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Publication Date

2017-12-01

DOI

10.1016/j.childyouth.2017.10.042

Peer reviewed

HHS Public Access

Author manuscript

Child Youth Serv Rev. Author manuscript; available in PMC 2021 July 15.

Published in final edited form as:

Child Youth Serv Rev. 2017 December ; 83: 201–208. doi:10.1016/j.childyouth.2017.10.042.

Challenges to conducting adolescent HIV prevention services research with court-involved youth

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Abstract

Multiple assessment studies demonstrate that juvenile offenders are at increased risk for contracting HIV and other STIs relative to their non-offending counterparts. Such data are used to support the implementation of adolescent HIV prevention interventions within the juvenile justice system. Despite the compelling data related to high rates of unprotected sexual activity, pregnancy, STIs, substance use and psychiatric symptoms, there are very few empirically supported HIV prevention interventions for this adolescent subgroup. Using our experience conducting HIV prevention research studies with court-involved, non-incarcerated (CINI) youth we identify salient and unique challenges to consider when conducting HIV prevention intervention research with this population. Obstacles to consider include lack of “buy-in” and engagement from justice staff and families about the need for youth sexual health promotion and HIV prevention services and logistical barriers (time, transportation, space) related to conducting intervention research with a community-based sample of justice-involved youth. We consider these various challenges and provide recommendations for researchers on how to overcome barriers to continue to develop evidence-based HIV prevention services for communities of youth in need.

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Conflicts of interest

None.

1. Introduction

Recent estimates indicate 1.3 million youth under the age of 18 are arrested annually (Puzzanchera, 2014) and that more than 31 million are under the juvenile court jurisdiction (Hockenberry & Puzzanchera, 2015). Sixty-eight percent of these youth are referred to juvenile courts rather than adult criminal courts (Puzzanchera, 2014). Involvement in the juvenile justice system is associated with a variety of adverse public health outcomes, such as substance use (Belenko et al., 2017), psychiatric symptoms (Dembo et al., 2007), sexual risk behavior (Schmiege, Broaddus, Levin, & Bryan, 2009; Teplin, Abram, McClelland, Dulcan, & Mericle, 2002; Teplin, Mericle, McClelland, & Abram, 2003), and higher rates of sexually transmitted infections (STIs) (Elkington et al., 2008). The majority of such research, however, has focused on samples of detained or incarcerated juveniles. These high-risk justice-involved subsamples represent only approximately 21% of arrested youth (Furdella & Puzzanchera, 2015; Sickmund & Puzzanchera, 2014). Little is known about how to develop and implement successful HIV prevention interventions for the 79% of justice-involved youth living in the community (herein referred to as Court-Involved, Non-Incarcerated or CINI youth) who have multiple co-occurring HIV/STI risk factors, such as psychiatric symptoms and drug use.

In studies of detained and incarcerated youth, high prevalence rates of drug and alcohol use, psychiatric symptoms and sexual risk behaviors are well-documented (Abram, Teplin, McClelland, & Dulcan, 2003; McClelland, Elkington, Teplin, & Abram, 2004; Puzzanchera, 2009; Romero et al., 2007). Between 50%–70% of detained juvenile offenders have a diagnosable psychiatric disorder, even when excluding conduct disorder (Fazel, Doll, & Långström, 2008; Gottfried & Christopher, 2017; Teplin et al., 2002; Teplin et al., 2003). Mental health problems increase criminogenic risk and, when paired with substance use, contribute to poor outcomes (Doherty, Green, & Ensinger, 2008; Elkington, Bauermeister, & Zimmerman, 2010). Nearly half of juvenile detainees have one or more substance use disorders and begin using substances earlier than non-detained peers (Schubert, Mulvey, & Glasheen, 2011).

The likelihood of acquiring HIV/STIs is also substantially increased among juvenile justice youth. Studies of juvenile detainees with co-occurring substance use and psychiatric concerns demonstrate that most are sexually active and more than half have had multiple partners and unprotected sex during the past month (Mauricio et al., 2009; Schmiege et al., 2009; Teplin et al., 2003; Teplin et al., 2005). Only a handful of studies, primarily those by Dembo, Belenko and colleagues (Belenko et al., 2008; Dembo, Belenko, Childs, Greenbaum, & Wareham, 2010; Dembo, Krupa, Wareham, Schmeidler, & DiClemente, 2017), have examined these primary outcomes (e.g., drug use, HIV/STI risk) among non-detained juvenile arrestees. The risk behaviors of these CINI juveniles mirror those of their peers in detention (Dembo et al., 2010; Teplin et al., 2003). Belenko et al. (2008) have demonstrated that juvenile arrestees have prevalence rates of STDs ranging from 13 to 19%, depending on gender. These prevalence rates are significantly higher than those published among non-legally involved peers (Dembo et al., 2016; Dembo, Belenko, Childs, Wareham, & Schmeidler, 2009) and consistent with our own work that shows juvenile arrestees engage

in significantly greater unprotected sexual activity and substance use during sex than their non-arrested counterparts (Tolou-Shams et al. (in preparation)).

Although cross-sectional data suggest that non-detained juvenile arrestees are at significant risk for drug use, HIV/STIs, psychiatric symptoms and recidivism, public health intervention development remains sorely behind for this child and adolescent population. Courts may be less concerned about a juvenile until they have had several juvenile court contacts, by which point public health concerns and problem behaviors are more entrenched and much more challenging to intervene upon (Tolou-Shams et al., 2007). Of the few evidence-based HIV prevention interventions tested, adapted and/or implemented with juvenile offenders (Tolou-Shams, Stewart, Fasciano, & Brown, 2010), the majority have been conducted with detained or incarcerated youth highlighting how public health concerns often only come to light when problem behaviors are more established. Juvenile courts may serve as a unique, innovative setting to capture an understudied, high-risk juvenile population. However, focusing on the development and implementation of HIV prevention interventions for these youth comes with its own unique set of challenges.

Lane, Goldstein, Heilbrun, Cruise, and Pennacchia (2012) provided a useful framework for examining barriers and challenges to conducting research within juvenile justice residential facilities. The authors suggest that obstacles to conducting such research may include obtaining institutional review board approval, working effectively with juvenile justice facilities, seeking parental permission and youth assent and juvenile justice system-related attrition. This paper considers the additional and unique challenges inherent in conducting research with court-involved, non-incarcerated (CINI) youth, particularly in the area of HIV/STI prevention. We will describe the process of implementing a pilot efficacy trial of a family-based HIV prevention intervention for juvenile drug court offenders (youth diverted from formal delinquency hearings and monitored by the court while living in the community). Our goal is to provide key challenges and recommendations to consider when developing, adapting, testing and/or implementing HIV prevention research trials in juvenile diversion (i.e., non-incarcerated or detention) community-based settings (Table 1).

2. Methods

2.1. Project RAP intervention

Project RAP (Risk reduction for Adolescents and Parents) is a family-based affect management (emotion regulation) intervention consisting of 5, 2 h family-based weekly sessions (8 h total of core intervention and 1, 2 h family-based booster session 1 month after the core intervention was complete) developed for substance using juvenile offenders (Tolou-Shams et al., 2017). Project RAP was developed as a family-based expansion of an adolescent-only affect management HIV prevention intervention for juvenile drug court offenders in response to the lack of effects of an adolescent-only intervention on young offenders' drug use and sexual risk behaviors (Tolou-Shams et al., 2011). Given that the majority of successful interventions which reduce substance use and conduct problems among young offenders include family (e.g., Multisystemic Therapy, Multidimensional Family Therapy), we hypothesized that a family-based affect management HIV prevention intervention may be more likely to have a significant effect on reducing substance use and

HIV/STD risk behaviors. Thus, we compared a family-based HIV prevention intervention (adapted partially from the few other family-based HIV prevention interventions in the literature, e.g., Project STYLE, Brown et al., 2014) to an adolescent-only health promotion (health psychoeducation) intervention matched for time and attention. Outcome results indicated that, at 3 month post-intervention follow-up, substance using youth randomized to the family-based substance use and HIV prevention intervention decreased their frequency of marijuana use and unprotected sex acts relative to their peers in the adolescent-only health promotion condition (Tolou-Shams et al., 2017).

2.2. Data sources

For the discussion that follows, authors relied on the experiences of the first author (M. Tolou-Shams) and study team (S. Conrad, S. Johnson, and L. Brown) in developing and implementing the intervention, in overseeing recruitment and retention processes and in leading staff discussions/meetings (within the family court setting and with juvenile justice staff) related to recruitment, referrals and retention. The study was not designed for nor had the resources to also include structured feedback from justice-system partners, e.g., through system stakeholder focus groups or individual interviews. Likewise, the only feedback elicited from the youth and caregiver participants was in the content of a pilot efficacy trial and thus focused solely on intervention content feedback (in the form of session feedback forms and exit interviews only with families assigned to the HIV prevention condition). Of the 233 families who were screened and determined to be eligible for the intervention, 60 consented to participate and enrolled. One hundred seventeen families refused to participate due to lack of interest, because they had too many other obligations, or because participation was too much of a time commitment. Study staff were unable to reach the remaining 56 families. See (Tolou-Shams and colleagues (2017)) for full consort sheet and additional details about participant recruitment and retention.

3. Results: key challenges and recommendations

3.1. Challenge #1: juvenile justice system “buy-in”

As the process of family recruitment began for our HIV prevention intervention study, juvenile court staff provided feedback to study staff suggesting that they (and the families in their caseload) did not perceive HIV prevention as relevant to the imminent needs of the juveniles they were serving. This perception of HIV prevention as a distal need to address with juveniles and their families was in opposition with the perception of the research team and made it sometimes challenging to collaborate on study goals. Juvenile court staff also expressed concern that families would only attend sessions until their child’s case was dismissed by the court. It was critical to be aware of juvenile court staff perceptions of barriers to families participating in the intervention because our study depended on their referrals and court staff perceptions that “families will not participate in any programs,” and that “HIV is not a concern for the families whom we serve” was likely associated with fewer study referrals. However, learning of court staff perceptions, experiences and concerns after the study was already underway was associated with increased challenges that could likely have been avoided and/or resolved had court staff involvement occurred earlier in the process.

3.1.1. Recommendations—Engaging key stakeholders from the start within the juvenile justice setting from which you expect research study referrals is key. A community-engaged research approach suggests that working with the key system stakeholders (e.g., those staff working directly with the families) as early as possible in the research process is advisable, such as during the initial development of the research idea and prior to grant submission (e.g., http://www.cbprcurriculum.info/). From an HIV prevention study perspective, ideally a researcher would collaborate on ideas they perceive as relevant to these youth (within the sexual health arena, such as pregnancy) and identity reasons why they may not perceive sexual risk behavior/HIV prevention as relevant and/or identify what aspects they see as relevant. A community-engaged approach allows the creation of a shared goal across systems and results in greater likelihood of successful implementation and sustainability of prevention programs (Coughlin, 2016).

3.2. Challenge #2: obstacles to family engagement

The Project RAP RCT study had a 26% rate of consent. We received referrals for 283 families, of which 233 were initially eligible. Of those, 60 families agreed to participate (see Tolou-Shams et al., 2017, of consort sheet). To some extent, the low consent rate confirms juvenile court staff perceptions that families are not willing to participate in family-based and/or HIV prevention interventions (research or clinical). Observed obstacles to maintaining interest among families included not being able to reach them by phone for follow-up (even if they agreed to allow us to contact them by phone for recruitment), families moving frequently (transient population), and lack of engagement consistent with what most other behavioral health treatment or program services experience with court-involved families. Even among those enrolled, frequency of contacts required to maintain engagement was high. The average number of phone or in-person contacts over the course of the study (approximately 20–22 weeks in total, including follow-up) for enrolled families was 14.67 (SD = 10.77) with a range of 1–44 contacts; thus resources to maintain frequent contact is critical to engaging court-involved families into HIV prevention intervention studies.

In addition, our experience led us to hypothesize that families may be fearful of research (or the “unknown” that research presents). They may not fully understand the distinction between what they have to do for court and volunteering for research study. In other words, even though families go through a systematic and detailed informed consent process, they may not trust that their responses will not go to the court and affect their court process.

Families may also feel overburdened with the amount of services they now have to engage in given their juvenile’s court involvement, particularly as part of the Juvenile Drug Court program. This program requires intensive substance abuse treatment, drug screens, attending school programs and any other interventions that the judge may deem necessary. Thus, the idea of signing up for an additional prevention program may be too overwhelming and burdensome for most court-involved families.

Unfortunately, these barriers lead then to an extremely protracted timeframe to achieve sufficiently large sample sizes. Many juvenile justice studies are plagued with small sample sizes that are underpowered to detect group differences. These sample size limitations also

lead to fewer results being publishable and in general, inhibit the field of HIV/STI prevention for juvenile justice youth in moving forward.

3.2.1. Recommendations—It is critical to have the support of the juvenile court case manager or intake worker and their endorsement of the intervention as a necessary program for these youth. Identifying staff who will endorse the program is key, as the court staff have a strong rapport with the family. Furthermore, the family perceives the court staff as being the expert in the area. With respect to engaging families, research staff and study protocols require immense flexibility. Asking permission for research staff to go by their home (in-person) if they are unable to be reached by phone, conducting parental consent and youth assent in the home or where they may choose (as long as privacy is available) is critical to engaging families into the research.

3.3. Challenge #3: participation in the study over time (intervention and research assessments)

There is natural attrition in engagement consistent with declining participation juvenile justice system; in other words, once juveniles and their families are no longer monitored by the court, they are less likely to stay involved with anything that reminds them of court. This has implications for longer-term research assessment follow-ups, which are likely to occur outside of the timeframe in which the juvenile is court-involved. In addition, the juvenile is at risk for reverting to “old/past behaviors” that may include noncompliance with medications, using substances and not attending school, all of which increase the difficulty in reaching the juvenile and family for any type of follow-up. In addition, families have to shift from their relationship with the court (and monitoring by the court) to their relationship with the research project, staff and retention/monitoring by the project.

Additional barriers concern logistics and resources. Many families are under-resourced and have little to no money for car or alternative transportation. Transportation concerns are a significant barrier, particularly for family-based intervention research where both parents and teens must attend (whether it be an intervention or research assessment session). Transportation is often included as part of efficacy trials, since researchers are testing whether the intervention works, not whether it can be reasonably implemented in real-world settings. If researchers know that transportation is a significant barrier to attending intervention settings, is it realistic that an intervention will ever be implemented outside of the home if transportation cannot be externally funded?

3.3.1. Recommendations—The extent to which families perceive the relationship between project staff and themselves as a partnership is key to successful retention over time. Developing appropriate and genuine relationships with enrolled parents and teens is critical to the success of finding families at follow-up to complete the study. In this spirit, we have incorporated various engagement and retention strategies, including obtaining multiple contacts for follow-up (up to 5 friends or relatives), sending out personalized birthday and holiday cards, using text messaging and social media (e.g., Instagram) tools to remind parents and teens of appointments and/or if they have been lost to follow-up with last known address.

Researchers should also consider home-based intervention for this population particularly when considering family-based HIV prevention interventions. Multisystemic therapy (MST) and Multidimensional Family Therapy (MDFT) are both very successful and flexible home-based interventions for antisocial, substance abusing youth. Only one of these interventions (MDFT) has incorporated HIV prevention intervention material (Marvel, Rowe, Colon-Perez, DiClemente, & Liddle, 2009; Rowe et al., 2016). For HIV prevention interventions, home-based interventions present the obstacle of lacking sufficient privacy to discuss very sensitive sexual risk information. Home-based interventions require significant resources (of clinicians) and flexibility, which includes increased cost. Despite these barriers, cost-effectiveness studies of MST have demonstrated that similar home-based interventions are largely cost-effective in reducing poor behavioral health outcomes for juveniles.

3.4. Challenge #4: unaddressed parent mental health and/or substance use concerns

Conducting family-based HIV prevention intervention includes intervention with at least one parent (typically the primary caregiver). Many of the youth in the juvenile justice system have parents who struggle with their own mental health and/or substance use difficulties. There are different concerns and challenges to conducting family-based intervention when a parent may be psychiatrically impaired or actively substance using (and not receiving treatment). Ethical concerns may be raised when issues related to a juvenile's safety come to light in the context of a research assessment (e.g., a parent who is too intoxicated to appropriately care for the juvenile or a parent who cannot control their anger and physically abuses a juvenile in the home in front of the research staff). This presents the challenge of having to make a child abuse and neglect call to state authorities within the context of a research study. Further, it presents the challenge of continuing to engage a family to remain in the study (for research retention purposes) while perhaps their knowing that the research team had to call state authorities about the parent's abusive or neglectful behavior. This scenario occurred several times during our study and resulted in losing families to follow-up as a result (i.e., they would not return calls or engage with study staff).

3.4.1. Recommendations—Researchers should consider the constructs they absolutely need to include in research assessments and try to avoid including items in which could "flag" participants for child abuse or neglect or other safety concerns, such as suicidality and homicidality. Studies demonstrate that juvenile justice youth are more likely to have a child abuse history than their non-justice involved peers, and that this history is often associated with future sexual risk behavior. From a scientific perspective, HIV prevention researchers often wish to include measurement of a history of abuse or trauma (particularly sexual) because of the important association and impact on sexual risk behavior. However, researchers will need to consider the "cost-benefit" to inclusion and for small pilot studies in which losing even several participants means losing a significant proportion of the sample, researchers must consider whether it is worth it to assess those sensitive constructs. If behaviors are observed by research staff outside of the assessment process (e.g., in the intervention), studies must have protocols in place for procedures on how to handle such clinical emergencies, which should include having a licensed clinician available for consultation (as our study did) to research study staff (who also knows state regulations related to reporting of child abuse and neglect).

3.5. Challenge #5: special requirements of randomized controlled trials (RCTs)

Requirements of RCTs, such as randomization, attention control conditions and detailed assessments, serve as some of the strongest barriers to referrals for study participation within the juvenile court system. Stakeholders, such as judges and juvenile drug court case managers, had a very difficult time understanding the process of and rationale for randomization. On the one hand, they reported liking that juveniles got a program or service regardless; however, court staff repeatedly asked why not all juveniles could receive the family-based intervention if we (as researchers) thought that that program worked better.

The time from referral to clinical services versus time to intervention within the context of a research study has also proven to be a significant barrier to obtaining intervention referrals from court staff. Court staff report that their families can receive mental health and/or substance use services in the community (although not necessarily HIV prevention) much more quickly than they are able to start our research-based intervention. The time it takes to complete the consent/assent process and the baseline computerized assessment questionnaire may delay the start of intervention services for the family. Thus, court staff are more likely to refer to clinical programs/interventions in the community versus programs that are research-based because of the delay (whether perceived or real) in time to start the program when they first have to do research assessments before getting the intervention. Additionally, court staff have familiarity with community-based treatment or prevention programs that youth whom they monitor have had positive experiences. Thus, they may also be reluctant to refer for a new service as part of a research trial when they are accustomed to making referrals to certain community-based mental health and/or substance use agencies.

3.5.1. Recommendations—Researchers should present randomization in layperson terms to key stakeholders as part of the initial community-engaged research process. If key stakeholders are involved with the grant-writing process early on, then these concepts will become more understandable over time. Researchers might also wish to consider alternative comparison conditions (e.g., waitlist control, standard of care comparison, stepped wedge design) that are scientifically rigorous and perhaps more externally valid. However, other comparison conditions are not without limitations. For example, if a juvenile is out of the court system before they initiate the intervention (in waitlist example) then how does the court handle that the juvenile never received intervention? What, if any, are the ethical concerns related to knowing that there are no evidence-based integrated substance use and HIV prevention interventions in the community, but a juvenile who is consistently reporting unprotected sexual activity with drugs is randomized to the standard-of-care (community-based) condition?

Researchers should also determine ways to shorten the delay from consent to questionnaire to program. As much as possible, researchers should try to reduce the length of their baseline assessment so that families may even be able to complete the consent/assent and baseline assessment on the same day that they are initially recruited. Completing that process, even when at the court for another appointment, would shorten the window in which families would be randomized to their condition (and hence hasten the linkage to intervention services).

3.6. Challenge #6: maintaining confidentiality

Conducting research with vulnerable children involved the juvenile justice system about topics related to drugs, alcohol and sexual activity results in utmost scrutiny about protecting these youth during the research trial. Researchers must contend with what to do with sensitive information that the juvenile may disclose in context of HIV prevention group or individual prevention session (related to abuse, statutory rape, dating violence). Institutional Review Boards and grant-reviewers often question why such sensitive information may need to be shared with the court in the context of a research intervention study. The court may not want to collaborate if they do not perceive researchers as partners in sharing important information, which they perceive as helpful to appropriately monitor the case for the court. Thus researchers have to balance protecting the rights and confidentiality of these juveniles and their families while still maintaining a relationship with the courts.

3.6.1. Recommendations—Researchers must outline clearly in the study consent about the limits to confidentiality, review those limits with court staff who are making referrals and come to agreement with what information the staff would like included in reports of compliance/cooperation to the court (e.g., what is their expectation of what will be included?). It will be important for researchers to provide education to court staff about the importance and relevance of collecting sensitive data in this context in order to accurately evaluate the impact of existing prevention interventions and/or develop relevant future interventions. If youth understand that their information will be passed along to the court and potentially incriminating, they may either refuse to answer questions or answer untruthfully, both of which will hamper prevention efforts. Researchers in this area may make multiple edits and revisions to their research protocol related to information sharing with the court over time depending on how the court key stakeholders change over time and have differing perceptions of what information would be most wanted/valuable/used by the court to assist juveniles.

In general, our studies have been able to distinguish information-sharing related to confidential research questionnaire/assessments from information that could be provided as part of a clinical or prevention program service in the community (e.g., attendance records, general level of participation in group/treatment etc.). No research data are ever made available to the court and we obtain a Certificate of Confidentiality related to protecting those responses from being requested by the court through subpoena. Both IRB and the courts have been happy with the balance in information-sharing to date, which has helped to preserve our relationship and collaborations with the juvenile court as well as continue to protect youth and families who are participating.

3.7. Challenge #7: sustainability of services

Despite differences in what justice staff, families and researchers may perceive as most clinically relevant or valuable, intervention research trials bring services to the justice system upon which they become reliant for referrals and family-based need. This makes issues of sustainability a concern for researchers, justice staff, youth and families alike. What does the system do when the grant funding discontinues for a research intervention trial that was providing a service for the court youth? How will the researchers' relationship

with the court, and ability to collaborate on future services research, be affected if a health service disappears? How does (and should) a researcher make a program, intervention, or service sustainable if the research does not clearly indicate efficacy? What does a researcher do about the "gap" in time (e.g., from end of trial to data analysis and dissemination) that may cause loss of buy-in from the system that participated?

3.7.1. Recommendations—Researchers should disseminate their findings as quickly as possible. It is not always necessary to disseminate the entire intervention. Sometimes adding a particular brief assessment or screening or changing the system protocol slightly or adding staff training based on the intervention effects helps the systems and preserves the researcher-system relationship. For example, in our prior adolescent-only HIV prevention intervention for juvenile drug court offenders (Tolou-Shams et al., 2017), despite not demonstrating significant reduction in adolescent risk behaviors, the system was more open to consultation from licensed clinicians (and psychologists) and partnered to develop an in-house juvenile court mental health clinic to address the mental health and substance use needs for community-based justice-involved youth.

Other ways to assist with sustainability include identifying staff early on who may be interested in being trained to lead the intervention. Researchers should establish from beginning that the project will be time-limited, with the ultimate goal of handing the intervention over to the court. Setting this expectation will likely assist the system in having a more positive, collaborative attitude. However, if the key system players are not interested in research or have an appreciation for the goals of research, then they may not understand why the intervention was not just handed over to them from the start as a service without the "testing" that is required of an RCT (see Challenge #5).

Researchers might also consider more hybrid study designs in which funding supports and data are being collected earlier on in the trial process to directly inform what relates to successful real-world implementation and sustainability post-efficacy trial.

3.8. Challenge #8: availability of Spanish-language interventions

At the time of this HIV prevention intervention study (2007–2012), approximately 22–25% of the court-involved families identify as Latinx and approximately 5% of parents were monolingual Spanish-speaking. However, to maintain strong internal validity, our RCT could only include English-speaking (or bilingual) families. Thus, we excluded monolingual Spanish-speaking parents or juveniles from participating in the family-based trial (even though research assessments were translated into Spanish). More recently collected data (from same setting but from 2013 to 2016) from a sample of 423 first-time offending CINI youth indicates that 44% of these youth identify as Latinx (Tolou-Shams et al. (in preparation)). Given the expected changing demographics of the US over the coming decades—the proportion of people who identify as Hispanic is projected to increase from 17.4% to nearly 30% of people living in the US by 2060 (Colby & Ortman, 2015). To our knowledge, there is only one published, empirically supported family-based HIV prevention intervention for monolingual Spanish speaking youth with delinquency and/or arrest histories (Prado, Cordova et al., 2012; Prado, Pantin et al., 2012). However, this intervention

has not been tested with or tailored to the unique needs of families involved in juvenile drug court. Thus, it is imperative that we consider developing and testing culturally-congruent and Spanish-language family-based HIV prevention and substance use interventions for court-involved youth, including those involved in drug court.

3.8.1. Recommendations—It is insufficient to only translate English-language HIV prevention interventions into Spanish for court-involved youth. Spanish-language interventions must be culturally tailored and congruent with the needs of court-involved, non-English speaking populations, which require significant time and resources for development, adaptation and pilot testing phases. Differences across subgroups of Latinx youth and families with respect to generational status and country of origin (e.g., Mexico versus Dominican Republic) require critical consideration and incorporation of cultural nuances into Spanish-speaking HIV prevention intervention development. Researchers must also consider translating consent and measures into Spanish to accommodate monolingual Spanish-speaking families and hire bicultural, Spanish bilingual facilitators. The use of interpreters is not recommended but may be allowable (with Institutional Review Board approval) for short-term or onetime use in urgent research protocol situations (e.g., consent process) in which a bilingual research team member is unavailable. Ultimately, the larger vision suggests that juvenile justice and health disparities researchers should collaborate to obtain funding to develop and test culturally tailored HIV prevention interventions for Latinx court-involved youth.

4. Discussion

Conducting HIV prevention research for community-supervised justice-involved (or CINI) youth presents multiple challenges. To be successful, projects must be led by a team of seasoned investigators who ideally have blended clinical, research and/or administrative juvenile justice experience that will help them to navigate the complex juvenile court systems. Investigators must have a thorough understanding of the critical relationships among key stakeholders, both within and outside of the court system. Researchers must also develop and maintain strong connections with justice staff and community partners. When challenges arise, partnerships with stakeholders in the court system are critical to minimize the impact on the study.

Large-scale RCTs present obstacles above and beyond other study designs. Because families of CINI youth are often managing multiple stressors and have limited access to resources, researchers need plentiful funds to recruit and retain the large number of participants required for a sufficiently powered clinical trial. RCTs for CINI youth need a high staff-to-participant ratio to maintain youth and family engagement. Given that yield from approach to enrollment is typically low in these studies (e.g., 25–30%), the amount of resources required to approach the number of youth and families to achieve needed large sample sizes is beyond that of many other study populations. Large scale RCTs also require a substantial time investment, as meeting regularly with court staff and key stakeholders is critical. Investigators should also regularly meet in person with judges, administrators, and staff members to integrate into the setting and promote further relationships and ties with the court system.

Challenges found in our work are not dissimilar found in studies with justice-involved youth in residential facilities (Lane et al., 2012), such as concerns around reporting sensitive information (privacy and confidentiality) and developing effective partnerships with justice staff. Challenges related to RCT designs, sustainability of services and availability of interventions in other languages (such as Spanish) are also not likely unique to behavioral health studies focused on justice-involved populations and settings. However, there are some separate and distinct challenges to note when specifically implementing HIV prevention trials in the context of court or legal involvement. For example, the area of focus for the system and families is predominantly related to legal consequences, i.e., what will help to get the youth get out of the legal system most expeditiously. The notion that sexual health or HIV prevention is "important" or "relevant" at this stage within the context of legal involvement presents unique challenges to achieving "buy-in" and effective implementation relative to implementation of HIV prevention interventions with other youth and family populations. The issues of privacy and confidentiality are also unique given that youth in the JJ system are worried about sanctions or punishments for risk behaviors (including sexual activity) or illicit behaviors and such concerns about sanctions for disclosure are not there in the same way around privacy/confidentiality of sharing about risk behaviors in other settings, e.g., in pediatric primary care.

Despite the myriad challenges, conducting research with CINI youth is possible. It is also necessary: although nearly 80% of justice-involved youth are not incarcerated (Furdella & Puzzanchera, 2015), an overwhelming majority of studies examining justice-involved youth sample only serious offenders, incarcerated or re-entry samples of youth. These samples are not representative of the larger community-supervised justice-involved population, and their conclusions are not generalizable to youth living in the community.

4.1. Future directions

Given the many challenges in conducting HIV prevention research in CINI youth, future work should expand beyond RCTs to focus on two main research goals: 1) evaluating the efficacy of interventions already disseminated and implemented in the community (and courts) with court-involved youth, and 2) implementing best practices into the existing juvenile justice system.

The first goal, evaluating the efficacy of already-disseminated interventions, is crucial for policy changes and further dissemination efforts. Given that these are programs already being delivered to justice-involved youth, determining if there is empirical support for these already widely disseminated interventions is an efficient way of expanding evidence-based health care for CINI youth. Such efficacy trials might be viewed as the "low-hanging fruit" of evidence-based practice in this area. Data can be more immediately disseminated back to the community and policymakers can expeditiously use these data to advocate for broader dissemination of HIV prevention programs. Efficacy trials of already implemented interventions might also be less disruptive to current justice system practices, and would bypass systems-level hurdles such as justice system buy-in (Challenge #1, above). Instead of developing new interventions, researchers would use the bulk of their resources for recruitment and for navigating real-world issues as they arise.

Implementation science trials are also critical to address systems-level barriers identified above. For example, principals of implementation science may be used to address justice-system buy-in (Challenge #1) by taking a community engagement approach and identifying goals shared by both researchers and justice-system staff. Implementation trials are also primarily concerned with participant engagement (Challenge #2) and sustainability (Challenge #7). Studies that collect stakeholder, structural and/or organizational-level data will greatly enhance our ability to make empirically-supported recommendations regarding successful implementation of HIV prevention interventions in the juvenile court setting. The National Institute for Drug Abuse (NIDA) has funded an ongoing large-scale implementation science trial focused on substance use treatments for justice-involved youth (Knight et al., 2016). This multi-site effort, Juvenile Justice— Translational Research on Interventions for Adolescents in the Legal System (JJTRIALS), aims to streamline care and ensure that justice-involved youth have access to and are retained in substance use treatment. Specifically, JJ-TRIALS seeks to improve receipt of substance use services along the "behavioral health services cascade" e.g. screening, referral, attending treatment (Belenko et al., 2017); a systems-level framework for improving substance use outcomes for justice-involved youth. Expanding this framework to HIV prevention interventions for these youth will be key. Prevention programs, especially those targeting HIV risk behaviors and substance use, are sorely needed for CINI youth.

5. Conclusions

Community-supervised justice-involved youth (or CINI youth) are in need of empirically supported interventions to improve health outcomes. In particular, more data are needed to support the development and implementation of effective HIV/STI prevention interventions, but researchers encounter multiple barriers when conducting research with this population, which substantially slows research progress. Barriers may include systems-level difficulties, such as problems creating "buy-in" with the justice system, as well as participant-level concerns, such as engaging and retaining participants. Gold-standard RCTs are especially difficult to conduct as legal systems are not keen on youth and families being randomized to a non-treatment condition. Despite such challenges, it is imperative that researchers identify alternative scientific designs and strategies that enroll the systems, youth and families to allow us to identify empirically-supported ways improving health outcomes for this vulnerable population of youth.

Acknowledgements

We wish to thank all of the juvenile justice collaborators and court-involved children and families, without whom this work could not have been possible.

This work was supported by the National Institute of Drug Abuse (K23DA021532, R01DA034538, R01DA035231, and T32DA007250). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Table 1.

Summary of key challenges and recommendations.

Key challenge	Description	Recommendations
1. Juvenile justice system "buy-in"	• Staff perception of relevance of HIV prevention • Staff perception of families' willingness to engage in HIV	• Take a community-engaged approach • Engage key stakeholders as early as possible
2. Obstacles to family engagement	• Families may be difficult to contact and engage • May be fearful of research • Despite the lengthy consent process, they may not trust that information they divulge to researchers will not be used in court proceedings • Families are overburdened with other services and requirements for court	• Researchers must have the support and endorsement of a juvenile court case manager or intake worker • Research staff and study protocols must be flexible in their approach to engage families
3. Participation in the study over time	• Once juveniles and their families are no longer monitored by the court, they are less likely to stay involved with anything that reminds them of court • Transportation may be difficult	• Employ a variety of retention strategies • Consider home-based interventions
4. Unaddressed parent mental health needs and/or substance use concerns	• As a result of caregiver mental health and substance use, safety concerns may arise which require study staff to report to state authorities about child abuse and neglect	• Consider omitting items in research assessment which may "flag" for safety concerns
5. Special requirements of randomized controlled trials	• Stakeholders had difficulty understanding and supporting the rationale for randomization • Increased lag time between referral and beginning of intervention due to research protocol (i.e. time to obtain consent/assent and complete baseline assessment)	• Present randomization in layperson terms to key stakeholders as part of the initial community-engaged research process • Consider involving stakeholders in grant writing process • Consider waitlist or standard of care comparison conditions • Shorten delay between referral and intervention
6. Maintaining confidentiality	• Youth and families may not wish to participate be truthful if sensitive information regarding risky behavior is shared with the court • Court may not wish to collaborate if information is not shared	• Clearly outline the limits of confidentiality to research participants • Researchers may wish to adapt information-sharing policies over the course of their relationship with the court in order to preserve good working relationships
7. Sustainability	• Difficulty sustaining changes after grant funding ceases • Lag between end of trial and dissemination may decrease stakeholder engagement and buy-in	• Disseminate findings quickly • Implement smaller parts of intervention rapidly
8. Lack of Spanish-speaking, culturally congruent interventions	• Few empirically supported family-based HIV prevention interventions for Latino/a youth	• Develop additional culturally tailored Spanish-language interventions for court-involved youth who use substances