APA RESOLUTION on Support for the Expansion of Mature Minors’ Ability to Participate in Research

AUGUST 2018

The promotion of health and prevention of disease are dependent on psychological research findings that are generalizable across samples and populations as well as specific to at-risk groups. Adolescent minors are at risk for a variety of sensitive health issues, such as human immunodeficiency virus and other sexually transmitted infections (HIV/STI) (Centers for Disease Control & Prevention [CDC], 2015a, 2016b) and substance abuse (CDC, 2016c). Furthermore, being part of stigmatized groups, including gender and sexual minorities (e.g., adolescent males who engage in same-sex sexual behavior; gay, lesbian, bisexual, and transgender youth) makes these young individuals more vulnerable to such health risks (CDC, 2015b, 2016a). Research that includes at- or high-risk minors is imperative to the design of effective prevention and intervention programs. The American Psychological Association (APA) recognizes and affirms the principle of autonomy, including the rights of parents to choose whether or not their children participate in research. However, studies examining stigmatized issues face participation barriers when obtaining parental permission may put the minor at risk of harm (American College of Obstetricians and Gynecologists [ACOG], 2016; Duncan, Drew, Hodgson, & Sawyer, 2009; Fisher, 2015; Fisher, Arbet, Dumont, Macapagal, & Mustanski, 2016; Fisher & Mustanski, 2014; Moore, Paul, McGuire, & Majumder, 2016; Mustanski & Fisher, 2016). Even though current federal regulations allow for the waiver of parental permission in certain instances, institutional review boards (IRBs) have been inconsistent in their application of the relevant regulations (Mustanski & Fisher, 2016).

WHEREAS requiring parental permission for mature minors’ participation in some research may undermine (a) the quality of the science, (b) the availability or application of evidence-based interventions for adolescents, and (c) addressing serious health concerns (e.g., HIV/STI among adolescents) (Culp & Caucci, 2013; Duncan et al., 2009; Fisher, 2015; Fisher & Mustanski, 2014; Fisher et al., 2016; Moore et al., 2016; Mustanski, 2011; Mustanski & Fisher, 2016; Society for Adolescent Medicine [SAM], 2003; Toner & Schwartz, 2003); and

WHEREAS minors who are willing to participate in sensitive research that requires parental permission and therefore knowledge of participation in at-risk behavior or membership in a stigmatized group may not be representative of the “true” population (Bruce, Berg, & McGuire, 2009; Culp & Cauci, 2013; Fisher & Mustanski, 2014; Fisher et al., 2013, 2016; Moore et al., 2016; Mustanski, 2011; Mustanski & Fisher, 2016; Rojas, Sherrit, Harris, & Knight, 2008); and

WHEREAS critical progress may be unintentionally hindered by IRBs through lack of (a) recognizing and applying federal regulations allowing mature minors to participate in research without parental permission, (b) extension of mature minor laws from health care to research, and (c) clarity on parental rights and minor decision-making capacity (ACOG, 2016; Coleman & Rosoff, 2013; Fisher, 2015; Fisher & Mustanski, 2014; Fisher et al., 2013, 2016; Moore et al., 2016; Mustanski, 2011; Mustanski & Fisher, 2016; Ruiz-Canela et al., 2013); and

WHEREAS guardian permission is intended to protect the minor, parental rights may be misunderstood to supersede those of the mature adolescent minor in cases when physical, psychological, or social harms may result for children if parents are informed about the study focus (Chenneville, Sible, & Bendell-Estroff, 2010; Duncan et al., 2009; Flicker & Guta, 2008; Moore et al., 2016; Mustanski, 2011; Office for Human Research Protections, n.d.; Pasternak, Geller, Parrish, & Cheng, 2006; Rojas et al., 2008; Ruiz-Canela et al., 2013; SAM, 2004); and

WHEREAS research supports that children as young as 14 years old can provide valid informed consent similarly to adults when information is presented at developmentally appropriate levels and the consent process is conducted under minimal stress (Berkowitz, 2006; Fisher et al., 2013, 2016; Moore et al., 2016; Mustanski & Fisher, 2016; Ruiz-Canela et al., 2013; SAM, 2003; Steinberg, 2013; Toner & Schwartz, 2003):

THEREFORE BE IT RESOLVED that APA reaffirms the federal regulations for the protection of research participants promulgated by Office for Human Research Protections (n.d.) and the Food and Drug Administration (Roth-Cline, Gerson, Bright, Lee, & Nelson, in press) that classify minors as “adults” if they have attained their state-determined age to consent to treatment or to study-related procedures.

FURTHER BE IT RESOLVED that APA supports the extension of mature minor laws from health care to research when participation in the study does not pose more than a minor increase in minimal risk of harm to the participant.
AMERICAN PSYCHOLOGICAL ASSOCIATION

RESOLUTION ON SUPPORT FOR THE EXPANSION OF MATURE MINORS’ ABILITY TO PARTICIPATE IN RESEARCH

FURTHER BE IT RESOLVED that APA encourages IRBs to be knowledgeable about, and require research protocols to include, current and contextually appropriate data on the ability of youth to independently consent (Dunn, Nowrangi, Palmer, Jeste, & Saks, 2006), how to tailor consent procedures to the decision-making abilities needs of mature minors, and use of participant advocates when appropriate.

FURTHER BE IT RESOLVED, in accordance with current regulations, that APA asks IRBs to waive the parental permission requirement when it could potentially harm the mature minor and when alternative and appropriate research protections are in place.

FURTHER BE IT RESOLVED that APA urges IRBs to allow minors fair access to research critical to identifying developmentally appropriate evidence-based interventions.

REFERENCES


Copyright © 2018 by the American Psychological Association.
Approved by the APA Council of Representatives, August 2018.