

Building Resilience in Families Where a Family Member Has Prader Willi Syndrome

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Introduction

Service providers play a significant role in promoting resilience in families where there is a need to manage Prader-Willi Syndrome (PWS). Along with specific knowledge about PWS, supporting buoyancy and flexibility is important in helping families to attain a comfortable level of coping. Service providers should not underestimate their ability to have a positive impact in helping families develop resilience when a family member has PWS.

The need to maintain a high level of structure and control in the lives of individuals with PWS puts additional demands on families. The routines, rules, and rigidity can be life-saving, and yet they are challenging to maintain and balance with the need for acknowledging and promoting individuals' developmental strengths, personal qualities and opportunities to make positive contributions to their communities.

For families where a member has PWS, risk and resilience factors include variables related to the individual child in terms of their intellectual abilities, health needs, temperament, and coping styles. Family variables, such as the level of family cohesion, clarity of roles and boundaries, parenting styles, and problem-solving and communication skills of family members all influence the level of resilience a family achieves at a particular time in their child's life. Times of transition and change offer challenges. The availability and use of both formal and informal supports, and their effectiveness, influences the development and sustainability of resilience.

Resilience

Resilience has previously been understood in relation to children who adjusted well despite having special needs. Terms such as "invulnerable" or "invincible" have been used to describe it. (Bernard, 1991). Current definitions focus on good outcomes in spite of adversity, sustained competence under stress, and recovery from trauma (Masten and Coatsworth, 1998). The concept of resilience has more recently been applied not only to children, but also to families and communities.

Families might be considered resilient when they reorient their patterns of functioning to face future challenges (Mangham, 1995). McCubin (1997) used the concepts of elasticity and buoyancy to explain resilience. He defined resilience as the family's ability to maintain its established patterns of functioning after being challenged and confronted by risk factors (elasticity). Further, he looked at the family's ability to recover quickly from a traumatic situation or event requiring a change in the organization of the family (buoyancy).

Resilience in families in which a member has been diagnosed with PWS might be thought of as healthy family coping and functioning in the face of risk factors. Risks for individuals with PWS include the risk for less than optimum developmental outcomes, health issues that require significant modifications to diet and exercise, and behavioural issues that impact the family's day-to-day routines. We may assist individuals with PWS, their family members, and service providers by exploring the protective factors that buffer the risks for these families.

There is a shared understanding in recent literature that resilience is a dynamic process rather than a static process. Factors that improve resilience at one point in time may change and be outweighed by risk factors at another point in time. This may happen as environments and demands change. A family's adaptations to the stresses of having a member with PWS might change over time and in different contexts, depending on the developmental level of the child, the context, the balance of risk and protective factors, and the family's shared outlook. Different factors within the environment and the family are important at different ages. For example, preschoolers may be in a child care situation, while an adult may be in a group home setting. Certain events (developmental or otherwise) experienced by the child or

family can constitute turning points that can be negative or positive for helping the child or the family cope. For instance, a child's growing need for independence or a parent's changing employment demands may influence the way a family copes.

Resilience may look different in different cultures. High context cultures, where people connect to one another closely and sustain their relationships over long periods of time, value interdependence. Coping well in a high context culture might be defined as a family reaching out and asking for help. Cultures that value more independence might see resilience as being able to carry on day to day functions and routines with little support.

Service providers can foster resilience in families in a variety of ways. One of the important aspects of family resilience is the way in which families view their problems. Service providers can gather information about how families make meaning out of adversity, or normalize their stress. They can determine how positive the family's outlook is. Determining how the family is organized and the family's style of problem-solving, communicating, and interacting with the community might lead to effective methods of providing support to that family. Service providers can also try to glean whether a family is able to use their spiritual beliefs to provide meaning and helpful perspectives. Normalizing stress, developing a positive outlook, and being able to transcend the situation using spiritual beliefs are all protective factors. Service providers can facilitate the development of protective factors in the families they are serving.

Family Functioning

Family functioning impacts children's developmental outcomes. Children generally develop better when their families function well. Healthy family functioning is also often related to children's social-emotional competence, and is associated with reports of fewer behaviour difficulties (Dickstein and Martin, 2002). Helping children achieve their best potential, and therefore reducing the stress of behavioural difficulties, supports smoother family functioning. Relationships within families, such as couple relationships and sibling relationships, need to be nurtured and supported to keep the family functioning well.

Some characteristics of strong families include:

1. **Adaptability**-being able to cope with different types of stress
2. **Appreciation**-doing positive things for one another
3. **Clear roles**-understanding roles and responsibilities in the family and being flexible
4. **Commitment**-recognizing each other's worth and being committed to the family system
5. **Communication**-being open and honest with each other and willing to listen to the views of others, being able to manage conflict in a positive way
6. **Community ties**-being involved with and connected to the community (Walsh, 2002)

Competence can be nurtured by helping people regain a sense of connectedness with one another, with those who came before them, with their daily patterns, rituals, and stories that impart spiritual meaning, and with tangible resources in their community. (Landau, 2007) Providers can also effectively facilitate a family's competence by helping parents to find strategies to reduce parenting stress and promote positive parenting behaviour.

Parents of children with Prader Willi Syndrome often need support and information to better adjust to their child's condition. Parenting a child with a disability can be an experience that spurs families to re-examine their values, belief systems, and ways of coping. Providing information and support can play a big role in helping parents and families understand and cope with their family member's condition.

Resilience involves an interaction of factors than can be either protective, in that they shield us from poor consequences, or risks, in that they can lead to poor outcomes.

Risk Factors

Risk factors specific to Prader Willi Syndrome can be categorized as established, biological, and psychosocial. Established risks include a level of developmental disability or restricted thinking patterns. PWS is a genetic disorder, and a lifelong condition. Biological risks include a malfunction of the hypothalamus. This malfunction results in lack of control over key aspects of the person's functioning, including mood, appetite, and growth. The individual experiences an inability to feel full, combined with a drive to eat. Uncontrolled eating can lead to significant health risks. Psychosocial risks include behaviors such as compulsions, perseverations, food obsessive behaviour, and tantrums when drives are thwarted. They also include high anxiety when change is required or there is uncertainty, or when the individual's

needs are not met. Lower levels of self control are often seen in individuals with PWS, resulting in further risk (Tjossem, 1976; Nugent, 2007).

A high level of structure and control is needed to address the risks for individuals with PWS. In order to minimize the risks associated with PWS, the family and the community must shift from a model of moving toward more independence and autonomy, to a model of maintaining structure and control. Although such a model is in contrast to the usual movement toward more independence and autonomy for individuals as they mature, it is necessary. The challenge is to find a level of “Just right” control, and “not too much anxiety” for the individual, the family, and the community. An understanding of the risks associated with PWS is essential.

In families where there is a need to cope with PWS, families have a need to review and perhaps modify their eating habits, exercise routines, household set-up, social activities, and daily routines. When the family member is cared for outside of the home, the care, educational, and workplace settings need to carefully consider and plan their routines and environments.

There are a number of risk factors that might be present in families in addition to having a child with Prader Willi Syndrome. Risks are increased when

- Parents have difficulty caring for themselves and other family members due to issues such as poverty, mental illness, or multiple and complex needs.
- Families focus on one or more members to the exclusion of others
- Families react to changes with rigid or chaotic responses, or little flexibility
- Families have inadequate support networks (isolation)
- Families are not able to talk openly with each other about their feelings (emotional connectedness)
- Family members are overly emotionally involved, or disengaged from one another (Garwick, 1996)

To foster resilience, an understanding of all of the risk factors impacting a family is important. Service providers often gain such an understanding over time and in the context of trusting relationships with the family.

Protective Factors

Family organization patterns dictate the ways families carry out essential tasks for growth and wellbeing. They include flexibility, connectedness, and social and emotional resources

Protective Factors include:

- Cohesion
- Problem-Solving
- Communication
- Supporting Clear Family Boundaries
- Fostering Positive Attributions
- Promoting Family Flexibility
- Social Capital
- Spiritual Beliefs

Cohesion

A sense of belonging has long been recognized as important in the development of individuals. A sense of unity, consistency, and pulling together offers security and predictability for families as well.

Cohesion can include:

- Family connectedness
- Historical connectedness between you and your past
- Social connectedness to your friends, neighbors, colleagues
- Connectedness to ideas and information, the feeling of being at home with the very wide and complex world of what is known and thought
- Connectedness to organizations where you work, play, or learn (institutions)

- Connectedness to what is beyond knowledge- a sense of being a part of nature or spiritual connectedness

Families that have a healthy level of cohesion benefit from that connectedness. Too high a level of cohesion results in enmeshment. This is seen when family members are overly involved in each other's lives, sometimes to the detriment of their own needs. In contrast, too low a level of cohesion results in disinterest, and might be seen in family members having little to do with each other (Hallowell, 1997). A healthy level of cohesion is somewhere in the middle, and is considered to be protective.

Symbols of connectedness and cohesion in families might include

- family pictures
- shared history (picture albums, stories, scrapbooks, mementos)
- shared activities that happen routinely such as daily habits and regular celebrations
- shared interests

Providers can help families to identify their level of cohesion by asking the following questions:

- What do you do for fun in your family?
- Who do you feel close to in your family?
- What routines happen in your family?
- What do you do to maintain the connection you have to others in your family?

As providers, it is important that we support rather than undermine family cohesion (Garwick 1996). Service providers can encourage families to consider and, if necessary, adapt the ways they spend time together. Providers can offer information about how to adapt routines to the needs of the individual with PWS. They can provide new or additional resources to meet the demands so that family can enjoy time together. Helpful strategies specific to PWS include ways to avoid food triggers, encourage exercise, and manage behaviors during specific activities and in particular environments.

Routines help to organize family life, define roles and responsibilities, reinforce family identity, and provide members with a shared and necessary sense of belonging. Routines must be functional, and in the "just right rigidity" zone-not too formal and repetitive, and yet structured. Repeated participation in shared, meaningful routines (greetings, mealtimes, bedtimes, and social games) with sensitive and responsive caregivers, helps children begin to internalize basic procedures for morality (i.e. turn-taking), and emotional regulation (for example, managing the distress of separation through a good-bye routine at child-care) (Emde, Korfmacher, and Kubicek, 2000). Taking part in routines also helps children begin to learn the beliefs, values, and practices of their family and culture (Kubicek, 2002).

In the context of PWS, we know through experience and through the literature that there is a strong need for consistency, structure, and predictability throughout the lifespan. Assisting families in establishing and maintaining routines is a key role that service providers can play.

The early years provide an important window of opportunity where parents have the most profound influence on how their children develop attitudes and routines. One of the most critical issues in families where a member has PWS is the family's attitudes and routines around food. Children learn from their families about eating habits, and how they feel about food, physical activity, and themselves (Connelly, 2007). Establishing routines that acknowledge the need for specific rules, routines, and avoidance of food triggers can go a long way in helping to prevent later difficulties. For example, providers might encourage families to make mealtimes functional, and have social interactions happen separately from mealtime. This may not reduce the constant feeling of hunger, but may reduce the anxiety of the family member with PWS.

Providers can help families instill a sense of belonging by encouraging them to celebrate special occasions such as birthdays and other festivities in ways that are adapted to deal with PWS triggers and stressors. They can help motivate and support families in maintaining regular routines such as bedtime routines, which give children a sense of security. In childcare and educational settings, routines can include mealtime, washroom, outdoor play, circle time, free play, quiet time, procedures such as "announcements", and schedules/timetables. In a home setting, routines can include a sequence of activities that is carried out in the morning, routines to use when the family or parent and child are traveling together, after dinner routines (a walk, watching a particular television show, listening to music),

and regular time spent in recreational activities that involve shared interests, such as sports, or crafts. When the family member is in a residential setting, setting up routines around times of visits and phone calls from the family, and activities where family is included might help the individual to maintain a sense of belonging without creating anxiety.

Providers might encourage families to spend time together, including outdoor activities such as biking or taking a walk, physical activity and exercise, participating in arts and crafts, social activities such as games night, and enjoying music, nature, or the arts together. The role a provider might take to encourage these activities could be helping to plan the activities to reduce food triggers and anxiety for the family member with PWS.

Encourage parents to provide regular opportunities for their children to take an active role in family routines. For example, they might be encouraged to give the child a single task, such as passing out cards for a card game. It is important to emphasize the need for a balance of active and quiet activities in which to engage in when planning daily routines. In residential settings, providers might consider developing routines where families are included. To address the need for exercise, shared activities might include active endeavors, like riding a bicycle, going to an exercise class, or playing active games as part of routines (Kubicek, 2002).

Individuals and families where PWS results in anxiety and obsessive thought patterns can benefit from relaxation and fear matery activites. Deep breathing, progressive relaxation, and visualization activities are good options. Regular aerobic exercise, yoga, or t'ai chi are also great activities that family members can participate in together (Heller, 1999).

Problem-Solving

Effective problem solving in families increases their resilience. When family members collaborate to come up with solutions, they are better able to cope with stressors. Collaborative problem solving involves identifying problems, stressors, options, and constraints. Steps involved often include:

- identifying a problem
- brainstorming possible solutions
- evaluating the possibilities
- deciding on the best solution
- trying it out, and
- evaluating the outcome (Shenfeld, 2007)

Providers can play an important role in supporting constructive problem solving for the families in which they are involved. They can provide information about effective problem-solving, model collaborative problem-solving in their interactions with families, provide supportive workshops and access to counseling when families have difficulty. Providers can support clear communication, and provide information, as well as play a role in supporting clear family boundaries, supporting family flexibility, and promoting positive attribution.

Communication

Effective communication is important in all families. It is especially protective in families where there is a member with a chronic illness or special need. Components of effective communication involve clarity, emotional expression, and collaborative problem-solving (Walsh, 2002). Clear communication is direct, specific, and honest.

Families foster resilience when they allow all members to constructively express their emotions, points of view and concerns, and make them feel they are listened to with empathy. Open emotional expression allows for sharing a wide variety of feelings and emotions, mutual empathy, a tolerance for differences, and little blaming. Family members take responsibility for their own feelings.

Service providers can increase family members' abilities and opportunities to share feelings and concerns safely, and they can respond to crisis by promoting effective communication. They can help families negotiate system changes to respond to new demands. For example, service providers might suggest informal weekly family meetings to plan the week, discuss current or upcoming issues, and talk about problems. Service providers might model effective communication by demonstrating to parents and children how to use "I statements" – "I feel worried when you don't come home right after school because

"I don't know where you are" – so family members don't feel judged and blamed. Help family members listen well by reminding them to not interrupt others, to nod their heads and to ask appropriate questions. If family members have difficulty controlling their tempers when communicating, clinicians can integrate anger management techniques into their sessions or suggest an anger management program. Service providers can encourage family members to remain non-judgmental and empathic. They can help families to identify negotiable and non-negotiable rules, and to plan far in advance. Specific suggestions might include: establishing a daily routine of reviewing the calendar and schedule, giving warnings about transitions, and rehearsing and practicing situations that might be "sticky" ahead of time.

Meeting the need for adequate, reliable information for managing safety is an essential role for providers. Before making any assumptions about how a family is coping, it is important to be sure that they have access to and have been made aware of the severity and far reaching implications of the diagnosis (Mandell, 2002). Meanings are influenced by past experiences and cultural backgrounds. Clinicians must assess each family's understandings about Prader Willi Syndrome. Misconceptions about PWS or its management can be corrected and updated information can be provided.

As a supportive community we need to make sure parents are aware that health, education, and community resources may be appropriate and helpful, including such resources as: pediatrician, dietician, social worker or psychologist, infant and child development services, treatment centres, and information/support groups. Service providers can supply information about available resources and help families to access them. Parents may benefit from being encouraged to check out all medical information with an informed physician, who demonstrates openness to discussion when questions or concerns are raised. Keeping communication open will help prevent parents from accepting information from sources that may be inaccurate or otherwise problematic.

Families change over time, therefore the adequacy and relevance of resources must be reevaluated periodically. Withholding pertinent information in the belief that it will make the parents unnecessarily anxious may be counterproductive and ultimately may increase the risk to the child (Mandell, 2002).

When families and individuals are in a crisis, they often need to hear the same information several times and in several ways before they can really absorb it. It is worth repeating the information.

Informing families about developmental issues is another important role for service providers. Developmental transitions often tip the balance in families until new roles and routines are negotiated. For example, a major developmental task for adolescents is to establish independence from their parents and other adults. Limitations imposed by PWS and its management can complicate the adolescent's struggle for autonomy. Family caregivers need specific information about their child's/ adolescents'/ adult's particular capabilities and limitations so they can support appropriate levels of independence, while providing necessary supervision. Providers can alert families to predictable changes over time, as the child matures, and arrange for connecting with the family at crucial times to offer support and help prevent problems.

Parents of a child with PWS may need more support when the child:

- begins to attend preschool or daycare
- shows readiness for experiences away from home (attending birthday parties or recreational programs without parents)
- stays at school for lunch
- goes on a trip
- moves from one educational setting to another
- moves to a new school (from preschool to elementary school, to middle school, to secondary school, to college)
- moves to a new living situation
- when a child is developmentally ready for more autonomy (Mandell, 2002)

It may be very practical to connect families to other families in the community who might offer strategies and suggestions that have been successful to them at these times. Behaviour management strategies can be highlighted for parents and reviewed in the context of new situations. Parent education courses can be offered early on to help parents to learn how to manage transitions, and avoid strategies that may later become problematic, such as using food as rewards.

Many families have already developed effective coping strategies. It is important for service providers to support those strategies and acknowledge the hard work families have done. Asking questions about what a family is already doing about day-to-day management allows us to support what is healthy and likely to lead to resilience, and provide support for developing further coping strategies.

Asking about the emotional aspects of coping with a family member with PWS allows us to acknowledge the stresses, strengths, and challenges the family faces. Meeting with all of the family members and caregivers for information sharing and follow-up should be considered to acknowledge that all have a role in managing the situation.

Supporting Clear Family Boundaries

Families have both internal and external boundaries. Internal boundaries include the various sub-systems within the family, such as the boundaries between parents and children, between siblings, and between males and females. External family boundaries set the family apart from the larger community by defining who is in and who is outside of the family.

Service providers can help families to recognize and support internal family boundaries. Parents can be reminded of the importance of taking time for themselves and their relationship, siblings can be encouraged to find ways to connect and develop common interests.

Families of individuals with PWS are at greater risk for boundary violations from outside agencies and providers because of their need for services. Providers can support healthy family functioning by respecting external family boundaries. It is essential to be aware of who the family members are, and how PWS affects them. Being clear with family members about our own roles as service providers is vital. We can work together with the family to plan care that is as minimally disruptive to family routines as possible, yet we are not part of the family. Clear communication between providers from different agencies helps families to know which provider to contact for particular issues and problems. Service providers can help families to anticipate change, plan transitions, and clarify family boundaries when their child leaves home. These steps may make it easier for the child to move on and for parents to let go and establish new boundaries (Garwick, 1996).

Fostering Positive Attributions

Meanings that family members attribute to conditions influence how they adjust to stressful situations (Patterson and Garwick 1994). Positive attributions, such as the optimistic attitudes about PWS and the child's capabilities, are associated with healthy child and family outcomes, such as enhanced self-esteem, and a sense of mastery. Negative attributions such as a sense of helplessness have been associated with negative outcomes like depression (Garber, Weiss, and Shanely, 1993).

Service providers can play an important role in promoting positive attributions by reinforcing child and family strengths rather than focusing on deficits. We promote positive attributions when we provide services that focus on competencies rather than weaknesses. Identifying opportunities to capitalize on strengths, build on existing skills, and make positive contributions to the family and community are important roles of service providers.

Promoting Family Flexibility

Positive outcomes in children are seen when families are flexible in setting rules, establishing roles, and defining expectations. Children typically challenge existing family rules as they assume new roles and responsibilities. Parents may react by rigidly enforcing old rules or abandoning family rules altogether. Teens, in particular, react to these strategies by further testing the rules. Parents help build independence when they respond renegotiating the rules to fit the child's new skills, while providing a safe structure. Parents of children with PWS need to maintain a high degree of structure and rules to meet the specific needs of their children.

Providers can support individuals with PWS and their families by helping them to set safe and reasonable rules. Although there may be room for small choices, too many choices creates anxiety in a person with PWS. Rules and routines, structure and consistency must remain very stable and clear to reduce anxiety for individuals with PWS, no matter what their age.

Social Capital

Supportive relationships outside the family are strong protective factors that contribute to resilience. Value is created by investing in relationships with others, through processes of trust and reciprocity (Walsh, 2002). Support networks decrease social isolation and provide a variety of emotional, informational and practical resources for families. Research has shown that the care and support of just one nurturing adult – a parent, other relative, teacher or mentor – can make a dramatic difference in a child's life (Emde, 2000). Families who are proactive in maintaining their social networks are better able to adapt to stressors related to PWS. Through interactions with others with similar situations, families learn new skills and discover resources for managing the condition in a variety of settings.

Service providers can facilitate support groups or make parents aware of existing support groups. They can offer opportunities for parents to talk to other parents, and for adolescents to talk to other adolescents by arranging social events. Service providers can support involvement of the extended family and community, so that families, no matter what their make-up, are not isolated and under-resourced. Often, service providers help clients to access respite to help care for family members with PWS. Service providers might assist clients in accessing day care, after-school programs and summer camps that are informed and able to adjust to their children's needs. Service providers can enhance support networks by acknowledging the importance of friendships, and reviewing ways to make friends with the individual with PWS, and family members. An important role for the service provider is to identify barriers that interfere with social relationships (such as food restrictions), and advocate for adjustments to accommodate special needs.

Developing Collaborative Relationships

Developing and maintaining collaborative relationships builds resilience in families. Effective family/professional collaborative relationships help both parents and service providers to establish adaptive patterns of behavior in response to needs and circumstances. Service providers can promote healthy collaborative relationships by:

- Listening to and respecting the individual with PWS and having knowledge about his or her family's understanding of the condition
- Being aware of the impact of PWS and its management on the family
- Sharing up-to-date, relevant information about PWS with the individual and caregiver
- Working together to manage particular situations by establishing common goals and objectives

- Providing developmentally appropriate information and guidance
- Fostering a sense of cohesion: newsletters, web connections, family events, etc

Spiritual Beliefs

Balance for many people comes from feeling connected to something larger than themselves which gives life meaning. For some it is a particular faith, for others, nature, for others the creating of something artistic (a poem, a song, a dance, a painting). Being able to transcend ourselves and merge with a larger entity provides a profound means of achieving inner security, strength, peace of mind and a kinder view of the world (Heller, 1999). Spiritual nourishment can be found in formal religions, or outside the realms of formal religion through a deep personal connection with nature, music, and the arts or to a higher power (Walsh, 2000). Shared beliefs help family members make meaning of crisis situations, facilitate a hopeful outlook, and provide transcendent or spiritual experiences (Walsh, 1987).

Clinicians can support families in building resilience by supporting them in keeping in touch with their faith communities, or tending to their spiritual needs. Supporting families in connecting with others and exploring spiritual meaning in the context of raising a child with a disability may increase coping. Encouraging family members to consider activities involving nature, music, and/or the arts may facilitate the development of resilience.

Conclusion

Service providers should not underestimate their ability to have a positive impact in helping families develop resilience when a family member has PWS. Along with specific knowledge about PWS, service providers need to have a good understanding of ways to support resilience and flexibility in helping families to attain a comfortable level of coping. Understanding the established, biological, and psychosocial risks associated with PWS is important in providing support to families. Just as important in providing support to families is promoting family resilience through supporting the development of cohesion, effective problem-solving and effective communication. Service providers can also support clear family boundaries, foster positive attributions, promote family flexibility, help families develop social capital, and support spiritual beliefs.

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