State of Wisconsin

WCDD

Council on Developmental Disabilities

Supported Parenting

Summary of Lessons Learned

From the MCHIP Grant to the Council on Developmental Disabilities

1987 – 1990

Knowledge gained from the three direct service sites, consultation with agencies across the state, and input from the Supported Parenting Advisory Committee revealed a number of common themes and issues encountered by public health service providers working with families headed by parents with Cognitive Disabilities\*.

1. **Long Term Support.** Parents with cognitive disabilities\* who need support services generally need them on a continuing basis. Short-term services are the norm in public health nursing. The lack of orientation toward long-term support tended to result in frustration, burnout and blame on the part of the worker and mistrust, despair, and cyclical crisis episodes for families. Where long-term support models were implemented there was evidence of the benefits of long-established working relationships with families; greater mutual trust and respect, a maturation in the ways that families used support, more opportunities for prevention and early intervention, and opportunities for workers to develop a more holistic approach (in contrast to a sole emphasis on one “presenting” problem).
2. **Intensive, Individualized, In-Home Support.** A greater degree of agency and family success was evident when intensive in-home support was available when needed. Common characteristics included: frequent home visits, a high degree of availability, flexible scheduling, instruction individualized to the learning style of the parent, and a willingness to provide “hands on” help with some tasks so instruction could focus on more essential skills.
3. **Care Coordination.** Because families were often involved with multiple agencies, the parents needed help in coordinating all the intervention they were experiencing. They needed someone to take the lead in helping them communicate across the various systems and coordinate a unified, consistent plan. When a family had a single point of contact for coordinating all services, support tended to be less overlapping, contradictory, and intrusive. Having someone with the title of “case manager” did not guarantee efficient service coordination. In more than one local interagency meeting, several agencies identified themselves as providing case management, but when examined, none took on the role of insuring that the various agencies involved with a family would get together to jo8intly plan their involvements with a family. Case management was often limited to the management of services provided within a particular agency.
4. **Case Load Size.** Project technical consultants observed case loads for individual workers that ranged from six to over 100 families. If support is to be intensive, individualized, flexible, quickly responsive, and long term, an optimum case load size is a maximum of ten or twelve families per full time worker.
5. **Interagency Coordination.** The project helped organize 13 local interagency coalitions whose membership usually included representatives from public health nursing, early childhood programs, and child protection services. Adult developmental disability community programs, community support programs for people with long term mental illness, day care programs, child abuse prevention and treatment agencies, district attorneys, schools, and health care providers also participated in many of the coalitions. While the purpose and activities varied among the local groups, common reasons for meeting included case coordination, sharing specialized skill and knowledge, pooling resources, combining training activities, and identifying and remedying system barriers.
6. **Family-centered v. Child-focused Interventions.** Often, an agency’s involvement with a family is on the child’s behalf and intervention is framed solely by parent deficits. The parent is seen as a problem, not as a “developing resource” so the agency develops a skeptical and punitive posture. The parent’s perceived shortcomings become such a prominent focus that contributing factors such as poverty, powerlessness, lack of community resources, and the stigma associated with disability receded from conscious attention. When support is organized from a family-centered perspective—“what can we do to support the survival of this family?”—interventions are more likely to be mutually agreed upon and involvement with an agency is seen to be less threatening by the family.
7. **Poverty.** While one shared characteristic of the families supported by the three direct service projects was the parents’ label of cognitive disability\*, another common characteristic—the families’ poverty—had perhaps the greatest impact on families. Virtually all the families lived below the poverty level. Most participants received Aid to Families with Dependent Children.

Housing was generally inadequate and often unsafe. Crumbing steps and porches made many homes hazardous. Families had old stoves and refrigerators. Several families had their gas or heating oil shut off. Some then used kitchen stoves or unsafe space heaters for heat.

Many neighborhoods were unsafe. Of the families served by the Milwaukee project, 85% lived in the central city, a low income, high crime area. Milwaukee has had an unprecedented increase in murders and shooting in the neighborhoods in the central area. People were afraid to leave their homes, workers and potential volunteers were reluctant to enter the neighborhood. The social isolation of families observed generally was of greater intensity in some low-income neighborhoods because of the siege-like atmosphere.

1. **Parent Vulnerability.** For some families, their impoverished financial status was compounded by the parent’s vulnerability to financial exploitation. For example a representative payee appointed to o9versee a family’s finances misused the meager funds. Several families had signed contracts they did not understand for goods they could not use. For example, a parent signed up for several magazine subscriptions offered over the telephone; another parent bought an expensive set of kitchen ware from a door-to-door sales agent. Other families signed on to expensive electronic equipment rental that they could not afford.
2. **High Incidence of Sexual Abuse of Mothers.** Interviews of mothers receiving support from the three direct service projects revealed a startling finding: the majority of mothers with cognitive disabilities\* were survivors of past sexual abuse. This is of particular concern because of the effects of sexual abuse on their own self-esteem and their capacity to develop healthy relationships with family members.
3. **Coping with Scarce Service Resources.** Most families will need some supportive services through the childhood years but are not likely to be able to get that help from a sole source. The challenge, then, is for service providers to achieve a balance between directly providing the needed services within an agency and brokering alternative support resources such as public health nurses, school staff, social service agencies, and volunteers.
4. **Independence.** One obstacle encountered in supporting parents who have cognitive disabilities\* is the assumption that the purpose is always to help a family achieve totally independent functioning. Many families will need help over the long term—some will need a substantial degree of support as long as the children are still at home. Some interventions will have the focus of training for independence. Other help may be instrumental, for example, child-proofing the home, giving a ride to the store or balancing a checkbook. Independence may take a back seat to the overriding goal of the health, safety, and emotional well-being of the family. Some workers need to overcome an attitude that families who need such a degree of support don’t “deserve” the resources they use. Rather than voicing concern about a family becoming “dependent” on services, it may be helpful to put that dependence in perspective and realize that no one is totally dependent nor wants to be. Our interdependence is what helps us feel socially connected.
5. **Judging the Survivability of a Family.** One of the most challenging aspects in supporting families headed by parents with cognitive disabilities\* is encountering the grey line that distinguishes parental care that is inadequate from parental care that is objectively harmful. Service providers often are called on to make a judgment about the family’s prospects that will influence whether or not a family stays intact.

Wisconsin child welfare law frames a policy of promoting the permanence of families—only compelling evidence of harm should trigger the termination of parental rights. The state’s permanency planning policy is premised on the idea that direct, time-limited interventions will lead to prompt answers regarding whether a family stays intact or a child is freed for another permanent option such as adoption. This approach can conflict with what we know about the complex continuing issues facing a parent whose disability is permanent. The rights of a child may be compromised by delaying court intervention; the rights of a parent may be compromised by actions that lead to a swift termination of parental rights. The immediate risk to a child may be alleviated by out of home placement, but the long-term harm of losing the identifying connection to the birth parent can be devastating.

Service systems and courts need to be more creative in their efforts to avoid permanently severing family ties and need to discover innovative methods of keeping families together such as shared parenting, parent mentors, combined child and adult foster care, and open adoption.

1. **Strengthening Informal Support.** A concern often voiced by families with their sense of social isolation. Parents wanted their children to have playmates in the neighborhood, they wanted the acceptance of their neighbors, and they wanted valued roles in their extended families. Formal support services usually were not able to help with this concern. The project looked at examples of parents being matched with volunteer (or nominally paid) parent mentors. These relationships were separate from the formal support services used by families and were guided by the interests and preferences of the parent rather than an agency’s assessment of need. These arrangements were likely to be successful when the parent was part of the decision-making process in matching and when the parent mentor had access to continuing training, consultation, and supervision.
2. **Parenting Classes.** Throughout the state, the most common parenting services available to families were parenting classes. This approach was unsuccessful for many parents who had low literacy skills and did not find verbal instruction the optimal technique. Many had a greater difficulty in taking the lesson learning in one context or environment (a classroom) and applying it in their home under different circumstances. For many parents, the problem was not a lack of information but a lack of skill in judgment and problem-solving—a problem less amenable to group instruction. Despite the historic lack of success in using classes or groups to teach parenting skills, many agencies relied on this approach because of its apparent low cost and sense of efficiency gained from having one staff effort reach multiple learners simultaneously. While parenting classes were an ineffective teaching strategy, they sometimes provided a setting for social interaction valued by parents attending the classes.