Prader-Willi SYNDROME NETWORK
Providing information and resources

BUILDING RESILIENCE IN FAMILIES WITH A FAMILY MEMBER WHO HAS PRADER WILLI SYNDROME

Trillium HEALTH CENTRE

Author: CATHERINE SONDERGAARD M.Ed., RECE., ECE.C.

PROTECTIVE FACTORS FOR FAMILIES

COHESION • COMMUNICATION • SOCIAL CAPITAL • PROBLEM SOLVING • SPIRITUAL BELIEFS

COHESION

- Family connectedness (history, relationships)
- Social Connectedness (friends, neighbours, colleagues)
- Connected to community (recreational, leisure, spiritual)
- Connected to information and ideas – being at home with what is known and thought
- Symbols of Cohesion in Families
- Family pictures
- Shared history (stories, picture albums, scrapbooks, mementos)
- Shared activities (daily routines, regular celebrations)
- Shared interests

COMMUNICATION

- Clear, direct, specific, honest
- Allows for constructively expression of points of view, emotions
- Family members take responsibility for their own feelings
- Differences are tolerated
- Little blaming
- Family members listen to each other with interest, empathy, respect

SOCIAL CAPITAL

- Building and maintaining relationships with others
- Building support networks
- Interacting with others in similar situations

PROBLEM SOLVING

- Collaborative within family roles
- Identifying problems, stressors, constraints
- Brainstorming possible solutions
- Evaluating possibilities
- Deciding on best solution(s)
- Implementing steps to solving problem
- Evaluating outcomes
- Adapting according to need

SHARED CULTURAL AND SPIRITUAL BELIEFS

"Being able to transcend ourselves and merge with a larger entity (nature, art, religious beliefs) provides a profound means of achieving inner security, strength, peace of mind, and a kinder view of the world."
(Heller, 1999)

- Provides balance, comfort
- Helps families to make meaning out of crisis or chaotic situations
- Facilitates a hopeful outlook

FAMILY RESILIENCE

- Good outcomes despite adversity
- Sustained competence under stress
- Recovery from trauma
- Engagement with risk rather than evasion (Rutter, 1987)
- Dynamic process (not static)

When Families are Resilient they are able to:

- Cope successfully with significant adversity or stress
- Maintain its established patterns of functioning after being challenged and confronted by risk factors (elasticity)

- Reorient their patterns of functioning to face future challenges (Mangham, 1995)
- Recover quickly from a traumatic situation or event requiring a change in family's organization (buoyancy)

CHARACTERISTICS OF STRONG FAMILIES

- Adaptable
- Appreciative of each family member (do positive things for one another, recognize each other's worth)
- Have clear roles – there is an understanding of roles and responsibilities
- Flexible enough to adapt to different situations
- Communicative – manage conflict in a positive way
- Connected to one another, their community
- Have social and emotional resources
- Committed to the family and family system

RISK FACTORS

- Parents who have difficulty caring for themselves and other family members, possibly due to multiple and complex needs, poverty, mental illness
- Focus is on one or more members to the exclusion of other members
- Reactions to change are rigid or chaotic
- Inadequate support networks (isolation)
- Poor or ineffective communication patterns
- Emotionally disconnected or overly involved

TIMES OF INCREASED STRESS FOR FAMILIES

TRANSITIONS

- When a child is:
  - Moving into a childcare situation
  - Moving into a preschool
  - Moving into a school situation
- Social experiences away from home
- Birthday parties
- Family celebrations
- Community events
- School trips
- Staying at school for lunch
- Developmentally ready for more autonomy:
  - preschool, school-age, adolescence, adulthood

CHALLENGES FOR FAMILIES WHERE A FAMILY MEMBER HAS PRADER WILLI SYNDROME

ESTABLISHED RISK:

- Raising a child with a disability can be a life-changing experience.
- PWS is a lifelong condition with a level of developmental disability or restricted thinking patterns.

BIOLOGICAL RISK:

- Malfunction of hypothalamus in individuals with PWS results in lack of control over appetite, mood, and growth
- Individual with PWS has an inability to feel full, combined with a drive to eat
- Uncontrolled eating can lead to significant health risks.

PSYCHOSOCIAL RISK:

- Increased risk for behaviours such as compulsions, perseverations, food obsessive behaviours, tantrums when drives are thwarted or change is required.
- High level of anxiety associated with change, uncertainty, or if needs not met
- Lower level of self-control
- Families are required to examine their values, belief systems, and ways of coping.
- Families need to review and adapt their:
  - Eating habits – healthy attitudes, healthy foods, structured meals and snacks
  - Exercise routines – need to happen every day, be fun, safe, realistic
  - Household set-up – avoid or manage food triggers
  - Daily routines –strong need for consistency, structure, and predictability
  - Social Activities- maintain social connectedness while avoiding food triggers
- Responsibilities of family members and the community shift from a model of moving toward more independence and autonomy, to a model of maintaining structure and control.

HOW PROVIDERS CAN HELP

COHESION

- Encourage participation in shared, meaningful routines
- Foster positive attributions for family members • Focus on strengths of all family members
- Ask questions to help family develop/recognize cohesion:
  - *What do you do for fun in your family?* – *Who do you feel close to in your family?*
  - *What routines happen in your family?*
- Provide information about how to adapt routines to the needs of individual with PWS (reduce food triggers, increase exercise, provide structure and predictability, promote flexibility)
- Provide new or additional resources to meet demands so that family can enjoy time together (respite, community activities, exercise resources, information about recreational activities, support groups)
- Added Value: Relaxation and Fear mastery Activities families can do as individuals or together: Deep breathing, progressive relaxtion, regular aerobic exercise, yoga, t-aai chi)
- Help the family to define each member's roles, responsibilities, boundaries (sense of belonging and relationships within the family)
- Help family develop routines (greetings, mealtime and bedtime routines, social games, turn-taking, goodbye routines, travel routines)

COMMUNICATION

- Demonstrate to parents and children use of "I" statements (I feel worried when you don't come home right after school because I don't know where you are"
- Teach/demonstrate listening skills – nodding head, not interrupting, asking appropriate and relevant questions
- Help family to: – Identify negotiable and non-negotiable rules
  - Plan far in advance – Give warnings about transitions
  - Make reviewing the calendar and schedule part of daily routine
  - Practice situations that may be difficult ahead of time
- Suggest informal weekly meetings to plan the week, discuss current or upcoming issues, and talk about problems
- Increase family members" ability and opportunity to share feelings and concerns, and respond to crisis
- Help families negotiate system changes to respond to new demands
- Provide information about counseling and family support as needed

PROBLEM SOLVING

- Provide information about needs of individuals with Prader Willi Syndrome
- Provide Information about Developmental Issues
  - Alert family to developmental transitions and need for new roles and routines to be negotiated
  - Discuss complications that may be imposed by PWS and its management (need for appropriate level of supervision, support for some independence)
  - Address misconceptions
- Meet Need for adequate, reliable information for managing safety
  - make sure that family has access to and have been made aware of the severity and far reaching implications of the diagnosis
- Provide information about supports available in the community
- Provide information about ways for families to developing resilience
- Model collaborative problem-solving in interactions with families
- Help parents find strategies to reduce stress
- Promote positive parenting behaviours – provide access to behaviour management supports (workshops, consultations)
- Provide access to workshops and supportive counseling when families have difficulty

SOCIAL CAPITAL

- Provide opportunities for parents to talk to other parents
- Provide and facilitate support groups or make parents aware of existing support groups and information
- Support involvement of extended family, community
- Help families access the support of extended family, respite, supports for their own needs
- Enhance support networks by acknowledging the importance of friendships, reviewing ways to make friends
- Encourage hobbies and interests
- Identify barriers that interfere with social relationships and advocate for adjustments to accommodate special needs (food restrictions, structure, safety)

SPIRITUAL/CULTURAL BELIEFS

- Put families in touch with their faith communities as they are comfortable
- Encourage family members to consider activities that allow them to nurture their spiritual/cultural needs (nature, music, the arts, religious/faith community activities)