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Reaching everyone: Promoting the inclusion of youth with disabilities in evaluating foster care outcomes

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ABSTRACT

Efforts to evaluate foster care outcomes must avoid systematic exclusion of particular groups. Although often unrecognized as such, youth with disabilities are highly overrepresented in the U.S. foster care system, and yet youth with some disabilities, including those with intellectual, serious emotional, and physical impairments may be underrepresented in research and evaluation studies evaluating foster care outcomes. The recruitment and retention of youth with various disabilities in such studies can be impeded by under-identification of disability and relatively high placement and school mobility. Furthermore, youth with various disabilities may experience more disappointing outcomes than foster youth overall, underscoring the importance of including these youth in outcome tracking efforts. This is especially relevant given the recent implementation of the National Youth in Transition Database (NYTD), which requires that state child welfare agencies gather baseline information about youth in foster care at age 17, and then survey outcomes at 19 and 21. To promote the full participation of foster youth with disabilities in such outcome evaluation, this paper describes successful strategies for identifying and retaining participants that were used in three separate longitudinal intervention studies. These strategies include the systematic recruitment of foster youth by special education status, and creative use of validated tracking and retention strategies incorporating minor accommodations as needed.

1. Introduction

As state child welfare agencies implement new requirements for tracking the outcomes of youth who age out of the foster care system, they will likely encounter significant recruitment and retention challenges that are familiar issues in research with this population. These barriers include the identification, recruitment, and retention of foster youth in outcome studies, all of which affect the generalizability of findings to inform policy and practice with these youth. Further, methodological challenges associated with measuring foster youths' outcomes may inhibit researchers and evaluators from including foster youth who experience identified disabilities in outcome studies. Yet, inclusion of youth with disabilities is particularly important because these youth are overrepresented in foster care and experience of disability may influence transition outcomes in ways that are relevant to policy and practice improvement.

These issues are especially timely given the implementation of the National Youth in Transition Database (NYTD) requirements of the John H. Chafee Foster Care Independence Program (CFCIP; Public Law 106-169), which mandate the systematic evaluation of outcomes of youth aging out of foster care. Thus, the dual purpose of this article is to discuss barriers to the inclusive representation of all youth in foster care outcome research, and to share successful strategies and lessons learned in the identification, recruitment, and retention of youth in care with disabilities, as derived from three longitudinal outcome studies conducted by the authors. The implications of these strategies are discussed as relevant to outcome research with older foster youth in

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[2] The Research Consortium to Increase the Success of Youth in Foster Care is dedicated to experimentally identifying approaches that improve the outcomes of young people in foster care. Other members of the Research Consortium to Increase the Success of Youth in Foster Care who contributed to this paper were: Diann Drummond, Portland Public Schools; Kevin George, Oregon Foster Care Program and Jackie Burr, Oregon Department of Education.

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general, as well as with youth in care who experience disabilities, and offered in the context of ongoing implementation of NYTD requirements by state child welfare agencies.

1.1. Barriers to identification

Youth with disabilities represent a disproportionately large subpopulation of young people served by child welfare systems, with studies suggesting prevalence rates of 30 to 60% (Geenen & Powers, 2006; Hill, 2012; Lambros, Hurley, Hurlburt, Zhang, & Leslie, 2010; Westat, 1991). In comparison, approximately 5.2% of children and youth ages 5–17 years of age, and 10% of youth and adults ages 18–64, were identified as having disabilities in the 2010 American Community Survey (U.S. Census, 2010), and the National Center on Educational Statistics reported that 13.2% of youth receive special education services (U.S. Department of Education & National Center for Education Statistics, 2011). The relatively high prevalence of disability among youth in foster care is likely related to factors such as maltreatment, parental substance abuse, educational barriers, and community disadvantage, which disproportionately affect youth in care (Courtney & Hughes-Heuring, 2005; Osgood, Foster, & Courtney, 2010; Pecora et al., 2005, 2003).

A prerequisite for accurately evaluating the outcomes of youth with disabilities in foster care is knowledge of disability status, and child welfare administrative data likely underestimates prevalence. Eligibility for special education services is often used to identify disability in children and youth; and is defined by the Individuals with Disabilities Education Act (2004) as having specific learning, intellectual, hearing, speech or language, visual, serious emotional, orthopedic, or health impairments, as well as autism, traumatic brain injury, deaf-blindness or multiple disabilities that impede learning and require special education services. Direct comparison of child welfare and state special education records tends to reveal additional youth with disabilities, such that Hill (2012) and Schmidt et al. (in press) found that 60% of the youth in foster care were identified as experiencing a disability.

While providing important information on disability status, access to special education records is complicated by two factors: (1) Individuals with Disabilities Education Act (2004) requirements (CFR §300.30) that identify the foster parent or another designated educational surrogate—who cannot be an employee of the child welfare agency—as legal representative for educational decision-making, and (2) Family Educational Rights & Privacy Act of 1974, 1232 g; 34 CFR Part 99 requirements that prohibit sharing of school data without permission of the child's legal representative. These barriers to information sharing increase the likelihood that child welfare caseworkers will be unaware of a youth's special education status and miss recording this information in administrative databases (Hill, 2009). This systematic under-identification of youth in foster care who experience a disability limits researchers' ability to accurately identify, specifically recruit, or reliably analyze outcomes by disability status.

1.2. Barriers to inclusion

Representative outcome studies can also be limited by barriers that make it difficult to access youth in foster care for large, population-based studies (Berrick, Frasch, & Fox, 2000; Gilbertson & Barber, 2002; Jackson, Gabrielli, Tunno, & Hambrick, 2012). These include obstacles related to confidentiality (e.g., identifying which youth are in foster care) and complexities around who must give legal consent for the recruitment and participation of youth in the study (e.g., child welfare administrators, caseworkers, district courts, caretakers, etc.). Researchers therefore often rely on foster parent and caseworker nominations to recruit youth participants (e.g., Jackson et al., 2012). However, this introduces the risk of biased sampling, as youth who are referred may differ in important ways from youth who are not identified as appropriate for recruitment. This may be due to assumptions about a youth's potential interest in participating in a study, but may also reflect biased perceptions that youth experiencing various disabilities would not be eligible for, or capable of, participation in the study protocol.

This bias may also lead to the categorical exclusion of foster youth with various disabilities from research based on the assumption that they wouldn't be able to participate fully in the study as designed. For example, The Midwest Evaluation of the Adult Functioning of Former Foster Youth did not include "youth with developmental disabilities or severe mental illness, and youth who were incarcerated or in a psychiatric hospital" (Courtney & Hughes-Heuring, 2005, p. 5), while the Casey Alumni Study did not include young adults who had a major physical or developmental disability (e.g., an IQ score of less than 70; Pecora et al., 2005, p.18). The SPARK project, a federally-funded longitudinal study examining resilience, excluded youth "if they demonstrated an IQ score in the mentally retarded range or if they had a diagnosis of autism" (Jackson et al., 2012, p. 1208). This concerning trend very likely reflects assumptions regarding the capacities of youth with certain types of disabilities to participate in research as well as the practical challenge of incorporating flexible research protocols and youth-specific strategies for inclusion and accommodation within outcome studies. Nevertheless, the exclusion of youth with these disabilities leaves the field with a dearth of information about a subgroup of young people exiting foster care who face additional hurdles while moving into adulthood.

1.3. Barriers to retention

The challenge of including youth with disabilities in foster care outcome research extends beyond biases that may be introduced in recruitment. In general, transition-age youth in care are likely harder to retain in longitudinal outcome studies relative to peers that are not child welfare system-involved, as foster care factors play a role in finding and retaining these participants. For example, youth in foster care are often not locatable through their parents like other adolescent research participants (Ribisl et al., 1996; Stephens, Thibodeaux, Sloboda, & Tonkin, 2007), they are more likely to change residences during the course of the research compared to other youth, and any relocation information likely depends on collaborative relationships with public agency staff, who may (intentionally or unintentionally) limit researcher access to updated information (Berrick et al., 2000). Indeed, Scott (2004) estimates that such "blocked access can create attrition rates as high as 50%, depending on the nature of the sample" (p. 32). These issues are especially salient within the subgroup of older foster youth who experience disabilities, as these youth may have especially poor outcomes relative to their peers in foster care.

Limited research on the experiences of youth in foster care with disabilities suggests these youth might be more difficult to follow into adulthood. For example, Anctil, McCubbin, O'Brien, Pecora, and Anderson-Harumi (2007) found that foster care alumni with physical or psychiatric disabilities had poorer physical health outcomes, more psychiatric diagnoses, and lower self-esteem than non-disabled foster care alumni. Smithgall, Gladden, Yang, and Goerge (2005) found that only 16% of foster youth in special education with a primary disability classification of emotional disturbance graduated from high school, and 18% left school because they were incarcerated. Hill (2012) and Slayter and Springer (2011) respectively discovered that foster youth with school-identified disabilities and with intellectual disabilities experienced more frequent placement changes than their peers without disabilities and they were less likely to be reunified with biological family or to be placed in relative care. Likewise, Geenen and Powers (2006) found that youth in both foster care and special education had lower academic achievement and school stability, compared to youth in foster care only or youth in special education only. These findings suggest heightened disadvantage for youth with disabilities in foster care, including placement instability, multi-system involvement, and separation from family. This may increase the difficulty of longitudinal outcome evaluation, but also underscores the necessity of successful recruitment and retention of these foster youth in outcome