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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.

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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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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

research. On the other hand, youth in foster care who specifically experience developmental disabilities may be easier to retain in longitudinal studies, given the higher likelihood that they are being served by multiple systems which could provide information about the youth. These factors underscore the need for flexible and individualized inclusion strategies for youth participation in research.

1.4. Relevance of representative participation

There are known obstacles to the full participation of older foster youth in outcome research, specifically among youth experiencing disabilities, and these are especially relevant as states fully implement outcome tracking programs to meet the objectives of the NYTD. As of 2010, state agencies are required to collect baseline data in several outcome areas for youth in foster care at age 17, and then survey these youth at ages 19 and 21, regardless of whether they are still in foster care (Social Security Act §477(f), 2010). Assuming a sufficient sample size, state agencies are required to reduce sampling bias by randomly selecting a cohort for follow-up. States also must report service data, including whether youth receive special education services. To be in compliance, the participation rate must be 80% for youth in foster care and 60% among youth who have exited foster care, and states with non-compliant participation rates can be penalized between 1–5% of their CFCIP funding (Social Security Act §477(e) (2), 2010). Thus, the ability to track these youth over time—regardless of whether these transition-age youth are hard to locate and/or engage in data collection efforts—has a direct impact on state agency funding.

The NYTD is intended to inform transition services for youth in foster care, but there is a risk of response bias if the youth who are most disenfranchised are also the most difficult to identify, track, and engage in data collection. If researchers, state agencies, and policy-makers intend to gather accurate data over time on the outcomes of youth exiting care, it is essential that the large proportion of these youth who face additional challenges associated with disability are accurately represented. Furthermore, it is crucial that the NYTD allowance for the exclusion of youth experiencing an incapacitating mental or physical condition not be misapplied to unnecessarily exclude youth who could participate in data collection with minor accommodation.

The following section introduces three longitudinal intervention studies conducted with transition-age youth in foster care who experience disabilities, for the purpose of contextualizing a number of successful identification, recruitment, and retention strategies that have contributed to an approximately 90% participant retention rate across multiple studies. These strategies and lessons learned are presented as relevant to the recruitment and retention of transition-age youth in foster care during follow-up data collection efforts, including the NYTD, which are designed to inform services based on the transition outcomes of foster youth with and without disabilities.

2. Strategies for the recruitment and retention of foster youth with identified disabilities

The strategies described herein reflect our experiences conducting three experimental evaluations of an intervention to increase self-determination among youth in foster care who experience disabilities as determined by special education status.

The first study, called *My Life* (Powers et al., 2012), randomly assigned 69 youth in foster care and special education, ages 16.5–17.5 at enrollment, to either an Independent Living Program (ILP) comparison group or to an intervention group. The intervention group received approximately 50 h of coaching over a one-year period to identify and achieve transition goals, develop relationships with adult allies, and self-regulate behavior (Powers et al., 2012). Originally designed as universally accessible for youth with and without disabilities, coaching is driven by each youth's future goals and promotes the application of self-determination strategies in carrying out activities and managing challenges. Youth also attended mentoring workshops led by "near peer" young adults with similar life experience who were employed and/or in college. The first My Life study provided preliminary evidence of the intervention's efficacy and the model is now being tested through a full-scale efficacy trial. The second My Life study has enrolled to date 185 youth in special education. The third study, *Project Success* (Geenen et al., 2012), enrolled a somewhat younger group of 133 youth in foster care and special education who were in grades 10–12 (mean age = 15.5). Participants were randomly assigned to a comparison group that received typical services, or an intervention group that participated in a self-determination intervention that was similar to *My Life*, but was shorter and focused on educational goals.

In all three studies, youth outcomes (e.g., levels of self-determination, employment, education) were assessed at three time points and intervention success was measured both in absolute terms and relative to comparison group outcomes. It was therefore very important to successfully track and retain both intervention and non-intervention group youth participants to assess follow-up outcomes.

At the first follow-up assessment for the initial *My Life* study (one year after enrollment), 60 of 69 intervention and comparison group youth were retained in the study. At the second follow-up (two years after enrollment), we located and assessed one of the youth who was missing at the first follow-up, and no additional youth withdrew or were missing. Thus, our attrition rate for *My Life* was 13% after one year and 11% after two-years (Powers et al., 2012).

Regarding the second My Life study currently underway, the attrition rate is 10% at the first follow-up assessment (one year post enrollment); the majority of the second follow-up assessments have not yet come due, so the two-year attrition rate cannot be reported. For the *Project Success* study, 123 of 133 youth were retained at the first follow-up (9 months after enrollment), and an additional four youth could not be located for the second follow-up assessment (18 months after enrollment), for an overall attrition rate of 10.5% (Geenen et al., 2012).

The attrition rates for our studies compare favorably to rates reported for other studies of youth in foster care conducted since 1990, which range from 14% to 51% attrition, with a median rate of 22.5% and average rate of 28.2% (Courtney & Hughes-Heuring, 2005). The following sections describe the tracking and follow-up assessment strategies used in the *My Life* and *Project Success* studies to successfully retain participants at a relatively high rate. First, however, we describe how we identified all possible eligible participants to ensure inclusive recruitment and enrollment, including examples of disability-related accommodations.

2.1. Comprehensive identification of all eligible youth

To ensure that recruitment was comprehensive (every eligible youth was identified) and systematic (every identified youth was contacted), we developed an interagency agreement to exchange information between the public child welfare agency and partnering school districts so we could identify every youth who was in both foster care and special education. As suggested by Hill (2009), we could not reliably identify youth with disabilities in foster care using only the child welfare administrative database, which did not systematically identify whether youth experienced a specific disability or participated in special education. To ensure recruitment of all youth with disabilities in foster care, the child welfare agency initially generated a list of all youth under child welfare guardianship who met the age and geographic eligibility requirements of each study. This list was provided to a school representative who cross-referenced it with special education records to identify which of these youth received special education services. This comprehensive interagency identification procedure was repeated every six months to keep up with the shifting demographics of the youth served by these systems.

2.2. Systematic recruitment of identified youth

Once a comprehensive list of all eligible youth was generated, a staff person from the school district contacted prospective youth and their families and arranged for an in-person orientation. Having a school representative serve as the first point of contact with youth addressed any confidentiality concerns the partnering agencies had, and study funds were dedicated to partially support this staff position. In all three studies, 85–90% of youth assented to participate, the child welfare agency consented to their participation, and their foster parents or other educational surrogates designated under IDEA signed releases permitting exchange of special education information from the schools to the researchers and the child welfare agency.

There were a few instances when caseworkers or foster parents were concerned that a youth was not appropriate for the study because he or she specifically experienced a significant cognitive disability. However, project staff with expertise in providing accommodations visited with these youth and then described for caregivers and caseworkers how various youth-specific accommodations could be used to include the young person in the study. Accommodations included additional support in the consent process, adaptations of the measures or assessment protocol, and tailoring of the intervention. For example, accommodations provided in the consent process included reading the consent form to a youth, reviewing the youth's understanding of one section at a time, substituting straightforward language and examples to clarify meaning, and asking consent comprehension questions twice to ensure consistency in understanding. Adaptations to study assessments included substitution of straightforward language (identified through pilot study cognitive interviews), using icons along with traditional response options, and narrowing down Likert-type scale response options by first asking questions in a “yes” or “no” format. If needed, we conducted the assessment over multiple meetings to accommodate youth who were less comfortable with a single, extended session. In some cases, with youth permission and participation, foster parents or other familiar adults provided answers to demographic and other questions asking objective information about the youth.

Caseworker outreach and education were essential to ensure our studies were as representative as possible, and we strategically deployed staff members who were comfortable and skilled in applying universal accessibility principles. Once caseworkers became familiar with the level of staff expertise in supporting youth participation, particularly youth with cognitive disabilities, consent was typically granted. Only five youth (1%) were excluded from the studies due to disability-related barriers around a consistent ability to give verbal or nonverbal “yes” or “no” responses, which were required for study assent and assessments, and for participation in the intervention, which necessitated that youth have a verbal or nonverbal way to express choice.

2.3. Develop ongoing relationships

Although participant tracking is a rudimentary part of longitudinal research, these efforts can take a back seat in intervention studies. However, if faced with a large subset of participants who cannot be located for follow-up evaluation, most would agree that earlier or more consistent tracking protocols are well worth the time and expense. Threats to internal validity due to attrition—or failure to locate and/or follow-up with research participants—are well-documented (Cotter, Burke, Loeber, & Navratil, 2002; Cotter, Burke, Stouthammer-Loeber, & Loeber, 2005; Flick, 1988; Navratil, Green, Loeber, & Lahey, 1994; Prinz et al., 2001; Scott, 2004; Sullivan, Rumptz, Campbell, Eby, & Davidson, 1996), and data collected can reflect a systematic bias if there are commonalities that make some participants harder to locate and/or retain.

For example, in our study we were at risk for differential attrition by condition because intervention participants developed close relationships with project staff and were generally easier to track and engage for follow-up assessments than youth in the comparison group. Fortunately, potential biases in attrition rates can largely be mitigated with rigorous tracking and consistent monitoring of who drops out of the study and why. Thus, we were able to quickly realize that our comparison group participants would be harder to track and retain, and retention efforts included regular, personalized contact to develop and maintain relationships with project staff on a much smaller scale. Specifically, we instituted regular check-INS by phone to maintain contact with youth in the comparison group, and whenever possible, had the same staff person conduct the check-INS over time, so that youth were communicating with a particular person who could become familiar to them.

This personal relationship often fostered an attachment between the project and comparison group youth, and also helped staff to develop a sense of the stability of a youth's living situation to better anticipate who might be most likely to change placements or run away. In some cases, we proactively established more intensive tracking plans for youth who appeared unusually at-risk for attrition (e.g., many recent placement changes, running away, or dropping out of school). Furthermore, we occasionally attempted a home visit to contact youth who were nonresponsive by phone, or we requested to meet in person with some of the harder-to-track participants to establish rapport and increase project buy-in. It was also effective to stay in touch by mail (e.g., birthday cards, thank-you notes, and assessment reminders) to keep youth engaged and to proactively monitor any returned mail for obsolete contact information in advance of upcoming assessments. Making sure written correspondence was personal (a hand-written note, ideally from a project staff person relatively familiar to the youth) increased its impact. Our experiences affirm the importance of maintaining regular contact with participants as an essential tracking technique, as reported in many other research studies (Cotter et al., 2002; Garner, Passetti, Orndorff, & Godley, 2007; Myers, Webb, Frantz, & Randall, 2003; Navratil et al., 1994; Prinz et al., 2001; Ribisl et al., 1996; Scott, 2004; Yancey, Ortega, & Kumanyika, 2006).

When possible, we also employed the communication strategies favored by many youth. First, text messages to participant cell phones very often proved more effective than voicemails, as youth may not have “minutes” but may have unlimited text message plans, and many youth are more accustomed to texting versus responding to voicemails. We also found that email addresses (which youth could access for free at a public library) and personal profile pages on social networking sites were useful methods to stay in touch with participants (or to locate them if they were missing), so we were careful to specifically ask for permission to contact the youth in these ways. In our experience, participants seemed to appreciate these more youth-friendly communication approaches.

2.4. Collect detailed contact information

Many transition-age foster youth experience a level of instability in their living situation that makes them particularly difficult to track over time without the help of other people in their social network. Foster youth may not only move to new addresses during the course of a study, but custodial decision-makers may change as well. For example, as youth move to and from foster and group homes, and when youth return to their families or are adopted, the current caregivers are not those who originally agreed to support the youth's participation in the study (Myers et al., 2003; Navratil et al., 1994; Scott, 2004). Further, youth exiting care become their own guardians and may live with other youth or adults who have no connection to the study. These shifting circumstances necessitate highly respectful outreach and communication with the youth and those in his or her life to maintain youth willingness to participate in a research study.

In our experience, initially gathering detailed contact information and regularly updating that information (typically every 1 to 3 months) was essential to maintaining a high participation rate. The strategy of gathering all possible contact information has been highlighted in other studies (Capaldi, Chamberlain, Fetrow, & Wilson, 1997; Cotter et al., 2002; Navratil et al., 1994; Scott, 2004; Sullivan et al., 1996), with Ziek, Tiburcio, and Correa (2002) recommending at least five alternative contacts. When first collecting contact information, we asked the youth where they were living and how best to reach them, and clarified that this information would only be used to check in periodically and schedule assessments. We also asked about relatives and kin, close friends, teachers and mentors, or any other significant people in their lives they were likely to remain in touch with for the duration of the study. In asking for this information, we emphasized our commitment to confidentiality and specifically asked for permission to contact these people if we had trouble reaching the youth directly. In our experience, courtesy, tact, and respect were essential when contacting relatives, friends, or other persons who may have had no familiarity with the project (e.g., a former foster parent or a new caseworker), and were therefore reasonably hesitant to provide contact information if they had it. We found that explaining who we were (a program the youth was participating in) and clarifying that the youth gave us their contact information usually resolved any suspicions (this technique is also discussed in Navratil et al., 1994; Ribisl et al., 1996). In many cases, these persons were quite willing to pass a message on to the youth requesting that they contact project staff, and this strategy was often successful.

Lastly, in our experience, retaining participants usually depends on cooperative access and established positive relationships with the agencies youth tend to interface with. At the time of entry into the project, youth and their guardians signed a formal release of information that gave permission for agencies, such as the local school district, to share information with the project. This provided another source of information we could access when we could not reach a youth. For example, in one case, the school assisted us by identifying a new contact person based on an address listed on a student's transcript, and in another case, we learned that a youth who had run away from her foster placement was still attending school every day, and we were able to leave a message for her there. In another case, the release of information allowed us to confirm with the family court that a youth had been incarcerated, and we were able to contact staff where he was located to arrange an assessment visit with him. Therefore, it is important to gather information about the services a youth may receive from other agencies, and maintain a current release from the guardian (or from the youth after they have exited care) that permits other agencies to share information. Guardianship can change as youth shift placements, are adopted, or reunited with birth families, and this circumstance usually requires orientations of new guardians to the follow-along process and signing of new release of information forms.

2.5. Maintain a current database

Successful tracking also requires that all contact information be stored in a systematic way that is easily updated. Such databases can be scaled for project needs and the number of participants, but maintaining accuracy is critical, such that obsolete information is quickly detected. We maintained the accuracy of the database by following known strategies for tracking participants, including calling regularly to check in and periodically sending mailings, and then monitoring returned mail and unreturned phone calls for indication that further effort was required (Capaldi et al., 1997; Cotter et al., 2002; Myers et al., 2003; Prinz et al., 2001; Ribisl et al., 1996; Scott, 2004; Sullivan et al., 1996). Our project made one staff person responsible for maintaining the database, and team members sent updated contact information directly to this person, rather than editing the database themselves, to prevent duplicated effort and minimize errors. The database was also used to record all tracking activities, including all attempted youth contacts, successful strategies used (e.g., looking for a youth at school, emailing the caseworker), and tips for working with a youth or family that might inform future tracking efforts (e.g., use the youth's preferred nickname, or call the foster parent in the evening instead of during the day). When contact information was updated, old information was never deleted, and it was sometimes useful to "circle back" to check formerly valid contact information that became outdated at some point. In our experience, youth often returned to previous placements or stayed in contact with former foster parents, and calling these older contacts sometimes yielded results. Similarly, disconnected phone numbers may be reconnected, and old addresses may still be a viable way to reach participants through friends or relatives. As Cotter et al. (2002) state, "following up on these leads can be time consuming and often result in dead-ends, yet project staff must remain persistent and exhaust every potential avenue to retain these individuals" (p.488).

2.6. Make it easy to participate

From the youth's perspective, it should be very easy to update contact information, ask questions, and reschedule or cancel an appointment. This may be as simple as providing a 24-hour toll-free number and giving youth stamped postcards that can be mailed in with new contact information (McKenzie, Tulsky, Long, Chesney, & Moss, 1999; Ribisl et al., 1996). We also provided accommodations such as "practicing" filling out the postcards with youth, or giving our contact information directly to adults that youth identified as helping them keep track of information. In one case, a participant experiencing multiple placement changes had difficulty staying in touch with the project until he and a staff person agreed that he would call the toll-free number on the first day of each month; from that point on, he remembered without fail to check in, even if it meant just leaving a message on a weekend, and the staff person always called him back to thank him for checking in. We also provided laminated participant identification cards with project contact information, which were especially helpful when youth needed to explain their involvement in the study to new caretakers or caseworkers (Capaldi et al., 1997).

It is up to the research team to make youth participation as convenient and rewarding as possible, partly by developing a team of friendly staff with non-judgmental attitudes and flexible schedules (Capaldi et al., 1997; Cotter et al., 2002; Prinz et al., 2001). Flexible accommodation of youth or family circumstances includes sensitivity to current stressors that may temporarily limit participant receptivity or availability, offering convenient meeting times and locations (in the evenings and on weekends, and somewhere other than the youth's home or the program office). It also helps to respond to missed appointments with non-judgmental understanding (e.g., call it a miscommunication and reschedule with no chastisement, as in Myers et al., 2003).

Another retention strategy is to attempt to relocate or re-engage youth who declined to participate at an earlier follow-up, as refusals may be circumstantial and temporary (Cotter et al., 2002, 2005; Navratil et al., 1994). Working with youth with behavioral disabilities, Cotter et al. (2002) found that youth required increasing contacts as they aged, and when they recommenced contact following a period of youth disengagement, they were able to re-engage 72% of these youth one year later. Prinz et al. (2001) similarly recommend staying in personal contact with disengaged youth who may eventually want to participate if circumstances change. In our experience, this approach has increased project retention. Most notable are youth who were placed in restrictive settings such as group homes, residential treatment, or detention settings, and then moved to less-restrictive foster homes where access to phones and email facilitated communication with the project. Perseverance in maintaining contact with participants in restrictive settings is particularly important for youth in foster care with disabilities, who are more likely to be placed in these settings (Barth, 2002; National Council on Disability, 2008).

2.7. Support tracking efforts

In our studies, social work students at the master's and doctoral levels were assigned a group of participants to follow, and they were primarily responsible for regularly contacting those youth and becoming familiar with their circumstances. This focus and continuity fostered stronger rapport between participants and the project and enabled staff to anticipate challenges that would make it difficult to locate or assess a youth in the future. Our students met weekly with their supervisors to problem-solve any barriers to locating youth, and once these strategies were exhausted, the case would be presented to the entire project team at a staff meeting to brainstorm new ideas (Myers et al., 2003; Ribisl et al., 1996; Scott, 2004). Bringing the case to the entire team helped us identify whether any team members had rapport with the youth we were trying to locate, or had an established connection with any of the youth's key contacts, such as a foster parent or a caseworker. Sometimes the staff person who initially enrolled the youth or conducted the first assessment could be enlisted with the hope that the youth would be more responsive to their efforts. This also alerted the team that a youth could not be found, in case someone had a chance meeting with the youth. In one case, a participant was reconnected with the study when a staff person recognized her at a gas station because she had enrolled the youth in the project two years earlier. We now store digital photos of participants in a password-protected file, so the team knows what an individual participant looks like in case they can't be located.

This team approach worked especially well when we were having trouble tracking a participant who had been in the intervention group for the first 9–12 months of their project involvement. In these cases, we often were able to strategize based on the youth's previous engagement with their intervention coach. In addition to suggesting youth-specific communication strategies, on occasion the coach could suggest places a youth might be spending free time, and we could unobtrusively stop by these location to try to reach out to the youth. For example, we once reconnected with a participant by visiting a video arcade we knew he frequented. Additionally, the established relationship with the coaches was helpful if youth had run away from a foster placement. Often, these youth would be reluctant to speak to project staff they didn't know personally, but would respond if contacted by their previous coach, who could then connect the youth with the staff person assigned to tracking. This relational approach had a positive effect on reducing attrition among the intervention group during the follow-along period, especially as these youth changed foster placements or transitioned from state care, but it is important to note that overall participant attrition rates did not differ significantly for the intervention versus comparison groups across the three studies.

2.8. Make participation worthwhile

Although some youth in the intervention group required similar tracking strategies during the post-intervention follow-along period, they were generally more connected to the project and comparatively easy to engage for tracking and assessment. Overall, it was more difficult to track and retain youth in the comparison group, who met with staff at orientation and for follow-up assessment over the course of 18–24 months, with periodic check-in phone calls (every 1–3 months, depending on youth mobility), mailings (birthday cards, etc.), and face-to-face contact if necessary. Beyond that, there was much less engagement with the project, which understandably made these youth less likely to stay in touch or to respond when contacted to schedule assessments. Furthermore, although there were efforts to personally engage these youth as much as possible without influencing the study results, staff could offer little by way of services or support to the comparison group during the study, or to the intervention group during the follow-along period, although appropriate referrals were made if a youth was in crisis. This situation was frustrating at times for some youth, and for staff members who had come to know them.

Given these circumstances, much can be gained when youth feel acknowledged and compensated for their willingness to participate from beginning to end of the project. Although staff persistence is a mainstay of retention (Cotter et al., 2002; Navratil et al., 1994), it is best followed by compensation that makes it worthwhile for youth to be found. Capaldi et al. (1997) recommend generous pay for demanding assessments, partly because participants may simply have better things to do, as well as thank-you cards and small gifts. In one study of treatment outcomes, adolescents cited compensation as their top reason for continued participation, and youth had a favorable attitude about their follow-up experiences overall (Garner et al., 2007). Some have justified the cost of searching for follow-up participants relative to the cost of attrition (e.g., Cotter et al., 2005), and the same can be said for the cost of maintaining youth involvement through rewarding contact with the project. For example, in our studies, youth were compensated $10 for each check-in conversation and $20 for updating their contact information by postage-paid postcard or by phone. We found that youth were generally happy to keep us updated when they understood the process and payment for updating contact information was not abused. Lastly, the project compensated youth approximately $20 for each hour of assessment time. Thus, our experience was that compensation was essential for respectfully acknowledging the time and commitment of participants as well as providing incentives that are particularly valuable to youth who unfortunately often live in very marginal circumstances.

A number of our retention strategies are illustrated in the case of "Mary", a youth in the comparison group who was due for her final assessment. Mary had moved to an out-of-state group home, and upon turning 18, she left the facility with no forwarding information. We emailed Mary's previous caseworker who provided contact information for Mary's grandmother. After speaking with the grandmother several times to explain the purpose of the call and to build trust, she directed us to Mary's previous foster parent. The foster parent was able to tell us that Mary had enrolled herself in a transitional housing program and was unable to receive calls, and after a few conversations, she agreed to relay a message to Mary. Mary called a few weeks later to schedule her assessment, and she shared that she was residing in a homeless shelter and had ultimately decided to call us because she needed the $20 for food. Mary's story demonstrates the importance of positive rapport with caseworkers, a respectful approach with third parties who are naturally reluctant to provide information, patience and determination on the part of tracking staff, and the necessity of making participation easy and worthwhile. Mary's story also illustrates the uncertainties that many of youth face as they transition out of foster care and into adulthood.

2.9. Limitations

The strategies described here resulted in nearly 90% retention of youth in foster care with various disabilities across the three studies (Geenen et al., 2012; Powers et al., 2012), well above the average of 71.8% retention reported for other foster youth studies (Courtney & Hughes-Heuring, 2005). However, it is important to acknowledge that the follow-along of youth in these studies is only 1.5–2 years, and half of the participants were involved in an intervention, which would be expected to increase retention relative to the comparison groups. However, the fairly equivalent retention rates in the intervention and comparison groups suggest that our strategies were largely effective across condition. Further, the success of these techniques in retaining participants within the two randomized groups suggests that these retention strategies may be similarly effective with youth with a range of propensity to voluntarily engage in tracking and data collection efforts. Lastly, our strategies were successful with youth who experienced various types of disabilities and as illustrated by the aforementioned examples, we often found that contextual factors (e.g., placement change, homelessness, incarceration, social isolation, etc.) had more bearing in retention than disability status, per se. It is also important to clarify that our

retention strategies balance accurate participant outcome evaluation—specifically with a hard-to-track subpopulation—with constant mindfulness of confidentiality concerns related to these strategies. For those who may replicate some of the approaches described here, note that staff members must be trained to obtain explicit participant consent to make extraordinary but respectful efforts to locate and contact them in the future regarding their ongoing study participation. This includes representing the research study in a way that maintains the confidentiality of participant status as "foster youth" or "disabled" based on their involvement in the study. These potentially stigmatizing labels should not be used when contacting third parties, such as school staff, or when attempting to contact youth face-to-face after regular tracking strategies like phone calls have failed. Participants are always welcome to opt out of such outcome studies, but this should never happen because they feel that their privacy has been violated or that their ongoing willingness to participate has been taken for granted.

3. Implications for outcome evaluation

This article describes strategies that were successfully used to identify, recruit, track, and retain almost 400 youth in foster care who experience disabilities and are one of the most disproportionately represented, least understood, and most at-risk groups in the child welfare system. Our experience underscores the feasibility of involving these youth in outcome evaluation efforts by demonstrating that validated approaches for promoting study retention in general (e.g., Booker, Harding, & Benzaval, 2011), and recent methods applied with at-risk youth populations (e.g., Lankenau, Sanders, Hathazi, & Bloom, 2010; Tobler & Komro, 2011), are generally effective in the successful retention of transition-age youth in foster care with disabilities. These validated practices, paired with principles of universal access and straightforward accommodation, enable youth with a variety of functional challenges to participate in evaluation activities.

The recruitment and retention strategies presented here are applicable to outcome evaluation studies with older youth transitioning from foster care, with or without disabilities. These strategies also may be valuable for NYTD researchers and administrators developing protocols for data collection and outcome reporting that ensure that the outcomes of all youth exiting foster care, including those with disabilities, are accurately captured. However, gathering meaningful and accurate information representing all youth in foster care will depend on the successful recruitment and retention of all participants. If at-risk groups of young people, such as youth experiencing a disability and/or high mobility, are systematically excluded from the NYTD or other data collection efforts, the results will present a skewed and overly-positive picture of how young people are faring after foster care.

This potential bias can be mitigated in any outcome evaluation by using the strategies presented here, which include: 1) engaging in comprehensive identification and systematic recruitment of all eligible youth; 2) establishing follow-along relationships through periodic check-ins; 3) collecting detailed contact information for youth and people they stay in touch with; 4) maintaining a current, detailed database or old and new contact information; 5) training and supporting tracking staff; and 6) acknowledging and compensating participants. Because it requires sufficient resources to effectively track and retain participants using these strategies, we recommend beginning with the easiest approaches first (calling, letters) before introducing more time-intensive techniques (such as contacting third parties or making home visits), which could be targeted to the most mobile or at-risk youth. A multi-pronged approach is often most useful when the experiences and circumstances of youth vary widely. Ultimately, it is most critical to remember that usually it is not that participants are unwilling to continue, only that you cannot find them to maintain participation (Ribisl et al., 1996).

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