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## Children's consent and the zone of parental discretion

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### Abstract

This paper briefly reviews highlights from decades of debates in medicine, law, bioethics, psychology and social research about children's and parents' views and consent to medical treatment and research. There appears to have been a rise and later a fall in respect for children's views, illustrated among many examples by a recent book on the zone of parental discretion, which is reviewed. A return to greater respect for children's views and consent is advocated.

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## Introduction

This paper began as a review of a book about parents' decisions on children's medical treatment. However, the book's omissions matter as much as its content. Children's own views up to the age of 18 are largely overlooked, which not only bypasses related law and ethics guidance, but also prevents doctors and parents from making decisions that are adequately informed by the views of the child concerned. The book review developed into a review of these omissions, and reflections on why they were lost not only from the book but also, increasingly it seems, from international policy and practice. The book on the zone of parental discretion is then reviewed, and new activity is recommended to restore and extend respect for children's views and consent.

Who should make decisions about medical and surgical treatment for legal minors? Beyond abstract debates in ethics and law, in everyday practice the informed willing consent of young children to life-giving treatment may be crucial. Unless daily insulin injections for Type I diabetes are understood and actively accepted and often administered by children themselves aged from about 4-years, then the child may fearfully resist and the adults can feel compelled to respond with forcible coercion that endangers the child's physical and mental wellbeing.<sup>1</sup> Successful heart-lung transplants, requiring daily, life-long, anti-rejection medication, also depend on each child's informed willing cooperation.<sup>2</sup>

This paper briefly reviews highlights from decades of debates in medicine, law, bioethics, psychology and social research about the crucial importance of respect for informed, willing consent, and of adults informing and listening to children and sharing decision-making with them. Respect for children's consent rose during the 1980s, but with the 'backlash against *Gillick*' and other pressures, it appears to have fallen. Renewed respect for children's views and consent is advocated.

## Developments relevant to children's consent

Global debates on children's consent fall broadly into three sectors: US-influenced views; English common law, which influences 53 British Commonwealth countries inhabited by over a billion people; and concerns from Africa and Asia that decisions for children should be less individualistic and more communal. This paper will mainly compare US- and English-influenced systems, which though very similar differ on standards for children. There is not space here to do justice to the third important sector, except to note that high standards of Anglo-American informed consent are an essential defence against potentially lethal exploitation by commercial research that is increasingly conducted in Asia and Africa.<sup>3</sup> First, developments from the 1940s onwards will be reviewed.

The crucial importance of international standards on informed voluntary consent to research by adult 'healthy volunteers' was agreed in 1947 in order to prevent Nazi medical atrocities from ever recurring.<sup>4</sup> In 1964, the standards were expanded to include 'therapeutic' research on patients, both adults and children.<sup>5</sup> The standards can apply to any informed, freely-made decision: does the decision-maker understand the nature, purpose, timing, methods and means of the plan/proposal, the hoped-for benefits, any risks, harms, costs and burdens, the likely personal effects, any alternatives, and what could happen if the proposal is rejected?

Although there may be structural pressures, such as illness, disability, poverty or lack of effective treatment, a voluntary decision means being free from personal

pressures: no 'element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion'.<sup>4</sup> Does the person 'have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision'? Does the person understand the right to consent or to refuse or withdraw?

A 1977 US report set new standards of informed parental consent and children's assent to research,<sup>6</sup> followed in 1986 by a UK report.<sup>7</sup> Previously, researchers had been held to little account and, until 1992, British guidelines allowed doctors to conduct covert research without informing their patients if they believed the research would be 'therapeutic'.<sup>8</sup>

New respect for informed consent to research developed through the 1980s through several channels: public demand for protection from the dangers of unregulated, exploitative and dangerous research; doctors', hospitals' and their lawyers' growing anxiety about costly litigation over harmful research; the new profession of bioethics, and the spread of research ethics committees and institutional review boards. Informed consent to research was increasingly seen as the device that transfers legal and financial liability for risks and harms from researchers onto the informed, willingly consenting research subjects, or their parents. Consent to medical treatment by patients or parents was gradually promoted for similar reasons.<sup>9</sup>

Meanwhile the US psychologist Carol Gilligan,<sup>10</sup> a research assistant to Lawrence Kohlberg, blew apart his theory of moral development: the slow age-related ascent through six stages with hardly anyone, especially hardly any women in the sexist tradition of Kant's Rational Man, attaining stage six. Gilligan showed, for example, that 10-year-old Amy's competent moral reasoning was different from Kohlberg's model, but was not inferior; it was wise, subtle and socially informed.

European social researchers of childhood were also rethinking Piagetian biology-related developmental stages. They moved out of the labs and into everyday life, to show how children are rational agents with views and experiences that are worth researching in their own right. Children gain competence and maturity through (often adverse) experiences in their highly diverse childhoods around the world, and they frequently disprove generalisations that tie ability to age.<sup>11</sup>

Another step towards children's emancipation was the *Gillick* case. In the mid-1980s, Mrs Gillick sued her English local health authority. The Roman Catholic mother of ten children wanted to ensure that her daughters could not access contraceptive advice or treatment without her knowledge or consent. The current law stated that competent minors (those without obvious mental health or learning difficulties) aged over 16 could give independent consent to proposed clinical treatment, though refusal was not mentioned, but the law was not clear about the rights of minors aged under-16 years.<sup>12</sup>

The eventual *Gillick* ruling was that minors aged under-16 have the legal right to consent provided they are competent to do so.<sup>13</sup> Lord Scarman defined a competent child as one who 'achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed' and 'has sufficient discretion to enable him or her to make a wise choice in his or her own best interests'.<sup>14</sup> Scarman ruled that 'as a matter of law the parental right to determine whether or not their minor children below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to understand fully what was proposed'.<sup>14</sup> He echoed Lord Denning's ruling in 1970 on the 'dwindling' parental right, which 'starts with a right of control and ends with little more than

advice'.<sup>15</sup> Mrs Gillick lent her name to a policy with which she disagreed, but the notion of 'Gillick competent' minors became widely respected.<sup>16 17</sup> *Gillick* concerns minors aged under-16, but may be mistakenly assumed to apply only to minors aged over 16, such as by the US bioethicist Weisleder.<sup>18</sup> The UK *Children Acts* also have influence around the Commonwealth. The 1989 *Children Act* repeatedly emphasises that authorities should have regard to 'a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding); (b) his physical, emotional and educational needs; c) the likely effect on him of any change in his circumstances'.<sup>19</sup> Although not specifically about medical treatment, the Act is taken to be generally applicable.

Far more globally influential is the 1989 *United Nations Convention on the Rights of the Child*.<sup>20</sup> The UNCRC has been ratified by every country except the US, meaning that governments undertake to implement the UNCRC, and to report regularly to the UN Committee on their progress in doing so.<sup>21</sup> The 42 main Articles enshrine children's right to protections, their access to services and amenities, and the key human rights to freedom of information and expression, thought and conscience. All these rights are said to be indivisible, complementing and reinforcing one another. Article 3 on the child's best interests and Article 12 on the child's views inform all the other Articles, although too often commentators illogically assume that children's own views of their best interests will inevitably be misguided, and conflict with adults' wiser views.

UNCRC supports three levels of healthcare decision-making. 1) Article 13 assures 'the freedom to seek, receive and impart information and ideas of all kinds'. 2) Article 12 requires that 'States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child' and 3) 'the views of the child being given due weight in accordance with the age and maturity of the child'. 'For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative...' and this includes healthcare decisions. *Gillick* adds a fourth level, the right of the child to be a co-decider or the main decider on whether to give consent or refusal.<sup>22</sup>

The question remained, at what age can children become first competent and second willing to give informed and voluntary consent? During 1989-1991, I asked 120 children aged 8- to 15-years before and after they had major orthopaedic surgery, their parents and 70 clinical staff, when each of them believed that the specific child (or for some professionals the youngest child they could recall) could give informed consent or refusal as competently as the parents could do.<sup>2</sup> On average, the children had already had more than four operations, sometimes the treatment had failed; 58 of them had two or more chronic disorders/disabilities, and eight had diagnosed learning difficulties. Most were very experienced and knowledgeable.

Children's replies ranged from an 8-year old with achondroplasia firmly deciding she would have agonising leg lengthening surgery, a decision she repeated at 15, while another girl with short stature equally firmly was against treatment and spoke of her equality and non-discrimination rights to be accepted and respected for herself. Some children aged up to 15 wanted others to decide for them. The mother and surgeon of a 12-year old with a mental age of around 6-years believed it was so vital to proceed with her cooperation and not attempt to enforce surgery that they spent a whole year gently persuading her to undergo three surgical corrections to her curved spine, which she

then endured bravely with her mother's support. Repeatedly, examples showed the vital need to inform and involve children as much as they wanted.

Views on the age of competence ranged from 21 to 3-years. One psychologist described an 'exceptional, brilliant' 3-year old with haemophilia. 'He explained the nature of his illness and how he could do his injections himself and what they meant and why he was doing it. He trotted it all out,' and answered detailed testing questions. Many children who experience serious illness are unusually mature. Our research with children with diabetes aged 3- to 12-years found remarkable insight and courage.<sup>1</sup> Children have unique, direct, embodied knowledge of their own case, which complements general professional knowledge, as a senior nurse in a heart-lung transplant unit described.

Children who have a chronic illness have an above average awareness of illness and what it means. A little girl of five who was dying of cystic fibrosis certainly knew 100% that she had a lung disease, exactly why she was in hospital, that her lungs could no longer function and what a lung transplant from a child who had died would involve, as well as what her own death would mean...[T]otal separation from her parents. She knew that no one could tell her where she went to, but she never came back. Her hopes were that her parents would someday join her... [These children] have an understanding greater than mine.<sup>23</sup>

If a child aged from around 7-years refused the offer of a heart-lung transplant, the unit policy was that the child would be on a waiting with time to think and possibly to change the decision, but a transplant could not be forced on an unformed, unwilling child. The sister described a girl of 7 who died unexpectedly after her transplant, which she has been unwilling to undergo.

Our qualitative research does not aim to generalise about ages of competence but to challenge generalisations that exclude young children. Only a few cases are needed to refute the fiction that children aged under-12 or -10 or -6 years can never give informed consent. Competence is not age or ability related, but depends on each child's experience and confidence, on the child-parents relationships and values, and whether or not they are used to sharing knowledge, risk-taking and control over decisions. Children therefore benefit when, instead of assuming incompetence, doctors start from a presumption of competence and work out with each child how willing and able they are to be informed and involved in decisions about their healthcare.<sup>22</sup>

## **The 'backlash'**

From 1985, respect for children's decisions seemed to rise, but then later to fall. This section considers possible reasons for the general lack of confidence in children's competence today. The reasons are not given in any order of predominance; some interact with others and reinforce them, contributing to a general climate of mistrust in children.

Part of the so-called legal backlash against *Gillick* was associated with two English court cases.<sup>23</sup> One problem they raised was on the cause of incompetence: the young women's questionable mental health might mistakenly be confused with the quite different immaturity of youth. Lord Donaldson was not convinced the girls were competent and he is often thought to have denied *Gillick* rights. However, although he decided that, if a minor aged under-18-years refuses, the parents can give

overriding consent, he also allowed that if the parents refuse, the child's consent can authorise treatment. His concern was with the key of consent turned by any one person to allow doctors to proceed.<sup>24</sup>

Countless social changes over the past three decades have undermined trust in children's independence.<sup>25</sup> These include: far more movement of families within and between countries and into cities, so that children tend to live among strangers and are much less free to roam on their own and with friends around trusted neighbourhoods; anxiety about road traffic casualties, crime, drugs, guns, the internet, grooming, trafficking, terrorism, and numerous other threats to children's safety; greater confinement of children at every age into care and education centres closely controlled by adults with 'zero-tolerance' discipline; extended years of fulltime school and post-school education, when young people are seen as expensive dependents instead of valued contributors; anxieties that children must adhere to adult-organised agendas that fill most of their days if they are ever to succeed as adults themselves.

Within dominant assumptions that childhood can no longer largely be entrusted to children, to enjoy as they please with plenty of free playtime and exploring, but instead must be colonised by adults, respect for children's decision-making is one casualty among many. The moral climate then favours further adult dominance. Instead of developing the positive child-respecting 1980s policies of UNCRC and *Gillick*, there is a strong negative influence from the US. The US is the single country that has not ratified UNCRC, and it has terrible records on child morbidity and mortality, poverty, and child prisoners.<sup>26</sup> It might be seen as the least suitable influence on international policy about children's rights and consent, especially as US authors include those most hostile to children's rights.<sup>27</sup>

One US concept is the 'intimate family'. True intimacy is more than physical proximity, which can be cruelly enforced. Emotional, moral intimacy exists when relative equals freely and trustingly share information and control. However, concern to preserve the seemingly fragile 'intimate family' involves the exact opposite of intimacy, by licensing parents to have complete control over their children, to deny them information and override the wishes even of their sick children.<sup>28</sup> Such tyranny can generate distress and anger that destroy intimacy. The static notion of fixed parental authority in the 'intimate family' also ignores ordinary changing family life when parents continually help children to gain new skills and independence and fulfil their potential.

Another US concept is 'assent',<sup>6</sup> which raises many problems detailed elsewhere.<sup>29</sup> Assent has neither the long history nor the definite meaning and detailed standards of consent.<sup>4, 5</sup> Assent does not even require that the child be informed at all. It is uncertain whether assent means expressing agreement, or not expressing active refusal, which children may be too uninformed, afraid, shy or embarrassed to express. Pharmaceutical commercial research interests<sup>30</sup> promote US-led international law on research<sup>31</sup> and favour assent as a means of streamlining and speeding up the parental consent process (as if there is no need to spend time informing children) and of clarifying legal liability (only adults sign the form). This law allows adults merely to 'consider' but then override children's views and wishes, and it assumes, implausibly, that parents always know and support their child's 'presumed will'. Those views have been criticised for raising confusing inconsistencies with *Gillick*, and for being unrealistic and disrespectful to minors.<sup>32</sup>

A third US concept, the 'mature minor',<sup>33</sup> refers to teenagers who are living apart from their parents or who refuse to involve their parents when they need help with

sexual, alcohol, drug or mental health problems. Ages range from 12-years in Arizona to 21-years in Mississippi.<sup>34</sup> The 'mature minor' legitimates professionals providing treatment when it is too complicated to involve the parents. However, the term does not include or respect the views of the (possibly more mature and law-abiding) majority: the young people who want to share decision-making with their parents. US law treats them all as immature, and assumes that whenever parents are involved they will always be the consent-givers. Scarman's ruling on *Gillick* competence respects all minors, accompanied by their parents and in accord with them or not, deviant or law-abiding. Yet In Britain, child protection agencies<sup>35</sup> promote the narrower ruling by Lord Fraser in *Gillick*, which like the US 'mature minors' concept can bypass parents. The Fraser ruling has the advantage that bereft minors can still receive medical treatment, but has the disadvantage that they are vulnerable to professionals' and researchers' agendas, and lack their own adult advocates and defenders.<sup>36</sup> The next section reviews ideas, which could only be accepted and published if the above history of reasons for the vital need to respect consent and children had been forgotten.

### **Zone of parental discretion (ZPD)**

Lynn Gillam's concept of the ZPD<sup>37</sup> has compassionate aims: to offer a clearer way to avoid or resolve prolonged disputes between doctors and parents; to allow more scope for parents' discretion; to respect their moral weight and family harmony. Described as 'an ethical tool that aims to balance children's wellbeing and parents' rights to make medical decisions for their children', ZPD proposes that 'parents are not ethically required to choose [in] the child's best interests'. They may make 'suboptimal' choices that could favour the parents' personal values or the interests of the whole family, as long as these do not harm the child. If decisions might be harmful, then ZPD ends and clinicians may intervene by refusing to provide requested treatment they see as unnecessary, or by trying to enforce treatment they deem clinically necessary, when they may refer families to the child protection services or the law courts.

Instead of serving the child's best interests test, which is said to be vague and 'only a "score" of 100% on advancement of interests is acceptable', ZPD accepts a lower standard: avoiding harm, although 'harm' is based on Feinberg's concept of a 'serious set-back of interests'.<sup>38</sup> So it is not clear how the ZPD approach, which conceals the best interests at the heart of paediatric dilemmas, can bring greater clarity.

ZPD has been discussed by 17 specialists working in paediatrics and/or clinical ethics, mainly in Australia or New Zealand.<sup>39</sup> They reviewed 26 'hard cases' in examples of children aged from birth to 17 years. After a decade of providing clinical ethics support, the book's editors wanted to establish theoretical foundations and consistent, systematic general guidance to assist others around the world who work and teach in ethics and paediatrics.

Three concentric circles<sup>40</sup> show the 'child's best interests', surrounded by ZPD, with the outmost zone being 'possible harm to the child' when clinicians might override parents' views. This concentricity implies consensus, a single central perspective, yet these three areas involve numerous sometimes conflicting views of parents, clinicians, other experts and children. A Venn diagram of partly overlapping circles, indicating separate perspectives, would be more realistic. Children's interests, for example, are not wholly within the authority of parents and clinicians but also have

independent reality, such as in the child's real but perhaps unrecognised suffering and need, and distinct interests also exist within children's own views and values.

If ZPD could offer an easier solution, it seems strange that this has not been discovered already. The English government prefers 'scope of parental responsibility' to 'zone of parental control' as less confusing to all concerned, as 'complementing language about decision-making and parental responsibility and [as] less legalistic in its tone'. This English preference underlies perhaps the most recent, detailed, respectful (though under-promoted) legal analysis in the world of children's healthcare right to consent and it explicitly relates children's consent to the 1998 *Human Rights Act*.<sup>41</sup>

Although Gillam acknowledges that ZPD does not escape the usual dilemmas of balancing risks, harms and burdens against hoped-for benefits to the child, or the need for personal interpretations and judgments about uncertainties and probabilities, no evidence is given that ZPD is a superior method of decision-making with better short- or long-term outcomes for families.

Adults agonise over dilemmas about sick and disabled children in claimed or agreed need of major treatment because the risks of accepting or refusing treatment entail danger, pain and uncertainty. Informed consent involves understanding the risks of unwanted effects and partial or whole failure of the treatment. My research with parents deciding whether to consent to heart surgery for their child saw them grappling with complex uncertainties. Rather than having a clear, safe, wanted choice, they felt forced to make the dreaded but seemingly 'least harmful' choice between either life-threatening surgery or, occasionally, acceptance that it was best to 'allow' their child to die.<sup>42</sup> The ZPD idea that parents' choices may be 'sub-optimal' falsely suggests that there is always an 'optimal' choice. And the previously mentioned idea that the 'best interests' test accepts 'only a "score" of 100% on advancement of interests' denies the hard reality that only relative partial benefits may be possible for many children with severe illness or disability.

The clinical ethics advisory service is said to be for clinicians. Direct contact by ethicists with parents and children (or with nurses who have vital insights) is not mentioned. Yet if they rely solely on doctors' accounts of families' wishes, how can the ethicists fully understand how wishes emerge from families' complex experiences and values? And how can advisers then avoid biased judgements that share clinical perspectives instead of critically questioning them, and that weight decision-making still further towards the already more powerful clinicians?

ZPD is most surprising in its silence on children's views, rights and wishes. The 'magnitude and probability of the effects on the child' and the 'significance' of harms and of the child's interests appear to be estimated solely through the adults' reports or through generalised assumptions about some imaginary standard child. The earlier example of the girls' views about their short stature is one among countless examples of how benefits and harms have to be understood, not only in how they are estimated by the child experiencing them, but in how they also partly originate from each unique child's physical-psychological-social being.

ZPD illustrates the above-mentioned international movement away from respect for children. Philosophical and legal traditions regard people as having the status either of persons or of property, and ZPD frames children as property for adults to dispose of as they see fit. US concepts of assent, mature minors and the intimate family are cited approvingly, and all minors are seen as immature and non-competent. The ratified UNCRC and the *Gillick*-informed Commonwealth law are very important in



the authors' countries,<sup>43</sup> but *Gillick* is not mentioned, and the sole reference to the UNCRC says that it 'focuses on children's wellbeing'<sup>44</sup> whereas the UNCRC's focus is, of course, children's rights.

In ZPD, parents' rights are repeatedly contrasted with children's welfare, and are seen as autonomous and extending beyond the duty to serve the child's best interests. However, rights exist primarily to prevent individuals having undue power over others, and to enable each person to follow and shape his or her own life and deepest desires as far as they are willing and able to do so, while respecting everyone else's equal right to do so. Individuals may desire, for example, to dedicate their life altruistically to others, but rights involve their choosing to do so, not being forced. Children's healthcare decisions can especially relate to their present and future identity and deepest desires and rights. Outside legal contracts (in theory freely agreed between equals), the single exception in modern law and philosophy to the veto on rights over law-abiding others is parents' rights, and these have only limited, provisional power. As Denning and Scarman said, the right dwindles as the child matures, and it is held only in so far as it serves the child's interests. One child's interests may or may not align with the parents' and siblings' interests, when parents face difficult choices, but the criterion for exercising parental rights is still to support the interests of the children. Children and adults are fallible and make unwise decisions, so that parents have to guard against their child's and their own misjudgements.

The 17 ZPD authors selected adult-centric references and avoided the large literature on children's healthcare rights, even quoting work on cosmetic surgery<sup>45</sup> and genetic testing<sup>46</sup> but ignoring the parts of that work devoted to the great importance of involving children in decisions. The Australian *Children and Young People's Rights in Healthcare Services Charter*<sup>47</sup> is mentioned solely for sections on best interests, protection and the right to healthcare. As the author of the original English *Charter*<sup>48</sup> from which it was developed, I question the authors' silence on the children's rights in the *Charter's* self-evaluation tool to be informed and involved in decisions, besides their right to privacy, and to a 'dignified death'.

Although the ZPD case studies aim to be rich and detailed and to bring to life the examples, they are one-sided when children's views are missing. That is reasonable in cases of babies and very young children but not in deeply personal decisions, such as the distress of a 13-year-old with life-limiting cancer about painful physiotherapy, or the 14-year-old girl with metastatic cancer who might endure another round of chemotherapy with little hope of success, or even a seemingly minor decision on whether an 8-year-old teased about her prominent ears should have cosmetic surgery. Perhaps the strangest example of avoiding a child's views is the 15-year-old whose mother requested cosmetic genital surgery, labioplasty. This is one of the few examples when an author discusses the limitations of ZPD, but there is nothing in the book on: respecting young patients' rights; actually informing, consulting and involving them in decision-making; avoiding the very serious harms of coercion, either through enforcing unwanted treatment, or denying them treatment they believe they need, without very careful detailed discussions and negotiations with them. Yet as shown earlier, these have been basic standards in ethical healthcare for decades.

## **Conclusion**

To inform and involve children in healthcare decision-making as far as they want and need is vital: legally and clinically, to observe high professional standards;

therapeutically, to promote effective care by encouraging children's comments and questions, their willing informed cooperation with treatment and their trust in its efficacy; ethically, to respect patients as persons and to avoid the coercion of fearful, uninformed, resisting children; psychologically, to prepare and support children, especially in the event that treatment is not wholly successful, when prior warning of risks can be vital in helping them to adjust and cope.

Many children need and want to be involved as much as many adults do, though there is a difference between giving informed, willing consent to treatment and signing the consent form, which not all the consenting children I interviewed wished to do. Anglo-American individualist law, ethics and medical routines tend to concentrate on the individual who signs the form. However, respect and support are needed for both child and parent in their shared negotiated decision making, such as when they journey towards the vital acceptance of high-risk treatment as less harmful than the untreated disease. To some extent, the child has to understand this logic, if treatment is not to be misunderstood as arbitrary cruelty or punishment.

Present confusions about minors' consent increase stress and uncertainties for all concerned, and they urgently need to be resolved by learning from the debates over past decades and by a renewed 'comprehensive review of legal policy and practice in this area'.<sup>49</sup> The review could consider first, why children's healthcare rights are being discredited and misunderstood; second, how they are central to children's healthcare and wellbeing; and third, how they can be promoted in all child healthcare policies and practices.

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