smith Magen

- Seizures, sleep and scoliosis
- Congenital heart, hypothyroidism, hearing and vision problems, Alzheimer’s
- Mitral Valve prolapse
- Congenital heart defect, seizure
- Diabetes mellitus, hypertension, sleep
- Seizures, sleep, scoliosis
- Hirschsprung’s, hearing loss, cardiac defect, liver cirrhosis, hypothyroidism, pulmonary insufficiency, hypothyroidism, peripheral neuropathy, cardiac, seizures etc.
Mental Health Issues

- Persons with Fragile X are inclined to experience extreme anxiety problems
- Dementia in persons with Down Syndrome
- Sleep disturbance is increased in many syndromes

Biomedical or behavioral models
The wrong question?

Common behaviors
- Biomedical factors and influence on behaviour
- Psychological vulnerabilities
- Learning styles and implications to task or avoidance of tasks
- Sensitivities to social/environmental situations been evaluated and changes incorporated?
- Stengths and challenges associated with the syndrome
- Syndromic implications for preventative or proactive approaches
- Functional replacements to help to ease functioning or distress
- Consequences that would be best to use or avoid
- Dissemination to all concerned

Guidelines

ELEMENT ONE WAS WELLBEING: PHYSICAL AND MENTAL

SPARK FOR MY PASSION

Element Two is Emotional Wellbeing
Physical Effects of Environment without Human Contact

An habilitatively appropriate environment

- An environment can play a role in influencing challenging behavior in individuals.
- So to, the environment can play a role in developing appropriate and prosocial behaviors.

STRUCTURE OF THE HABILITATIVELY APPROPRIATE ENVIRONMENT

- Established Expectations
- Known contingencies
- Strong social motivation
- Choice
- Positive social role, self-labels, self-concepts, and positive feelings about oneself and one’s attributes
- Skills of recognizing, labeling and expressing negative emotions appropriately

Normalized

- Rhythm of the day
- Involvement participation in all aspects of daily life
Normalized

• Caution: Even community agencies can be institutional

PHYSICAL CHARACTERISTICS OF THE HABILITATIVE ENVIRONMENT

Proper Conditions-safe/clean/comfortable
Clustering
Space and Size
Stability
Opportunities for stimulation and learning

Promotes learning

• Learning skills to increase independence
• Learning skills to increase coping
• Learning skills to increase enjoyment
• Learning skills to increase relationship development
• Learning skills to increase personal safety and wellbeing

Provides an Enriched Lifestyle

• Activities
• Relationships- staff and housemates, neighbors
• Inclusion and social inclusion

Individualized

• Choice
• Autonomy
• Unique differences and preferences

Physical pain is often short lived whereas social pain can last a lifetime.

Safety and Security

Studies show that people can relive and re-experience social pain more easily than physical pain and the emotions they feel are more intense and painful. Chen, Williams, Fitness, Newton, 2008
AN HABILITATIVELY ENVIRONMENT IS THE FOUNDATION FOR A GOOD LIFE

If rehabilitation is designed to return a person to a state of dignity,
Then habilitation should be designed to establish a state of dignity that the person may have never previously been afforded.

Your life:
• What makes your life good?
• What can interfere with your good life?
• What about your life makes you feel secure?
• What can challenge your security?
• What creates comfort and peace for you?
• What can disturb your comfort or peace?
• What makes you feel good about yourself?
• What can make you doubt yourself or feel less able?

Primary goals of Good Lives Model
• To create
  — a state of affairs,
  — state of mind,
  — activities,
  — interactions
  — personal characteristics,
  — experiences
  — relationships
• that the person would seek to create and for which achievement of them provides a good quality of life and personal wellness.

Trauma in the lives of persons with intellectual disabilities:
The hidden mental health challenge to wellbeing

PATH OF RETRAUMATIZATION

The Good Lives Model adapted
To General Habilitation With Persons with Intellectual Disabilities

• Habilitation: If rehabilitation is returning someone to a state of dignity; then habilitation is providing individuals the skills and life that provide dignity.
• For persons with intellectual disabilities we need to provide the dignity they may never have been afforded.
Conflicting Approaches

- Traditional ABA response to self-injury in a person who has experienced trauma, when the self-injury is shown to have the function of "seeking attention"...so do we reduce attention to not strengthen the SIB and teach alternative ways to get attention?
- Traditional Trauma Approach for a person seeking attention might be to identify the behavior as a need for comfort and respond by giving the person needed attention at these times of distress?

PATH OF RETRAUMATIZATION

Reconciliation of Theories

- Create an habilitative environment where the individual is provided a consistently positive sanctuary (Bloom 2005) of safety (reducing all the motivational operations for stress and increasing elements of security) that is trauma informed or trauma sensitive and whose attention is non-conditional, of ample frequency, duration, quality and intensity.
- Plus ensure the person has the skill to ask for and seek support when feeling distress and that the individuals in the environment are responsive to these requests.
- Then if self-injury occurs, respond to the person to give comfort but ensure that the frequency, intensity, duration, and quality of that attention is different than and not as strong as the attention provided unconditionally or at other times when the behavior is not occurring.

PATH OF TRAUMA RESPONSIVE SETTING

A CONDUIT OFTEN TO ESTABLISHING THE ENVIRONMENT TO MATCH EMOTIONAL NEEDS ESPECIALLY IN CASES OF SEVERE CHALLENGE LIKE TRAUMA IS IN POSITIVE BEHAVIORAL SUPPORT

Element Two

- Wellbeing
- Emotional Wellbeing

Element Three is Lifelong Learning

The Lost Art of Teaching

- In the 1970s and the heyday of behavior management, the focus of much intervention was teaching.
- The art of teaching unfortunately has largely been lost in the field.
- Although teaching has shifted from just functional skill development (i.e., toileting etc.) to skills that allow the person to access growth opportunities and personal choice, current front-line staff have not been trained as teachers.
- Habilitative learning opportunities are not occurring because we as field have lost the skills.

What allows us to cope when things are not right?

- Skill:
  - Allows you to have enhanced freedoms and opportunities
  - Allows you control when things don’t go to your liking by either altering reaction/coping skills to a negative event or using our skills to change the situation

SOCIAL SKILLS THAT GENERALIZE

- Select relevant behaviors
- Use participants that have common social networks
- Do not use participants that have the same needs
- Train in the natural environment
- Train social skillfulness not just discrete social skills
- Apply multiple examples
- Reinforce the new skill and tie it in to the natural occurring reinforcements

*Adapted from: *Fern & Fox, 2017*

Griffiths, Feldman, & Tough, 1997

Outcomes (Accreditation Ontario, 2000)

- Choice of personal goals, where and with whom they live, where they work, their daily routines, services with whom they share personal information, of access to intimate relationships.
- Satisfaction with services and personal life and the realization of their personal goals.
- Access to friends and natural connections.
- Inclusion in use of their environment, participation, interaction, integration, and social roles in the community.
- Human Rights issues such as respect, fair treatment, the exercise of rights, freedom from abuse, health, safety, and the experience of continuity and security.
The goals of therapy should be more than the reduction of problem behavior.

Outcomes of value should also reflect:
- A) increase in skills and self control, &
- B) improved quality of life now afforded the individual.

Element Three
- Wellbeing
- Emotional Wellbeing
- Lifelong learning

Element Four is Leisure Pursuits

Element Four
- Wellbeing
- Emotional Wellbeing
- Lifelong learning
- Leisure pursuits

Element Five is Natural Connections

IMPORRTANCE OF PEER RELATIONSHIPS

Element Six

- Wellbeing
- Emotional Wellbeing
- Lifelong learning
- Leisure pursuits
- Natural connections

Element Six
Empowerment
• Emerging Practice is based on both solid science and respect for philosophical/humanitarian perspectives.

Empowerment

• Recognition of rights.
• Increased focus on self-advocacy, setting personal goals, making life choices, and asserting themselves in time of disempowerment.
• A culture of respect for the rights of all and an ownership of the responsibility that is assumed in the exercise of those rights.

• 3Rs—rights, respect, responsibility


• A Basic Principle is the respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons (Article 3)

Self Determination

• “Refers to the attitudes and abilities required to act as the primary causal agent in one’s life and make choices regarding one’s actions free from undue external influence or interference.” (Wehmeyer, 1992, pp. 305)

Rise of Self-Determination

History behind the rise of self-determination for persons with intellectual disabilities:
Wave 1: Professionalism
Wave 2: The Parent Movement
Wave 3: Self-advocacy

Traditional Planning

• Traditionally planning
  — orchestrated around government initiatives and agency planning
  — often does not take into account individual differences and preferences &
  — can lead to a decreased quality of life and can often represent a vulnerability for emotional and behavioral challenges

Individual Centered Planning
Greatest changes in outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Baseline</th>
<th>Follow-up</th>
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</thead>
<tbody>
<tr>
<td>Choose where to work</td>
<td>20.7</td>
<td>44.8</td>
</tr>
<tr>
<td>Have friends</td>
<td>15.5</td>
<td>37.9</td>
</tr>
<tr>
<td>Have intimate relationships</td>
<td>32.8</td>
<td>58.6</td>
</tr>
<tr>
<td>Decide when to share information</td>
<td>51.7</td>
<td>79.3</td>
</tr>
<tr>
<td>Live in integrated environments</td>
<td>8.6</td>
<td>32.8</td>
</tr>
</tbody>
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Person centred plans vs. behavioral plans

Rights vs. Risks and Responsibilities

Element Six

- Wellbeing
- Emotional Wellbeing
- Lifelong learning
- Leisure pursuits
- Natural connections
- Empowerment

Element Seven is SOCIAL INCLUSION
Element Seven

- Wellbeing
- Emotional Wellbeing
- Lifelong learning
- Leisure pursuits
- Natural connections
- Empowerment
- Social Inclusion

Element Eight is

Self-Esteem

PERSONAL ACHIEVEMENTS

Element Eight

- Wellbeing
- Emotional Wellbeing
- Lifelong learning
- Leisure pursuits
- Natural connections
- Empowerment
- Social Inclusion
- **Self Esteem**
Elements of Life Quality

Wellbeing and health
Emotional wellbeing
Lifelong learning
Leisure pursuits
Natural connections
Empowerment
Social inclusion
Self esteem ..........these together spell

WELLNESS!!!

Key References


