



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

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OVC Caveats to Today's Presentation

- Questions and clarification—ask your OVC grant manager!
- OVC's interpretation of "Research vs Evaluation"
 - DOJ attorneys provide interpretation of applicable federal statutes
 - OVC funds do not support research
- See your grant special conditions!
 - Confidentiality and Privacy Certificate requirements



Topics to be Covered

- Ensuring voluntary participation during recruitment and informed consent
- Risks and benefits of referral procedures based on screening tool
- Protecting confidentiality and sharing information
- Crises management and mandated reporting
- Key elements of informed consent



Ensuring Voluntary Participation During Recruitment and Consent

- “Additional safeguards” for “populations vulnerable to coercion or undue influence”



Voluntariness: Ethical Challenges in Service Delivery Settings

- Screening tool evaluation vs. service delivery distinction
- Role of tool evaluator versus role of service delivery staff
- Fear of punitive action if participation is refused
- Consequences of excluding participants



Evaluation-Service Distinction

- Does the definition of screening tool evaluation adequately reflect the participant's educational level, familiarity with terms and research experience?
- Does recruitment and consent take place in a location that helps the participant understand the tool evaluation vs service delivery distinction?
- Does description of potential referral services following participation in the evaluation blur the tool evaluation-service distinction? How can that be corrected?



Evaluation-Service Staff Responsibilities

- Which staff is conducting the recruitment and consent?
- Does the staff also provide services to the prospective participants?
- What measures have been taken to effectively communicate the distinctive tool evaluation role of the staff?
- What steps have been taken to ensure that staff with dual responsibilities maintain objectivity, competence or effectiveness in either the tool evaluation or service role?



Fear of Punitive Action for Participation Refusal

- Is communication regarding the voluntary nature of participation fitted to the educational level, fears, hopes and concerns of participants?
- Will they believe a simple statement that refusal will not be penalized and they can withdraw at any time?
- Are participants provided with specific ways they can refuse or withdraw from participation?



Additional Factors Influencing Voluntary Participation

- How are prospective participants approached during recruitment? Are there public-private concerns?
- Are different recruitment/consent methods required for individuals who are new to or experienced with the services?
- How are inclusion/exclusion criteria explained during recruitment? Is the explanation sufficient to reduce perceived discrimination, stigmatization, or fears they have disappointed service staff?



Risks and Benefits

IRBs often expect

- Risks to subjects are minimized
- Risks are reasonable in relationship to anticipated benefits
- Using procedures which are consistent with sound screening tool evaluation design



Referral Policies for Items Not indicative of Child Abuse/neglect

How does one determine the validity of referral decisions based on an assessment tool that is in development?

What are potential referral risks and benefits for children and families if victimization is over-estimated?

What are potential referral risks and benefits for children and families if victimization is under-estimated?



Ethical Challenges of an Additive Scoring System for Referrals

Is the nature of the item clearly defined in terms of level of harm?

- Question: "*Has child been in a place where they were exposed to gun shots?*"
- Will participants interpret this question as hearing gun shots at a distance or in close proximity?
- Are these interpretations equivalent in level of victimization?



Are all Victimization Items Equivalent in Harm?

- Are all physical risks equal in establishing referral need: A score of 2 "Teased, bullied or harassed" versus items related to coerced sexual acts?
- Are all mental health items equal in establishing referral need? E.g. "trouble concentrating" vs "Tried to hurt himself or herself?"
- Are some items overlapping in significance?



Population Generalizability

- Will item language be similarly understood by children, adolescents and parents?
- Is the item language and examples (e.g. going to bed without dinner?) culturally equivalent?
- Is the wording of the items more likely to indicate victimization for some minority groups versus others?



Ethical Challenges in Referrals

- Given the developmental status of the tool, how does one prevent family over-estimation of child's problems if a referral is provided?
- How is the nature of the referral determined?
- Will standard procedures for *specific* referrals be linked to *specific* item responses?
- What are potential problems if nature of referral is left to the evaluator?



Confidentiality Risks for Participant Population

- Over- Under Estimation of Risk
- Legal (mandatory reporting; undocumented)
- Economic
- Social
- Dignitary



Confidentiality: Services Context

- How is identity of individuals who agreed and who refused participation kept confidential from service staff?
- Are administrative records used as validation? If so, who provides the records?
- Are the results of the development tool going to be entered into administrative records?
- Is referral or reporting to child services going to be included in administrative records?
- Where will testing take place?



Agency Crises Intervention

- What are the benefits and risks of safety estimations based on the yet to be validated tool?
- Will the agency crises intervention be placed in the child/family's administrative record?
- How does one minimize legal, economic, health or other risks associated with crises intervention?



Mandatory Child Abuse Reporting

- Does item language meet statutory definitions of abuse and neglect?
- How will parents/children be made aware that reporting has become necessary?
- Will they be encouraged to participate in reporting?
- What specific guidelines can be created to achieve uniformity (and fairness) in assessing whether item responses meet mandatory reporting requirements?



Informed Consent

- Information: Participants provided with all pertinent information needed to make a *reasoned* choice about participation
- Appreciation: The consent process provides parents/youth with adequate information to avoid over-or under-estimation of how participation may benefit or harm them personally.



Key Elements of Informed Consent

- A statement the study involves evaluating the usefulness of a screening tool
- Purpose of conducting a screening tool evaluation
- Expected duration
- Description of procedures
- Identification of which procedures are experimental



Key Elements of Informed Consent

- Reasonably foreseeable risks and discomforts
- Description of any benefits
- Disclosure of appropriate alternative procedures if any that might be advantageous to participant



Key Elements of Informed Consent (IC)

- Extent and limits of confidentiality, including whether documents are de-identified and how they are maintained
- Voluntary nature of participation and right to withdraw without penalty



Key Questions for IC Language

- Are participants proficient in English? How will this be assessed?
- What is the reading level and vocabulary of participants? How is it assessed? Will IC be read to some participants? How will that be determined?
- Has the consent adequately defined the difference between the screening tool evaluation and comprehensive assessment services?



Benefits of Evaluation

- Referrals as a benefit: “Increased opportunity for you to access services that may not have been identified otherwise”
- Avoid over-stating benefits – are limits of assessment based on the development status of the tool adequately explained?
- Are the referral benefits uniform across participants?
- Will all participants receive referrals based on their participation even if measure does not indicate need?



Therapeutic Misconception (TM)

- Therapeutic misconception occurs when participants confuse the role of a person conducting an evaluation of a screening tool with the role of a service provider.
- In the case of testing a screening tool, TM would occur when participants assume they are receiving a validated victimization or mental health assessment.
- Does the IC language avoid therapeutic misconception?



Key Risks to Describe in IC

Does the description of the study adequately communicate that in addition to victimization experiences, participants will be asked to identify who perpetrated the victimization

- Legal risks
- Risks to family cohesion
- Small world risks—others in the community will be familiar with questions



Clarity of Reporting Procedures

- Does the IC adequately describe the situations in which crises intervention will be instituted?
- Does it adequately define what types of responses would require mandatory reporting?
- Is it clear participation depend upon agreeing to permit mandatory reporting?
- Is such an agreement consistent with protections and consent requirements of NIJ 42 US Code 3789g



Clarity of Disclosure Risks

- Are all risks to confidentiality included in one place so that participants have a comprehensive understanding of what will and will not be reported to staff or protective services?



Authorization for Use of or Entry of Data into Administrative Records

- What type of authorization is required if results of screening tool are linked to administrative records?
- What type of consent is required if data from tools is entered into administrative records



Child Assent & Sharing Information with Parents

- Are child assent forms written at an appropriate developmental level?
- Will the child's dissent over-ride guardian permission?



Sharing Information With Parents

- What information if any will be shared with parents in terms of child's responses? Does it depend on age of child?
- What are the risks and benefits of sharing information with parents? Are there cultural differences in attitudes toward shared information?
- Is the limits and extent of information sharing adequately described to parents and children?



Procedures for Asking Questions

- Participants should be given sufficient opportunity to discuss and consider whether or not to participate in a manner that minimizes the possibility of coercion or undue influence
- Taking the informed consent document home prior to making a participation choice
- Procedures that encourage questions and that are able to provide answers tailored to participant informational needs



Questions/further discussion

