

Disabled Children's Childhoods: Findings from a three-year study

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Introduction

The Inclusive Early Childhood Service System (IECSS) is a 7-year partnership that seeks to understand the institutional interactions of families who have young children with disabilities. The study begins with the premise that understanding families' earliest experiences with early childhood services helps us as a society to understand the construction of some children as disabled. Through annual interviews with families over a 6-year period our ultimate goal is to inform social policy, and theoretical understanding of childhood disability from the perspective of families, and to create a more complex discourse on early childhood disability that is grounded in recognition of the value of diverse childhoods.

Method

Our key methodological approach in this research is Institutional Ethnography (IE). The intention of IE is to understand institutional cultures and practices from the standpoint of families. Institutional ethnography is concerned with how "ruling relations" shape everyday lives. Ruling relations are the administrative, managerial, professional, and discursive organization of the regulations, and the governing structures of a society (Smith 2006 and 2009).

Mapping

Social relations are illuminated through research. Institutional mapping examines the ideology behind the institution, and the processes that are in place to do the work of the institution. Our aim is to provide empirical evidence of the ideology, the processes, and the social relations (Graheme, 1998), through documenting the work of families as they interact with early intervention and education. Fundamental to the approach is mapping the actual activities of the institution (Campbell & Gregor, 2008).

Research Questions

1) How do the institutions work/hold power?

The system works because families work and mothers work. The institutions have processes that families and frontline workers must comply with in order to gain and maintain access.

2) What processes lead to action in the system?

The early intervention system operates on a medical model that is deeply entrenched.

3) What do families contribute to the system?

The more services a family has, the more the system needs from them (time, money, energy, relationships, etc.).

Findings

- Accessing disability supports and services is a lot of work for families. Family members become **responsible for normal**, in a series of requirements on the part of institutions for them to simultaneously act as advocates for their children and to comply with the structural requirements of programs. Families are making continual micro decisions to **comply or to resist the power of the state**.⁵
- The system of services for young disabled children is predicated on a medical model, which makes diagnosis or designation of disability central to how the system works. This approach is not consistent with many cultural viewpoints regarding disability and is used as a gatekeeper for services that may be central to inclusion and quality of early learning and childcare for children with disabilities. A **theory of disability** matters. Often a theory of disability is operating as a meta text: a professional discourse that is taken for granted.
- The institution holds power by creating a **textual record of disability** and by governing the actions of families, children and workers through **procedural and managerial actions**. Most discourse on childhood disability centres on gaining access to the services.
- **Disability justice** requires recognition of the complex identities, communities and intersectional oppressions that families and their children experience in their daily interactions. This means that attention must be paid to colonialism, racial and ethnic status and discrimination, gender, economic disparity, geographic and political contexts.

References

- Campbell, M., & Gregor, F. (2008). *Mapping social relations: a primer in doing institutional ethnography*. Toronto, ON: University of Toronto Press.
- Graheme, P.R. (1998). Ethnography, Institutions, and the Problematic of the Everyday World, *Human Studies*, 21(4), pp. 347-360.
- Smith, D. (2006).
- Smith, D. (2009).
- Underwood, K., Church, K., & van Rhijn, T. (in press). Responsible for Normal: The Contradictory work of Families. In S. Winton, Carpenter, B., & Parekh, G.

(Eds) *Critical Perspectives on Education Policy and Schools, Families and Communities*. Charlotte, NC: Information Age Publishing (IP).

- Underwood, K., Smith, A., & Martin, J. (2018). Institutional mapping as a tool for resource consultation. *Journal of Early Childhood Research*, 1-11. DOI: 10.1177/1476718X18818205.
- Underwood, K., Frankel, E., Spalding K., & Brophy, K. (2018). Is the right to early intervention being honoured? A study of family experiences with early childhood studies. *Canadian Journal of Children's Rights*, 5(1), 56-70. DOI: 10.22215/cjcr.v5i1.1226.