SUCCESSFULLY SUPPORTING PEOPLE WITH PRADER-WILLI SYNDROME: A HANDBOOK FOR PROFESSIONALS

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The Handbook for Professionals provides practical information about best practices in supporting people with PWS. The primary focus is on staff who work on a day-to-day basis with people with PWS; families and other professionals will also find the information helpful.

Contents:

1. **An Overview of Prader-Willi Syndrome**
   What PWS is; what causes PWS; diagnosing PWS

2. **Characteristics of PWS**
   People with PWS are, of course, individuals with their own personalities. However, because they share a genetic problem, there are many symptoms they have in common. Topics covered are: physical appearance; health issues; intellectual abilities; behaviour patterns; emotional/mental health.

3. **Service Delivery: Philosophy and General Guidelines for Practice**
   A discussion of the philosophy of service delivery and some recommended general principles for all types of services. It is crucial that the issue of philosophy be addressed since supporting people with PWS requires a revision of the commonly accepted values in the developmental services system.

4. **Weight Control: Food and Exercise**
   Weight control is a major focus of life for people with PWS. Excess weight is the cause of potentially lethal health conditions and challenging behaviours. Therefore, it is important to devote a Chapter to the issue of controlling food and increasing exercise levels with people who have PWS. Sample menus and photographs of meals are included.

5. **Behavioural Strategies**
   This chapter reviews functional behaviour assessment, as applied to a number of ongoing challenging behaviours associated with PWS. There is a discussion of general behavioural strategies to use, followed with some specific techniques that are extremely helpful with PWS.

Specific Services:

6. **Early Intervention**
   Beginning with Infant and Child Development services, PWS in infants and preschoolers is discussed, outlining the shift in issues the family must manage as the child grows. Establishing good routines and strategies early in life will stand the child in good stead for the future.

7. **The School Years**
   As the child with PWS moves into the school system, both child and family face a new set of challenges. This chapter discusses the school years from two perspectives: the school staff and the parents.

8. **Residential Services**

   Once adults with PWS leave the family home, they typically move into a residential program, which becomes their prime support. The focus of this chapter is on the group home model, and covers the physical set up of the home, day-to-day management, relationships with families and staffing.

9. **Vocational Programs and Day Activities**

   After finishing their education, the next step for individuals with PWS is to pursue day activities that are enjoyable, meaningful and can support the structure these individuals require. Options and strategies are outlined, with the priority being on options that maintain the physical and mental health of the individual. Sample weekly activity schedules are included.

10. **Staff Training**

    Staff working with individuals with PWS should complete extensive training before they can do this job well. This chapter recommends a general format for staff training, highlighting some key components: basic PWS information; observation; demonstration of skills and knowledge.

11. **What Does the Future Hold?**

    Once staff have helped people with PWS to accomplish the goals of weight loss, food control, regular exercise and a structured lifestyle, what does the future hold for these individuals?

The Author: Jo Anne Nugent, of Nugent Training and Consulting Services, provides training, writing, consulting and facilitation services to public sector agencies and private companies. Her other books and curricula include *Setting the Stage for Successful Behaviours: A Teamwork Approach to Challenging Behaviours, A Handbook on Dual Diagnosis,* and *Best Practices for Infant Development Programs.*