

Assessing and Enhancing the Research Consent Capacity of Children and Youth

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This study examined the capacity of 291 4th, 7th, and 10th graders, as well as college students, to understand their rights in research and the extent to which this capacity can be enhanced following exposure to The Research Participants' Bill of Rights. Comprehension of the research procedures, risks and benefits, voluntary nature of participation, and confidentiality protections improved in all grades following exposure to the Bill of Rights. Fourth graders performed poorer than older respondents when asked to match rights definitions, identify true and false statements about specific research rights, and label and recognize rights violations in hypothetical research vignettes. Data suggest that 7th graders, when compared to older participants, are still struggling to understand their veto power over adult permission, their right to be protected from harm, and to be informed about research procedures and results. Overall, 10th graders' responses did not differ from adults'. Implications of the findings for informed consent procedures are discussed.

Voluntary informed consent has been viewed by many as the best means of protecting the rights and welfare of individuals asked to participate in research (Freedman, 1975). The ethical value of informed consent rests on the assumption that prospective participants are able to (a) comprehend the nature and rationale of experimentation; (b) understand their research rights, including the right to freely volunteer and withdraw participation, to receive and understand information about this study, and to have their responses remain confidential; and (c) protect themselves against rights violations. However, in both law and ethics minors have been presumed to lack these capacities because of immature cognitive skills, inadequate experiences in situations analogous to the research context, and the actual and perceived power differential between children and adults (Fisher, 1993; Fisher & Rosendahl, 1990; Grisso & Vierling, 1978; Keith-Spiegel, 1983; Koocher & Keith-Spiegel, 1990;

Thompson, 1990). Based on this premise, federal guidelines (Department of Health and Human Services [DHHS], 1991) and ethics codes (e.g., the American Psychological Association [APA], 1992; Society for Research in Child Development [SRCD], 1993) require guardian consent to ensure that children are not vulnerable to rights-violations (Fisher, 1993; Fisher, Hoagwood, & Jensen, 1996; Melton, Koocher, & Saks, 1983).

Out of respect for children as developing persons, federal regulations and professional codes also stipulate that a child's dissent normally overrides parental permission and require the assent of the child-adolescent to participate in research if the minor is judged capable of providing such assent. Federal regulations do not, however, stipulate a specific age at which assent must be sought. For each research protocol, investigators and their Institutional Review Boards [IRBs] must make that determination taking into account the nature of the research and age, maturity, and psychological state of the minor involved (Fisher, 1993).

The conviction that guardian consent is always in a youthful participant's best interest has also been called into question (Gaylin & Macklin, 1982). For example, the requirement for parental permission may be inappropriate if there is serious doubt as to whether the parents' interests adequately reflect the child's interests (e.g., research on child abuse or neglect; genetic testing of a healthy sibling of an ill child) or cannot reasonably be obtained (e.g., research on runaways; DHHS, 1991, 45 CFR 46.408 [c]). Furthermore, some have sug-

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gested that the requirement for parental permission be waived when adolescents decide to participate in research that explores reasons for and reactions to medical and mental health problems (e.g., venereal disease) for which states permit them to autonomously seek and receive treatment (DHHS, 1977; Fisher, 1993; Fisher, Hatashita-Wong, & Isman, 1999; Fisher, Hoagwood, & Jensen, 1996; Holder, 1981; Rogers, D'Angelo, & Futterman, 1994; Scarr, 1994).

Given the ethical importance of insuring that research consent procedures adequately protect the rights of children and youth, assessing and enhancing minor research participants' understanding of their rights should be an ethical priority for developmental scientists. To date, however, there has been a paucity of scholarship on children's understanding of research rights and methods to enhance their assent capacity.

Developmental Perspectives on the Consent Capacities of Minors

Reflecting a growing societal concern for children's rights to self-determination in legal, educational, social service, and medical settings (Baumrind, 1978; Takanishi, 1978), Grisso and Vierling (1978) were among the first to call for an empirically based developmental perspective on the capacity of minors "to assume the roles that self-determination rights require" (p. 412). They suggested that although limited social experience and immature encoding and representational skills may exclude preadolescent children from meaningful consent, increasing social autonomy and the emergence of more efficient cognitive strategies might provide psychological grounds for assuming that by age 15 minors can provide competent consent.

The small body of research on minors' consent capacity lends support to early adolescence as an important marker for rights self-determination. For example, Melton (1980) found that younger children view self-determination as arbitrarily granted by adults, whereas early adolescents begin to see rights as part of a conventional social order shifting in late adolescence to conceptions based on abstract and universal concepts such as civil liberties. In more recent studies, Ruck, Abramovitch, and Keating (1998) and Ruck, Keating, Abramovitch, and Koegl (1998) described a similar age-related progression for self-determination rights.

The earliest studies of actual consent capacity in minors focused on their understanding of medical and psychological treatments. For example, Lewis, Lewis, and Ifekwungue (1978) found that 6- to 9-year-olds were able to articulate a choice about participation in an influenza vaccine trial, and with increasing age, were able to ask questions about the risks and benefits of the trials. In a now classic study, Weithorn and

Campbell (1982) found that 14-year-olds, but not 9-year-olds, were as competent as adults to make informed consent decisions about four hypothetical medical treatments. Later, Morton and Green (1991) found that although comprehension by psychiatric inpatients who were 10- to 17-years-old increased developmentally, minors of all ages were at risk for misconceptions about both the nature of psychotherapy and their rights to refuse treatment.

More recently, investigators have begun to focus on minors' understanding of informed consent for participation in research. Abramovitch, Freedman, Henry, and Van Brunschot (1995) and Abramovitch, Freedman, Thoden, and Nikolich (1991) found that although 5- to 12-year-olds understood the purpose and procedures of nonclinical research, understanding the risks, benefits, right to withdraw, confidentiality, and the voluntary aspects of research was poor. Nannis (1991) also observed that third and fifth graders had difficulty understanding that a research study designed to assess their ability to detect math errors was not intended to directly help them improve their math skills.

Enhancing Consent Capacities

IRBs are increasingly pressing for ways in which investigators can enhance and evaluate participant's understanding of their rights in research (Prentice, Reitmeir, Antonson, Kelso, & Jameton, 1993; Rogers, 1997). Preliminary findings on the efficacy of brief educational presentations on enhancing prospective participant's comprehension of rights in treatment and research though scarce, are promising. Belter and Grisso (1984), studying rights comprehension in a hypothetical counseling session, found that when educated about treatment rights through a brief video presentation, 15-year-old minors were able to recognize rights violations and protect themselves as well as adults. By contrast, the benefit of rights education for 9-year-olds and adults was minimal.

Tymchuk (1992) found simplified written or videotaped forms of a patient bill of rights enhanced understanding of treatment rights for mentally retarded and emotionally disturbed adolescent inpatients. More recently, Abramovitch et al. (1995) found that children were more likely to exert their right to withdraw from a study if an experimenter asked if they wanted to stop or clarified that she would not be angry if the child wanted to withdraw.

It is important to note that the education provided by Belter and Grisso (1984) and Tymchuk (1992) focused on treatment settings. To date, no studies have empirically explored the value of such education in normative, nontreatment research.

Aims of This Study

The goal of this study was three fold. First, we sought to evaluate children's, adolescents', and college students' understanding of their research rights in a study for which they had provided assent or consent. Second, we wanted to examine minor participants' understanding of their rights in normative, nontreatment research. Specifically, developmental differences in comprehension of rights definitions, the true or false nature of rights statements, and the ability to label and be aware of rights violations in hypothetical research vignettes were assessed. Third, we sought to assess the extent to which a brief lesson, *The Research Participants' Bill of Rights*, could improve rights related consent capacities in normative, nontreatment research that employs more active and informed consent procedures. An ongoing ethical challenge for developmental scientists is balancing the obligation to respect the rights of children and adolescents to freely assent or dissent to research participation, with the need to ensure that ill-informed or incompetent decisions do not jeopardize the informed and voluntary nature of their decision. The long term goal of this study is to assist investigators in their efforts to balance these dual obligations by presenting preliminary data on developmental variations in understanding and applying rights information within the context of research, and to provide a practical means for helping children and adolescents to better understand and exert their research rights.

Method

Participants

The sample was comprised of 82 fourth graders (M age = 9.5, range 8.9–10.7), 63 seventh graders (M age = 12.6, range 9.9–13.8), 75 tenth graders (M age = 15.5, range 14.9–17.6), and 71 college students (M age = 19.6, range 17.9–26.8; 28% freshman, 49% sophomores, 23% juniors). For all age groups females comprised approximately half the sample and the majority (on average 73%) identified themselves as White, with approximately 16% as Hispanic, 4% Asian, and 7% as Other. Most participants were from middle-class households as indicated by an average Hollingshead (1957) indexes score of 42 (range = 17–72). Data on each student's religion was not collected. However, the school principals reported that the majority of the 4th through 10th graders in each school were Christian. The college was a Jesuit University.

Instruments

Overview. Two lessons were developed for this study: *The Research Participants' Bill of Rights* and

Psychology: The Science of Human Behavior. Five comprehension measures were also developed:

1. Consent Form Comprehension.
2. Rights Definition.
3. True–False.
4. Rights Violation Labeling.
5. Rights violation awareness.

The first assessed their comprehension of the nature of this research study. The four additional measures were developed to examine the ability to define and understand specific research rights and identify when they were violated.

Instrument development and validation. Recognizing that research rights language and concepts may risk taxing the comprehension of the younger children and convey a natural advantage to the college students, words for definitions and questions were selected at the simplest level possible to preserve the underlying meaning of the research right. Given the abstract nature of rights, the simplest level sometimes meant our measures were written at a level slightly above the reading level of our youngest group of participants. To ensure that the concepts would be accessible to the youngest participants we piloted an initial set of materials items with a small group of fourth graders ($n = 21$). Pilot students were tested individually to allow the researchers to ask questions following completion of the measures. The survey directions and questions were read aloud to the students as they followed along with a written copy of the materials. To determine if the directions were understandable, the researcher observed the students to make sure they were completing the tasks correctly (i.e., following the directions). After completion of the surveys, students were asked several questions to assess their understanding of the terms used. For example, students were asked to tell us in their own words what each right meant. When an incorrect answer was given students were asked to explain why they chose that answer. The final revised set of instruments yielded Flesch-Kincaid reading levels (Microsoft® Word 2000, Version 9.0.3821) of 5.3, 5.9, 3.2, 4.5, 6.2, and 6.5 for the following tasks Consent Form Comprehension, Rights Definition, True–False, Rights Violation Labeling and Awareness, Bill of Rights, and Psychology lesson, respectively. To further reduce any effects of reading level, as described in the Procedures section, all items were read out loud to students during testing.

Construct validity for the Consent Form Comprehension Task was established by having three experts in child-development research read the assent forms for children and the consent forms for the college students. They then indicated the correct answer to each question and highlighted where in the forms the information was

located. All three experts had 100% agreement. Construct validity for Rights Violation Labeling Task and Rights Awareness Task was established by having the three experts sort each vignette into categories by right and categories reflecting if the right was violated or not. Two experts had 100% agreement. These raters differed from the last expert on one question, reflecting a 97% agreement. After discussion between these raters regarding this one question, 100% agreement was obtained. The Rights Definition and True–False Tasks had face validity as well as content validity as the questions were drawn from the Bill of Rights.

The Research Participants’ Bill of Rights and Psychology: A Science of Human Behavior. The rights education groups received *The Research Participants’ Bill of Rights* (see Appendix) that included brief explanations of eight essential research rights drawn from federal regulations (DHHS, 1991) and the ethical codes of the APA (1992) and the Society for SRCD (1993). The eight rights included the right to

1. Be fully informed about the research.
2. Ask questions.
3. Participate or not in this study.
4. Withdraw from this study.
5. Have privacy and confidentiality protected.
6. Be protected from harm.
7. Know the results of this study.
8. Understand these rights.

The title or name of each right was presented followed by its definition or an explanation of the right.

The other lesson, *Psychology: A Science of Human Behavior*, served as a control condition, and contained descriptions of eight aspects of the discipline:

1. What is psychology?
2. Areas within psychology.
3. Jobs in psychology.
4. Research: The scientific method.
5. Research: Making a hypothesis.
6. Research: Collecting data.
7. Research: Analyzing and interpreting the data.
8. Research: Writing a summary.

Consent form comprehension task. This task consisted of seven 4-item multiple-choice questions tapping participant’s understanding of information provided during the informed assent–consent procedures for this study. The questions addressed the following elements of factual information:

1. Purpose, “Why is this study being done?”
2. Procedure, “What will you do in this study?”
3. Consent, “Who gave permission for you to be in this study?”

4. Right to withdraw, “What will happen if you want to stop being in this study?”
5. Confidentiality, “Who will find out how you answered the questions in this study?”
6. Research benefits, “What is a good thing that could come out of this study?”
7. Research risks, “What are the risks in this study?”

One point was earned for each correct choice. This measure was completed prior to the lessons.

Alternative choices were selected following an assessment of children’s common misconceptions reported in the literature as well as from our pilot testing. For example, choice alternatives to Question 1 were designed to assess whether participants could distinguish between the actual purpose and other information provided during the consent process (e.g., reading scores will be analyzed, participants’ will be asked to identify rights in stories about research on risky behaviors). Choices for “Why is this study being done?” were (a) “To test and compare children, teenagers, and adults’ reading ability”; (b) “To learn about risky behaviors in elementary school, high school, and college”; (c) “To learn how well children, teenagers, and adults understand their rights in research”; and (d) “To learn at what age children, adolescents, and young adults have rights.” As another example, choices to Item 4, “What will happen if you want to stop being in this study?” illustrated common misconceptions about the voluntary nature of participation: (a) “Nothing. I will not get punished or in trouble”; (b) “I will have an extra homework assignment”; (c) “I will have to continue in this study”; and (d) “I will have to convince the researcher that I have a good reason for quitting.”

Rights definition task. The first task following exposure to the Research Rights or the Psychology lesson required participants to match each of the eight rights presented in the Bill of Rights with its appropriate definition. Definitions were taken verbatim from the Bill of Rights lesson. One point was earned for each correct match.

True–false task. Students’ erroneous definitions and understanding of rights during pilot testing were used to construct false questions for each of the eight rights described in the Bill of Rights lesson. True questions were drawn directly from the Bill of Rights. Two questions were written for each right, with an additional statement to ensure that all 3 elements of the right to be fully informed were covered (see Appendix). Participants thus identified the truthfulness (e.g., “If you participate in a research project, it is okay if you do not answer all the questions”) and falsehood (e.g., “The researcher can tell your teachers and parents how you answered each question”) of 17

rights related statements. One point was earned for each correct response.

The Rights Violation Labeling and Rights Awareness tasks. Sixteen brief vignettes about the conduct of investigators researching different risk-taking behaviors familiar to children and adolescents were developed (e.g., cutting classes, riding a bike without a helmet, cigarette smoking). There were two vignettes for each of the eight research rights. One vignette described a researcher violating the right (e.g., students handed in their research surveys to their teachers who were allowed to read them; an investigator did not answer participant questions because time was running out), and one described a researcher maintaining the right (e.g., an investigator privately interviewed children one-on-one in an office rather than the back of a small classroom; after explaining a study an investigator asked if there was anything else students wanted to know).

For each vignette participants responded to two questions. The first question required participants to identify the research right represented in the vignette by selecting its name from a list of the eight rights presented in *The Research Participants' Bill of Rights*. Each correct response was given a score of one. The second question asked participants to identify whether the researcher did anything wrong in the story. Participants earned one point for each correct response. Possible scores for each task ranged from 0 to 16.

Verbal skills. Previous research has demonstrated a relation between the skills underlying reading performance and comprehension of information presented during informed consent (Handelsman & Martin, 1992; Kaser-Boyd, Adelman, Taylor, & Nelson, 1986; Tymchuk & Ouslander, 1991; Young, Hooker, & Freedberg, 1990). To assess the influence of these skills on the development of consent capacity and response to research rights education, participants' reading and verbal skills were assessed via available standardized test scores. Following parent and child permission, reading scores on the Stanford Achievement Test were obtained from the school for 4th, 7th, and 10th graders. College students gave permission for verbal scores on the Scholastic Aptitude Test to be obtained from the university. The inclusion of these age appropriate, but different tests was not to address developmental differences, but to examine the potential effect of reading level within each age group.

Procedure

The project was described to all fourth, seventh, and tenth graders in their classrooms by the first author. The concept of rights was introduced through class discussion of definitions of the term and examples of ev-

ery day rights that persons of their age have. For example, younger participants were told they have the right to be safe at school and home, and high school and college students were told they have the right to pick their classes at school. This was followed by an explanation of the project's purpose (to compare children's, adolescents', and college students' understanding of their rights in research) and procedures, the amount of time needed to complete this study, the voluntary nature of their participation and their right to withdraw, the confidential nature of their responses, this study's potential risks and benefits including the incentive for participation, how they would be given the results, and when appropriate the need for guardian permission.

Students were also given the opportunity to ask questions. Those interested in participating were given a letter explaining this study and a guardian permission slip to take home. They were also given a letter reminding them about the project's details and an assent form. To encourage a joint-decision between guardians and children, the guardian permission forms encouraged parents to discuss this study with their child prior to granting permission for participation (Fisher & Rosendahl, 1990; Weithorn, 1983) and students were encouraged during the explanation of the project to talk with their guardians regarding why they may or may not want to participate. Students were instructed to return the signed permission slips and assent forms to their teachers. Fourth, seventh, and tenth graders who returned parental permission and assent forms (65%, 52%, and 64% of 4th, 7th, and 10th graders, respectively) were tested 1 week after the consent forms had been explained and distributed. To refresh their memory, the testing session began with a reiteration of the project information described previously.

College students responded to sign-up sheets giving a brief description of this study's purpose and procedures and participation incentive. Students who came to the scheduled time for participation were provided the more detailed information provided to the younger participants and were given the opportunity to ask questions. Interested students signed written consent forms and began participation in this study.

All participating students received an age-appropriate incentive for participation (e.g., small party favors, course credit for introductory psychology, or a drawing for a gift certificate). In all grades groups of students were randomly assigned to either the rights education or psychology lessons described next.

In the first phase of this study, participants were given the Consent Form Comprehension Task to tap their understanding of the nature of this study for which they had agreed to participate. The questions were read aloud as students following along with a written copy of the questions. Students were then provided one of two 5½' × 8½' two-page lesson booklets describing their rights in research or a description of

the field of psychology. Lessons were read aloud and students were encouraged to ask questions. Students then completed the four additional rights comprehension tasks detailed previously. All test-items and lessons were read aloud to participants who followed along with their written materials, with ample time allowed for participants to answer each question.

While completing all measures, students were asked not to refer back to their lesson booklets. This procedure was selected as most similar to many actual research settings. Although the ideal research setting would have the consent forms readily available for participants to review, in practice, it is often the case that for research conducted in school settings the consent and assent forms that were sent home are collected prior to the testing day and are not brought in at the time of testing, or if available participants do not refer back to them.

Results¹

Verbal Scores

To determine if reading–verbal scores should serve as a covariate in subsequent analyses, correlations between these scores and students' scores on each measure were computed. A Bonferroni correction was used to control the Type 1 error rate at $\alpha = .05$. Results revealed reading–verbal scores were significantly correlated at this level to all five measures, except the Consent Form Comprehension Task. Because these results indicated that reading–verbal scores affect the dependent variables, next we set out to determine if these effects were evenly balanced. An independent sample *t* test was used to assess if there were treatment group differences on reading–verbal scores and univariate analysis of variance (ANOVA) was used to ascertain if there were grade differences on reading scores. Results indicated that reading scores did not differ significantly by treatment group or grade. Therefore, even though reading–verbal scores affect the dependent variables, these effects are evenly balanced. That is, the dependent variables will not be biased due to the effects of reading, and the data do not support using reading–verbal scores as a covariate.

Preliminary Examination of Ethnicity and Gender

Although not anticipated, ethnic and gender differences on participants' understanding of research rights was explored. Because there was a small number of participants identified as Asian, this group was com-

bined with the those identified as Other. Therefore, there were three levels of ethnicity (i.e., White, Hispanic, and Other). Scores for the Consent Form Comprehension Task and for each postlesson task were submitted to a 3 (ethnicity) \times 2 (gender) multivariate analysis of variance (MANOVA). Neither the main effects nor interactions were significant. Thus ethnicity and gender were not included in further analyses.

Understanding Information Provided in Assent and Consent Procedures for Participation in This Study

The mean number of correct responses (out of a possible 7 points) to the Consent Form Comprehension Task were 5.84 ($SD = 1.38$), 6.21 ($SD = .11$), 6.43 ($SD = .09$), and 6.77 ($SD = .06$) for fourth, seventh, tenth, and college students, respectively. A one-way analysis of variance (ANOVA) with grade as the independent factor yielded a significant main effect of grade, $F(3, 283) = 13.86$, $p < .001$. Tukey's honestly significant difference (HSD; Maxwell & Delaney, 1990) tests indicated significantly poorer scores of fourth graders when compared with 10th graders and college students ($p < .001$) and poorer scores for seventh graders when compared to college students ($p < .01$).

To further explore the grade differences we tested for equal proportions of answering each of the seven questions on the Consent Form Comprehension Task correctly in the four grades. Except for Question 2 (procedure), the number of participants in certain cells of the cross tabulation by grade and answer (correct or incorrect) was small (i.e., less than 5), thus Fisher's exact test was performed using SAS PROC FREQ procedure (SAS Version 8.0). Analyses indicated significantly poorer performance for younger participants when asked about the purpose of this study, who consented to participation, their right to withdraw, and confidentiality (see Table 1). However, as indicated in Table 1, even in fourth grade the percentage of students comprehending the seven factual elements of consent for this study was quite high.

Rights Definition, True–False Identification, and Rights Violations Labeling and Awareness

Scores for each of the postlesson tasks were submitted to a 4 (grade) \times 2 (treatment group) MANOVA. The analysis yielded main effects for grade, $F(12, 715) = 16.43$, $p < .001$; and treatment group, $F(4, 270) = 5.46.02$, $p < .001$. The interaction of grade and treatment group was not significant. Tables 2 and 3 provide means and standard deviations for task performance by grade and treatment group, respectively.

Grade effects. Univariate *F* tests yielded significant main effects of grade for all tasks, Rights Defini-

¹Except where indicated, analyses were conducted using SPSS version 10.1.0.

Table 1. Percent of Participants by Grade Answering Each Consent Form Comprehension Question Correctly

Question	4th Grade	7th Grade	10th Grade	College
No. 1: Purpose**	73	90	93	94
No. 2: Procedure	88	87	76	87
No. 3: Consent**	83	94	97	100
No. 4: Right to withdraw**	62	63	91	99
No. 5: Confidentiality*	89	90	95	100
No. 6: Benefits	95	98	96	100
No. 7: Risks	94	97	94	97
<i>n</i> ^a	82	63	72	70

^aNumber of participants in each grade who completed all items on the task: Three 10th graders and 1 college student did not complete all items.
p* < .05. *p* < .001.

tion Task, $F(3, 273) = 37.23, p < .001$; True–False Task, $F(3, 273) = 40.18, p < .001$; Rights Violation Labeling Task, $F(3, 273) = 55.09, p < .001$; and Rights Violation Awareness Task, $F(3, 273) = 27.03, p < .001$. Tukey’s HSD tests were applied to subsequent grade comparisons. Results indicated that seventh graders, tenth graders, and college students each had significantly higher scores on all four tasks than fourth graders ($p < .001$). College students also had significantly higher scores than seventh graders on all four tasks ($p < .01$ for Rights Definition and True–False; $p < .001$ for Rights Violation Labeling; and $p < .05$ for Rights Violation Awareness). Seventh graders and 10th graders differed significantly only on the Rights Violation Labeling Task with 10th graders performing better ($p < .01$). College students performed significantly better than 10th graders on the True–False task ($p < .05$).

Lesson effects. Univariate *F* tests revealed a main effect for lesson on the Rights Violation Labeling scores, $F(1, 273) = 18.45, p < .001$; and Rights Violation Awareness scores, $F(1, 273) = 11.01, p < .01$. No main effects for the lesson emerged for the Rights Definition nor the True–False scores. The significant main effects are reflected in the higher mean scores for those receiving the rights lesson.

Comprehension of Specific Rights

Exploratory analyses on students’ understanding of specific rights were conducted. A composite score was derived for each right by summing the correct response for items representing the right across all four tasks. For each right the range of possible scores was 0 to 7, with the exception of the “right to be informed,” which

ranged from 0 to 8 because of the additional true–false question. Means and standard deviations for each right by grade and lesson group are presented in Tables 4 and 5, respectively.

A 4 (grade) × 2 (treatment group) MANOVA on the composite scores for each of the eight rights yielded a main effect for grade, $F(24, 773) = 10.55, p < .001$; and treatment group, $F(8, 266) = 3.63, p < .01$. The interaction was not significant.

Grade effects. Univariate *F* tests also yielded significant main effects of grade for all eight rights:

1. To be informed, $F(3, 273) = 53.08, p < .001$.
2. To ask questions, $F(3, 273) = 21.12, p < .001$.
3. To participate voluntarily, $F(3, 273) = 44.73, p < .001$.
4. To withdraw from this study, $F(3, 273) = 20.78, p < .001$.
5. To have responses kept confidential, $F(3, 273) = 29.87, p < .001$.
6. To be safe from research harms, $F(3, 273) = 14.61, p < .001$.
7. To know study results, $F(3, 273) = 57.79, p < .001$.
8. To understand these rights, $F(3, 273) = 42.46, p < .001$.

Tukey’s HSD tests indicated similar developmental patterns across tasks. Seventh graders, 10th graders, and college students each had significantly higher scores on all eight rights than fourth graders ($p < .001$, except for the right to be safe, where $p < .05$). Tenth graders had significantly higher scores on three rights compared to seventh graders: The right to be informed

Table 2. Means and Standard Deviations for Task Performance Across Age Groups

Grade	Definition		True/False		Rights Labeling		Violation Awareness	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
4	4.68	2.05	12.29	2.60	5.22	2.67	11.44	2.38
7	6.58	2.00	14.67	1.81	8.08	2.78	13.24	1.88
10	7.09	1.88	14.95	2.01	9.59	3.05	13.63	2.26
College	7.58	0.97	15.79	1.47	10.70	2.58	14.20	1.59

Table 3. Means and Standard Deviations for Task Performance Across Treatment Groups

Group	Definition		True-False		Rights Labeling		Violation Awareness	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Bill of Rights	6.56	2.09	14.49	2.42	8.90	3.67	13.45	2.25
Psychology	6.33	2.12	14.18	2.46	7.68	3.18	12.67	2.35

Table 4. Means and Standard Deviations for Composite Scores for Each Research Right by Grade

Grade	Informed		Ask Questions		Volunteer		Withdraw		Confidentiality		Safe		Know the Results		Understand These Rights	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
4th	3.88	1.21	4.81	1.41	3.49	1.24	4.56	1.65	4.54	1.51	4.50	1.42	3.29	1.30	3.82	1.37
7th	5.00	1.31	5.55	1.00	4.63	1.18	5.82	1.19	5.84	1.10	5.06	1.07	4.61	1.30	5.15	1.37
10th	5.73	1.46	5.80	1.21	5.24	1.38	5.87	1.30	6.05	1.11	5.32	1.08	5.36	1.35	5.67	1.07
College	6.50	1.09	6.23	0.62	5.66	0.97	6.16	0.99	6.28	1.10	5.71	0.93	5.78	0.91	5.82	0.98

($p < .01$), the right to participate or not in this study ($p < .05$), and the right to know the results of this study ($p < .01$). College students had significantly higher scores than seventh graders on six rights:

1. The right to be informed ($p < .001$).
2. The right to ask questions ($p < .01$).
3. The right to be safe ($p < .01$).
4. The right to participate or not in this study ($p < .001$).
5. The right to know the results of this study ($p < .001$).
6. The right to understand these rights ($p < .01$).

College students scored significantly higher than 10th graders on only the right to be informed ($p < .01$).

Lesson effects. Univariate F tests revealed significant treatment group main effects for six of the eight rights. Participants who received the Bill of Rights scored significantly higher on the right to

1. Ask questions, $F(1, 273) = 11.76, p < .001$.
2. Participate or not in this study, $F(1, 273) = 44.73, p < .01$.
3. Withdraw from this study, $F(1, 273) = 6.50, p < .05$.
4. Be protected from harm, $F(1, 273) = 22.63, p < .001$.
5. Know the results of this study, $F(1, 273) = 6.49, p < .05$.
6. Understand these rights, $F(1, 273) = 8.23, p < .01$.

Comprehension of the right to confidentiality and the right to be informed also improved, although not significantly.

Discussion

Ethical decisions by investigators and their IRBs concerning the capacity of children and adolescents to assent or consent to research have not been sufficiently informed by empirical data. The purpose of this study was to contribute to the growing literature on developmental trends in minors' consent capacity and to explore whether this capacity can be enhanced.

Comprehension of Consent and Assent Form Information

The first step in this research was to compare the ability of fourth, seventh, and tenth graders and college participants to understand rights relevant information presented during the informed consent and assent procedures for this study. Although performance increased with grade, the majority of respondents comprehended the purpose and nature of the research, research risks and benefits, the voluntary nature of participation, and confidentiality. However, the right to withdraw was not well understood by the two youngest groups of participants.

Fourth graders' good performance on questions regarding research risks and benefits, as well as confidentiality, differ somewhat from those reported by Abramovitch and colleagues (1991, 1995). The fact that we used a multiple choice rather than the more cognitively taxing free recall procedure employed by Abramovitch et al. (1995) may explain why our sample evidenced better understanding of investigator descriptions of potential risks and benefits. Second, fourth graders' correct answers to the confidentiality question (only the experimenter will find out how you answered questions in this study) confirms the spontaneous responses of children in the earliest study by Abramovitch et al. (1991). However, those authors

Table 5. Means and Standard Deviations for Composite Scores for Each Research Right by Lesson

Grade	Informed		Ask Questions		Volunteer		Withdraw		Confidentiality		Safe		Know the Results		Understand These Rights	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Bill of Rights	5.35	1.67	5.79	1.15	4.86	1.48	5.74	1.42	5.75	1.39	5.44	1.16	4.89	1.56	5.23	1.43
Psychology	5.14	1.59	5.36	1.29	4.59	1.45	5.39	1.48	5.56	1.42	4.82	1.22	4.56	1.56	4.92	1.46

found that children changed their response following probes about whether the experimenter would tell their parents. The reason for this shift is not clear. It may be that follow-up questioning in the Abramovitch procedures may have led children to believe their first answer was wrong or they may have wanted to give the investigator an answer they thought he or she was looking for (Ceci, Ross, & Toglia, 1987).

Another explanation may lie in the redundant exposure to consent information that children received in our study: The purpose, nature, and rights associated with this study were explained in detail prior to children taking home parental permission and assent forms and again at the beginning of testing. Such redundancy may not be typical of most developmental studies, and may have contributed to the high levels of consent comprehension exhibited by our fourth graders. However, their ability to grasp the consent concepts under these conditions supports the potential validity of assent procedures for this age group. Caution is required, however, because the Abramovitch et al. (1991) study suggested children's grasp of some aspects of consent information is fragile. Thus, as Abramovitch et al. (1991) suggested, children as old as 12 may not fully understand or believe what they are told about confidentiality. This may be especially true in school settings where teachers and counselors are legally mandated to report suspected child abuse and neglect and for research tapping risky behaviors for which children and adolescents expect that a knowledgeable adult will help a minor in jeopardy (Fisher, Higgins-D'Alessandro, Rau, Kuther, & Belanger, 1996; O'Sullivan & Fisher, 1997).

Two areas of potential confusion observed in our younger children also merit discussion. First, a notable minority of fourth graders seemed confused about the purpose of the research. During the assent procedures we described the multiple measures we planned to use to assess participants' understanding of research rights (e.g., reading scores, vignettes about research on risk behavior). The ability to consider many elements simultaneously, systematically, and exhaustively is immature at this age (Beyth-Marom & Fischhoff, 1997; Flavell, 1985; Keating, 1990). Accordingly, fourth-graders' confusion may have reflected their difficulty in simultaneously considering and differentiating the multiple tasks involved in the research (Grisso & Vierling, 1978).

Second, consistent with reports by Abramovitch et al. (1991, 1995), the highest percent of errors for comprehension of consent form information emerged in fourth and seventh graders' responses regarding the right to withdraw from participation. One possible explanation for this inferior understanding is the lack of relative lack of autonomy children have. It is not until age 14 that the unilateral relationship children have with their parents is replaced with a reciprocal relationship based more on cooperative decision mak-

ing and autonomy (Youniss, 1980; Youniss & Smollar, 1985). Related to this is social power. Young children see authority figures as powerful (Damon, 1977, 1988); authority is respected for their wisdom (Youniss, 1980). As such, these younger participants may not feel they truly have permission to withdraw. They may choose to continue their participation because it is what they believe adult authorities prefer (Melton, 1999). Contrary to this, adolescents, who are beginning to view authority figures as cooperative equals (Damon, 1977, 1988) and rely less on parents (Lewis, 1987), may feel sanctioned to withdraw from research. In addition to children's lack of autonomy and social power differential, children also do not have experience with having the right to refuse participation in school-based activities. This coupled with the fact that their assent was preceded by prior parental permission, may have attenuated the ability of these younger participants to understand, or perhaps believe, that withdrawal is a real option in research (Belter & Grisso, 1984; Thompson, 1990).

Evaluating Rights Comprehension

This research also examined the ability to match a research right with its correct definition, recognize when a rights related statement was true or false, and appropriately label and recognize rights violations described in hypothetical research vignettes. Across the different tasks and different research rights, the data confirm the consent vulnerability of grade school children when compared to adolescents and adults (Abramovitch et al., 1991, 1995; Belter & Grisso, 1984; Ruck, Abramovitch et al., 1998; Ruck, Keating et al., 1998). However, when considering the range of understanding displayed by the younger participants relative to the older participants, this vulnerability appears minimal, suggesting an emerging competence that culminates with the capacity of older adolescents understanding their research rights and recognize rights violations at adult levels (Belter & Grisso, 1984; Grisso & Vierling, 1978; Weithorn & Campbell, 1982).

The data also underscore the ambivalent status of early adolescence when it comes to the capacity for self-determination decisions (Melton, 1983; Ruck, Abramovitch, et al., 1998; Ruck, Keating, et al., 1998). Consistent with previous research, composite scores suggest that seventh graders when compared to high school students are still struggling to understand their veto power over adult permission, their right to be protected from harm, and to be informed about research procedures and results (Abramovitch et al., 1995; Ruck, Keating, et al., 1998).

Our findings raise an additional question: Can minor participants apply their knowledge of informed consent facts by exerting these rights? Implementing a behavior consistent with their understanding, however,

may be thwarted by their perceived power differential with adults (Damon, 1977, 1988; Melton, 1999). This potential gap between cognition and behavioral competence could not be explored with our data. However, it is a question warranting further investigation.

Enhancing Rights Comprehension

Providing a brief rights lesson improved rights comprehension at all age levels. The effectiveness of *The Research Participants' Bill of Rights* may therefore largely reflect lack of exposure to research right as well as familiarity with rights terminology. For example, improvement on items tapping the voluntary nature of research participation suggests that unless this right is emphasized by an investigator, most children may assume that they must acquiesce to adult requests, especially in school settings. The data also suggest that adults may not be aware that during consent procedures they have the right to ask questions about the investigation and that the scientists is obligated to inform them of and minimize harms.

This study was not designed to assess specific cognitive capacities or social experiences underlying the development of research rights understanding. The area of consent capacity is thus a fertile ground for research on the role that cognitive changes in selective attention, encoding and retrieval, metacognition, and metastrategy (e.g., Kuhn, Garcia-Mila, Zohar, & Anderson, 1995; Siegler, 1991; Weinhart, 1986) play in the ability of children and adolescents to both understand and exert their rights in research. Changes in cognition and reasoning that may underlie rights understanding do not occur in isolation from changes in experience. Instead, effective reasoning is also dependent on the amount of exposure to a content area and familiarity within that content area (Case & Okamoto, 1996; Chi & Ceci, 1987; Keating, 1990). The brief lesson on research rights may have enabled both children and adults to merge new information about the informed consent process with existing cognitive skills and social knowledge to move toward a fuller understanding of their rights in research and when these rights are violated (Grisso & Vierling, 1978; Holder, 1981; Siegler, 1991; Thompson, 1990; Youniss & Smollar, 1985).

Limitations

The results of this study add to the small but growing literature on research participants' understanding of the informed consent process. These findings support previous scholarships in suggesting that by middle adolescence, minors may be as competent as adults to consent to research participation and that prospective research participants of all ages can benefit from a brief rights lesson prior to giving their consent to re-

search participation (Belter & Grisso, 1984; Weithorn & Campbell, 1982).

The majority of children, adolescents, and adults participating in this study were from White, middle-class backgrounds. The extent to which these results generalize to developmental trends in the way children and adolescents from other ethnic, socioeconomic, and language backgrounds respond to research consent procedures needs to be explored in future research. For example, the impact of racial mistrust toward scientists expressed by members of ethnic minority communities has been an overlooked variable in evaluating the ways in which prospective participants comprehend and respond to research recruitment and informed consent procedures (Fisher, Jackson, & Villarruel, 1997; Fisher & Wallace, 2000). Generalization of these results is also limited to research conducted in school contexts. Despite efforts to ensure students that participation was voluntary and that the measures were not designed to test academically related abilities, the fact that this study was conducted at their school may have led some students to view this study as nonoptional or as a test situation. Additional research, therefore, is needed to examine the demand characteristics of different experimental settings on research rights comprehension.

This research and the majority of other studies investigating children's rights understanding, have relied in part on responses to hypothetical vignettes. Additional research is needed to assess the degree to which children and adolescents can fully apply their capacity to identify rights violations and exert their rights in actual research contexts. Furthermore, despite evidence of developmental trends in minors' capacity to understand consent information, the influence of individual differences such as temperament, intelligence, and decision-making experience should not be underestimated when investigators consider the consent capacity of potential participants. Moreover, the role that both developmental and individual characteristics play in determining minors' consent capacity needs to be evaluated in terms of the procedures, risks, and benefits associated with each unique research context.

The research design employed in this was a posttest only design. Although this design controls for testing effects, the conclusion regarding the efficacy of the Bill of Rights is limited by the fact that equivalence of the treatment and control groups prior to testing cannot be established on the dependent variables. Therefore, it cannot be concluded with certainty if the treatment effects are due to the Bill of Rights or preexisting differences between the two treatment groups.

The method we used did not allow participants to refer back to their lessons while completing outcome measures, which were written in a force-choice format. Therefore, correct answers required recognition memory for information. The alternative method of free re-

call is more cognitively taxing (du Plessis, 1994), and as such a more stringent test of comprehension.

Implications for Ethical Practice

Although fourth and seventh graders showed good understanding of the information provided during assent procedures for this study, their poorer performance relative to 10th graders and college students on other rights related tasks suggests that it is prudent for an investigator to assume that children below the age of 10 are not fully capable of understanding their research rights and thus need the protections that guardian permission provides. Our data indicate also that youth between the ages of 10 and 15 are nearing, but have not obtained, adult levels of understanding and exerting their research rights. One approach to balancing the need for protection that guardian permission affords with respect for the emerging capacity of these youth to understand and assert their rights is to provide the Bill of Rights, along with a description of this study, to the youth prior to sending home parental permission forms, encouraging them to discuss their views and preferences for participation with their guardians. During childhood and early adolescence, exposing youth to *The Research Participants' Bill of Rights* is desirable, not as a test of comprehension nor a substitute for parental permission, but consistent with Melton's (1999) learner's permit model, as a means of providing minors with an opportunity to gain knowledge of and experience in asserting their research rights.

Quite different ethics-in-science decisions are informed by the finding that adolescents as young as 15 years old comprehend consent information and recognize rights violations at adult levels. Research examining the development of teenagers in maladaptive family environments or the behaviors, attitudes, and life circumstances of adolescents engaged in health compromising behaviors, raise difficult ethical questions regarding when it is appropriate to waive the requirement for guardian permission. Federal regulations allow for such waivers when guardians are unavailable (e.g., run away youth), parents are known to be neglectful or abusive, or when solicitation of parental consent may violate a teenager's privacy or jeopardize his or her welfare (DHHS, 1991, 45 CFR 46.408[c]; Fisher et al., 1996).

Investigators need to be cautious in applying any measure of consent capacity to decisions regarding parental permission waiver. First, the methods employed in our study do not adequately assess the judgments involved in high-risk research, such as treatment or biomedical research, and our findings are not generalizable to such settings. In addition, ability to comprehend self-determination rights in normative, nontreatment research, do not necessarily translate into an ability to exert these rights. Despite more frequent opportunities

to make autonomous decisions, teenagers remain subject to adult authority and are thus vulnerable to coercion and rights violations. These vulnerabilities when viewed within the context of older adolescents' capacity to understand consent information, suggest that in situations meriting waiver of parental permission, the rights of teenagers will best be protected by ethical procedures that include participant assent and the involvement of an independent advocate who can ensure that assent is voluntary (Fisher et al., 1996).

Another ethics-in-science decision that is informed by these findings is the value of rights education for potential research participants in normative, nontreatment settings. This study has demonstrated the effectiveness of brief exposure to *The Research Participants' Bill of Rights* for enhancing the consent capacities of children, adolescents, and young adults. These findings suggest that cognitive maturity and social experiences may not sufficiently prepare older adolescents and even adults to fully comprehend their rights in research. The fact that exposure to a brief lesson on research rights improved performance in these age groups suggests that providing preconsent information, like that appearing in *The Research Participants' Bill of Rights*, is a promising avenue and warrants consideration by investigators conducting normative, nontreatment research that requires more active and informed consent procedures. A word of caution is warranted, however. Researchers conducting minimal risk, normative, descriptive research should consider whether the warnings and attention on rights has the potential to erroneously imply a gravity or risk of potential harm not associated with the particular research project.

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**Appendix:
The Research Participants'
Bill of Rights**

As a research participant,

YOU HAVE THE RIGHT TO BE FULLY INFORMED ABOUT THIS RESEARCH.

You have the right to be given all the information you will need to help you decide if you want to participate in this project. Some of the things you have the right to know are why this project is being done, what you will be asked to do if you participate in this study, and how long it will take you to finish.

YOU HAVE THE RIGHT TO ASK QUESTIONS.

You can ask questions before, during, and after this project. The researcher must answer you honestly and explain anything you do not understand.

YOU HAVE THE RIGHT TO PARTICIPATE OR NOT IN THIS STUDY: PARTICIPATION IS VOLUNTARY.

You have the freedom to be part of this study or refuse to be part of it. If you do not participate in this study, you will not get in trouble or be punished.

YOU HAVE THE RIGHT TO WITHDRAW FROM THIS STUDY OR NOT ANSWER ANY QUESTIONS.

If you do participate in this study, you can stop at any time. You also have the right to refuse to answer any questions. If you stop participating or do not answer all the questions, you will not get in trouble or be punished.

YOU HAVE THE RIGHT TO PRIVACY AND CONFIDENTIALITY.

Everything you say, do, or write in this study is private; no one except the researchers will know what you said or did. Results are reported about students your age, not about you alone or any other student alone.

YOU HAVE THE RIGHT TO BE PROTECTED FROM HARM.

The researcher must protect you from being or feeling hurt. If you do get hurt some how, the researcher must help you. For example, if you get upset while being in this study, the researcher will talk to you or assist you in finding help.

YOU HAVE THE RIGHT TO KNOW THE RESULTS OF THIS STUDY.

When this study is finished and all the people participating have completed this study, the researchers will tell you what they found. This will be a written summary of the research and it will be written so you can understand it.

YOU HAVE THE RIGHT TO UNDERSTAND THESE RIGHTS.

The researcher should explain all the rights listed previously in a way you can understand them. If you do not understand any of your rights, the researcher will help you.

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