



ETHICAL RESEARCH INVOLVING CHILDREN

Centre for Children
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ETHICAL GUIDANCE: INFORMED CONSENT

Obtaining consent from parents/carers and children is central to the research relationship and signals respect for the research participant's dignity, their capability to express their views and their right to have these heard in matters that affect them. Informed consent is an explicit agreement which requires participants to be informed about, and have an understanding of, the research. This must be given voluntarily and be renegotiable, so that children may withdraw at any stage of the research process.

INFORMED CONSENT

BEST PRACTICE REQUIRES THAT YOU:

- Obtain consent from all children participating in research.
- Make sure children are fully informed as to the purpose of the research and what their involvement will be.
- Respect children's decision about participating in research, including their dissent or unwillingness to participate.
- Carefully consider the strengths and limitations of obtaining parental consent.
- Ensure that children (and others) understand that consent is negotiable and that children can withdraw at any point.
- Design the consent process to take into account the evolving capacities of the child as well as the overall research context.
- Consult locally to ascertain if informed consent needs to be obtained from community leaders or representatives.

Obtaining consent from parents/carers and children demonstrates respect for the individual research participant's dignity; their capability and right to make decisions about matters that affect them.

KEY CONSIDERATIONS

Obtaining consent from parents/carers and children is a usual part of the research process (Powell et al., 2011). It is the cornerstone of the research relationship and reflects important underlying ethical considerations, including demonstrating respect for the individual research participant's dignity; that is, their capability and right to make decisions about matters that affect them. This extends to respecting the participant's knowledge about their own situation and ability to assess potential risks associated with research participation, recognising that children may be best placed to assess any risks to themselves (Laws & Mann, 2004). Such respect underpins researchers' responsibility to uphold children's right to **dissent**, that is, to refuse participation and to withdraw at any time and to prioritise this over their parents' or others' wish for them to participate. Gaining participants' informed consent also shows honesty, in that the researcher has not deceived the participant about the research study or the nature of their relationship.

Informed consent has four main features: consent involves an explicit act (for example, verbal or written agreement); consent can

only be given if the participants are informed about and have an understanding of the research; consent must be given voluntarily without coercion; and consent must be renegotiable so that children may withdraw at any stage of the research process (Gallagher, 2009). These four main features, which are often challenging to put into action, are explained below.

Consent involves an explicit act

A critical issue for researchers is deciding who is involved in the act of consent and how it is signified. There are unique ethical complexities in research involving children as there are multiple research relationships, which centre on a triad (rather than a participant/researcher dyad) consisting of the researcher, child participant, and parent or carer. Obtaining children's consent directly, for their participation in research, signals respect for their autonomy and human rights. Children's right to participate in decisions that affect them is a basic human right, and emphasised in two of the key participation Articles of the UNCRC, in particular Articles 12 and 13.

Parental consent (or guardian/carer consent) is also usually required for children's participation in research. Children's right to consent on their own behalf may be regulated by law. For example, in Norway, youth between 16 and 18 years are usually allowed to give their own consent, while the parents are informed, but depending on the character of the proposed research. Below the age of 16 years children may consent in special circumstances, while children under the age of 12 years always need their parents' active consent before they can be asked to participate (E. Backe-Hansen, personal communication, October 12, 2012). Given the usual requirement for parental consent, researchers are frequently in the position of balancing two ethical imperatives: ensuring that children can freely choose to participate (respecting their autonomy) and acknowledging parental responsibility to ensure children's safety and well-being (Munford & Sanders, 2004).

In addition, researchers are at times compelled to seek consent from a range of adults in children's lives (for example, school boards, school principals, teachers, community leaders/chiefs, health professionals and social workers) and negotiate a hierarchy of gate-keeping (Hood, Kelley & Mayall, 1996) before children are allowed to be approached about participating in research. In some cultural contexts the focus on individual consent for participation in research is at odds with cultural and societal customs, in which the right to consent and pass on knowledge is a collective concern, involving the wider family and community (Suaalii & Mavoa, 2001). Local consultation is therefore an important aspect of determining who, other than the children themselves, should be approached regarding children's participation in research. A factor to consider in local consultation is the research topic. For example, it may be more appropriate to set limits on the status and number of people from whom consent is sought or who have access to information about the research in sectors such as violence against children, in order to ensure children's ongoing safety.

Consent must be informed

A requirement of ethical research is that participants are informed and have an understanding of the research activity, whatever research methodology is being used. Therefore, children must be provided with information that is appropriate to their age and

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competencies, bearing in mind the environmental context, differing experiences and evolving capacities of each child [as discussed in the Background section of the ERIC compendium]. An approach to research that is informed by children's rights and the UNCRC "requires that, in appropriate circumstances, children are given information (Articles 13, 17) and adult guidance (Article 5) while their views are in formation, in order to be assisted in determining and expressing what will then be both a formed and informed view (Article 12)" (Lundy & McEvoy, 2012, p.140).

Children must understand what the research involves, including the risks and potential benefits. Giving children information allows them a meaningful choice about participation, preserves their trust in researchers and the research enterprise, and demonstrates respect (Spriggs, 2010). If children are involved as researchers, both they and the children from whom data is being collected, need to be aware of the purpose of the research, the potential benefits and risks of participation, and the time commitment required.

Other people giving consent for children's participation must also be provided with information about the research. Parents and gate-keepers may need and welcome guidance about their child's role in research and their own role and responsibilities. Information can be provided which underlines children's capacity to be involved in research and helps parents to assist children to make decisions about taking part, rather than substituting their own views or acting on their own convenience, except in situations when the child is unable to express a view or is especially vulnerable. For some children, for example, those with particular disabilities, proxies or advocates, who speak on behalf of or about the children and decide whether to consent to their participation in research, make it possible for them to be included (National Disability Authority, 2009). However, to respect children's autonomy, the use of proxy informants should be minimised. The child needs to give informed consent as well as the person who is acting as the proxy wherever possible.

Consent must be given voluntarily

The requirement for consent to be given freely and without coercion has additional nuances in research involving children. The nature of power relations between adults and children means that it can be difficult to ascertain that children's consent is given freely. [This is discussed further below, in Challenges You Might Meet]. The order in which consent is gained, as well as from whom, can have an impact on children's subsequent participation, with children potentially feeling constrained or empowered by their parents' consent or lack thereof.

Consent must be renegotiable

Consent is conceptualised as an ongoing process throughout research (Alderson & Morrow, 2011; Hood et al., 1996). This process includes, but is not limited to, the initial agreement to participate prior to data collection commencing. Consent is therefore viewed as negotiable throughout the research activity, with informed dissent being as important as informed consent. Different research paradigms produce different time-periods over which participation may be required. For example, in longitudinal studies that take place over many years and in which the research aims may change significantly

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Consent is negotiable throughout the research activity, and informed dissent is as important as informed consent.

over time, ongoing consent that is aligned with the child's evolving capacities is ethically warranted. Similarly, in group contexts that involve research taking place over time, re-negotiating consent with each phase is an ongoing ethical challenge. In addition, negotiating consent in group contexts requires time to ensure that the rights of all individuals are respected in regard to research participation. Ethical issues raised in obtaining voluntary, informed consent when conducting research in a group context are discussed in the case study by Muireann Ni Raghallaigh and Robbie Gilligan, in relation to a project with asylum seeking young people in a residential hostel.

Case study 12: Obtaining informed and voluntary consent in a group context, by Muireann Ni Raghallaigh and Robbie Gilligan (see Case Study section p.138).

CHALLENGES YOU MIGHT MEET

Consent to participation in research is an ethical consideration that has been discussed extensively in the literature (Powell et al., 2012). However, it continues to raise significant challenges and requires ongoing clarification. Whilst general guidance can be (and has been) given in ethical guidelines, researchers are encouraged to consider each research study individually, taking into account the local context and the children's age, capacity and understandings in determining how consent should be obtained and signified. The topic of the research and means of gaining consent also have to be considered in the light of social, political and cultural considerations within the local context. A reflexive approach allows for the consideration of relevant contextual issues and tailoring of the consent process to meet the needs of all involved in each research study.

Are all children capable of providing consent?

The UNCRC recognises children's evolving capacities (Article 5) and it is clear that consent processes need to be designed in accordance with these. This is particularly important as the age at which children are considered capable of providing informed consent for research is a contentious subject, varying between countries and in relation to different contexts within countries. The inconsistent and contradictory requirements, and underlying assumptions about children's capabilities, can be a source of frustration for researchers (Powell et al., 2011).

However, assumptions in certain contexts that children lack the cognitive maturity and/or moral development to make informed decisions about their involvement in research are challenged by studies showing that children, including those who are very young or have learning difficulties, are able to make informed decisions when provided with appropriate information (Powell et al., 2012). When such children are deemed to be unable to give consent, their exclusion from the decision-making process reinforces the view of their dependency and incompetency (Gallagher, 2010). Resolving this issue is perhaps less about determining whether children are capable of providing consent and more about researchers' abilities to provide information and creatively adapt consent processes to meet the needs of children, while simultaneously ensuring that rigorous research practice is maintained.

Is it better to gain children's consent or assent?

Assent is frequently referred to in the documentation, particularly in the North American and international biomedical guidelines (such as those reviewed by Avard et al., 2011). Some researchers advocate the use of assent, the affirmative agreement of a child, rather than consent, in certain situations. However, these do not have to be mutually exclusive and both assent and consent can be used within the same study.

However, the use of assent is not universally recognised or supported. Criticism includes that it can be used: to refer to an agreement by minors who have no legal right to consent, despite arguments that support children's competence to consent (for example, **Gillick competence** in England and Wales); in place of consent if children do not fully understand the issues required for consent, meaning children are only partly informed; or it may mean 'at least not refusing' and so be misused to cover children's wish to not participate or non-verbal refusal (Alderson & Morrow, 2011).

On the other hand, the use of assent has been advocated as providing researchers with a way of navigating and transcending differences in language, ability, cultural, social and international borders, and ensuring they can access children's agreement to participating in research (Cocks, 2006). This is particularly significant as the focus on competence has inadvertently led to some children, for example those with language impairments, being excluded from research. However, it is important to note that Cocks contends that "'assent' cannot be in itself sufficient in ensuring ethical integrity, rather it is complemented by the researcher operating reflexively and within a framework of ethical reflection" (p.249).

What material form should consent take?

Consent usually involves the participant providing a written signature or thumb print, but sometimes a verbal agreement is made. Flexible means of providing information and signifying consent are essential for children, or parents, who are not able or willing to use written methods. Signing consent forms can be problematic and/or intimidating for those who are not physically able to, and populations who are not literate or are particularly vulnerable. For example, undocumented migrants may prefer not to sign documents. In some cultural contexts written consent may be highly problematic, if written practices are different or hold other meanings, for example, related to deception, domination or abuse. This may create distress for people if they are required to sign something they do not understand well. Flexible and appropriate methods of providing information can be employed [see following sub-section, How Can Researchers Ensure That Children Are Fully Informed?] and consent can be indicated verbally or actively. In situations where children or parents do not provide written consent it is important to have a planned process and witnesses (or means of auditing) that can verify a proper process was followed and can confirm that the child appears to have given their consent freely.

Obtaining informed consent can be difficult in online research, because of the transient nature of many online environments, the fluctuating form of the research population who may be difficult to identify and the mediated nature of the relationship which makes it more difficult

Obtaining online consent has additional complexities to consider.

to ascertain the participant's genuine understanding (Jones, 2011). Jones suggests that informed consent may not be reasonably sought or obtained online prior to the research taking place and considers that it may be a better ethical judgement to obtain informed consent when the research is at the point of reporting and the participants can see what is to be reported. However, regardless of the additional complexities involved in online research, it is critically important that consent is obtained and consideration needs to be given to exploring this and the means of ensuring that it is genuine and informed.

How can researchers ensure that children are fully informed?

Researchers can provide information appropriate to children's age and competencies in written form and verbally, and this is emphasised in existing ethics guidance. Rather than using a formal and scientific ('jargonistic') form of language, researchers need to translate ideas into very simple terms to promote and enhance understanding in communication between researchers and participants. Innovative methods of informing children can also be used, for example, using photographs or video vignettes to decrease reliance on written consent forms. The case study by Jennifer Thompson provides an example of using photographs in a visual consent form, to facilitate informed consent in a community with relatively low levels of literacy and limited access to technology.

Case study 13: Picturing consent: Using photographs in a visual consent form, by Jennifer Thompson (see Case Study section p.141).

It is important that children have a source of information for future reference about what they are consenting to. Information should include the research topic, the purpose of the research, what participation involves, any potential risks or benefits that the researcher is aware of, the ongoing option to withdraw, and practical matters, such as where the research will take place and how long it will take. In addition, children should be informed as to what the researcher intends to do with anything they produce in the process of doing research, including, for example, drawings, artwork and photographs. If the intention is that such products will be taken away by the researcher then this should be made explicit to the children, and issues of ownership and acknowledgement discussed and clarified in order for consent to be given.

However, ensuring that the information is received and understood by children (and parents) can be problematic in practice, regardless of how comprehensive and encompassing it is. Mismatches in understanding are likely and difficult to detect (Gallagher et al., 2010). This is particularly highlighted when the researcher/interviewer and children participating do not speak the same language. The use of interpreters presents unique challenges, with another layer of communication to be navigated in ensuring that the intended meaning of the information is conveyed and received. Simply providing information (particularly in written form) is not enough to ensure understanding; researchers need to engage with ways of ascertaining if potential participants and their parents understand. Cognitive testing of research instruments can be helpful, but even with information provided and understanding indicated, it is difficult

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for anyone, including children, parents and researchers, to fully anticipate the outcomes of participation and what all the potential risks or benefits may be. The case study by Kate McAlpine discusses challenges occurring in relation to the application of ethical standards, for example in gaining informed consent in fieldwork practice.

Case study 14: Responding to real world ethical challenges when conducting research with young children in Tanzania, by Kate McAlpine (see Case Study section p.145).

Another consideration in long-term research projects, such as longitudinal studies, is whether there is a need for children to receive additional information as the project progresses, appropriate to their age and capacities, in order to 're-consent' to participation. Some projects have clearly defined phases, which lend themselves to gaining children's consent at each consecutive stage. An important aspect of this is ensuring that children are informed about, and in agreement with, the storage and use of their personal data over time, particularly in cases of secondary analyses of previously collected data.

What about obtaining consent from non-participating children in research using visual methods?

When using visual methods with children, such as data collection involving children taking photographs, there is another level of informed consent required, as other people (including children) may appear in the pictures taken by the participants (Phelan & Kinsella, 2013). The ethical consideration of gaining informed consent in relation to the child appearing in the visual images can be challenging, particularly as it is likely to be the child research participant taking the photo and who is then in the position of asking the child and/or parents for consent, with the researcher unlikely to be present. This adds a further layer to the already complex task of ensuring that children and parents are fully informed and understand both the present context of the research and the future use which may be made of the photograph, for example in publications, reports and presentations. In a study by Phelan and Kinsella (2013) the following questions were used to design the assent process for children: "Why are you being asked to be in a picture? What will happen to you? What will happen to the pictures?" (p. 83).

How can researchers ensure that children's consent is freely given?

As noted, the nature of power relations between adults and children means that it can be difficult to ascertain that children have a genuine choice regarding participation and that their consent is given freely. Indeed, "children's consent must be seen in the context of constraints, obligations and expectations over which researchers have little control" (Gallagher et al., 2010, p. 479). For example, in some contexts, such as educational or medical settings, children's compliance with adult/authority requests and requirements is often compulsory. Children in school settings are likely to view the researcher as a school visitor and feel obliged to co-operate (Gallagher, 2010; Hill, 2005). It may therefore be difficult for children to decline the request to participate in research and participation could verge on coercion (David, Edwards & Alldred, 2001).

Power relations between adults and children means that it can be difficult to ascertain that children's consent is given freely.

Cultural considerations, such as strong expectations regarding obedience of children to adults or collective decision-making, impact on children's autonomy and their expressions of willingness to participate, or decline participation, in research. Some researchers argue that the impact of power relations on children's freely-given consent to participate in research is thrown into sharp relief in developing countries, in which children are most often subordinate to adults and obedience is strongly entrenched (Clacherty & Donald, 2007). Children's consent can be influenced by wanting to show respect to adult caretakers (Nyambedha, 2008), or constrained by power relations in the community (Ahsan, 2009). In addition, cultural standards and traditions may impact significantly on consent in ways that researchers from outside the community or area are unaware of, or unsure of how to respond to respectfully. For example, the ethics of hospitality are very strong in some cultures and may influence consent and research relationships, with people unable to decline participation and sharing food or other items with researchers that they can ill afford [see Case study 1 by Sadaf Shallwani in the Harms and Benefits subsection of the Case Studies section in this compendium].

Cultural considerations impact on children's autonomy and their expressions of willingness to participate, or decline participation, in research.

While it is critically important to provide children and parents with information and gain their informed consent in all research, particular care must be taken in biomedical and clinical studies in line with the specific risks. Some children have had their rights infringed through being subjected by business enterprises to unnecessary or inappropriate biomedical research without their or their parents' full and informed consent being given (United Nations Committee on the Rights of the Child, 2012). Special care must be taken in gaining consent to avoid any risks of 'therapeutic misconception' in which individuals do not understand that the defining purpose of clinical research is to produce generalisable knowledge, regardless of any potential benefit (WHO, 2011). This is an especially high risk in clinical research when participation in research may be perceived by participants and their families as an opportunity to access medical treatment, and in social and epidemiological research when it may be seen as a route to accessing services or benefits. Similarly, children and parents need to be informed of and understand that results from genetic research are more likely to be less certain and may involve clinically unvalidated tests, compared to those used in clinical genetic procedures (Patenaude, Senecal & Avard, 2006).

Another area for potential misconceptions concerns the nature of the researcher-participant relationship. For example, in ethnographic studies, children may have expectations of continued friendship with the researcher, and thus feel hurt or confused when the research participation ends. Researchers may need to be cautious in this regard, particularly with young children or those with certain types of disabilities, for example, learning disabilities (Stalker, 2003). Consent is thus influenced by raised expectations and unrealistic perceptions of beneficial outcomes.

Consent can be influenced by raised expectations and unrealistic perceptions of beneficial outcomes.

How can children's dissent to take part in research be respected?

Respect for children requires researchers to accept children's decisions regarding participation. It requires them to actively engage with children and assist them to exercise their power and decline participation should they wish. This has particular implications in focus group research. If consent is obtained in a group setting it may be difficult for children to indicate their dissent, due to social and power dynamics at play. For example, doing so may risk disapproval

and subsequent bullying or ostracism from their peers. Researchers may build in some informal time before activities begin to allow those who do not want to participate to leave without being noticed. Strategies can be discussed and rehearsed with children, assisting them to exercise their dissent or withdraw their participation in the research study (Ahsan, 2009), for example, with younger children, using 'stop signs' can be practised in a playful way before interviews. Even with these strategies in place it may be difficult for children to stop their participation in the face of potential or perceived adult disapproval. Hence, it is important to attend to children's visual, verbal and non-verbal cues to monitor unspoken expressions of unease or dissent (Ahsan, 2009; Cree, Kay & Tisdall, 2002) and recognise these points of resistance as children using the power they have to express their response to research participation.

In research that involves children in group settings there are consequences of an individual's decision to decline participation or withdraw consent.

In research that involves children in group settings there are consequences of an individual's decision to decline participation or withdraw consent. The issue of consent when engaging in ethnography within a confined space presents added difficulties that do not exist within other forms of research. For example, when a parent or child refuses consent, but the researcher nonetheless remains in the setting conducting the research with some other children present. [See Case study 12 by Ni Raghallaigh and Robbie Gilligan in the Informed Consent subsection of the Case Studies section in this compendium.] Respect for the individual child suggests that researchers should ensure there is no note taking or other data collection techniques used that involve the dissenting child (for example, when they are interacting with the rest of the group). This limits, though does not completely preclude, data collection as a whole in these contexts. The case study by Michael Gaffney discusses challenges in obtaining informed consent in ethnographic classroom-based research with children who have a disability.

Case study 15: The challenge of ongoing consent?, by Michael Gaffney (see Case Study section p.147).

It is also important that salary and reward structures for research field staff do not unintentionally provide a perverse incentive to encourage consent from participants. For example, payment per interview for field staff, rather than salary, may provide an incentive for staff to persuade potential participants to take part in the research (WHO, 2011).

Behavioural and verbal signs of dissent need to be sensitively observed and attended to by researchers.

Behavioural and verbal signs of dissent need to be sensitively observed and attended to by researchers. Very young children, such as babies and pre-verbal infants (Dalli & Stephenson, 2010), or those with physical disabilities, may not be able to move themselves out of situations in which they are uncomfortable. Children who are able to verbalise may not make an explicit spoken request to withdraw from research (Spriggs, 2010). As noted by Clark (2005), listening to children is an active process of communication that is not limited to the spoken word. Behavioural signs of dissent include: passivity; lack of cooperation; fussiness; silence; crying or puckering; constant looks towards the door; lack of eye contact with the researcher; and signs of boredom such as multiple yawns (Keith-Spiegel, 1983). Verbal indicators of dissent made by young children may include: 'I want to go to the toilet'; 'I'm tired'; 'When will I be done?'; and responding repeatedly to direct and age appropriate questions with 'I don't know'

(Keith-Spiegel, 1983). Even in one-off questionnaire-based studies children may signal dissent by not doing this very comprehensively, by making obviously irrelevant answers, or by not participating again if the study is repeated.

Is parental/adult consent always required in research involving children?

Decisions about ethical research practices are made within a cultural context, including whom consent is required from (Bogolub & Thomas, 2005), and the usual requirements for parental (and other adult) consent reflect underlying understandings and assumptions about children, childhood, child-parent and wider community relationships. Contextual understandings of children's capacity to give informed consent in some countries are influenced by conceptualisations of childhood which frame children as immature and vulnerable. This is particularly true for younger children. In these contexts children usually cannot be approached directly, "their sociopolitical positioning means that adults must give permission" (Hood et al., 1996, p. 126). Consequently, research in institutional hierarchies, such as schools, can give rise to an ethical tension around consideration of the child's agency versus the need to first obtain consent from school principals, teachers, parents and other adult authorities (Gallagher, 2010). Across different contexts, care needs to be taken to ensure that focusing on individual capacity to consent does not lead to overlooking the social aspect of consent. In school settings, for example, the child's relationship with parents, teachers and peers is likely to influence the consent process (Gallagher, 2010).

Adults in gate-keeping positions may govern children's access to research, particularly when the children are considered especially vulnerable, such as children in care, and researchers are advised to establish sound relationships with gate-keeping adults (Bogolub & Thomas, 2005; Thomas & O'Kane, 1998). Researchers involving younger children may also be confronted with a higher threshold for getting parental consent than with older children, especially if the topic of research is considered sensitive (for example, related to violence against children). Consequently, parents and other adults play a significant role in restricting researchers' capacity to include children's views and limiting children's participation in research (Powell et al., 2011).

It is critically important to acknowledge that parents and other adults in gate-keeping roles have an important and positive function in protecting children from potential harm. However, they can also use their power to censor young people (Masson, 2004) and may not always have the best interests of the child in mind. While the vast majority of parents care deeply and act in the interests of their children, in some instances, the assumption (usually made in gaining parental consent) that parents will always act in their children's best interests simply may not be true, and the child's parent may have reasons for not wanting the child to participate based on their own concerns or interests. Parents who are abusive, for example, may not consent to their child participating in particular research studies for fear of the child revealing the abuse and the researcher subsequently reporting it to authorities. The case study by Lucie Cluver, Franziska Meinck and Mark Boyes discusses the dilemmas faced conducting research with children affected by HIV and AIDS in South Africa in regard to obtaining informed caregiver consent when guardians were unavailable, unable or unwilling to provide this.

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Parents and other adults have an important, positive function in protecting children, but some may use their power to censor children and young people and may not always have their best interest in mind.

Case study 16: Caregiver consent for child participation in research: Reaching and protecting the most vulnerable, by Lucie Cluver, Franziska Meinck and Mark Boyes (see Case Study section p.150).

Passive consent procedures, in which parents are only required to let researchers know if they do not want their child to participate, allow researchers to bypass the usual parental consent requirement, and children to participate and contribute in research. However, this is a contentious area, particularly for young children and those with decision-making impairments. The ethics of this have mostly been debated in relation to sensitive research topics, when gate-keeping is more likely to occur (Powell et al., 2012). Ethics committees tend to favour active consent, or 'opt in' consent procedures, which respect people's privacy and allow for autonomy, but also have the effect of silencing children who are dependent on someone else giving consent for them to participate (Alderson, 1995).

In some contexts there are valid reasons for not gaining parental consent.

Some researchers consider that parental consent, or consent from those in a parental role, should be the rule and not the exception, and that researchers should need to argue from case to case why such consent is not necessary, but not the other way round. Valid arguments for not gaining parental consent might include the risk of suppression of children's information, or situations in which it is impossible or inappropriate (see section below).

What if researchers are unable to obtain parents' consent?

The already complex matter of obtaining the informed consent of parents or carers is further complicated in some contexts by certain practical challenges. These may include difficulties identifying and locating parents or guardians, low rates of literacy, scepticism about signing documents, and concern that signing a consent form may carry risk to participants or their families in certain contexts (Abebe, 2009; Clacherty & Donald, 2007; Hutz & Koller, 1999).

In the absence of parental support, children's participation in research should be guided by the best interests of the child and the involvement of child advocates.

Undertaking research involving children who are unaccompanied or orphaned significantly complicates issues of consent. The conditions around which this occurs may include humanitarian emergencies, such as situations of civil war, conflict and peace-keeping, or natural disasters. It may also include unaccompanied children migrating to seek refuge in response to humanitarian emergencies or for other reasons. In such situations children are exceptionally vulnerable and the research may be driven by political or other imperatives which are operating under time, resource and other constraints. Therefore, in the absence of parental support and concern for their children's welfare, it is critically important that the primary factor in deciding children's participation in research is the best interests of the individual child and that responsible child advocates are involved in the consent process.

Usually, there are caretakers or legal guardians who, in accordance with domestic laws in force, may have the same responsibility and powers as parents. In some instances, the state may have a role regarding responsibility for children that needs to be respected. To this end, some ethical guidelines stipulate a descending order of people from whom consent should be sought or a waiver required. Guidelines prepared by the Human Sciences Research Council of

South Africa (2010), *Informed consent guidelines re minors (including orphans and vulnerable children (OVC)) and parental substitutes*, for example, suggest the order should be: parent; guardian; foster parent (per order of Children's Court); caregiver (per Children's Act); or if minor is a caregiver in a child-headed household then consent should be sought from a responsible person (per s137 Children's Act), or a trusted adult nominated by the minor, including but not limited to social worker, community worker or teacher.

What if it is inappropriate or impossible to seek parental consent for children?

There are some situations whereby it may be inappropriate or impossible to seek parental consent, for example when children are 'runaways' and homeless (Meade & Slesnick, 2002), living on the streets (Richter, Groft & Prinsloo, 2007; Vakaoti, 2009), or emancipated minors (King & Kramer, 2008).^{xviii} This is particularly relevant when the children being sought for the research are older, for example, young people over 15 years of age. Some researchers also argue that it is not appropriate to ask for parental consent in certain contexts, such as studies with sensitive research topics that require confidentiality and privacy for the protection of the young people participating. This applies, for example, in studies concerning sexuality (Valentine, Butler & Skelton, 2001) or drug use (Langhinrichsen-Rohling, Arata, O'Brien, Bowers & Kilbert, 2006). Gaining consent poses particular challenges when seeking to engage hidden populations of young people to participate in research. In such contexts, other people's knowledge of the young person's involvement in the research may be a breach of their privacy and/or a serious and potentially dangerous threat to them, and the young person is unlikely to respond to conventional (and relatively public) approaches to gain their consent.

Is it ethical to hide or disguise the purpose of the research?

An ethical consideration is the extent to which it is permissible (if at all) to hide or disguise aspects of the purpose of the research. There may be an inherent tension for researchers between wanting to ensure that research participants are fully informed, with consent freely given, and wishing to maximise participation in their research (Hill, 2005). This tension arises when it is anticipated that full disclosure of information will limit the number of people who are likely to participate. Some researchers argue that limiting information is not acceptable for the purposes of increased recruitment and is only acceptable when there is good reason: for example, where disclosure may place the children in the path of potential harm; the research involves no more than low risk to participants; potential benefits justify the limited disclosure and possible risk to trust in research and researchers; and the precise extent of limited disclosure is defined and articulated (Spriggs, 2010). Not disclosing information, or covert research, challenges the ethical principles of respect, justice and honesty, and considerable ethical debate exists as to whether deceit of participants can ever be fully justified (H. Fossheim, personal communication, December 14, 2011).

Not disclosing information, or covert research, challenges the ethical principles of respect, justice and honesty.

^{xviii} In some countries/states statutes allow minors to become legally emancipated and treated as an adult for legal purposes, for example, through marriage or based on petition from the minor or the minor's parents (King & Kramer, 2008).

The nature and use of deception in research may vary depending on the topic of the study, methodology and research paradigm. For example, in naturalistic observations, participants' knowledge of the specific behaviours that are being recorded (such as, altruistic behaviours - sharing toys or helping another child) may alter the behaviours that are demonstrated by the participants, and thereby reduce the validity of the study's findings. Similarly, in some experiments, participants' knowledge of the study's purpose/ research question, experimental conditions and how the scores on outcome variables will be interpreted, may change their responses and potentially reduce validity and benefits of the findings.

Debriefing procedures are of vital importance to all research, but particularly so if any deception is used.

For example, in repeated measures designs in which participants experience all conditions of the experiment, their knowledge of the conditions could lead to manipulation of responses, thus producing a response bias and inaccurate data. The tension between provision of informed consent and minimising harm versus producing valid results with potential beneficial outcomes needs to be carefully considered, within a context of respect for the dignity and rights of the children participating, by researchers' who are contemplating the use of any degree of deception. Provision of debriefing procedures is of vital importance to all research, but particularly so if any deception is used. Researchers need to fully explain to children the purpose and procedure of the study, the risks involved and the benefits expected, in a manner suitable for their age and competency. Researchers also need to provide age and competency appropriate answers to any questions the children have before, during and after their participation, and to provide support for any ongoing issues arising from their participation.

What about using information provided without consent by children for research purposes?

A significant amount of meaningful and important knowledge about children and their lives can be generated without involving children directly, for example, analysing registries and other statistical information. However, there are important ethical issues raised for researchers who access, or have privileged access to, children's information that was provided for other than research purposes. These might be further heightened if the organization holding the records is highly specialised and easily identifiable. For example, a practitioner working in a therapeutic service for children might want to conduct research based on the children's files, or researchers may want to use information provided by children to child helplines. This raises the question of whether it is ethical to use information, perhaps for a cause such as raising awareness about issues children face, without having asked the children who provided the information for their permission to do this. Realistically, it may not be feasible to ask a distressed child in crisis whether the service might at a later date use their case to raise awareness or influence change. One option, without having gained consent, is for researchers to try turning children's cases into anonymous vignettes. However, the children themselves may still have the impression that their experience, disclosed in confidence, is being used to influence others or for publicity purposes.

An ethical issue is raised when researchers want to use information provided by children without having asked the children for their permission.

WHAT GUIDANCE CAN WE DRAW FROM THE UNCRC IN RELATION TO INFORMED CONSENT?

- Children are entitled to see, receive and impart information; they have the right to know what the research is about and what it involves. Adults have a responsibility to ensure that the information makes sense to children and the research does not place them at harm (Article 13).
- Children have the right to give their opinion about research and participation, and for adults to listen and take children's views seriously (Article 12).
- Children have the right to find out things and share what they think with others, by talking, drawing, writing or in any other ways, unless it harms or offends other people (Article 13).
- Children should be aware of their rights in research. Researchers should know about these rights and help children learn about them too (Article 42).

KEY QUESTIONS

Who else do you need to consult to involve children in the study?

- Which adults, if any, do you need to meet in the family or local community in order to understand the needs and rights of the children involved?
- Whose consent do you need for children to be involved?
- What information will you need to provide them with?

What information do children need to consent to being involved?

- What information do children need to enable them to consider giving consent?
- How will you find out the information children need?
- How will you tell children about the study?
- What procedures have been put in place to prevent children being coerced to participate?
- What further information will children need (in long-term or longitudinal projects) as the study progresses to enable them to consider their continued consent, and at what stages?

What form should the information provided for children take?

- Will you provide written information for children? If so, why?
- If you do not provide written information, how will you convey the information? Why have you chosen this method?
- Is there a designated person that the child (and/or parents) can go to if she/he has any questions or concerns (now and in the future)?

Do children require extra support to contribute?

- How will you identify the special needs of individual children?
- How will you respond to these needs?

How will you assess the competence of children to consent?

- How will you ensure children understand what consent is? How will you support children to understand and weigh up any risks?
- How will you ensure that children are able to withdraw without negative consequences?
- How will you ensure children understand that they are able to withdraw consent at any time without penalty?
- How will you make provision for gaining children's informed consent or allowing their dissent at different stages over long-term projects?