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Ethical Implications of Developing and Piloting a Victimization Screening Tool for Children and Youth

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Ethical Implications of Developing and Piloting a Victimization Screening Tool for Children and Youth

This document is a synopsis of the webinar "Ethical Implications of Developing and Piloting a Victimization Screening Tool for Children and Youth" created for the Linking Systems of Care (LSC) Project for Children and Youth by Dr. Celia Fischer, Director of the Center for Ethics Education at Fordham University, and Meg Garvin, JD, Executive Director of the National Center for Victim Law Institute.

Voluntariness

One vital aspect of piloting a screening tool for children and youth is ensuring voluntary participation. Generally, voluntary participation in a study requires two things:

1. free choice, including the ability to withdraw from the study; and
2. the absence of coercion or compulsion.[1]

In any study, it is unethical to force or coerce individuals into participating in a study, and safeguards must be put in place to protect participants. Additionally, potential participants must be given an opportunity to refuse to participate in the study or to withdraw from the study at any time.

Additional concerns exist when a study involves children. For child participants there are additional considerations including the child's competence, age, parental influence, and where the screening takes place. It can be difficult for children to understand that they have the right to refuse to participate in a study and for a screener to determine if a child is truly participating voluntarily in the study. This is especially true if the screening tool is conducted along with other activities that are not voluntary. It can be difficult for youth to tell the difference between a study being voluntary and other activities being involuntary.

Certain communities and populations are particularly vulnerable to coercion and undue influence. This vulnerability is often caused by two situations. First, the population being screened may need services and will agree to screening only to access services. Second, the population being screened may believe that their responses to the screening tool or participation in the screening study may have legal consequences. For example, if a family is involved in the child welfare system a parent may believe they have to participate in the screening to access court-ordered services or that the screening tool is part of the court-ordered services. Given these vulnerabilities, federal law requires "additional safeguards" for "populations vulnerable to coercion or undue influence." [2]

Voluntary participation is especially important when working with youth in custody. The parent of a child in custody may also be unable to tell the difference between voluntarily allowing their child to participate in a screening and being required to do so. This is especially true if the screening is being administered in a custodial environment. For

example, if a probation officer requires a minor to answer standard screening questions and then asks the youth if they would like to participate in the screening study, the youth may feel obligated to answer “yes” and agree to participate. Additionally, children, especially those in detention or custody, may believe they will be punished if they do not agree to participate in a screening. System-involved youth, including those in residential or foster homes, may have difficulty telling the difference between being asked to voluntarily participate in a screening, and following directives from staff or foster parents.

Youth who have been disciplined by staff may also feel obligated to participate in a screening, especially if they are still under the care and custody of the staff. Additionally, the interactions a youth has had with figures of authority can affect a youth’s voluntary participation and consent. Therefore, it is especially important to explain voluntariness and consent in situations where youth have been disciplined by staff.

The Code of Federal Regulations, specifically 21 C.F.R § 50.25 and 38 CFR § 16.116, explains that informed consent for participation requires:

> *A statement that participation is voluntary, that refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and that the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled.*

Another key aspect of working with vulnerable populations is to ensure that the youth participating in the screening understand the separateness between participating in the screening tool and any potential services. It is important for youth to understand that the sole purpose of the screening tool is to determine if the youth needs any services. The screening itself is not a service. Additionally, it is important to explain that simply participating in the screening does not guarantee access to services; it merely provides a referral to services. It is also important to explain to the youth exactly what the screener can and cannot do.

When explaining the voluntariness of the screening tool to youth, it is crucial to explain it in a way that is tailored to the educational level, competency, and language capacity of the youth.

Written Consent Forms

Although written consent forms are helpful for obtaining consent, they are not required or guaranteed to ensure confirmed consent. Youth may not be able to read or have limited reading comprehension or learning disabilities. Simply relying on the consent form may not be enough to ensure children and youth understand that they can refuse to participate. Youth may not understand the form or believe the form, or they may believe that if they refuse to participate in screening they will not be allowed to receive help and be denied services.

Additionally, screeners who are staff members at a detention facility or similar environment should be mindful of requests from the youth during screening. This is crucial because youth may interpret responses to mean that participation in the screening is mandatory to have their request addressed.

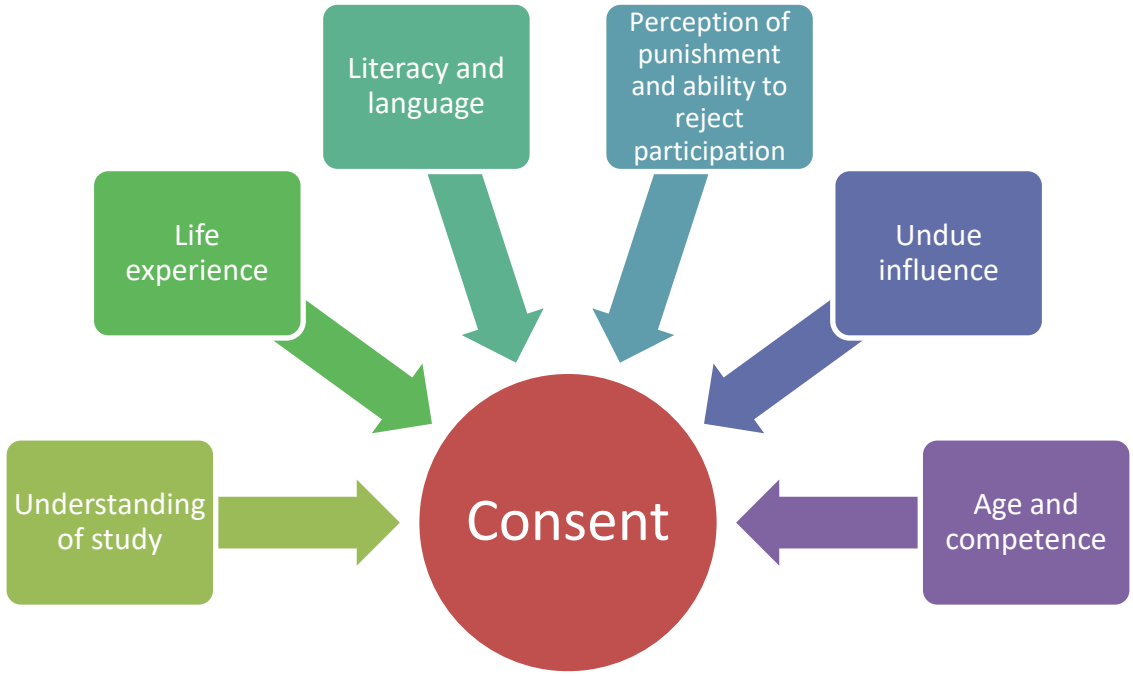
It is a good practice for a screener to stop after every major section of a consent form to go over the information rather than waiting until the end of the consent form to ask if the youth has any questions. Additionally, asking the youth to explain the consent form in their own words ensures the youth actually understands the form and is giving informed consent to participate in the screening.

The setting of the screening is also relevant for purposes of voluntariness and consent. If a youth is detained or in a custodial setting, the youth may feel required to participate in the screening or be penalized for not participating.

As mentioned previously, any communication with a youth should be in a language that the youth can understand and be developmentally and educationally appropriate. Words like assessment, evaluation, and screening may need to be simplified into language the child can understand. Similarly, the process and procedure for the screening and the role of the screener should be explained in simple and easy to understand language.

Adult Language Example	Child Friendly Language Example
We are conducting a clinical study	We are doing a study to learn more about _____.
This is a screening tool	This is a set of 10 questions we ask you. These questions help us learn more about you.
We need your consent.	We need your permission to ask you these questions, but you can say no, and that's okay.

When obtaining consent, screeners should also consider whether the language used can have different definitions based on linguistic, socio-economic, or cultural differences. For example, the term "sexually coercive" may be difficult to understand for someone who is bilingual or speaks English as a second language (ESL). Similarly, the question "have you ever gone to bed without dinner" can result in a "yes" response in families that are poor or homeless, but it does not necessarily mean there is neglect or victimization. Additionally, different cultures may interpret wording differently, which can result in differing responses to the screening tool. Also, if there is a large group of youth and only some are screened it is important to explain for the youth not being screened that there is not a specific reason that some youth are not being screened and that not being screened is not a punishment.



Role Clarity

Role clarity is vital when conducting a research study. Youth participating in screening may not understand the various roles a screener can play and how these differing roles can affect the way screeners interact with a youth. For example, if a staff member provides direct services to a youth, but also administers the screening tool to a youth, the youth may believe the screening tool is part of the direct services provided by the service provider. This is an example of therapeutic misconception.

Therapeutic misconception occurs when a participant mistakenly believes that a study or screening tool is a form of treatment or therapy rather than a study or referral tool. This is an especially important consideration during the pilot phase of a screening tool as a youth may confuse the goal of research to determine the usefulness of a screening tool with the goal of providing services for a youth. Therapeutic misconception can also occur if a youth overestimates the significance of the screening study or believes the study to be an aspect of their overall care.[3]

It is incredibly important for screeners to be mindful of the different ethical obligations associated with their different roles. During the pilot phase, a screener takes on the role of evaluator, and their primary concern is to validate and evaluate the screening tool compared to the role of a service provider whose primary concern is the well-being of the youth. Additionally, professional clinicians such as therapists or physicians have mandatory ethical rules they must follow. These roles can overlap and the person conducting the screening should evaluate any overlap and the impact it may have on the youth. This is especially important if the screener has worked with the youth before. Here, the screener needs to explain to the youth the difference in their usual role as service provider versus their role as a screener.

Screeners who serve a dual role as a screener and service provider should take extra care to clearly separate these two roles. For example, once a screener learns information through screening, they cannot easily ignore or "forget" the information in other interactions with the youth. Similarly, staff who have previously assessed youth may have information about the child's life experience that influences how they interpret a youth's response to the screening tool. Either situation can affect the validity of the screening tool. For these reasons, it is important for staff to ignore the information they learn during screening.

An additional element of role confusion to consider is the difference between a referral based on the agency's procedures and a referral based on the screening tool. A referral through the screening tool may not hold the same validity or weight as a referral through the agency.

Mandatory Reporting

Mandatory reporting is a topic frequently raised due to the possibility of the screening tool uncovering child protection concerns. Mandatory reporting is an important consideration when creating a screening tool because under- or over reporting victimization can have serious implications.

For example, if a screening tool does not correctly trigger a mandatory report, a family may not reach out to state authorities because there was no prior intervention for the information that should have triggered a mandatory report, and the family may feel as though no one cares. Alternatively, if a family is incorrectly reported, the family may avoid all interaction with state authorities to avoid another mandatory report. Unjustified mandatory reporting can lead to harmful legal consequences and unnecessary involvement with child welfare or criminal justice systems. Given the serious implications of mandatory reporting, it is crucial for screeners to explain what types of responses would require mandatory reporting.

In addition to mandatory reporting, assessing risk can be a concern. Additive scoring systems assign a numerical value to the cumulative number of positive or negative answers in a screening tool. The more positive answers there are, the higher the score, which will indicate an increased level of risk. Conversely, the fewer positive answers there are, the lower the score, which indicates a lower level of risk. Using an additive scoring system can result in under- or overestimation of risk or victimization. For example, a vague response may raise or lower the additive score incorrectly based on the screener's interpretation. For example, if a question asks, "has the child been in a place where they were exposed to gun shots?" there may be different responses with differing levels of harm, but they will be scored equally. For example, a youth may have heard gunshots during a family hunting trip or may have been a bystander during a drive-by shooting. Although these two situations are extremely different, both situations result in the same additive score.

This concern can also present itself when looking at mental health symptom presentation as various symptoms could be scored equally, but vary in severity. Additionally, a positive response to a particular symptom does not necessarily identify the severity of a mental health issue without additional information, screening, or assessment. For example, if a youth responds yes to having "difficulty concentrating" this could be a symptom of a number of concerns including fatigue, lack of sleep, Post-traumatic Stress Disorder (PTSD), or Attention Deficit Hyperactivity Disorder (ADHD).

Referrals are another aspect of mandatory reporting that should be considered. Referrals to child welfare systems can affect youth and families due to labeling, stigma, and the possibility of further evaluation or investigation by child welfare. Mandatory reporting can have significant impacts on families and these consequences should be addressed in trainings for pilot sites. Especially during the validation phase of the pilot process, utilizing an invalidated tool and overestimation of mental health concerns could lead to potential bias among service providers, law enforcement, and education officials. Specifically, if states utilize particular systems (mental health, juvenile justice, child welfare, etc.) it is important to consider and remember the collateral effects of simply being system involved. Screeners should also explain to youth and families that a referral to a mental health agency does not necessarily mean there is a mental health concern; it could just be a referral for further assessment. Furthermore, subjective decision-making should be eliminated from referral procedure, and the referral procedure should be standardized.[4]

Confidentiality

Ensuring confidentiality is also an important part of screening. It is key to keep data gathered through the screening separate from the data gathered through service provision. Additionally, screening data needs to be stored separately from other internal facility records, and only authorized users should have access to screening data. Also, if administrative records are used to generate part of the responses to the screening tool, they may also require separate consent forms.

Pilot sites and pilot agencies should be very careful about how they store completed screening tools and identifiable information. Such information could become the target for court subpoenas. This is a potential legal risk of participation, and screeners may want to discuss this risk with youth and families. This also applies for the protection of the identity and confidentiality of individuals who chose not to participate in screening.

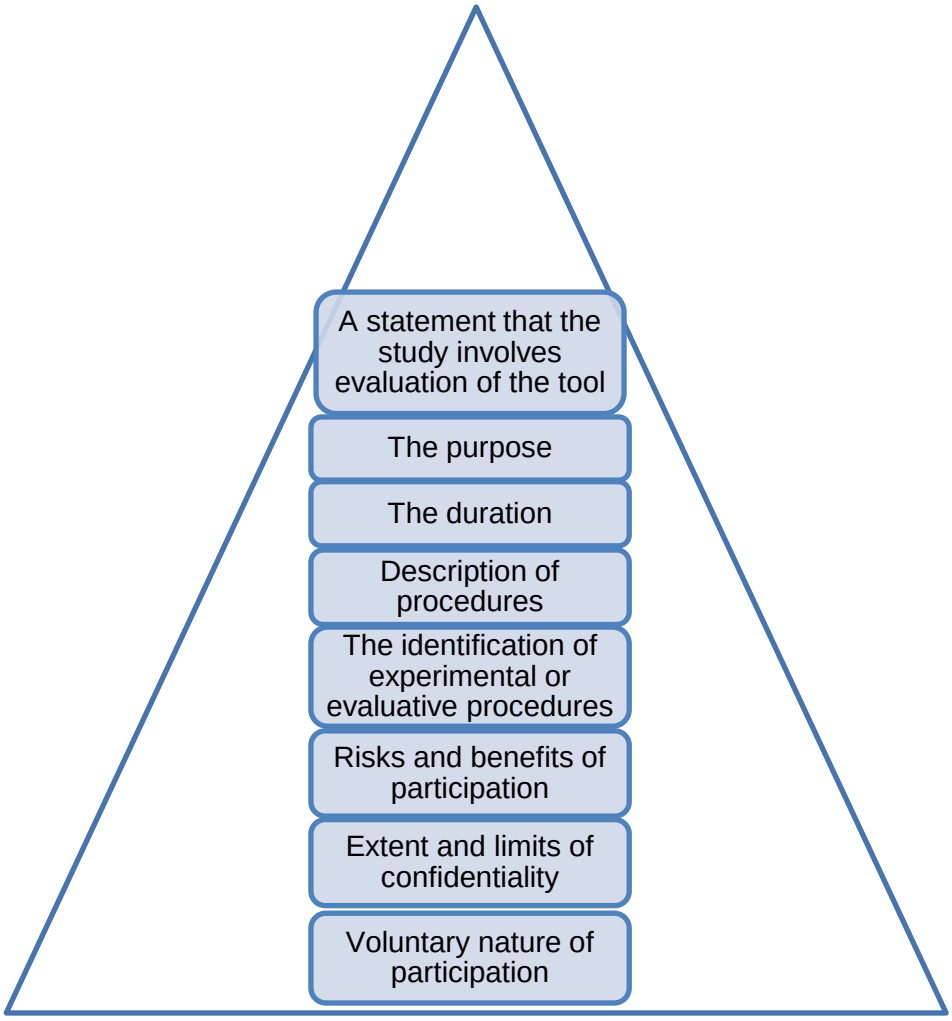
Screeners should be mindful of recording responses exactly as they are given and not making assumptions. This is especially important as screening tool responses may be subject to discovery. For example, if a screener categorizes a response as “physical abuse” without the complete information and the minor later explains that it was sexual abuse, individuals may believe the youth was lying. If the youth is involved in a court case, the defense counsel may interpret the inconsistency to mean the youth changed their story even though the minor has only responded in a truthful manner.

Another important dimension of confidentiality is crisis intervention. If crisis intervention, such as a referral or report to child services, is ordered as a result of a screening, the question becomes where and how is the record of the screening and the intervention kept. A record of the crisis intervention will refer to the screening tool, which is confidential. Confidentiality can also be compromised if the record of the intervention is placed in the youth’s or family’s administrative record. Therefore, it is important to create a standardized procedure to respond to a crisis and ensure that those records are kept confidential. Given the serious implications of risks to confidentiality, it is important to list and explain all of these risks in one place so screening participants have a thorough understanding of what will or will not be reported to staff or protective services. Although crisis intervention can provide needed services to a family, it is important to consider the legal, economical, health, and other risks associated with crisis intervention and how they can impact a youth and their family.

Informed Consent

The key elements of informed consent are:

1. a statement that the study involves evaluating the usefulness of a screening tool;
2. the purpose of conducting a screening tool evaluation;
3. the expected duration;
4. the description of procedures;
5. the identification of which procedures are experimental versus which are evaluative;
6. the potential risks and benefits of participation;
7. extent and limits of confidentiality; and
8. the voluntary nature of participation.[5]



Informed consent requires ensuring that the youth and family participating in the screening know and understand the potential risks and benefits of the screening. A screener does not need to discuss all possible risks and discomforts if they have a low probability of occurring or a low magnitude of harm; however, the screener needs to be sure to explain the risks and discomforts in a language that the youth and their family can understand. Informed consent also requires ensuring that the individual knowingly and voluntarily agrees to participate in the research project, meaning that the individual understands the risks and benefits of participation and knowingly agrees or declines to participate in the research project. To ensure knowing and informed consent, some important questions to consider are:

- Are the participants proficient in English? How will their proficiency be assessed?
- What is the reading level and vocabulary of participants? How will this be assessed? Will informed consent be read to some participants?
- Does the informed consent clearly explain the difference between screening tool evaluation and comprehensive assessment services?

- What, if any, information will be shared with parents in terms of the child's responses? Does this depend on age of the child?
- What are the risks and benefits of sharing information with parents? Are there cultural differences in attitudes toward shared information?
- Does the informed consent clearly explain the limit and extent of information sharing to parents and children?
- Does the informed consent clearly explain the situations that could result in crisis intervention? Does the informed consent explain what crisis intervention could look like?
- Do participants have sufficient opportunity to discuss and consider whether or not to participant in the screening? Do they have the opportunity to take informed consent documents home before making their participation choice?
- Does the informed consent procedure encourage questions from participants? Are screeners able to provide clear answers to those questions?

Signed informed consent is the standard expectation for research projects involving human subjects. For individuals under the age of 18, assent by the child and parental informed consent are standard requirements. Screening policy should clarify if a child can override their parent's decision to participate in screening. Generally, a child's decision not to participate in screening will override a parent or guardian's decision to participate in the screening.

An additional part of informed consent involves explaining the de-identification process. De-identification is the procedure used to remove names and other personal or identifying information of the youth and the family gathered through the screening process. For example, names can be substituted with code numbers. This discussion should include who will have access to screening participants' names and other identifying information. For example, although the name and personal information of the individual responding to the screener are de-identified, a screening tool may ask the individual to identify the perpetrator of the victimization. This and other responses may require a mandatory report which could identify the participant as well as a parent or family friend.

Referral

Referrals are an essential part of developing and piloting a victimization screening tool. After completing a screening, a youth may be referred to services or further assessment and it is crucial to determine how the referral process will work and the policies and procedures attached to it. Will there be a standard referral no matter the responses on the screening tool or will there be specific referral procedures that are linked to specific item responses? Another important issue to address is whether or not screeners may override threshold levels to refer a youth to services even if they do not meet the threshold number. For example, during screening a screener may learn information that makes them concerned about the youth and they may wish to refer the youth to further assessment and services; however, the youth scored six points instead of the eight points needed to qualify for a referral. Does the screener have the authority to refer the

youth or do they have to follow the threshold procedure anyway? This is an important consideration and can have far-reaching implications. If screeners have the options of overriding the threshold levels to refer youths who do not meet the threshold, there may be a flooding of the system due to too many, and potentially unnecessary, referrals. Conversely, if screeners do not have the authority to override threshold level, a youth may not receive services they truly need. The referral process also requires having discussions and close relationships with service providers to ensure services can be provided to youth and their families. Therefore, the referral process is incredibly important to the development and piloting of a screening tool.

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[1] Patricia A. Marshall et al., 15 BMC Med Ethics 38, Voluntary Participation and Comprehension of Informed Consent in a Genetic Epidemiological Study of Breast Cancer in Nigeria (May 2014)
[2] CFR 46.111.
[3] Gail E. Henderson et al., Clinical Trials and Medical Care: Defining the Therapeutic Misconception, 4 P.L.O.S. 324 (Nov. 2007).
[4] Note: This is also very important for legal purposes. Individualized decision making for referrals may violate state law regarding the practice of social work.
[5] For more information on the elements of informed consent, see 21 C.F.R. § 50.25 (West, 2017), *see also* 45 C.F.R. § 46.116.

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