

Special-Population Children at the CAS of London and Middlesex: Developmentally Challenged and Medically Fragile Children ¹

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Child protection advocacy groups have stressed the possibility that children currently in the child welfare system have more developmental complexities than children who entered care in the late 1980s (Klee, Kronstadt & Zlotnick, 1997). Children with developmental delays are most at risk for remaining in foster care for extended periods than children without such challenges (Horwitz, Simms & Farrington, 1994). The needs of children with developmental delays may exhaust the resources of child welfare agencies. This drain has been hypothesized to impact foster placement stability (Takayama, Wolfe & Coulter, 1998; Denby, Curtis, Alford & Nielsen, 1998).

Relative to specific child outcomes, children who are developmentally challenged are compounded with other vulnerabilities that these young children experience, such as physical health problems, the trauma of abuse and/or neglect, lower educational achievements, and the subsequent removal from the child's home of origin (Silver et al., 1999; Blome, 1997). The existence of developmental delays in children has been found to affect the parent-child relationship (Hauser-Cram, Warfield, Shonkoff & Krauss, 2001).

Capen and Delow (1998) describe medically fragile children as complex, fragile children that require significant technological support and intervention, although children who do not require technology can also be medically fragile. A review of the stresses in families with medically fragile children in the general population found that these families report financial worries over equipment, supplies, and care delivery as a source of major family stress (Ratliffe, Harrigan, Haley, Tse & Olsen, 2002). This finding is further supported by families experiencing major job changes as a direct result of having a medically fragile child in the home (Burke, Kauffmann, Harrison & Wisken, 1999). Ratliffe et al. (2002) report that families with medically fragile children often feel isolated in the home, with decreased social contacts and supports, which tends to increase the stress of family isolation.

The present research collected information related to children who are developmentally challenged and medically fragile and receiving service through the CAS

of London and Middlesex. The low frequency of children with special needs in both the 1995 and 2001 sample precludes significance testing. Descriptive information on these two groups of children is presented. Data was not collected on the specific nature of the child's developmental delay. Thus, children defined as developmentally challenged in this sample reflect those who speech-language delays, cognitive delays, fine and/or gross motor delays.

Table 1

Descriptive Information for Developmentally Challenged Children Seen at the CAS of London and Middlesex in 1995 and 2001

	1995 (n = 450)	2001 (n = 592)
Number of children involved in a developmental service program	20 (4.4%)	38 (6.4%)
Children's mean age in years at time of developmental service program*	2.73 (2.6)	3.75 (3.9)
Age range	0-9 years	0-14 years
Number of males involved in a developmental service program	12 (60%)	25 (66.5%)
Number of females involved in a developmental service program	8 (40%)	13 (33.5%)
Developmentally challenged children in the care of the CAS at the time of the current CAS referral	8 (5%)	33 (9%)
Prior CAS placement history of developmentally challenged children	10 (48%)	20 (53%)
Nature of the developmental service involvement**:		
• In-home parent support	8 (40%)	5 (13.2%)
• respite care	3 (15%)	6 (15.8%)
• special education classes at school	3 (15%)	12 (31.6%)
• developmental assessments	6 (30%)	6 (15.8%)
• speech therapy	--	6 (15.8%)
• special-needs camp	--	1 (3%)
• missing information regarding service	--	2 (5%)

* standard deviation in parentheses ; ** percentages may not add up to 100 because of rounding

Table 2

Descriptive Information for Medically Fragile Children Seen at the CAS of London and Middlesex in 1995 and 2001

	1995 (n = 450)	2001 (n = 592)
Number of medically fragile children	16 (3.6%)	21 (3.5%)
Mean age in years* of medically fragile children at time of CAS referral	2.82 (3.7)	3.95 (5.1)
Age range	0-12 years	0-15 years
Gender		
• males	10 (62.5%)	8 (38.1%)
•		

Table 3

List of Medically Fragile Disorders for Children Seen at the CAS of London and Middlesex in 1995 and 2001

	1995 (n = 450)	2001 (n = 592)
Medically Fragile Disorder*		
• failure to thrive	4 (25%)	2 (9.5%)
• premature birth	2 (12.5%)	1 (4.8%)
• shaken baby syndrome	--	2 (9.5%)
• cystic fibrosis	1 (6%)	--
• cerebral palsy	1 (6%)	2 (9.5%)
• spina bifida	--	3 (14.2%)
• spinal meningitis	--	1 (4.8%)
• osteogenesis imperfecta	1 (6%)	--
• bronchopulmonary dysplasia	--	1 (4.8%)
• respiratory problems	--	1 (4.8%)
• heart disease	1 (6%)	2 (9.5%)
• fetal alcohol syndrome	1 (6%)	--
• drug dependent	1 (6%)	--
• bladder exstrophy	1 (6%)	
• hematoma	1 (6%)	1 (4.8%)
• Epstein's anomaly	1 (6%)	--
• severe allergies and asthma	1 (6%)	--
• viral flu	--	1 (4.8%)
• hypoglycaemia	--	1 (4.8%)
• hypotonia in limbs	--	1 (4.8%)
• missing information related to medically fragile disorder	--	2 (9.5%)

*percentages may not add up to 100 because of rounding

Discussion

The summary of data on developmentally challenged and medically fragile children highlight a number of critical issues for children with special medical needs or developmental problems in child welfare. In both the 1995 and 2001 sample, the rate of developmentally challenged children is lower than most published studies of children in the child welfare system. Leslie et al. (2002) report the prevalence rates of developmentally delayed children, mostly in out-of-home care, to range from 13% to as high as 62%. The rates in the current sample are comparable with prevalence rates for developmental delay in the general population, which are estimated to be between 4% - 10% (Fox & McManus, 1996). Given the variability in the definitions of developmental delay,

however, data on the prevalence of developmentally challenged children in the general population and child welfare is limited.

The high rate of developmentally challenged children admitted to CAS care at the time of the current CAS referral in 2001 is striking. Thirty-three of the 38 developmentally challenged children are admitted to CAS care, and more than half of these children had been in a CAS placement prior to the current placement. It has been suggested that placement in care for children with developmental problems has repercussions after reunification, when children return to parents who may be uninformed about their health care needs and are inadequately prepared to provide appropriate care (Silver et al., 1999). As a result, the child's well-being is compromised and the family is again vulnerable to child welfare intervention. Leslie et al. (2002) report that children with delays, especially in the cognitive/language domains are difficult to place with any type of caregiver. Training programs for parents should target all types of caregivers, including biological parents, foster, and kin, to ensure that appropriate expectations for the child's emotional, cognitive, and physical capabilities are met. Additionally, child protection workers would benefit from training related to young children's development with or at risk for developmental delay.

The phrase "medically fragile" is used to characterize children who are profoundly disabled from various causes. In the present sample, the type of medically fragile disorders among children seen at the CAS of London and Middlesex in both years varies considerably. Caring for a child with complex medical problems at home is an extraordinary challenge, commitment, and strength on the part of the caregivers. Thus, it is not surprising that the vast majority of reasons for referral of medically fragile children seen at the CAS in both 1995 and 2001 are for diminished parenting capacity. A family with a medically fragile child must not only be highly motivated to care for the child, but must also have adequate financial resources, and be well connected to available community services. This may explain why more than half of the medically fragile children in the 2001 sample are admitted to CAS care. It has been suggested, however, that because parents of medically fragile children are especially stressed and often feel like prisoners in their own home, out-of-home care is an important service for the family and should not be ignored (Harrigan, Ratliffe, Patrinos & Tse, 2002). The level of care

required by most medically fragile children is prodigious, and all families need to have support from a cohesive family intervention plan to buffer the distresses that constantly arise. It should be kept in mind, however, that a major source of stress for families with medically fragile children are the very professionals in the community for whom they rely on for support (Ratliffe et al., 2002; Harrigan et al., 2002).

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