The Right of Children to Be Heard in Participatory Research on Violence

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Abstract

Involvement of children in research on different aspects of children's rights, including research on violence against children, is continuously increasing, as is the interest in participatory approaches (European Agency for Fundamental Rights [FRA], 2014; Larsson et al., 2018; UN Committee on the Rights of the Child, 2011). Svevo-Cianci et al. (2011) noted that 'as researchers commit to learning from community members, including children and adolescents themselves, it has become more clear that an understanding of the lived reality and definition of violence for children in their individual communities, is essential to envision and implement effective child protection' (p. 985).

In this chapter, the legislative context regarding children's rights to be heard and participate is initially discussed; currently applied age requirements for children to acquire rights across the countries of the European Union (EU) are briefly presented; and children's potential roles and relevant provisions for their participation in social research are explored. The last part is dedicated to the presentation and discussion of the General Data Protection Regulation (GDPR; Regulation [EU] 2016/679, 2016) – specifically, children's personal data—related recitals and articles; the importance of the definition of a legal basis for personal data processing according to the GDPR, including consent; and the necessary information to be provided to children before their data are processed.

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Introduction

According to the General Comment 12 released by the UN Committee on the Rights of the Child (2009), children's participation involves ongoing processes, which include 'information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes' (p. 3). In 2018, the Secretariat of the Lanzarote Committee drafted guidelines for the implementation of child participation in relation to 'the protection of children against sexual exploitation and sexual abuse facilitated by information and communication technologies' (Title). Child participation, in this document, means that all children, individuals or groups, without discrimination on any grounds, have the right, means, space, opportunity and where necessary, support to freely express their views, be heard and contribute to decision-making on matters affecting them (Secretariat of the Lanzarote Committee, 2018). It specifically mentions that children's views should be given due weight in accordance with their age and maturity; the rights of children and young people to participate applies without discrimination on any grounds, including race, ethnicity, colour, sex, language, religion, political or other opinion, national or social origin, property, disability, birth, sexual orientation or other status; and particular efforts should be made to enable participation of children and young people with fewer opportunities, including those who are vulnerable or have special needs.

However, despite general agreement about children's participation, particularly in social research and development of interventions, when research focusses on sensitive issues, potential children participants are treated as vulnerable beneficiaries who should be protected by adults rather than as rights holders entitled to contribute to the decision involved. This leads to strict gatekeeping procedures that prevent some children from participating, compromising their participation rights (Powell & Smith, 2009). As a result, when researchers try to obtain approval and support for children's participation, they have to deal with challenges often related to different perspectives or conflicting interests, needs, or expectations from relevant adult stakeholders, including parents and professionals working with children and human research ethics committees (Powell et al., 2020). In this context, research focussing on violence against children raises concerns related to issues involving the research process as a whole and specific aspects such as obtaining consent, confidentiality and protection of personal data (Laws & Mann, 2004).

Strengthening Child Participation

On 24 March 2021, the European Commission adopted the European Union (EU) strategy on the rights of the child, which includes more than 40 actions that

the commission will implement or start implementing by 2024. To improve the situation, child participation in political and democratic life was included as the first thematic area of the strategy, understood as the right for children to be heard and an obligation for adults to facilitate and organise their involvement in a meaningful, inclusive and safe way. Safe child participation, which is a precondition of participation, means that children have a safe space to express their views, participate in activities, complain and voice their concerns. Inclusive child participation means that efforts are made to include and engage with children from different geographical areas, socio-economic backgrounds and minority groups, including children with disabilities. Such participation ensures gender and age diversity. Meaningful child participation is based on mutual respect, transparent and voluntary, moderated using child-friendly tools and working methods, and supported by training and access to information. Any activity involving children must include access to clear and age-appropriate information about the objectives, procedures, timing, involvement of third parties and safety procedures, and must finish with a feedback or follow-up session. In the same line, the third thematic area of the EU strategy on the rights of the child concerns EU actions that help children become free from violence; specifically, the first of 10 principles for integrated child protection systems states that every child must be treated as a unique and valuable person with due regard to their right to participation.

Age Requirements for Children to Acquire Rights Across the EU

In 2017, European Agency for Fundamental Rights (FRA) published a mapping of age requirements for children to acquire rights across the EU based on data collected through FRANET, FRA's multidisciplinary research network, through 2016. The objective was to assist member states in addressing children's rights relevant issues and facilitate the EU in exercising its competence to support and coordinate member states' actions related to children and youth. Specific data values for all countries and variables are available online for several policy areas, including, among others, children's right to access justice, relevant procedural rights such as to be heard and right to provide consent in the digital world. Although no updated mapping for age limits for children to participate in research is included, selected age requirements for children to acquire their rights are presented here.

Concerning the right to be heard (FRA, 2018), the age at which a child can formally issue a complaint of abuse or violence to judicial and law enforcement authorities varies among EU countries: In 18 countries, there is no minimum age (Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Germany, Denmark, Estonia, France, Italy, Luxembourg, Latvia, Malta, Poland, Sweden, Slovenia, Slovakia and the United Kingdom). Age thresholds in the remaining member states are as follows: 12 years old (Greece); 14–16 years old (Croatia, Finland, Hungary, Lithuania, Netherlands and Portugal) and 18 years old (Ireland, Romania and Spain). As for the age at which a child has the right to be heard as a victim of violence, abuse or neglect, 13 countries have no minimum age (Austria,

Belgium, Estonia, Greece, France, Lithuania, Luxembourg, Latvia, Poland, Portugal, Romania, Slovakia and the United Kingdom), whereas age thresholds in the remaining countries are 10–12 years old (Bulgaria, Czech Republic, Italy, Netherlands and Spain) or 14–16 years old (Croatia, Denmark, Finland, Hungary and Sweden). Last, five countries have no relevant regulation (Cyprus, Germany, Ireland, Malta and Slovenia).

Information regarding requirements for children in the digital world (FRA, 2017) focusses on the age at which children can provide consent to disclose their images and personal data and consent to the use of their personal data. Requirements in the first case are 15 or 16 years old (Finland, Hungary, Netherlands, Romania and Spain) or 18 years old (Croatia, Bulgaria, Estonia, France, Greece, Italy, Latvia, Lithuania and Poland). In four countries, age limits depend on the child's maturity (Belgium, Czech Republic, Germany and Slovakia), whereas in 10 countries, no relevant data are available (Austria, Cyprus, Denmark, Ireland, Luxembourg, Malta, Portugal, Slovenia, Sweden and the United Kingdom). As for the latter topic, the age at which children can provide consent for the use of their personal data is 14-16 years old (Bulgaria, Hungary, Netherlands and Spain) or 18 years old (Croatia, Cyprus, Estonia, Finland, France, Greece, Ireland, Italy, Latvia, Portugal, Romania and Slovenia). In seven countries, the age limit depends on the child's maturity (Belgium, Czech Republic, Denmark, Germany, Malta, Slovakia and Sweden), whereas in five countries, no relevant data were available as of April 2016 (Austria, Lithuania, Luxembourg, Poland and the United Kingdom).

Role of the Child Participating in Social Research

According to Shier's (2001) pathways to participation model, children's and young people's participation in research can be distinguished at five levels, from participating as a passive informant to contributing as an active agent in a partnership position. Similarly, a scoping review by Larsson et al. (2018), which analysed 41 studies published during 2000–2017, found that the level of children's and young people's participation in research varied. In some cases, they were involved only as informants; in other cases, they had greater participation in quantitative and qualitative terms; and in yet other cases, they were active agents involved as coresearchers, although the distribution of participation was not equal on these different levels. Therefore, the role of children in research ranges from being informants, or a source of knowledge, by simply participating as a subject of the research (although they are informed, are listened to, express their views and are taken into account, thus influencing the outcome) to being a producer of knowledge, having a role similar to a coresearcher, who may initiate projects and share decision-making powers. In practice, as suggested in the literature, various degrees between those two levels of participation can be identified.

Considering the issues of when and how children participate in research, Broström (2012) suggested that participation is considered more meaningful if the children are involved at all stages of the research, including the research design,

data collection, interpretation and analysis, and dissemination of the findings. Such meaningful involvement of children can have benefits for both the research and the child because child participation increases the validity of data (insider perspective) and children gain knowledge and valuable skills for cultural and political participation. On the other hand, participation of children in research involves several challenges. Among the main challenges are the relationship between vulnerability and participation, especially for specific groups of children such as those in alternative care (Garcia-Quiroga & Salvo Agoglia, 2020); the power relationship between adult and child; the adult perspective on children (insider and outsider perspectives are difficult to balance); and child protection issues such as appropriately ensuring informed consent, handling disclosure and emotional well-being, and protecting children's personal data (Broström, 2012).

Provisions for Children's Participation in Social Research

To ensure that the best interests of the children is the primary consideration, research in general has to be carefully designed, based on appropriate consultation, and properly conducted, whereas applied methodology needs to be in alignment with relevant rules, regulations and guidelines; suitable to the research purpose and inclusive concerning all voices that need to be heard.

A non-homogeneous situation similar to that of age requirements for children to participate by acquiring their rights across EU countries was mapped regarding children's participation in research. In 2014, FRA published the results of this mapping project concerning legal requirements and ethical codes of conduct of child participation in research in EU member states. According to this effort, such provisions are in place in all EU countries, although each country has different rules and prerequisites for the participation of children in research, either more general rules or age-specific guidelines. These include legal frameworks and ethical codes of conduct, particularly concerning the role of children and parents, role of schools, residential care institutions or other settings, procedures for granting ethical approval and processes to ensure informed consent.

Provisions related to child participation in research can be identified in country-specific documents, including personal data protection or other relevant regulations and laws; articles in civil codes; statutory instruments; child protection-related acts; codes of ethics or conduct of professional associations; codes of ethics for research or social research; national standards; and recommendations and operational guidelines issued by ethical review committees or national data protection authorities.

Age is often a crucial parameter for child participation in research because it is related to the child's capability to provide consent, which is a prerequisite for participation in social or similar research. Therefore, it is important for researchers to be aware of the age when a child can freely provide their consent to participate in a research programme. What are the accepted types of consent that a child can provide to participate in research? What are the conditions (other than age) under which the child does not have the capacity to provide consent? Are

there any specific provisions and guidelines for the assessment of a child's level of maturity and capacity for insight? Researchers should also be aware of the role of the parents or guardians of the child, if and when parental consent is required, and the accepted types of consent (active and passive) that a parent can provide for the child to participate in research. Especially regarding parental consent, the situation varies considerably – in some countries, parental consent is always required for children up to 18 years old; whereas other countries require parental consent for children younger than 15 or 16 or younger than 14 years old; and in some countries, parental consent varies depending on contexts and is required for children up to 18 years old in school settings (FRA, 2014).

In case of research in specific settings (such as schools and residential care institutions) or specific ways (for example, online), researchers also should be aware of whether there are setting-specific consent-related provisions for surveys, who can provide consent for child participation apart from parents (such as guardians or teachers), whether there are specific predefined consent forms in each case and what are the mandatory procedures. Some of these elements can be conditional and depend on factors like: (1) setting type (e.g. for schools: public or private and grade; for residential care institutions: type, legal status as public, private or charitable, and age group of children); (2) geographical region (potential differences from municipality to municipality); (3) children's conditions (disability or other conditions); (4) research topic (especially for sensitive issues like drugs use and child maltreatment); and (5) data to be collected (whether personal data are included, anonymous data etc.).

As for internet-based research (online surveys), researchers should be aware whether there are additional provisions, apart from consent-related provisions for research with children in person, and provisions on the type of children's data that can be collected, processed and disseminated.

Last, researchers should be aware of the procedures and prerequisites to apply for ethical approval of their research protocols involving children. They should be aware of whether there are specific institutions involved in this process (national or local ethics-related committees or services under relevant ministries such as the Ministry of Education) and specific procedures, such as whether they should provide a written request to competent authorities in advance that includes details on research protocols (methods, procedures, tools, informed consent forms, data collection, processing and dissemination) and receive written feedback before they start the research (opinion or final decision regarding approval or rejection).

General Data Protection Regulation

The General Data Protection Regulation (GDPR) came into force on 25 May 2018, repealing the 95/46/EC Data Protection Directive. As stipulated in the GDPR, although a high level of protection must be ensured with regard to personal data processing, this should be balanced against other fundamental rights in accordance with the principle of proportionality.

According to the GDPR (Article 4 Definitions, p. 33), 'personal data' means 'any information relating to an identified or identifiable natural person ("data subject"); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person', whereas 'processing' means 'any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction'.

To this end, any activity involving personal data processing, including research activities in which children participate in any possible way, is subject to the GDPR. There is only one condition, as described in Recital 26, where the regulation is not applicable: when data are anonymous and processing concerns anonymous information, including for statistical or research purposes. Specifically, the principles of data protection are not applicable to information that does not relate to an identified or identifiable person or personal data rendered anonymous in such a manner that the data subject is not identifiable.

Therefore, any research activity involving child participation of any extent, ranging from children as passive informants to co-authors, and not fully anonymous personal data should take into account the provisions of the GDPR for the protection of personal data. It should be clear to researchers that personal data protection provisions and required protection measures are different than prerequisites for acquiring ethical approval for research with child participants.

Children's Personal Data-Related GDPR Recitals and Articles

Although all GDPR provisions apply also to children, the following section outlines GDPR recitals and articles related to the protection of children's personal data – namely, the main points of Recitals 38, 58, 65 and 75 and Articles 5, 6, 8, 12 and 40.

Recital 38 notes that children merit specific protection regarding their personal data because they may be less aware of the risks, consequences and safeguards concerned and their rights in relation to the processing of personal data. It clarifies, however, that the consent of the holder of parental responsibility should not be necessary in the context of preventive or counselling services offered directly to a child.

Recital 58 provisions are related to the principle of transparency of information; concerning children, it notes that given that children merit specific protection, any information and communication where processing is addressed to a child should be clear and plain language that the child can easily understand.

In Recital 65, the right of participants to have their personal data rectified, if and where needed, and the 'right to be forgotten' are included. These rights also

apply for cases where consent was given in the past, when a person was child and personal data continue to exist and are processed when the person is an adult. A classic example here is Amber Alert announcements for missing children. Automated processing of personal data evaluating the personal aspects relating to a person (profiling) is not allowed for children.

Finally, Recital 75 notes that personal data processing potentially implies a risk to the rights and freedoms of participants, which could lead to physical or other type of damage, particularly when the personal data of vulnerable people – especially children – are processed. People should be explicitly informed about potential risks of personal data processing in advance (before processing takes place).

In Article 5, the main principles for processing of personal data are presented. The controller of the data shall be responsible for and able to demonstrate compliance with according to these principles:

- Lawfulness, fairness and transparency: Personal data should be processed lawfully, fairly and in a transparent manner in relation to the data subject.
- Purpose limitation: Personal data should be collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes should not be considered incompatible with the initial purposes.
- Data minimisation: Personal data should be adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.
- Accuracy: Personal data should be accurate and where necessary, kept up to
 date; every reasonable step must be taken to ensure that personal data that are
 inaccurate with regard to the purposes for which they are processed are erased
 or rectified without delay.
- Storage limitation: Personal data should be kept in a form that permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods if they will be processed solely for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes subject to implementation of the appropriate technical and organisational measures required by the regulation to safeguard the rights and freedoms of the data subject.
- Integrity and confidentiality: Personal data should be processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and accidental loss, destruction or damage, using appropriate technical or organisational measures.

Article 6, relating to the lawfulness of processing, mentions that in some cases, the legal basis for personal data processing could be the legitimate interests of the controller or a third party. However, this is not possible if such interests are overridden by the interests or fundamental rights and freedoms of the data

subject, which require protection of personal data, particularly if the data subject is a child.

Article 8 contains provisions about the conditions applicable to a child's consent in relation to social information services (e.g. social networks or other online services). In such cases, the processing of the personal data of a child is lawful if the child is at least 16 years old. If the child is younger than 16, such processing is lawful only if and to the extent that consent is given or authorised by the holder of parental responsibility over the child. Member states may provide for a lower age for those purposes by law, provided that this lower age is not below 13 years.

In terms of transparency (Article 12 regarding transparent information, communication and modalities for the exercise of the rights of the data subject), there are clear provisions requiring the controller to take appropriate measures to provide information to data subjects that are related to processing of personal data. The controller should provide such information in a concise, transparent, intelligible and easily accessible form using clear and plain language, particularly for any information addressed to a child. The information should be provided in writing or by other means, including electronic means, where appropriate. When requested by the data subject, information may be provided orally, provided that the identity of the data subject is proven by other means.

Last, Article 40 suggests associations and other bodies representing categories of controllers or processors to prepare codes of conduct or amend or extend such codes to specify the application of the regulation, such as regarding the information provided to and the protection of children and the manner in which the consent of the holders of parental responsibility over children is to be obtained.

Legal Basis for Personal Data Processing According to the GDPR and Child Participation

As previously described (GDPR, Article 6, p. 36), to comply with data protection law, before researchers can collect and use any personal data, they need to establish a 'legal base'. Namely, at least one of the following must occur:

- the data subject has consented to the processing of his or her personal data for one or more specific purposes;
- processing is necessary for the performance of a contract to which the data subject is party or to take steps at the request of the data subject prior to entering into a contract;
- processing is necessary for compliance with a legal obligation to which the controller is subject;
- processing is necessary to protect the vital interests of the data subject or another person;
- processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller and

60

• processing is necessary for the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject, which require protection of personal data, particularly if the data subject is a child.

Processing of 'special category' data such as religion, race and ethnic origin needs a further legal basis that could involve public interest. Recital 52 notes, among other provisions, that derogating from the prohibition on processing special categories of personal data should also be allowed under certain conditions. Such a derogation may be made for health purposes, including public health and the management of health care services, especially to ensure the quality and cost-effectiveness of procedures used for settling claims for benefits and services in the health insurance system or for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes.

Consent as a Legal Basis for Processing Personal Data

The GDPR imposes very strict requirements for consent to be valid (including use of information and communications technologies): it must be freely given (Recital 43); specific; informed (covering all relevant purposes for the processing by all relevant parties, appropriate and age-adapted) and unambiguous. Also, positive action is required to opt in. Failure to opt out does not constitute consent for the purposes of the GDPR. Moreover, individuals may withdraw their consent at any time.

If consent is selected as a legal base for processing personal data in research, it should always be considered whether the individual child has the competence to understand and consent. If not, the child's consent is not valid. If a child is not competent to give consent, the consent of someone with parental authority over them will need to be obtained (and such consent should be verified, where appropriate). Agreement of a teacher in the child's school, for example, is not sufficient to constitute consent for the purposes of the GDPR. Researchers should think carefully about relying on consent as their legal basis for processing personal data or if it would be more appropriate to work on another legal basis, such as a task carried out in the public interest.

Obtaining informed consent from individual participants when consent is not the legal basis for processing is usually necessary to obtain ethical approval for research involving children. Consent to participate in research, however, is not the same as using consent as the legal basis for processing personal data under the GDPR. For example, people may be asked to consent to participate in research and informed that if they agree to participate, data about them will be processed for a task in the public interest. In this case, the legal basis for data processing is a task carried out in the public interest rather than consent (UCL Legal Services Data Protection Office, 2018). Consent to participate in a project obtained for ethical purposes must be also fully informed and freely given when a child is competent enough to consent to participate in a particular research intervention.

It is still a good practice to involve their family as part of the decision-making process unless the child asks the researcher not to do so. Therefore, it should be clear to researchers that there is a distinction between children's participation in research and processing of participating children's personal data. They need to obtain the informed consent of individual participants for their involvement in the research to obtain ethical approval of the research protocol. However, to use consent as a legal basis for processing of participants' personal data, they should clearly and appropriately inform the participants and ask they consent for processing their personal data.

Information to Be Provided to Children Before Their Data Are Processed

For the processing of personal data to be fair and lawful under the GDPR, individuals (here, children participating in research and their parents or guardians, where necessary) must receive information on the processing to be carried out, including for what reason the data will be used, with whom they will be shared and how long they will be kept for (fairness and lawfulness). Moreover, they have to be informed of the risks inherent in the processing and the safeguards in place in the context of the research (transparency). Information notices to children should be written in a concise, clear and plain style; age appropriate and presented in a way that appeals to a young audience. In case that the target audience covers a wide age range, provision of different versions of informational sheets and notices should be considered. In case that the research relies on parental consent as the lawful basis for processing, researchers should provide parents or guardians and children with separate and appropriately prepared privacy notices. To comply with the accountability requirement under the GDPR, controllers (here, the responsible researchers) must demonstrate compliance with data protection legislation, which practically means that, in addition to establishing a legal basis for processing, they documented the selected basis and kept evidence justifying the fair processing of data.

Preparing Child Participation in Social Research

Relevant information for provisions concerning child participation in social research, including research on violence, for each EU country was published by FRA, reflecting the situation as of 2014, as already discussed. To update this information, a tool for collecting European country-specific terms and provisions for children's participation in social research was developed in the context of a working group on 'promoting participatory approaches to child maltreatment surveillance' of the Euro-CAN Action's (2020) 'Multi-Sectoral Responses to Child Abuse and Neglect in Europe: Incidence and Trends'. The aim of this initiative is to update available information and add further information on developments at national and European levels since 2014, including the introduction of the GDPR in 2018, which is considered a milestone for personal data protection. Specifically, during the planning of research, researchers should be fully aware of what is required according to national legal frameworks and ethical codes of conduct for research involving children. They should know at what age a child has the legal capacity to make legally effective decisions – namely, the child is presumed by law to be competent – and whether there are consent-related obligations for child participation in social or similar research. Regarding children's role, researchers should know the age at which a child can freely provide consent to participate in research, the accepted types of consent that a child can provide (such as informed consent or assent, written or orally), and whether there are conditions (other than age) under which the child does not have the capacity to provide consent (for example, provisions for the assessment of the child's level of maturity and capacity for insight). As for the role of parents and caregivers, it should be clear when parental consent is required, the accepted types of consent that a parent can provide (active or passive, opt in or opt out), and any relevant procedural issues (such as timing of parental consent acquirement). If researchers are interested in conducting research in specific settings, such as schools or educational settings, residential care institutions and internet-based (online) surveys, they should know whether there are special consent-related provisions (such as forms or templates of consent forms that should be used) and whether the process depends on setting-specific factors – e.g. school type (public or private); grade (preschool, elementary, secondary); geographical region; participants' conditions (disabilities or other conditions); research topic (sensitive issues like drug use or maltreatment) and data to be collected (personal or anonymous data). Last, concerning ethical approval, researchers should know whether there are specific institutions or committees involved in ethical approval of social research protocols (methods, procedures, tools, data protection etc.) involving children and if so, if there are defined procedures that should be followed.

The updated version of such a mapping of what it is provisioned and required at a national level for the active involvement of children in research is expected to serve as a practical tool, especially for young researchers who are interested in conducting participatory research on topics like child protection and violence prevention—related issues.

Conclusion

Promoting the involvement and participation of children in social research, especially on the topic of child maltreatment, is considered an important step to strengthen children's rights to participate and be heard. Developments in legislation, however, such as the introduction of the GDPR, along with the existence of diverging rules and regulations in different EU countries, may represent a challenge for researchers when it comes to research projects on sensitive child well-being—related phenomena, especially when the research involves several countries. Rules and prerequisites should be fully considered and applied to ensure that relevant efforts are of benefit to children.

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