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Who Speaks for Me? Addressing Variability in Informed Consent Practices for Minimal Risk Research Involving Foster Youth

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ABSTRACT

BACKGROUND: Youth in protective custody (i.e., foster care) are at higher risk for poorer physical and mental health outcomes compared with those who are not in custody. These differences may be due in part to the lack of research on the population to create evidence-based recommendations for health care delivery. A potential contributor to this lack of research is difficulties in obtaining informed consent for empirical studies in this population. The objective of this study was to describe the approaches to obtaining informed consent in minimal risk studies of foster youth and provide recommendations for future requirements.

METHODS: We conducted a systematic review of the literature to characterize the informed consent approaches in published minimal risk research involving youth in foster care. We searched PubMed, CINAHL, PsychINFO, Embase, ERIC, Scopus, and EBMR. Inclusion criteria were: studies conducted in the United States, included current foster youth, minimal risk, peer reviewed, and published in English. Full text was reviewed, and individuals required to consent and assent were extracted.

RESULTS: Forty-nine publications from 33 studies were identified. Studies required 0 to 3 individuals to consent. Individuals required to give consent included case workers (16, 48%), foster caregivers (12, 36%), biological parents (7, 21%), judges (5, 15%), and guardian ad litem

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(2, 6%). Twenty-nine (88%) studies required the youth's assent. The studies used 14 different combinations of individuals. One (3%) study utilized a waiver of consent.

CONCLUSIONS: There is no consistent approach for obtaining informed consent for foster youth to participate in minimal risk research. Consent should ideally involve individuals with legal authority and knowledge of the individual youth's interests and should not be burdensome. Consensus regarding consent requirements may facilitate research involving foster youth.

Keywords: foster care, informed consent, child welfare, custody, research

INTRODUCTION

Over 430,000 children are in protective custody (i.e., foster care) in the United States (U.S. Department of Health and Human Services, 2016). Retrospective chart reviews suggest that foster children face a wide range of health challenges (Szilagyi, 2015; Beal & Greiner, 2015; Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994; Hansen, Mawjee, Barton, Metcalf, & Joye, 2004; Jee & Simms, 2006; Takayama, Wolfe, & Coulter, 1998). Nearly half of foster children have chronic medical conditions (Kavaler, 1983; Leslie et al., 2005; Steele & Buchi, 2008; Stein et al., 2013) and one-third to one-half have developmental delays/cognitive impairment (Jee et al., 2010). Rates of preventable health issues, including mental health concerns and acute health problems, are also greatly elevated in foster children, particularly among older youth (Simms, Dubowitz, & Szilagyi, 2000). Studies of young people who were emancipated from foster care when they were between 18 and 21 years of age also indicate poorer outcomes: they experience higher rates of sexually transmitted infections, pregnancy, drug use/abuse, and chronic medical conditions compared to young adults who were never in foster care (Courtney, 2005). Young adults formerly in foster care also experience lower access to needed medical care and self-rated quality of health (Courtney, 2005). It is important to identify ways to improve these health outcomes.

Despite identified health disparities, there is a limited evidence base to inform providers of the origin and course of the health problems in foster youth and potential interventions that would improve their lives. Existing research studies are primarily qualitative and descriptive with small sample sizes or analyses of administrative data. Health care providers often face challenges implementing these interventions in children in foster care because the child welfare system itself introduces unique dynamics into the patient's care, such as uncertainty regarding the stability of a given foster placement, the identity of the primary caregiver, and the method of securing consent for treatment (Szilagyi, 2015).

The lack of evidence-based treatment recommendations may be due in part to decreased research opportunities related to difficulties obtaining informed consent (Liu, Cox, Washburn, Croff, & Crethar, 2017). Informed consent, the understanding and voluntary agreement to participate in research, is believed to be one of the most important research protections because it protects the autonomy of the subject and thereby ensures that the welfare and interests of the subject are always the highest priority (Gupta, 2013). When the research subject is a child, informed consent is generally provided by the parent(s) or guardian(s) with assent from the child when developmentally appropriate (National Institutes of Health, 2016).

Children in foster care do not have a traditional parent serving as a guardian to promote and protect their welfare and interests and provide informed consent. Instead, foster youth have a variety of adults who serve in different roles: the biological parent(s) may retain the right to see the child and participate in medical decision making, the foster caregiver oversees the child's day-

to-day activities and has an obligation to meet the child's daily needs, the caseworker is the temporary legal custodian and oversees the child's healthcare decisions, the guardian ad litem (GAL) and court appointed special advocate (CASA) serve as the legal representatives and advocate for the child's interests, and the judge or magistrate is the final decision-maker regarding the child's stay in foster care. It is frequently unclear who can and should provide informed consent for foster youth to participate in research. Requiring multiple individuals to consent may be logistically burdensome.

Additionally, institutional review boards (IRBs) sometimes consider youth in foster care vulnerable to coercion or undue influence and require extra protections with respect to informed consent and assent. While the Office for Human Research Protections (OHRP) provides guidance on the protection of foster children in research and obtaining informed consent, it has not provided guidance to clarify who among a number of eligible individuals acting on behalf of the child as custodian or in loco parentis should provide consent for children in foster care.

The objective of this study was to identify the informed consent requirements used in published minimal risk research involving foster youth to better understand what approaches investigators and IRBs have considered acceptable and to make recommendations for future consent requirements.

METHODS

A systematic review of the literature was conducted to characterize the informed consent requirements in published minimal risk research involving youth in foster care. Studies were included if they were conducted in the United States; included current, as opposed to former, foster youth; were minimal risk; peer reviewed; and published in the English language. Eligibility was limited to studies conducted in the United States because child welfare practices vary by country. To maximize the number of studies included in the review, the search was not limited to specific years.

A search of PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsychINFO, Embase, Education Resources Information Center (ERIC), Scopus, and Evidence-Based Medicine Reviews (EBMR) was completed on June 2, 2015. With support from a medical librarian, search strategies were developed that varied by database. For example, the PubMed query utilized terms for foster care, informed consent, children, and English (see Supplemental Material). Additional studies were identified through the personal knowledge of investigators and from references in published papers. Articles were screened through review of the titles and abstracts and then through the analysis of the full text. Two individuals conducted the review and discrepancies were resolved by a third reviewer.

Reviewers then evaluated articles meeting the inclusion criteria to determine whether a waiver of consent was granted or informed consent was required. If informed consent was required, the reviewers identified which types of individuals were required to provide consent and/or assent. Data extraction was done independently by 3 reviewers and discrepancies resolved by consensus. In cases where consent procedures were unclear or inadequately described, an investigator attempted to contact the corresponding author for clarification (Figure 1).

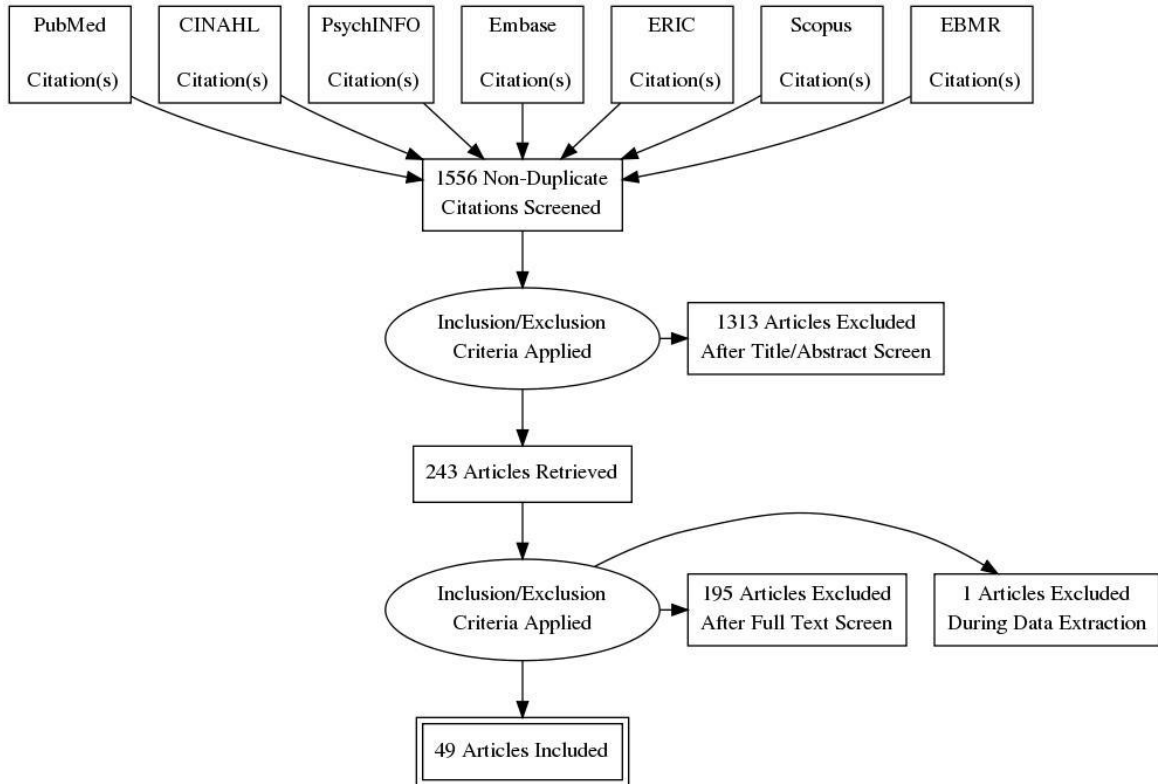


Figure 1. Literature review inclusion

RESULTS

The review process identified 1556 unique articles through database searches and other resources; 243 remained after screening of the titles and/or abstracts, and 49 fulfilled the inclusion criteria based on the review of the full text. These 49 articles reflected 33 unique studies. The method of consent was not clear in eight studies. Four of the corresponding authors of the eight studies responded to requests to provide additional information, allowing seven additional articles to be included in this review.

Of the 33 studies, 1 involved a waiver of consent and 32 required informed consent and/or assent (See Supplemental Table 1). The study permitting a waiver was a study to help youth improve their ability to negotiate and cope with changes. Among studies where a waiver was not granted, youth's assent or consent and the consent of an additional 0 to 3 other individuals was required, most frequently (25, 78%) requiring 1 person to consent. The individuals required to consent, in decreasing order of frequency, were case workers (16, 48%), foster caregivers (12, 36%), biological parents (7, 21%), judges (5, 15%), and GALs (2, 6%). Twenty-nine (88%) studies required the youth's assent and 2 (6%) the youth's consent alone (Table 1).

Biological Parent	Foster Caregiver	Caseworker	GAL	Judge	Youth	Number of Studies
	X				X	5
X					X	4
X		X			X	2
		X			X	9
		X	X		X	1
	X	X	X		X	1
				X	X	2
		X		X	X	1
	X	X		X	X	1*
	X	X		X	X	1
	X					2
X						1
					X	2
						1**

*This study required judge OR caseworker consent in addition to caregiver consent and youth assent

**This study had a waiver of consent and assent

Table 1. Studies by individual required to consent and/or assent

The studies solely requiring the youth's consent enrolled participants greater than or equal to 16 or 17 years old. We identified 14 different combinations of individuals required to consent and/or assent. The most common (9, 28%) was caseworker consent and the youth's assent (Table 2). No clear patterns were present in study content or question and consent procedures across studies.

Consent Process	# Studies	# Publications
Caregiver consent, youth assent	5	9
Biological parent consent, youth assent	4	6
Biological parent and caseworker consent, child assent	2	2
Caseworker consent, youth assent	9	17
Caseworker and GAL consent, youth assent	1	1
Caseworker, GAL, and caregiver consent, youth assent	1	1
Judge consent, youth assent	2	2
Judge and caseworker consent, child assent	1	1
Judge or caseworker consent, caregiver consent, youth assent	1	1
Judge and caseworker and caregiver consent, youth assent	1	3
Caregiver consent only	2	2
Biological parent consent only	1	1
Child consent only	2	2
Waiver of consent and assent	1	1

Table 2. Summary of consent approaches

DISCUSSION

Our literature review revealed significant variation in the approach to consent and assent for foster youth's participation in minimal risk research. Studies varied significantly in the types and number of individuals required to consent and/or assent.

This variation is likely to contribute to the limited research on foster youth. Without clear consensus and guidelines, investigators may be less likely to pursue studies of foster youth, IRBs may be less likely to approve applications or require impractical protections, and journal editors may be less likely to publish studies. In turn, limited research may have a negative impact on youth in foster care by contributing to an absence of evidence-based interventions tailored to the unique challenges presented by foster care, such as placement instability. It is therefore imperative to develop clear informed consent guidelines that adequately protect foster youth without creating burdens that exclude them from the benefits of research. This is consistent with the Revised 2016 Council of International Organizations of Medical Sciences International Ethical Guidelines, calling for inclusion of children and persons incapable of giving consent in research investigations, with appropriate safeguards in place (van Delden & van der Graaf, 2017).

To the degree that they are able to assent, youth's assent should be required. There is no reason to believe that youth in foster care are less capable to assent.

A number of criteria can be used to evaluate potential candidates to consent for foster youth to participate in minimal risk research. Individuals should have legal authority to consent. In theory, legal authority should be coincident with moral standing, but this is not always the case in practice. The decision whether or not to enroll the child should be based on the child's best interest: "acting so as to promote maximally the good of the individual" (Buchanan & Brock, 1989). While minimal risk research does not have the prospect of direct medical benefit, it may have the prospect of indirect medical, psychological, or pedagogical benefit (Ross, 1998). Knowledge of the child is needed to individualize decisions about whether participation involves risk. For example, while a venous blood draw is generally considered minimal risk, some children have an excessive fear of needles and the risk designation could be higher when that is the case. The decision maker should also not have a significant conflict of interest that would impair his/her decision making. Given the value of research and the potential indirect benefits to participants, logistical considerations also have a legitimate, albeit secondary, role.

Potential candidates to provide consent include biological parents, foster caregivers, case workers and directors of the child welfare agencies, GAL or CASA, and judges.

While the child's biological parents have had many of their parental rights suspended when the child enters foster care, they typically retain medical decision-making authority. While some biological parents have their child's best interests at heart, others have been charged or convicted of abuse. They may have spent limited time with their child recently and may not be aware of their child's current interests. They may also have conflict of interests impairing their decision making. Parents, for example may refuse to give informed consent out of frustration with their child being in foster care. Finally, from a practical standpoint, they may be difficult to contact.

Foster caregivers hold no legal rights over the child. Depending on the duration of the placement, they may not know the child well enough to determine what is in the particular child's best interest. However, in many cases, foster caregivers facilitate the child's participation in a study, e.g., they bring the child to study visits. Their understanding and participation may be important to the study's success. Participation may conflict with the parents' and other children's

needs. Lack of consideration of these needs is a limitation of the best interest standard, and these needs are not generally considered a conflict of interest.

Child Welfare (the county or the state) actually holds custody of the child in foster care and as custodian, appear to have the strongest legal argument to give consent. Determining which individual within the child welfare system, if any, should give consent is, however, difficult. Caseworkers have varying knowledge about individual children and their best interests and typically do not have the authority to make decisions regarding non-routine medical treatment. Caseworkers also carry heavy caseloads and, therefore, it may be difficult to reach them, and they may be reluctant to accept additional responsibilities. The director of the child welfare agency typically has the most authority for decision-making but has the least information about the individual foster child's preferences to consider best interest.

GALs, typically attorneys or social workers, and CASAs, typically volunteers, are specifically appointed by the juvenile court to identify and represent the best interests of the child while in foster care. Variable backgrounds, training, and workloads, however, result in wide discrepancies in level of knowledge about a specific child. An assumption cannot be made that anyone in a GAL or CASA role is adequately informed to represent the child's best interests for research participation.

A legal argument can also be made for juvenile court judges or magistrates giving consent. They have few if any conflicts of interest. They therefore may be more objective and also have experience evaluating children's best interests in other contexts, e.g., divorce proceedings. They, however, often do not know individual children well enough to analyze risks and benefits to them to assess best interest. They can also be difficult to access and may be reluctant to expand their responsibilities.

Unfortunately, no single individual typically fulfills all the criteria which would be desired for consent in research for youth in foster care. The case worker in a well-functioning child welfare system may come the closest. Alternatively, including all the individuals involved in a child's life to fulfill all of the legal obligations and ensure the involvement of representatives who best know the individual child is appealing but logistically impractical. It would be difficult to convene deliberations and to address unresolved conflicts. Finally, individualized determination of the relevant parties to consent for each youth is not practical for investigators.

This study demonstrates that there is no widely accepted practice for informed consent and assent for youth in foster care; this variability likely reflects the complicated nature of the lives of children in state or county custody. To advance the discussion we offer the following recommendations:

1. Participation in minimal risk research should be offered to all youth in protective custody (e.g. foster care), when they are otherwise eligible, as research is essential to improving evidence-based care to improve outcomes for these youth.
2. Consent for minimal risk research studies should be sought from a legal representative AND a best interest representative who has knowledge of the child and his/her particular interests, for all youth in foster care.
 - a. The legal representative could be a child welfare caseworker, the director of child welfare, or a juvenile court judge.
 - b. The best interest representative could be a biological parent, a foster caregiver, a child welfare case worker, or a GAL/CASA.

- c. At times, a legal representative may also serve as a best interest representative, e.g., a case worker who has worked with a child for multiple years through many placements may have the best working knowledge of the child's current welfare and interests.
3. Assent should be required from youth in foster care for minimal risk research as it is for other youth.

While this approach will continue to have practical limitations, such as disagreements between the representatives when two are identified, it at least allows an opportunity for a consistent, ethically justifiable approach towards consent for youth in foster care for minimal risk research. Also, as the reported literature review demonstrates that historically over 20% of studies utilized 3 or more individuals to consent, this is anticipated to be a decrease in burden for research investigators and thereby increase participation. The standardization is an improvement over the current system and allows for evaluation in the future for modification of recommendations.

The study has a number of limitations. As with all systematic literature reviews, relevant articles may not have been identified or may have been inappropriately excluded. There is a risk that unpublished studies used other consent requirements. Other limitations include inadequate descriptions of the consent process in published manuscripts and the potential that investigators misinterpreted the consent process described in published manuscripts.

CONCLUSIONS

Significant variation exists in informed consent practices for minimal risk research involving youth in foster care. Published studies have required the consent of varying numbers and types of individuals. A consistent approach that recognizes the need for both legal validity and individualized assessment of interests may support investigators, IRB members, and journal editors and facilitate research and improve foster youth health outcomes.

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SUPPLEMENTAL MATERIAL

Pubmed Search Terms

PubMed query

“Search ("out of home"[All Fields] OR "out-of-home"[All Fields] OR "child welfare"[MeSH Terms] OR "child welfare"[All Fields] OR "children's services"[All Fields] OR "foster home care"[MeSH Terms] OR ("foster"[All Fields] AND "home"[All Fields] AND "care"[All Fields]) OR "foster home care"[All Fields] OR "fostering"[All Fields]) AND ("informed consent"[MeSH Terms] OR ("informed"[All Fields] AND "consent"[All Fields]) OR "informed consent"[All Fields]) AND ("infant"[MeSH Terms] OR "infant"[All Fields] OR "child"[MeSH Terms] OR "child"[All Fields] OR "adolescent"[MeSH Terms] OR "adolescent"[All Fields]) AND "english"[Filter)”.

Supplemental Table 1. Included data sets and articles for literature review

Administrative Data Articles					
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
Patterns of Care (POC) Study (Garland et al, 2001)	Sample of youth 6 to 17 y.o. from five publicly funded sectors of care in San Diego County	1,715 youth	Mix of youth and caregivers	Caregiver consent, youth assent	Eligible if youth received services from any of 5 public service sectors serving youth with substance abuse issues
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Aarons, G. A., Brown, S. A., Hough, R. L., Garland, A. F., & Wood, P. A. (2001). Prevalence of adolescent substance use disorders across five sectors of care. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i> , 40(4), 419-426.		To examine the level of concordance between reports of substance abuse by youth enrolled in public sectors of care and their parents, and identify potential predictors of parental awareness of substances	1,036 enrolled (after missing data excluded)	13-18 y.o.	Ages 6 to 17 were eligible; 12,662 identified, 3,402 randomly selected, 2,555 located, 1,715 completed 1 interview
Leslie, L. K., Weckerly, J., Landsverk, J., Hough, R. L., Hurlburt, M. S., & Wood, P. A. (2003). Racial/ethnic differences in the use of psychotropic medication in high-risk children and adolescents. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i> , 42(12), 1433-1442.		To investigate race/ethnicity differences in the rates of psychotropic medication use by youth	1,342 enrolled (after missing data excluded)	6-17 y.o.	Ages 6 to 17 were eligible; 12,662 identified, 3,402 randomly selected, 2,555 located, 1,715 completed 1 interview
Garland, A. F., Hough, R. L., McCabe, K. M., Yeh, M. A. Y., Wood, P. A., & Aarons, G. A. (2001). Prevalence of psychiatric disorders in youths across five sectors of care. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i> , 40(4), 409-418.		To examine prevalence of psychiatric disorders among the 5 public sectors	1,618 enrolled (Diagnostic Interview Schedule for Children data available)	6-17 y.o.	Ages 6 to 17 were eligible; 12,662 identified, 3,402 randomly selected, 2,555 located, 1,715 completed 1 interview
Leslie, L. K., Aarons, G. A., Haine, R. A., & Hough, R. L. (2007). Caregiver depression and medication use by youths with ADHD who		To examine the relationship between caregiver depression	390 enrolled (out of 444 eligible)	6-17 y.o.	3,417 randomly selected, 1,715 completed 1 interview, 444 diagnosed w/ ADHD via Diagnostic Interview Schedule for Children

receive services in the public sector. <i>Psychiatric Services</i> , 58(1), 131-134.		and medication use by youths with ADHD			
Aarons, G. A., Monn, A. R., Leslie, L. K., Garland, A. F., Lugo, L., Hough, R. L., & Brown, S. A. (2008). Association between mental and physical health problems in high-risk adolescents: A longitudinal study. <i>Journal of Adolescent Health</i> , 43(3), 260-267.		To examine the relationship between mental and physical health problems in a sample of high-risk youth	1,332 enrolled (after missing data excluded)	9-18 y.o.	Ages 6 to 17 were eligible; 12,662 identified, 3,402 randomly selected, 2,555 located, 1,715 completed 1 interview
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
Great Smokey Mountain Study	A longitudinal epidemiologic study of mental health problems and service use within a predominately rural region of southeastern US	1,346 eligible	Mixture of youth and caregivers	Biological parent consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Farmer, E. M., Burns, B. J., Chapman, M. V., Phillips, S. D., Angold, A., & Costello, E. J. (2001). Use of mental health services by youth in contact with social services. <i>Social Service Review</i> , 75(4), 605-624.		To compare mental health service need and use between three different subsections of youth including youth in foster care	1,073 enrolled	9, 11, 13 y.o.	Sample of 4,500 youth from public schools in 11 counties, 4,067 found to be eligible, 1,346 met inclusion criteria
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
LONGSCAN	A coordinated set of 5 prospective studies of the causes, correlates, and consequences of child abuse and neglect	Not Reported	Data collection from multiple informants, including maternal caregivers	Biological parent consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Runyan, D.K., Hunter, W.M., Socolar, R.R., Amaya-Jackson, L., English, D., Landsverk, J., Dubowitz, H., Browne, D.H., Bangdiwala, S.I. and Mathew, R.M. (1998). Children who		To examine the relationship between social capital and developmental and	667	2-5 y.o.	Cross-sectional analysis of participants in North Carolina (141), San Diego (146), Baltimore (196), and Seattle (184)

prosper in unfavorable environments: the relationship to social capital. <i>Pediatrics</i> , 101(1), 12-18.		behavioral outcomes in high-risk preschoolers			
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
National Longitudinal Study of Adolescent Health (Add Health)	Large, nationally representative sample of youth with waves of data across 80 US high schools and 52 US middle schools collected over 6 years	15,197	Varied	Biological parent consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Ahrens, K., DuBois, D. L., Lozano, P., & Richardson, L. P. (2010). Naturally acquired mentoring relationships and young adult outcomes among adolescents with learning disabilities. <i>Learning Disabilities Research & Practice</i> , 25(4), 207-216.		To determine if naturally acquired mentoring during adolescence is related to improved adult outcomes	1,714	7th - 12th grade	90,118 had interview, 20,745 had second interview 1 year later, 15,197 had interview 2-6 years after first interview
Ahrens, K. R., DuBois, D. L., Richardson, L. P., Fan, M. Y., & Lozano, P. (2008). Youth in foster care with adult mentors during adolescence have improved adult outcomes. <i>Pediatrics</i> , 121(2), e246-e252.		To examine the impact of adult mentors on outcomes of youth in foster care	310 youth only	14 – 18 y.o.	90,118 had interview, 20,745 had second interview 1 year later, 15,197 had interview 2-6 years after first interview
Ahrens, K. R., Richardson, L. P., Courtney, M. E., McCarty, C., Simoni, J., & Katon, W. (2010). Laboratory-diagnosed sexually transmitted infections in former foster youth compared with peers. <i>Pediatrics</i> , peds-2009.		To study the relationship between being in foster care and risk of sexually transmitted infections	14,322	7th - 12th grade	90,118 had interview, 20,745 had second interview 1 year later, 15,197 had interview 2-6 years after first interview
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
National Study of Child and Adolescent Well-Being (NSCAW)	A longitudinal study examining the characteristics, needs, and outcomes of children for alleged abuse and neglect	Variable	Mixture of youth and caregivers	Caseworker consent, youth assent	Most studies dealt with youth who had contact with the foster care system within a 15 month time period beginning in Oct 1999
Article		Objective	# Enrolled	Ages Included	Enrollment Plan

Leslie, L. K., James, S., Monn, A., Kauten, M. C., Zhang, J., & Aarons, G. (2010). Health-risk behaviors in young adolescents in the child welfare system. <i>Journal of Adolescent Health, 47</i> (1), 26-34.	To examine rates and patterns of health-risk behavior among youth in foster care	993 (out of 5,501)	11 – 15 y.o.	Spanning 96 counties across 36 states, children were randomly selected from a population of children between 0-15 years, then those below 11 and above 15 were excluded
Leslie, L. K., Hurlburt, M. S., Landsverk, J., Barth, R., & Slymen, D. J. (2004). Outpatient mental health services for children in foster care: A national perspective. <i>Child abuse & neglect, 28</i> (6), 697-712.	To examine factors influencing the use of outpatient mental health among youth in foster care	462 (out of 1,291)	2 – 15 y.o.	Cohort included children 0-14 y.o. with out-of-home placement for at least 1 year
Traube, D. E., James, S., Zhang, J., & Landsverk, J. (2012). A national study of risk and protective factors for substance use among youth in the child welfare system. <i>Addictive Behaviors, 37</i> (5), 641-650.	To examine the association between baseline psychosocial risk and protective factors	827 (out of 5,501)	11 – 14 y.o.	Data were collected between 1999 to 2002 resulting in 5,501 eligible children, 1,180 were between 11 and 14, 1,030 were interviewed at waves 1, 3, and 4 of original study, 827 had substance use data available
Burns, B. J., Phillips, S. D., Wagner, H. R., Barth, R. P., Kolko, D. J., Campbell, Y., & Landsverk, J. (2004). Mental health need and access to mental health services by youths involved with child welfare: A national survey. <i>Journal of the American Academy of Child & Adolescent Psychiatry, 43</i> (8), 960-970.	To study the relationship between need for and use of mental health services among foster youth	3,803 (out of 5,504)	2 – 14 y.o.	5,504 eligible from randomly selected cohort, restricted to ages 2-14 resulting in 3,803 participants
Stahmer, A. C., Leslie, L. K., Hurlburt, M., Barth, R. P., Webb, M. B., Landsverk, J., & Zhang, J. (2005). Developmental and behavioral needs and service use for young children in child welfare. <i>Pediatrics, 116</i> (4), 891-900.	To examine the developmental and behavioral needs and service utilization for children with child welfare involvement	2,813 (out of 5,504)	Less than 6 y.o.	5,504 eligible children identified with child welfare involvement, children less than 6 were included resulting in 2,813 children
Raghavan, R., Zima, B. T., Andersen, R. M., Leibowitz, A. A., Schuster, M. A., & Landsverk, J. (2005). Psychotropic medication use in a national probability sample of children in the child welfare system. <i>Journal of Child & Adolescent Psychopharmacology, 15</i> (1), 97-106.	To examine the psychotropic medication use among children in the child welfare system	3,114 (number eligible not reported)	2 – 14 y.o.	Excluded children in foster care for 1 year at time of sampling as well as children less than 2 y.o.
Leslie, L. K., Raghavan, R., Zhang, J., & Aarons, G. A. (2010). Rates of psychotropic	To examine use of psychotropic	2,521 (out of 5,501)	2 – 16 y.o.	Included youth ages 2 to 16

medication use over time among youth in child welfare/child protective services. <i>Journal of Child and Adolescent Psychopharmacology</i> , 20(2), 135-143.		medication over time among foster youth			
Leslie, L. K., Raghavan, R., Hurley, M., Zhang, J., Landsverk, J., & Aarons, G. (2011). Investigating geographic variation in use of psychotropic medications among youth in child welfare. <i>Child abuse & neglect</i> , 35(5), 333-342.		To examine geographic variation in psychotropic medication use among youth in child welfare	2,504 (number eligible not reported)	2 – 15 y.o.	Included youth ages 2 to 15
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
National Study of Child and Adolescent Well-Being II (NSCAW II)	Includes a cohort of children who had contact with the child welfare system within a 15 month period that began in Feb 2008	5,872	Mixture of youth and caregivers	Caseworker consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Stein, R. E., Hurlburt, M. S., Heneghan, A. M., Zhang, J., Rolls-Reutz, J., Landsverk, J., & Horwitz, S. M. (2014). Health status and type of out-of-home placement: Informal kinship care in an investigated sample. <i>Academic pediatrics</i> , 14(6), 559-564.		To assess sociodemographic health and mental health of children in out-of-home living situations	1,608	0-17.5 y.o.	Included only children who began living in foster care or formal or informal kinship care after the child welfare investigation
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
NSCAW & Add Health	Same description as above	Not Reported	Mixture of youth and caregivers	Caseworker consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Fettes, D. L., Aarons, G. A., & Green, A. E. (2013). Higher rates of adolescent substance use in child welfare versus community populations in the United States. <i>Journal of studies on alcohol and drugs</i> , 74(6), 825-834.		To compare psychosocial factors to lifetime and current substance abuse rates among foster youth	4,445 Add Health; 730 NSCAW	12 – 14 y.o.	Ages 12-14 at time of first interview, whose caregiver also participated, and for whom sample weights were available

Fettes, D. L., & Aarons, G. A. (2011). Smoking behavior of US youths: A comparison between child welfare system and community populations. <i>American journal of public health, 101</i> (12), 2342-2348.		To investigate factors associated with smoking among youth	4,472 Add Health; 740 NSCAW	12 – 14 y.o.	Ages 12-14 at time of first interview, whose caregiver also participated, and for whom sample weights were available
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
LA County Department of Child and Family Services (DCFS)	Management Information System of children aged 6 through 12 living in out-of-home placements from three of the eight county service areas between July 1996 and March 1998	2,103	Youth	Caseworker, GAL, and caregiver consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan
Zima, B. T., Bussing, R., Crecelius, G. M., Kaufman, A., & Belin, T. R. (1999). Psychotropic medication treatment patterns among school-aged children in foster care. <i>Journal of Child and Adolescent Psychopharmacology, 9</i> (3), 135-147.		To examine levels of psychotropic medication use and patterns of treatment among foster care	302	6 – 12 y.o.	2,103 children during the 21-month study period, 472 randomly selected, 330 verified eligible by caseworker, 302 completed the first home interview.
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes
San Diego County Administrative Data	Cohort of children and adolescents (ages 0-17) who had entered out-of-home care due to maltreatment between May 1990 and October 1991 and remained in placement for at least 5 months	1, 221	Mixture of youth and caregivers	Judge and caseworker and caregiver consent, youth assent	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan

Litrownik, A. J., Newton, R. R., & Landsverk, J. A. (2005). Assessment of depressive symptomatology in young maltreated children. <i>Journal of Human Behavior in the Social Environment</i> , 11(3-4), 135-156.		To explore depression in young maltreated children	197	3-7 y.o.	354 eligible 3-7 y.o., 197 completed study, 157 either couldn't be located or refused to participate	
Leslie, L. K., Landsverk, J., Ezzet-Lofstrom, R., Tschann, J. M., Slymen, D. J., & Garland, A. F. (2000). Children in foster care: factors influencing outpatient mental health service use. <i>Child abuse & neglect</i> , 24(4), 465-476.		To determine factors affecting outpatient mental health service use by children in foster care	480 (out of 1,078)	4-17 y.o.	Inclusion criteria included (1) remained in out-of-home care at 4 months after entry into foster system, (2) were placed in SD County, (3) had Department of Social Services data available	
Newton, R. R., Litrownik, A. J., & Landsverk, J. A. (2000). Children and youth in foster care: Disentangling the relationship between problem behaviors and number of placements. <i>Child abuse & neglect</i> , 24(10), 1363-1374.		To examine relationships between changes of placement and problem behaviors over 1 year period	415	2-17 y.o.	1,221 eligible children from larger cohort, 934 had data obtained, 465 met interview timing criteria, 50 excluded due to incomplete data	
Data Set	Description	# Eligible	Participants	Consent Method	Other Notes	
Lucas County Children's Services Independent Living Program (ILP) and Post-emancipation Program (PEP)	List of current and emancipated youth in either ILP or PEP programs within Lucas County, Ohio	Not Reported	Youth	Child consent only	Data reviewed included 72 foster youth enrolled in ILP on 1/1/2008, 108 ILP youth who emancipated from care from 1/1/2005 to 12/31/2007, and 43 emancipated youth who received PEP services from 1/1/2006 to 12/31/2007	
Article		Objective	# Enrolled	Ages Included	Enrollment Plan	
Mares, A. S. (2008). Needs Assessment of Emancipating Foster Youth in Lucas County, Ohio Final Report. Retrieved January, 12, 2009.		To inform future service-oriented requests for proposals to aid emancipating youths	31	16 y.o. and older	Focus groups consisted of ILP youth in foster homes, ILP youth placed in treatment homes, 8 PEP young adults, and 5 emancipated youth who didn't receive PEP services	
Non-Administrative Data Articles						
Article		Objective	# Enrolled	Ages Included	Consent Method	Enrollment Plan
Green, A. E., Bekman, N. M., Miller, E. A., Perrott, J. A., Brown, S. A., & Aarons, G. A. (2011). Parental awareness of substance use among youths in public service sectors. <i>Journal of studies on alcohol and drugs</i> , 72(1), 44-52.		To examine the level of concordance between reports of youths enrolled in public sectors of care and their parents and	985 (out of 1,418)	11-18 y.o.	Caregiver consent, youth assent	Participants drawn from a representative group

	identify potential predictors of parental awareness of substances				
Garland, A. F., Saltzman, M. D., & Aarons, G. A. (2000). Adolescent satisfaction with mental health services: Development of a multidimensional scale. <i>Evaluation and Program Planning, 23</i> (2), 165-175.	To develop a multidimensional scale of adolescents' satisfaction with mental health services	180 (out of 584)	13-18 y.o.	Caregiver consent, youth assent	584 eligible based on criteria, 225 randomly selected
Price, J. M., & Landsverk, J. (1998). Social information-processing patterns as predictors of social adaptation and behavior problems among maltreated children in foster care. <i>Child Abuse & Neglect, 22</i> (9), 845-858.	To determine if social information processing patterns are predictive of later social adaptation and behavior problems	124 (number eligible not reported)	5-10 y.o.	Caregiver consent, youth assent	0-18 y.o maltreated children eligible; siblings randomly selected
Gardner, H. (1996). The concept of family: Perceptions of children in family foster care. <i>Child Welfare, 75</i> (2), 161.	To explore perceptions of children in family foster care settings	43 with 42 matched controls (number eligible not reported)	8-15 y.o.	Caregiver consent, youth assent	Five foster care agencies selected 51 children between 8 and 15 who have been in care more than 1 year
Taussig, H. N., Clyman, R. B., & Landsverk, J. (2001). Children who return home from foster care: A 6-year prospective study of behavioral health outcomes in adolescence. <i>Pediatrics, 108</i> (1), e10-e10.	To describe behavioral health outcomes for youth who were reunified after placement in foster care in comparison to those who did not reunify	214 (out of 287)	7-12 y.o.	Biological parent consent, youth assent	287 youth in foster care for at least 5 months in San Diego, California from 1990-1991
Johnson, P. R., Yoken, C., & Voss, R. (1995). Family foster care placement: The child's perspective. <i>Child Welfare, 74</i> (5), 959.	To explore the impact of foster care from child's perspective	59 (out of 95)	11-14 y.o.	Biological parent and caseworker consent, child assent	95 randomly selected children in family foster homes in Illinois
Taussig, H. N. (2002). Risk behaviors in maltreated youth placed in foster care: A longitudinal study of protective and	To examine protective and vulnerability factors in youth in foster care	214 (out of 287)	7-12 y.o.	Biological parent and caseworker consent, child assent	Children placed in Southern California county's shelter

vulnerability factors. <i>Child abuse & neglect</i> , 26(11), 1179-1199.					facility for maltreated youth
Poulton, R., Van Ryzin, M. J., Harold, G. T., Chamberlain, P., Fowler, D., Cannon, M., ... & Leve, L. D. (2014). Effects of multidimensional treatment foster care on psychotic symptoms in girls. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i> , 53(12), 1279-1287.	To test whether a comprehensive psychosocial intervention can alter psychotic symptoms during adolescence	166 (number eligible not reported)	13-17 y.o.	Caseworker consent, youth assent	Girls in court mandated community based out-of-home care due to delinquency
Narendorf, S. C., Fedoravicius, N., McMillen, J. C., McNelly, D., & Robinson, D. R. (2012). Stepping down and stepping in: Youth's perspectives on making the transition from residential treatment to treatment foster care. <i>Children and youth services review</i> , 34(1), 43-49.	To explore perspectives of youth transitioning from residential to treatment foster home programs	8 (out of 46)	16-18 y.o.	Caseworker consent, youth assent	Youth in foster care for at least 5 months who were in residential treatment
McMillen, J. C., Narendorf, S. C., Robinson, D., Havlicek, J., Fedoravicius, N., Bertram, J., & McNelly, D. (2015). Development and piloting of a treatment foster care program for older youth with psychiatric problems. <i>Child and adolescent psychiatry and mental health</i> , 9(1), 23.	To describe the development of a program to aid in step down from residential to treatment foster care homes	14 (out of 46)	16-18 y.o.	Caseworker consent, youth assent, foster caregivers also consented	Youth in foster care at least 9 months living in residential facility
Tanaka, M., Wekerle, C., Schmuck, M. L., Paglia-Boak, A., & MAP Research Team. (2011). The linkages among childhood maltreatment, adolescent mental health, and self-compassion in child welfare adolescents. <i>Child Abuse & Neglect</i> , 35(10), 887-898.	To examine the relationships between child maltreatment and self-compassion	117 (out of 561)	16-20 y.o.	Caseworker consent, youth assent	Youth in foster care, group care, independent living, or in-home getting child welfare services
Courtney, M. E., Piliavin, I., Grogan-Kaylor, A., & Nesmith, A. (2001). Foster youth transitions to adulthood: A longitudinal view of youth leaving care. <i>Child welfare</i> , 80(6), 685.	To examine how foster youth fare during/after transition to independence	141 (out of 149)	17-18 y.o.	Caseworker consent, youth assent	Youth approaching aging out of foster care in Wisconsin in 1995 and 1996
Raghavan, R., Shi, P., Aarons, G. A., Roesch, S. C., & McMillen, J. C. (2009). Health	To determine whether youth in foster care	404 (out of 450)	17 y.o.	Caseworker consent, youth assent	Adolescents leaving foster

insurance discontinuities among adolescents leaving foster care. <i>Journal of Adolescent Health</i> , 44(1), 41-47.	who lose Medicaid can secure other insurance				care in 8 counties in a midwestern state
Weisz, V., Wingrove, T., Beal, S. J., & Faith-Slaker, A. (2011). Children's participation in foster care hearings. <i>Child abuse & neglect</i> , 35(4), 267-272.	To determine impact of children's participation in dependency court hearings	93 (out of 150)	8-18 y.o.	Caseworker and GAL consent, youth assent	Children involved in abuse/neglect court system in single county
Hobbs, S. D., Goodman, G. S., Block, S. D., Oran, D., Quas, J. A., Park, A., ... & Baumrind, N. (2014). Child maltreatment victims' attitudes about appearing in dependency and criminal courts. <i>Children and youth services review</i> , 44, 407-416.	To investigate attitudes of maltreated children involved in court hearings	137 (out of 218)	7-10 y.o.	Judge consent, youth assent	Children recruited awaiting court hearings
Block, S. D., Oran, H., Oran, D., Baumrind, N., & Goodman, G. S. (2010). Abused and neglected children in court: Knowledge and attitudes. <i>Child Abuse & Neglect</i> , 34(9), 659-670.	To explore maltreated children's knowledge and attitudes about their court experiences	85 (number eligible not reported)	7-10 y.o.	Judge consent, youth assent	Children recruited awaiting court hearings
Wandrey, L., Lyon, T. D., Quas, J. A., & Friedman, W. J. (2012). Maltreated children's ability to estimate temporal location and numerosity of placement changes and court visits. <i>Psychology, Public Policy, and Law</i> , 18(1), 79.	To examine maltreated foster youth's temporal knowledge	167 (number eligible not reported)	6-10 y.o.	Judge and caseworker consent, child assent	LA County dependency court
Aarons, G. A., Covert, J., Skriner, L. C., Green, A., Marto, D., Garland, A. F., & Landsverk, J. (2010). The eye of the beholder: Youths and parents differ on what matters in mental health services. <i>Administration and Policy in Mental Health and Mental Health Services Research</i> , 37(6), 459-467.	To examine the degree to which youths and caregivers evaluate mental health services	526 individuals (out of 306 families)	11-17 y.o.	Judge or caseworker consent, caregiver consent, youth assent	306 youth and caregivers interviewed
Chamberlain, P., Price, J. M., Reid, J. B., Landsverk, J., Fisher, P. A., & Stoolmiller, M. (2006). Who disrupts from placement in foster and kinship care?. <i>Child abuse & neglect</i> , 30(4), 409-424.	To identify predictors of foster placement disruption	246 (number eligible not reported)	5-12 y.o.	Caregiver consent only	Child in foster care or kinship care in California

Chamberlain, P., Price, J., Leve, L. D., Laurent, H., Landsverk, J. A., & Reid, J. B. (2008). Prevention of behavior problems for children in foster care: Outcomes and mediation effects. <i>Prevention Science</i> , 9(1), 17-27.	To evaluate effectiveness of parent management training on foster children	700 (number eligible not reported)	5-12 y.o.	Caregiver consent only	Randomized trial of 700 foster and kinship families
Kirk, C. M., Lewis, R. K., Brown, K., Nilsen, C., & Colvin, D. Q. (2012). The gender gap in educational expectations among youth in the foster care system. <i>Children and Youth Services Review</i> , 34(9), 1683-1688.	To examine the effect of gender on educational expectations	550 (number eligible not reported)	6th-12th grade	Biological parent consent only	Enrolled adolescents in foster care from Kansas Kids Program
Keller, T. E., Salazar, A. M., & Courtney, M. E. (2010). Prevalence and timing of diagnosable mental health, alcohol, and substance use problems among older adolescents in the child welfare system. <i>Children and youth services review</i> , 32(4), 626-634.	To determine the prevalence of mental health and substance use disorders among youth approaching age of emancipation from child welfare system	732 (out of 880)	17+ y.o.	Child consent only	Adolescents in custody age 17 and older in out-of-home care for at least one year
Van Ryzin, M. J., Mills, D., Kelban, S., Vars, M. R., & Chamberlain, P. (2011). Using the bridges transition framework for youth in foster care: Measurement development and preliminary outcomes. <i>Children and Youth Services Review</i> , 33(11), 2267-2272.	To assess foster care youth's understanding of transitions	569 (number eligible not reported)	Not Reported	Waiver of consent and assent	Youth in foster care preparing for independence