

Are Children of Disabled Parents at Risk for Parentification?

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Sometimes when we get out of the van I ask my nine-year old daughter to take my crutches out for me. Every so often she tries to use the crutches herself, holding them out from under her arms, and measuring how much she's grown since last time. We might make a comment or a joke together, say, about her wanting to reach my lofty height of five feet. I am aware of other people watching us, and I know that some might think it is inappropriate for my daughter to get my crutches for me, that they think this task is just another *burden* placed on the children of parents with disabilities. The concern is that such children become *parentified* by the ways in which they take care of the parents with disabilities.

The term parentification has been used to describe an unhealthy process whereby children, in the absence of functioning parental and adult figures, take on psychoemotional or caregiving tasks at inappropriately young ages. For example, the child of a parent who is actively alcoholic may make meals, call work to say the parent is out ill, pay bills, and provide nurturance and care for younger children. Such use of the term may be warranted. However, this concept of parentification has been applied to children of parents with disabilities without consideration of whether it is accurate. For example, a review of a recent book entitled "Lost childhoods" (Jurkovic, 1997) says that the process of creating parentified children "is found in families experiencing such diverse crises as...*physical* or emotional disability" (emphasis added). There is a general image of parents with disabilities as "dependent and selfish in their needs for assistance from their children" (Olsen, 1995, p. 47). But is it true that children of parents with disabilities are parentified?

In fact, virtually nothing is known about the tasks—or their nature, frequency and intensity—that children of parents with disabilities perform because of the parent's disability, nor the gender and age of these children. Yet a pervasive assumption is that parents, limited by their physical disabilities, and overwhelmed by the caregiving tasks associated with raising a child, will over-rely on their able-bodied child for tasks that burden that child at a too-young age. There are four problems with this assumption. First, it is based on prejudice. Families with disabilities are viewed through a lens of pathology which guides the research and clinical work, doing a great disservice to the population it supposedly serves. The second problem with this assumption is that there are no normative data on how children help and what chores and tasks children do, so deciding what is over-burdensome is presumptuous. Third, there are great cultural and socioeconomic differences in the expectations for children's helping behaviors. Fourth, this assumption is not supported by the literature. In fact, at least one study (Cohen, 1997) that paid careful attention to the issue of burden found the opposite--that parents with disabilities take great care not to overburden their children because of the parent's disability, perhaps even erring in the other direction. Another study, on children of fathers with spinal cord injury (SCI), examined the issue of helping. Results indicate that "although children reported helping SCI fathers more than able-bodied fathers, they did not resent providing aid to their

fathers” (Buck & Hohmann, 1983, p. 223). Indeed, clinical impressions (c.f., Kirshbaum, 1988; Kirshbaum & Rinne, 1985) are supported by research indicating that parents will overburden themselves and even put themselves at risk of injury rather than overtaxing the child (Tuleja & DeMoss, 1999).

However, we cannot simply dismiss the issue of parentification. Anecdotal clinical evidence (M. Kirshbaum, 1997, personal communication) indicates that in some instances even very young children may perform personal caregiving tasks to parents (e.g., assistance with bathing or toileting), in the absence of suitable levels of resources and support for getting these needs met in other ways (e.g., through personal attendant services). We need to be thoughtful in our approach to this issue. Further, we can’t assume that a child is performing a task *because* of the parent’s disability. The need for assistance with the task may be prompted by other factors such as poverty, unemployment, social class, or number of children in the household.

It may be possible to develop a template for thinking about parentification, a list of questions that might be posed about any task, in trying to decide if it is appropriate for a child to take on. Below is a baker’s dozen of factors that could be considered in evaluating the appropriateness of the child performing the task (Olkin, 1999).

- (A) The age and developmental level of the child being asked to perform the task;
- (B) The nature of the task itself;
- (C) The symbolic meaning of the task;
- (D) Whether the task causes any pain or discomfort to the recipient;
- (E) The frequency the child performs the task;
- (F) If the child is the sole person performing the task and/or has primary responsibility for ensuring it is done;
- (G) The consequences of not performing the task;
- (H) The degree of support the child has in performing the task;
- (I) The relationship of the child to the person for whom the task is performed;
- (J) The roles of the other able-bodied members of the house;
- (K) Time of day or night the task must be completed;
- (L) The total number of such tasks;
- (M) Any positive benefits to the child for performing the task.

Let’s consider some tasks using the list above. I asked my thirteen year old son to install an automatic curtain opener, but did not ask him to install grab bars. I have him put chemicals in our spa, but do not have him help me in and out of it. I’ll ask my daughter to fetch my black shoes, but not sanitary napkins. These tasks may be similar in many dimensions listed above, but they differ critically in other ways that substantially alter the nature of the tasks.

What is important is not that we designate specific tasks as appropriate or inappropriate in advance, but that we use reasonable guidelines for decision making. If children are performing caregiving tasks inappropriately, it is possible that the problem lie with the roles within the family. However, it also is likely to stem from inadequate resources to meet needs. If the latter is the case then problem is better addressed by social policy and the service delivery systems, not by pathologizing the family.

It seems that families attempt to differentiate among the three related but quite distinct concepts of parentification, responsibility, and interdependence. The latter two are emphasized while the former is to be avoided. “We need to be careful of assuming that the caring tasks

themselves deprive children of what would otherwise be a ‘normal’ childhood” (Olsen, 1996, p. 46).

As I send my daughter out to the driveway to get the newspaper every morning, the issue of parentification is not just an abstract idea to me. From making dinners to cleaning their rooms, my kids perform a variety of household and family tasks. With each job they take on in part or in full, I am aware of the need for me, as a parent with a disability, to take on the extra task of asking myself a series of questions to ensure that the job does not cross some fine line between participation and parentification. Thus it is I who incurs the extra burden, namely the need to take a defensive stance against accusations of parentification, and to prevent whenever possible my children from sharing in the stigma of disability.

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