

## INFORMED CONSENT OF 16- TO 18-YEAR-OLD PARTICIPANTS IN EVALUATIONS

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**Abstract:** Ethics policies require parental consent for “children” less than 18 years old. This article examines whether parental consent should be required for youth aged 16 to 18 years. It examines the current position of youth vis-à-vis services, informed-consent requirements, the quality of parental consent, and youths’ legal and developmental capacity to consent. It concludes that youth have the capacity to consent. Recommendations are made to revise the parental-consent policy and to address the impacts of stress, emotion, and inexperience on youth’s decision making at all evaluation process.

**Résumé :** Les politiques d’éthique exigent le consentement parental pour les « enfants » âgés de moins de 18 ans . Cet article examine si le consentement parental devrait être exigé pour les jeunes âgés de 16 à 18 ans. Il examine la position actuelle des jeunes vis-à-vis des services, les conditions de consentement éclairé, la qualité de consentement parental, et la capacité légale et développementale des jeunes à consentir. Il conclut que les jeunes ont la capacité à consentir. Des recommandations s’ensuivent pour réviser la politique de consentement parental et adresser les impacts du stress, de l’émotion, et de l’inexpérience dans la prise de décision des jeunes à tout processus d’évaluation.

### INTRODUCTION

█ Evaluators are responsible for engaging in ethical evaluation research practice.<sup>1</sup> Part of our ethical practice must include understanding and obtaining informed consent from all participants generally and from vulnerable groups, including children and youth, specifically.

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Sometimes the requirements for “ethical” practice create situations that could be considered “unethical.” For example, youth can be excluded from participation based on the requirement for parental consent and on ethics policies’ refusal to allow their informed consent. Limited youth participation can limit knowledge development about youth services and potential improvements to services.

The irony of ethics policies contributing to unethical practice becomes especially evident when academic- and medical-based evaluators seek ethics approval through ethics review boards. They must either accept policy requirements regarding youth or challenge them by illustrating the policy’s potential unethical impact.<sup>2</sup> Evaluators working in other settings do not generally tend to seek ethics approval, but they do obtain informed consent from evaluation participants. Increasingly more client organizations are requiring ethics approval from evaluators.

In Canada, a system of ethics oversight was established by the three major academic- and healthcare-based funding bodies, known as Tri-Council: Canadian Institutes of Health Research (CIHR), Social Sciences and Humanities Research Council (SSHRC), and National Science and Engineering Research Council (NSERC). The ethics policy of CIHR et al. (2010) defines *children* as a vulnerable group comprising those who are 18 years of age and younger. Parental consent, coupled with the child’s assent, is required for a child’s participation. The age range that defines children does not take into account differences in children’s capacities at different ages. The capacity of a 5-year-old to understand project information and provide informed consent is vastly different than that of a 16- to 18-year-old. Although it is possible to obtain a waiver of parental consent (Canadian Institutes of Health Research, Social Sciences and Humanities Research Council, & Natural Science and Engineering Research Council, 2010), the evaluator must argue for it and can be refused. Depending on the actual capacities of these youth, the policy and the boards that implement it may be denying youth’s autonomy and placing youth as a group at risk.

Examining whether youth 16 to 18 years of age<sup>3</sup> should qualify to provide informed consent to participate, this article argues that requiring parental consent of any type (active or passive) has the potential to result in unethical practice for multiple reasons, including denial of a youth’s autonomy where capacity exists.

Four major areas are examined. *Transitional-aged youth* services are examined as the primary youth services that require evaluation. The structure of services and problems associated with the division between adults' and children's services and the limited availability of services (Children's Mental Health Ontario, 2011) are potential impediments to access that may result in youth "falling through the cracks" of the system (Davidson & Capelli, 2011). Services provide the context that affect and are affected by the policy regarding informed consent by youth.

*Informed consent in research and evaluation* is examined historically to demonstrate how ethics are based in medical-scientific, positivist perspectives that incorporate imbalanced power in the researcher-participant relationship (Rhodes, 2005). Provision of information about the research to support informed decision making by the participant can balance the power. Within this context, children under 18 years of age are considered a vulnerable group who require parental consent to participate (CIHR et al., 2010).

The question of whether *youth are capable of providing informed consent* is then examined. Youth are legally able to provide consent for many activities, including activities that may have serious impacts on the remainder of their lives (e.g., medical interventions). In addition, current knowledge of brain development indicates youth have the capacity for rational decision making at age 14 despite some decrease in this capacity when experiencing high emotional and stress levels and mental health issues (Hester, 2004; Petersen & Leffert, 1995).

Finally, the question of whether *16- to 18-year-old youth should be permitted to provide informed consent* is addressed. Parental consent, regardless of whether passive- or active-consent approaches are used, is generally of limited quality (Coyne, 2010, p. 231). Requiring parental consent may actually violate a youth's privacy rights. It may also result in biased samples and limit youth participation in research/evaluation projects (Chartier et al., 2008; Courser et al., 2009; Johnson et al., 1999; Pokorny et al., 2001; Smith, Boel-Studdt, & Cleeland, 2009), thereby affecting the quality of knowledge about services and identification of improvements to them. Youth 16 to 18 years of age can provide consent without their parents' involvement. However, given the potential impact of emotion, stress, and mental illness (Dorn, Susman, & Fletcher, 1995; Petersen & Leffert, 1995; Schachter, Kleinman, & Harvey, 2005), it is important to consider

approaches to dealing with youth to balance power in the researcher-participant relationship and mitigate the impacts of various types of evaluation on youth at each stage of the evaluation process.

## TRANSITIONAL-AGED YOUTH SERVICES

Transitional-aged youth are at a difficult age regarding the developmental tasks they face and the structure and accessibility of service-delivery systems available to them. Although many youth live in their parents' or guardians' home and attend school, some are emancipated, living in other arrangements (e.g., with a friend, on their own, on the street). Youth are consolidating their identities sexually, physically, psychologically, emotionally, and socially. Some youth are dealing with potentially difficult issues such as sexual-minority orientation, physical or sexual abuse, or mental illness, among others. Some may need services and may have to deal with the obstacles presented by various service-delivery systems (e.g., health, mental health, child welfare, and education). These are the very systems that are likely to be the focus of evaluators' work with youth.

Difficulties that youth experience in accessing service-delivery systems arise in part from how the systems are structured. Responsibility for service delivery usually rests with provincial/territorial governments. These governments tend to divide responsibility into services for children and for adults. Larger governments, such as Ontario's, assign these responsibilities to different ministries. For example, the Ministry of Health and Long-Term Care is responsible for adult mental health while the Ministry of Children and Youth Services is responsible for children's mental health. In practice, these divisions can overlap, duplicating services and/or excluding youth from services. For example, children's mental health services are provided to children up to 16 years of age but for those who are receiving services as they turn 16, services can be extended to 18 years of age (Child and Family Services Act, 1990). If services are needed after age 16 and the children's mental health criteria do not apply, youth must seek services from the adult system. In practice, transitional-aged youth tend to "fall through the cracks" between the child and adult systems, receiving no services or services that are not well suited for them (Davidson & Capelli, 2011). The situation is compounded further by a dearth of appropriate services for youth. Finally, specialized services for specific groups of youth (e.g., mentally ill) are often unavailable or have extensive wait lists, mak-

ing it more difficult for youth to access required services (Children's Mental Health Ontario, 2011).

It is against this backdrop that youth's informed consent should be examined.

## INFORMED CONSENT IN RESEARCH AND EVALUATION

### Ethics Codes: Early Development and Content

Examining the requirements for youth's informed consent requires a basic understanding of research ethics and informed consent, including the origins and intent of current approaches. Informed consent to research is a socially constructed concept (Miller & Boulton, 2007) built on concepts from two major areas: positivist research and law regarding consent and capacity.

Ethics requirements were developed in response to human-subject medical research undertaken in World War II Nazi concentration camps. The first ethics code, the *Nuremberg Code*, set standards for ethical medical research. It was developed by expert witnesses at the request of the Nuremberg Trial judges in 1947 (Rhodes, 2005). In 1964, the World Medical Association's *Declaration of Helsinki* maintained and expanded the concepts of informed consent for clinical medical research. Both documents incorporated positivist notions of research based on medical and scientific approaches to research (Weindling, 2001). These concepts continue to be refined and incorporated in ethics council policies worldwide.

Conceptualizations of the researcher-participant relationship underlying ethical codes are based in medical-scientific, and therefore positivist, perspectives. Research is viewed as potentially dangerous to, and exploitative and abusive of, the participant (Juritzen, Grimen, & Heggen, 2011; Rhodes, 2005). The relationship is considered hierarchical. The researcher is a powerful expert while the participant is vulnerable to the researcher's power. The power needs to be balanced to give the vulnerable participant power to protect him/herself against exploitation and abuse. Informed consent is a mechanism that can balance the power (Juritzen et al., 2011). Armed with information about the research, the potential participant can voluntarily decide whether to participate. Once s/he provides formal consent, the participant is responsible for determining whether to withdraw

later in the project. The researcher must revisit informed consent only when the research changes (CIHR et al., 2010).

Initial research ethics developments were based on notions that research was dangerous, the researcher was powerful, the participant was vulnerable, and the power relationship needed to be balanced to decrease the participant's vulnerability. Informed consent was necessary to ensure the participant voluntarily participated and understood both the intent of the research and the risks and benefits involved.

## ETHICS AND INFORMED CONSENT

Informed consent must be provided within the context of any ethical evaluation. Ethical projects must meet four standards:

1. Potential participants freely make informed decisions about whether or not to participate.
2. The research does not inflict harm.
3. The research benefits others.
4. People are treated equally in the research process.  
(Wiles, Heath, Crow, & Charles, 2005)

To meet the first standard, potential participants must

1. have the capacity to consent;
2. provide consent based on comprehensive information about the research; and
3. give consent voluntarily.  
(CIHR et al., 2010; Schachter et al., 2005)

Capacity to consent for any purpose, including evaluation, is a legal concept. The individual must have the capacity to understand information about the project, including potential consequences (i.e., risks and benefits) of participation. If the individual is capable of this, s/he has the capacity to provide informed consent.

National research ethics councils, including Canada's, identify "vulnerable" groups whose members may lack capacity to provide informed consent. Such groups include "children, the elderly, women, prisoners, those with mental health issues, and those with diminished capacity for self-determination" (CIHR et al., 2010, p. 10). All children are assumed to be incapable of providing consent. For

vulnerable group members who lack capacity to consent, a lawfully designated decision maker must provide consent. For children, this is the parent or legal guardian.

Parental consent is obtained using either active or passive consent (Johnson et al., 1999). For *active consent*, the evaluator provides the parent with project information necessary for informed consent. The parent must sign and return a consent form to permit his/her child to participate. For *passive consent*, the evaluator provides the parent with project information that includes a statement that consent will be implied if the parent does not contact the evaluator to exclude his/her child. Only children whose parents contact the evaluator to withdraw consent are excluded.

Many research ethics councils worldwide, including Canada's, define children as those younger than 18 years old (Rhodes, 2005). Although some countries strictly adhere to the requirement for parental consent, Canadian policies allow waiver of parental consent (CIHR et al., 2010). When parental consent is required, the child must usually also provide assent before participating. If parental consent is not provided, the child's wishes are not considered.

Considering youth as children who require parental consent assumes that youth lack the capacity to consent. This assumption may be inaccurate.

## ARE YOUTH CAPABLE OF PROVIDING INFORMED CONSENT?

To provide informed consent, an individual must have the capacity to understand the purposes, objectives, and processes of the evaluation; what participation entails; and the risks and benefits associated with the evaluation.

### Legal Capacity to Consent

If youth were considered legally incapable of providing informed consent, no laws would allow them to provide consent. In Canadian law, there is no specific age at which youth are considered capable of providing consent. Although the federal and provincial/territorial governments split jurisdiction for many areas of law, even within a single level of government a wide range of ages of consent exists.

In Ontario statutes, ages for consent are associated with specific activities that may pose serious risks and benefits to youth when they consent and throughout their lives. For example, youth can legally give consent at 16 years for health-related services (e.g., counseling) but at 12 to 15 years if the service provider discusses involving the parent as soon as possible after service commences (Child and Family Services Act, 1990); 18 years for marriage without parental consent or 16 years with parental consent (Marriage Act, 1990); 19 years for consumption of alcohol (Liquor License Act, 1990); and 16 years for driving a vehicle (Highway Traffic Act, 1990).

The federal government typically sets 18 years as the age at which one is capable of providing consent, although there is variation. Eighteen-year-olds have the right to vote (Canada Elections Act, 2000). Likewise, criminal law applies to offences committed by people 18 years and older. For those 12 to 18 years of age at the time an offence is committed, the Youth Criminal Justice Act (YCJA) applies (Youth Criminal Justice Act, 2002). The YCJA includes provisions for a youth to be tried and/or sentenced as an adult. Approaches at each stage of the justice process ensure that the youth's developmental stage is considered in case processing. Youth have a right to legal counsel that works on the youth's behalf only. Regardless of parental involvement, it is the youth who instructs his/her lawyer on how to deal with the case. That such decision-making responsibility rests with the youth demonstrates that youth are legally deemed capable of providing consent.

Clearly there is no specific age at which a youth is legally considered capable of consenting. Those as young as 12 years old can consent to some things but must be considerably older to consent to other things. Regardless of age, youth can consent to potentially risk-filled and harmful activities. It is therefore important to examine a youth's capacity to rationally consider project information, including risks and benefits, and provide consent.

### Adolescent Development and Decision Making

The inconsistency in Canadian law regarding ages at which youth can provide consent is not fully supported by the literature concerning adolescent development and capacity to consent. During adolescence, decision-making and consent capabilities are affected by brain development. The frontal lobe develops significantly, increasing capacity for thinking and logic. This increases youths' ability to think

problems through and make decisions. Frontal lobe development is not complete until youth reach their early 20s (Australian Law Reform Commission, 2008; Poletti, 2009). However, research addressing adolescents' capacity to consent indicates that by approximately age 14, youth are able to make informed consent decisions for a range of activities (e.g., medical intervention, research participation) as well as adults can (Hester, 2004; Petersen & Leffert, 1995). Further, youth 15 years and older understand the risks and benefits of participating in a study and their relevant rights in the situation at a level comparable to adults (Hester, 2004). They are also able to weigh risks and benefits for decision-making purposes (Petersen & Leffert, 1995).

While thinking and logic functions develop throughout adolescence, youth's decision-making capacity can be affected by emotions to a greater extent than adults', especially in emotion-charged and highly social situations. In these circumstances, adolescents may fail to fully evaluate courses of action. Decision making can also be affected by the emotional impact of hormonal changes during puberty (Petersen & Leffert, 1995). Petersen and Leffert found that as adolescents develop cognitively, stressful and new situations can cause difficulty with decision making. In new situations, adolescents lack experience to draw on for decision making. Inexperience may increase stress levels, thereby affecting decision-making capacity. Dorn et al. (1995) found that the greater the level of youth's emotion, the lower their level of understanding of what participation would mean. Emotions had a greater impact on adolescents' level of understanding than did age or level of cognitive development (Dorn et al., 1995). The presence of mental health issues also had an impact. Adolescents with mental health issues could understand information provided to them for informed consent as well as others but were less able to reason based on that information (Schachter et al., 2005). While adolescents may have understood risks, they tended to underestimate the extent to which risks can affect them personally (Tillett, 2005). In summary, by age 15 adolescents can provide consent but the quality of consent can be affected by stress, emotions, and inexperience.

Regardless of general decision-making development, there is variation in development between adolescents and for an individual over short time frames. Although most adolescents are able to make informed decisions at 15 years, some may not yet be sufficiently developed. The individual's behaviour sometimes alternates between child-like and adult-like (Petersen & Leffert, 1995). Similarly, some

adolescents under 15 who developed earlier than the norm are capable of making decisions and providing informed consent.

The developmental literature suggests that adolescents 15 years of age and older have the capacity to understand information and provide informed consent, but consent may be affected by the youth's stress levels, emotions, and inexperience. That said, adults' capacity can also be affected by their levels of emotion, stress, and inexperience. Although it would be helpful to have a standardized age in law at which a youth can consent to all activities, the development literature does provide support for the capacity of youth 16 to 18 years of age to provide informed consent for evaluation purposes.

### SHOULD 16- TO 18-YEAR-OLD YOUTH BE PERMITTED TO PROVIDE INFORMED CONSENT?

Although it may seem odd, youth are legally able to consent to procedures and activities that are potentially more harmful to them than participation in most human-subject-evaluation projects but, absent a waiver, they need parental consent to participate in ethics-reviewed research/evaluation. It is therefore important to consider whether youth should be able to provide consent for evaluation/research.

#### Issues Regarding Parental Consent and Youth's Capacity to Consent

Given the inconsistency between youth's ability to consent to activities (e.g., medical procedures) and to research/evaluation participation, it is important to examine the implications of parental consent for research/evaluation purposes.

Whether or not parental consent should be required should be determined in part by

1. the likelihood of parental consent safeguarding youth; and
2. the effects of passive- and active-consent approaches on knowledge development about services.

Parental consent is intended to safeguard children by ensuring their interests are considered by someone who has legal authority to act on their behalf. This assumes that the parent is able to understand the project specifics, make quality decisions on the child's behalf, and thereby protect the child. However, "parents often find it difficult to

comprehend and absorb the implications of the research for their child ... Therefore it cannot be assumed that parents will be able to weigh benefits and risks of research and that their consent will safeguard children's best interests" (Coyne, 2010, p. 231).

Different approaches to obtaining parental consent affect participation rates. Passive-consent approaches resulted in higher participation rates generally and also higher participation rates among those children who were "at risk" for various problems (e.g., depression, child welfare involvement) (Chartier et al., 2008; Courser et al., 2009; Johnson et al., 1999; Pokorny et al., 2001; Smith, Boel-Studdt, & Cleeland, 2009). Courser et al. (2009) found that active consent resulted in demographically biased samples: participants were "significantly younger, in lower grades, and were less likely to be male" (p. 390); while Johnson et al. (1999) found a tendency for fewer racial minority participants, low academic achievers, latch-key children, and youth involved in drugs. With active-consent approaches in school settings, they also found that parental consent rates could be increased by connecting directly with parents to remind them to return consent forms (Johnson et al., 1999). While costs associated with increasing the rate were low relative to previous studies, the costs and time expended made obtaining active parental consent problematic.

Finally, requiring parental consent of any type can be problematic for some groups of youth. For example, Mustanski (2011) showed that requiring parental consent for involvement in research related to lesbian, gay, bisexual, transgender, two-spirit, queer, questioning, or intersex (LGBTQQ) programming decreased the likelihood that LGBTQQ youth under 18 would participate. The requirement resulted in underrepresentation of youth who made no suicide attempts in the preceding year, binge drank less, were racial/ethnic minority members, were bisexual, or had less family support (Mustanski, 2011).

Requiring parental consent is problematic. It neither safeguards youth nor ensures unbiased samples. If active-consent approaches are used, the groups most likely to opt out are the very at-risk groups that youth services serve—those who need services requiring evaluation (e.g., LGBTQQ programming, mental health counselling, domestic violence services). Obtaining an unbiased sample is more costly and requires more staff time to encourage parents to consent. While passive consent may result in higher participation rates, it requires release of the youth's information to ask for consent. Agencies providing youth services cannot authorize evaluator access to parents

without violating a youth's right to privacy. Youth are unlikely to agree to that access if their parents do not know they are receiving services (Mustanski, 2011). If the evaluator cannot get an unbiased sample, these youth are negatively impacted because knowledge about service effectiveness does not get developed and evidence-based changes to increase effectiveness do not occur. Given the situation of transitional-aged youth vis-à-vis services, it is likely that they continue to "fall through the cracks." All of these concerns make the requirement of parent consent for youth indefensible.

The requirement for parental consent becomes more questionable within the context of current knowledge concerning youth's capacity to consent. The developmental literature dealing with youth capacity clearly indicates that by age 15 the brain is sufficiently developed to have capacity for informed consent. Although a youth's emotions can influence the quality of consent, the youth is capable of the understanding that is legally necessary to provide consent and can legally provide consent for many activities.

Because capacity exists, denying youth their right to participate without parental consent is especially problematic given that parental consent may not safeguard the youth, increases the likelihood of biased samples or requires greater effort and budgets to obtain unbiased samples, can violate youths' privacy rights, may prevent knowledge about program effectiveness from developing further, and can prevent evidenced-based program improvements from being made.

### Dealing with Youth Consent

The ethics policy requiring parental consent for youth participation should be revised to permit informed consent by youth, thereby making the policy congruent with current knowledge about youth development and acknowledging the potential insufficiencies of parental consent for safeguarding youth and resulting sampling impacts. The need for program knowledge and improvements to safeguard youth who receive services could also be better addressed through evidence-based improvement of youth services.

The literature indicates that youths' decision making may be more influenced by emotions and a sense of invulnerability than adults'. Despite this, their capacity to consent exists. In acknowledging youths' capacity and right to provide informed consent, evaluators should ensure they address emotion's potential influence on youth.

Youth are likely to be inexperienced at participating in evaluations and may experience increased emotional and stress levels through participation, thereby affecting the quality of their decisions about participation. Youth also need to have a sense of self-control and of their power. We therefore need to balance the power distribution between the evaluator and youth to increase the youth's sense of self-control, power, and emotional well-being. Approaches to balancing power will also affect the complexity, duration, and potential level of risk and impact on youth participation in evaluations.

The nature of the evaluation must also be considered as an influencing factor for youth's emotions and the quality of informed consent. Evaluations may range from straightforward to complex in design, duration, and type of participation. Provision of consent for one-time completion of a survey used in a straightforward process evaluation of a youth recreation program will likely have fewer impacts on youth than ongoing participation involving multiple in-depth interviews among other data collection approaches in a complex outcome evaluation of a cancer treatment program in which youth are patients. Youth are likely to experience more significant stress and emotions as a result of participation in the latter. The approaches to addressing impacts should be consistent with the needs related to the nature of the evaluation.

We should consider factors about youth and about the nature of the evaluation in the context of several key areas as we design and implement evaluations that address issues of stress, emotion, and power.

**Target Group:** The more "at risk" that youth participants are, the more likely it may be that evaluation participation will create stress and higher levels of emotion for youth. We should consider the degree to which youth are at risk, the potential impacts of participation on them, and the quality of their consent at every evaluation stage. We should identify approaches that reduce stress and emotion and balance power as much as possible. For evaluations that entail a high risk of negative impact on youth, it may be important to include regular check-ins regarding a youth's continued participation and the impact of participation to date on him/her. This can be done at key points in the evaluation and on an ongoing basis as data collection occurs (e.g., as revisited during interviews).

**Topics Addressed:** Stress levels and emotions increase when sensitive topics are discussed. We need to determine whether youth consider the evaluation topics to be sensitive and develop approaches to dealing with the emotion and stress they experience for sensitive topics. One approach is to select data collection methods that increase youths' comfort or decrease their level of emotions. For example, interviews rather than focus groups may aid youth when sensitive topics are involved. Depending on the topics and level of risk, the evaluator can check in with the participant occasionally and, when indicated, remind them that they can choose to withdraw. The evaluator may also need to ensure that approaches are in place to refer youth to services in the event that very sensitive topics cause the youth distress (e.g., discussion of experiences with relevant topics to a participant who has posttraumatic stress disorder). Topics addressed will require detailed consideration of staffing requirements such as the level of professional training required, skills in interviewing, skills in dealing with crises, and level of evaluation staff experience.

**Design:** The type of program evaluated (e.g., cancer treatment program, sports program) will influence evaluation complexity and the anticipated level of youths' stress, emotion, and perspectives on power. The type of participation expected and the duration of the participation will also have an influence. The evaluator can anticipate that longer periods of involvement in the evaluation coupled with data collection approaches that involve more intrusive involvement in the project (e.g., interviews on sensitive topics, collection of bodily fluids) may contribute to higher levels of stress and emotion. Consideration of how best to collect data to obtain the information needed while minimizing the impacts on youth must be made. Data collection approaches, approaches to obtaining informed consent and checking in with youth to determine whether or not they continue to consent to participate, and arranging for resources that can aid youth in dealing with impacts should be considered as appropriate to the type and nature of the evaluation. Processes can be developed that aid in addressing evaluation impacts (e.g., foreshadowing possible impacts of participation, formal and informal checks on youth's well-being and desire to participate).

Youth are often sensitive to power and control. They may feel most comfortable when they have a sense of control and do not feel forced into doing things. If they feel controlled and lacking power, their level of stress and emotional response will increase and potential-

ly affect their decision making. We should therefore consider the power relationships inherent in various evaluation designs we use. Karnieli-Miller, Strier, and Pessach (2009) note that the nature of the overall power relationship is related to the type of study. Hierarchical relationships can be present in quantitative, anthropological/ethnographic, and sociological/psychological-based studies. Feminist/constructionist studies tend to involve low-hierarchical power relationships, cooperative research involves equal partnerships, and collaborative studies tend to be highly egalitarian (Karnieli-Miller et al., 2009). Where the design is characterized by hierarchical relationships, we need to consider youth's potential response to it as well as ways to balance the power during the evaluation.

**Minimizing Stress and Emotion Through Power Distribution:**

Rather than viewing the researcher-participant relationship as hierarchical and the researcher as powerful, we can consider the distribution of power as “relational as well as structural, and as dynamic and constantly changing” (Juritzen et al., 2011, p. 642). This allows us to work within natural changes in power distribution at different project stages and to distribute power to aid in reducing the youths' stress and emotions when possible to ensure ongoing, quality consent.

During the *design stage*, power tends to rest with the evaluator for most designs (Karnieli-Miller et al., 2009). We should consider approaches to the issues of youth development, dealing with stress and emotions to influence the quality of informed consent, sensitivity of the topics addressed, optimal design to deal with power differentials, and/or ways power distributions can be used throughout the evaluation.

During the *recruitment stage*, power shifts to the potential participant (Karnieli-Miller et al., 2009) as we try to recruit youth and obtain formal informed consent. While youth have the power to determine whether or not to participate, we can influence the quality of their decisions. For evaluations involving sensitive issues and/or at-risk youth, we can anticipate and address the items that increase stress and emotion to decrease youth's concern. Selecting how we provide information will aid this. For example, we can provide information in person to allow the youth to ask questions and the evaluator to address areas of concern, and/or in writing to allow the youth to later refer back to the information.

Distribution of power during the *data collection stage* depends to some extent on our data collection approach(es) (Karnieli-Miller et al., 2009). For data collection that does not involve face-to-face interaction (e.g., survey, art, photography), we can be available to address the youth's issues. We can ensure that interviews are collaborative, with power shifting from us to participant as s/he determines what information to share. We can also be attentive to verbal and body language that indicates the youth is uncomfortable and invite him/her to discuss this, to refrain from responding if s/he wants, and, in some instances, to remind him/her of the option to withdraw consent.

During the *data cleaning and verification stage*, we can increase youths' power by providing them with their interview transcripts to make changes. This can provide them with a sense of control over their information. Although there is a risk in involving youth at this stage because important data could be excluded, discussions can occur about items the youth wishes to exclude, assuming the youth feels respected.

During the *analysis stage*, we can involve youth participants (Karnieli-Miller et al., 2009). Both the analysis and participants can benefit from this. Our joint interpretation of results can give a fuller understanding of the subject matter.

We can involve youth during the *reporting stage* to provide input on draft reports.

While not all of these suggestions are directly related to informed consent, they address issues that can reduce stress and emotions and give the youth a sense of control and power, and so they can influence youth's ongoing participation in the evaluation and the quality of the consent they provide.

## CONCLUSION

Youth 16 to 18 years of age who wish to participate in evaluations should be excluded from requirements for parental consent because several issues arise with that requirement. Given the quality of parental consent, safeguarding the child does not necessarily occur. Regardless of the method through which parental consent is obtained, it can result in low participation rates. Active-consent approaches can result in biased samples. Requiring parental consent can also violate a youth's rights to privacy and confidentiality. These issues can result

in restriction of knowledge development and service improvement when valid service-evaluation results cannot be obtained.

Youth have the capacity to consent, both legally and developmentally. They are legally capable of providing consent for activities that are potentially more risk-filled and harmful to them than participation in most research and evaluation projects. The literature indicates that by 15 years of age, youth are capable of understanding project information at the level of an adult, including potential risks and benefits. However, a youth's decision making may be more influenced by stress, emotions, and inexperience than an adult's is. Regardless, their capacity to consent exists. It is therefore problematic to deny a youth's autonomy to provide consent through a policy that considers youth as children incapable of consent.

Evaluators can address youth consent issues related to stress, emotions, and inexperience at each evaluation stage by considering these issues and ensuring that the youth retains power to determine how s/he wishes to be involved in the evaluation.

## NOTES

- 1 Evaluation research is a specific form of research that I will refer to as *evaluation*, with the exception of the discussion regarding the origins of research ethics, where the term *research* is used. Although evaluation research aims to provide information for decision making, like other forms of research it contributes to knowledge development.
- 2 Although evaluation research is technically excluded from ethics review, many evaluation projects are reviewed by ethics boards.
- 3 Youth 16 to 20 years of age are "transitional-aged youth." In this article, this term or the term *youth* refer to the subgroup of those 16 to 18 years of age.

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