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Who Are We Missing? The Impact of Requiring Parental or Guardian Consent on Research With Lesbian, Gay, Bisexual, Trans, Two-Spirit, Queer/Questioning Youth

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 A B S T R A C T

Purpose: The purpose was to examine whether a requirement for parental or guardian consent systematically limits which lesbian, gay, bisexual, trans, two-spirit, queer/questioning (LGBT2Q+) youth participate in research.

Methods: A total of 60 LGBT2Q+ youth (aged 14–18 years) completed measures assessing gender and sexual minority identity, depression and anxiety, help-seeking intentions, and social support.

Results: A substantial proportion (37.6%) of youth reported that they would not have participated in the research if parental or guardian consent was required. Those who would not have participated had more negative attitudes about their sexual and gender identity, less family support, lower levels of help-seeking intentions, and higher levels of negative affect.

Conclusions: The results suggest that requiring parental or guardian consent may exclude the most at-risk youth. Policy and practice decisions regarding the health and mental health outcomes of LGBT2Q+ youth might be based on incomplete and unrepresentative data.

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IMPLICATIONS AND CONTRIBUTION

The results of this brief report suggest that requiring guardian consent may exclude the most vulnerable lesbian, gay, bisexual, trans, two-spirit, queer/questioning youth. IRBs should carefully weigh the trade-offs between requiring guardian consent when researching health and mental health outcomes with lesbian, gay, bisexual, trans, two-spirit, queer/questioning youth.

There is a need for ongoing research on the health trajectories for lesbian, gay, bisexual, trans, two-spirit, queer/questioning (LGBT2Q+) youth. These youth face well-documented health disparities compared with their heterosexual and cisgender peers in areas such as mental health, problematic substance use, and sexual health [1–3]. There is a paucity of research involving LGBT2Q+ youth aged <18 years, which hampers prevention and

intervention efforts and may lead to biased conclusions [4]. Much of the existing research is retrospective, and results may be influenced by recall bias, may not reflect the changing social culture, and may not take into consideration the developmental changes that occur around the age of 18 years [4]. Non-retrospective research involving youth often requires guardian consent to protect youth from undue harm. In Canada, Institutional Review Boards (IRBs) typically require guardian consent for research with youth aged <16 years (if community based) or 18 years (if school based).

However, requiring parental consent as a matter-of-course may be inappropriate. National ethics standards in Canada note

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that decisions regarding consent ought to be determined by the person's decision-making capacity rather than age [5], and the default requirement of guardian consent by IRBs does not support young people's agency and may also undermine their dignity and integrity. Empowering research participants and treating them with dignity is a principal purpose of the research consent process [6]. Furthermore, the rigorous consent process required by many IRBs may be overly conservative in the context of social science research. Whereas the traditional requirements for parental consent make sense in health research where there is a risk of serious bodily harm, the risk of harm stemming from the completion of questionnaires, interviews, and focus groups is relatively small [6].

Moreover, there are serious ethical and practical concerns that stem from the requirement of guardian consent in LGBT2Q+ populations, such as systematically excluding an important subset of LGBT2Q+ youth, placing youth at risk, and forming biased conclusions regarding policy and practice. LGBT2Q+ youth with the most rejecting families are at increased risk for homelessness or precarious living arrangements and would not have access to guardian consent to participate in research [7]. To cope with homelessness and the severe mental and physical health challenges involved in living in the streets [8], LGBT2Q+ youth may have unofficial living arrangements with friends or siblings [9] and would not have access to guardian consent to participate in research. The requirement of guardian consent may increase the risk for youth who have not disclosed their sexual orientation and/or gender identity to their guardians or simply dissuade youth from participating in research [4]. Importantly, the requirement for guardian consent might lead to a biased sampling procedure that leads us to make policy and practice decisions based on data from unrepresentative samples.

The purpose was to examine whether a requirement for guardian consent systematically limits which LGBT2Q+ youth participate in research.

Methods

Participants were ($n = 60$) youth aged 14–18 years who were involved with a Genders and Sexualities Alliance/Gay-Straight Alliance at their school or from a community support center for LGBT2Q+ persons in Ontario, Canada. Although school districts typically require guardian consent for research participation with their students, our partners in this study waived the requirement of guardian consent because they were interested in the research question at hand and because they wanted to provide all LGBT2Q+ youth an opportunity to participate. All procedures were approved by Western University's Non-Medical Research Ethics Board.

As part of a larger study, participants answered an item about whether they would have participated if guardian consent was required and then completed the Lesbian, Gay, Bisexual Identity Scale [10], which demonstrates a three-factor structure in adolescent samples (positive identity, identity exploration, and negative identity; Cwinn, Daly & Crooks, in preparation), the General Help-Seeking Questionnaire [11], the Multidimensional Scale of Perceived Social Support [12], and the Depression, Anxiety, Stress Scale-21 [13]. All scales used have adequate internal consistency and validity [10,11,14,15].

We explored demographic differences between youth who would participate regardless of the requirement of guardian consent and those who would not participate if guardian consent

was required. A series of independent samples t tests was conducted across several variables and the consent groups to determine differences.

Results

As seen in Table 1, youth who are white, older, and either cisgender or living in their felt gender "all the time" were more likely to participate regardless of guardian consent was required. As seen in Table 2, adolescents who would not participate if consent were required had more negative attitudes toward their LGBT2Q+ identity ($t(55) = -4.94$; $p < .001$), less family support ($t(55) = 3.35$; $p < .01$), and more anxiety ($t(55) = -2.13$; $p < .05$). There was also a nonsignificant trend indicating that non-consenting youth expressed lower levels of help-seeking intentions (adjusted $t(31.35) = 1.95$; $p < .1$) and higher levels of negative affect ($t(55) = 1.91$; $p < .1$).

Discussion

Summary and conclusion

The results of this study demonstrate that a substantial proportion of LGBT2Q+ youth would not participate in research requiring guardian consent, and these youths are among the most vulnerable. These findings have serious ethical and practical implications. The Canadian Tri-Council Policy on Research Ethics states that researchers have a responsibility to obtain information about all types of people impacted by a problem area, even if it is difficult to recruit them [5]. According to the UN Convention on the Rights of the Child, youth have the fundamental right to have their voices heard on matters that concern them [16]. Other researchers have noted that IRBs can be paternalistic [17] and may overestimate youths' need for protection and underestimate their abilities as autonomous decision-makers [18]. By requiring guardian consent, IRBs may inadvertently be silencing an important subset of LGBT2Q+ youth. Practically, excluding these youth means that we are obtaining a

Table 1
Demographic characteristics for each consent group

	Yes, I would still participate		No, I would not have participated ^a	
	n	%	n	%
Overall	36	60	22	36.7
Age (years)				
14–15	11	50	11	50
16–18	25	69.4	11	30.6
Ethnicity				
White	16	69.6	7	30.4
Visible minority	20	57.1	15	42.9
Gender identity				
Cisgender	24	66.7	12	33.3
Gender minority ^b	12	54.5	10	45.5
Living in felt gender				
Yes—all of the time	28	66.7	14	33.3
Yes—some of the time	7	53.8	6	46.2
No	1	33.3	2	66.7

^a Two participants (3.3%) did not answer the consent question resulting in <100% for row percentages; all percentages reported are row percentages.

^b Our sample self-identifies by several gender identities including transgender, gender fluid, nonbinary, two-spirited, and other—not defined.

Table 2

Differences in attitudes, support, help-seeking intentions, and distress between consenting and nonconsenting youth

	T score	df	Yes, I would participate	No, I would not participate
			M (SD)	M (SD)
Negative identity attitude	−4.94***	55	14.14 (4.85)	21.67 (6.58)
Positive identity attitude	.63 ^{ns}	55	36.19 (7.19)	35.05 (7.54)
Identity uncertainty	−1.36 ^{ns}	54	10.28 (3.83)	11.00 (5.21)
Help-seeking intentions	1.95 ^{+a}	31.35	24.17 (4.08)	21.33 (5.89)
Family support	3.35**	55	18.69 (6.13)	12.76 (6.99)
DASS total	−1.91 ⁺	55	55.64 (16.70)	63.71 (14.51)
DASS depression	−1.45 ^{ns}	55	19.28 (6.92)	21.95 (6.37)
DASS anxiety	−2.13*	55	17.72 (6.23)	21.19 (5.34)
DASS stress	−1.47 ^{ns}	55	18.64 (5.95)	20.57 (4.75)

DASS = Depression Anxiety and Stress Scales; M = mean; SD = standard deviation.

*** <.001, **<.01, *<.05, + nonsignificant trend <.1.

^a The assumption of equal variances is not met, and the adjusted T-score is reported.

biased picture of the types of risks, needs, and intervention outcomes when working with LGBT2Q+ youth.

Some alternatives to requiring parental consent would be to explain the study and provide the consent form in advance and encourage the youth to ask a trusted adult for guidance, clearly explaining and normalizing that many youth choose not to participate and explaining the reasons why some youth would not want to participate and ensuring adequate training for consent procedures with community partners as well as researchers. It is acknowledged that some parents may feel betrayed or angry that they were not consulted for research if they discovered their child's research participation in the future. This harm could be mitigated by agencies having information letters sent to parents explaining the types of research where consent would be gathered, and those where consent would not be required and ensuring that there is a well-trained researcher whom guardians can contact if they have questions. More research is needed on the actual risks and benefits of youth participation in such research, as well as the advantages and disadvantages of some of the proposed alternatives, to help IRBs and research partners (such as school districts) make data-based decisions about consent requirements.

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