

# Fostering Inclusivity for Children with Intellectual Disabilities through Data Protection by Design

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## Abstract

Children with intellectual disabilities have consistently occupied a marginalised position within the digital landscape. While they might reap benefits from using digital products and services, they are also particularly vulnerable to online risks due to cognitive deficiencies and lower critical literacy skills. As a result, children with intellectual impairments frequently encounter various predicaments, encompassing online sexual solicitation, exposure to inaccurate information and manipulative behavioural designs, as well as various privacy and data protection concerns. Regarding these challenges, utilising data protection by design under Article 25(1) GDPR can play a pivotal role in dismantling certain barriers. This approach allows digital service providers to take children's evolving capacities into account and implement technical and organisational measures appropriate for their age and developmental stage. The aim of this article is to explore what challenges children with intellectual disabilities might confront in the digital environment and examine how data protection by design can help prevent or mitigate these challenges. Specifically, the article proposes a series of potential measures as the following: (1) presenting information transparently and in a manner accessible to children with intellectual disabilities; (2) crafting an inclusive user interface that enables these

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children to actively and autonomously engage with the digital environment; (3) integrating interactive assistive tools, such as AI bots, to offer guidance and support; and (4) introducing parental control mechanisms that allow parents to provide assistance in alignment with their children's needs and preferences.

**Keywords:** data protection by design, GDPR, children's rights, intellectual disabilities, evolving capacities, age-appropriate design

## 1. Introduction

Nowadays, digital technologies play a vital role in children and young people's lives. It is estimated that globally one in three Internet users is underage, and they are increasingly reliant on digital devices and services.<sup>1</sup> These technologies enable children to seek knowledge, develop social relationships, engage in educational activities, and explore novel forms of play. However, potential threats to children's rights and welfare have also arisen, such as exposure to inappropriate online content, violation of privacy, and cyberbullying. Among underage users of digital technologies, findings indicate that children with disabilities are particularly vulnerable compared to their peers, especially those with intellectual impairments.<sup>2</sup>

Intellectual disabilities are usually identified during childhood and tend to have long-lasting impacts on an individual's development. Children with such impairments might have problems processing new or complex information, comprehending abstract concepts, and coping independently under different circumstances.<sup>3</sup> These cognitive deficiencies can lead to even greater struggles when online, such as understanding the implications and purposes of data processing,<sup>4</sup> engaging in virtual activities, and interacting with others in cyberspace. Furthermore, those with intellectual disabilities have constantly been a marginalised group in the digital environment. Since the conditions constituting intellectual disabilities are more complicated than other disability groups, digital service providers often struggle to

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<sup>1</sup> UNICEF, Growing Up in a Connected World: Understanding Children's Risks and Opportunities in a Digital Age, November 2019, <<https://www.unicef-irc.org/growing-up-connected#sectionDownload>> accessed 31 August 2023.

<sup>2</sup> Council of Europe, Two Clicks Forward and One Click Back: Report on children with disabilities in the digital environment (2021) <<https://rm.coe.int/two-clicks-forward-and-one-click-back-report-on-children-with-disabili/168098bd0f>> accessed 31 August 2023.

<sup>3</sup> Australian Disability Clearinghouse on Education and Training (ADCET), Intellectual Disability <<https://www.adcet.edu.au/inclusive-teaching/specific-disabilities/intellectual-disability>> accessed 31 August 2023.

<sup>4</sup> Leanne McRae & others, 'Privacy and the Ethics of Disability Research: Changing Perceptions of Privacy and Smartphone Use' in Hunsinger & others (eds), *Second International Handbook of Internet Research* (Springer, 2020) 423–425.

sufficiently tailor their products and services to those special needs.<sup>5</sup> Such a situation not only disproportionately undermines intellectually impaired children's opportunities to access and enjoy the benefits of digital technologies but also poses severe threats to their rights under the United Nations Convention on the Rights of the Child 1989 (UN CRC)<sup>6</sup> in various aspects.

The UN CRC has recognised challenges for children with (intellectual) disabilities in its General comment No. 25 on children's rights in relation to the digital environment (CRC GC25). The Committee stresses the importance of implementing technological measures in fulfilling the needs of children with functional difficulties and ensuring the accessibility and inclusiveness of digital products and services.<sup>7</sup> Additionally, the UN Convention on the Rights of People with Disabilities (UN CRPD), which addresses accessibility and inclusive designs to persons with disabilities, on an equal basis with others, also applies to digital products and services.<sup>8</sup> Article 9(1)(b) UN CRPD specifically stipulates that measures of identifying and eliminating obstacles and barriers to accessibility should apply to information communications services, aiming to empower people with disabilities to equally participate in life autonomously.<sup>9</sup> Furthermore, Article 7 UN CRPD provides that children with disabilities should enjoy the protection of rights on an equal basis with other children, referring also to the best interest of the child and the right of the child to be heard,<sup>10</sup> both of which are

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<sup>5</sup> Helen Kennedy, Simon Evans & Siobhan Thomas, 'Can the Web Be Made Accessible for People with Intellectual Disabilities?' (2011) 27 *The Information Society* 29, 29–30.

<sup>6</sup> UN Convention on the Rights of the Child, adopted on 20 November 1989 by General Assembly resolution 44/25, entry into force: 2 September 1990, in accordance with Article 49, available at <<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>> accessed 31 August 2023.

<sup>7</sup> United Nations Committee on the Rights of the Child, General Comment No. 25 (2021) on children's rights in relation to the digital environment [CRC/C/GC/25] (2 March 2021), para 11.

<sup>8</sup> UN Convention on the Rights of Persons with Disabilities, adopted on 13 December 2006 at Sixty-first session of the General Assembly by resolution A/RES/61/106, entry into force: 3 May 2008, in accordance with Article 45(1), available at <<https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>> accessed 31 August 2023.

<sup>9</sup> See Article 9(1)(b) UN CRPD: 'To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to *information and communications, including information and communications technologies and systems*, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia: ...b) *information, communications and other services, including electronic services and emergency services.*' (Emphasis added by the authors).

<sup>10</sup> Article 7 UN CRPD reads as follows: '(1.) States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. (2) In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. (3) States Parties shall ensure that children with disabilities have the right to express their views freely on all

fundamental principles underlying the UN CRC.<sup>11</sup> Hence, state parties should pay special attention to the needs of children with disabilities and provide age-appropriate assistance in realising their rights both offline and online, thus facilitating them to achieve individual development and social integration with dignity and self-reliance.<sup>12</sup>

To enhance the inclusivity and accessibility of digital products and services, it is important to understand that the environments where children play, learn, and socialise can create real barriers, hindering their participation in recreation, education, social interaction, and information access.<sup>13</sup> This applies not only to physical spaces but also to the digital realms facilitated by digital technologies. In this regard, experts from relevant fields have consistently emphasised the value of the 'data protection by design' principle, as outlined in Article 25(1) of the General Data Protection Regulation (GDPR) in the European Union (EU), as a potent tool to advance children's rights in the digital domain.<sup>14</sup> Although it might appear as a broad provision, the requirement of implementing data protection by design not only offers the opportunity to ensure a robust level of data protection but also facilitates children's rights.<sup>15</sup> For children with intellectual disabilities, utilising data protection by design is particularly crucial in addressing their unique needs and surmounting the aforementioned challenges.<sup>16</sup>

The central question being addressed herein is how data protection by design can help in overcoming or at least mitigating some of the challenges in the digital environment for children with intellectual disabilities. The structure of this article is as follows. In section 2, after a brief characterisation of intellectual disabilities, the challenges that children with intellectual disabilities might face when using digital technologies are discussed. Section 3 then sets out what data protection by design

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matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.'

<sup>11</sup> See respectively Articles 3 and 12, UN CRC.

<sup>12</sup> In line with children's right to personal development (Article 6 UN CRC) and to rights of children with disabilities to 'enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community' (Article 23 UN CRC).

<sup>13</sup> Garrison Lansdown, 'The Evolving Capacities of the Child' (2005) <<https://www.unicef-irc.org/publications/384-the-evolving-capacities-of-the-child.html>> accessed 31 August 2023.

<sup>14</sup> Simone van der Hof & Eva Lievens, 'The importance of privacy by design and data protection impact assessments in strengthening protection of children's personal data under the GDPR' (2018) 23 *Communications Law* 33, 35-38.

<sup>15</sup> Van der Hof & Eva Lievens (n 14) 33.

<sup>16</sup> Data protection by design strategies that are effective in tackling online barriers to children with intellectual disabilities include the following: enhancing information transparency and accessibility, providing specially designed interfaces, and providing suitable parental control tools. These measures will be further elaborated in section 4.

means and why it can contribute to ensuring inclusivity and accessibility of digital services. In section 4, the article elaborates on the application of data protection by design that are particularly relevant to children with intellectual disabilities. The article concludes in section 5, which answers the central research question.

## **2. Challenges for Children with Intellectual Disabilities in the Use of Digital Technology**

### **2.1 A Characterisation of Intellectual Disabilities**

This article focuses the specific vulnerability of children<sup>17</sup> with intellectual disabilities as a group. Before delving into the challenges these children face, among others, the article will first give a brief characterisation of children with intellectual disabilities.

According to a UNICEF report from January 2022, approximately 240 million children worldwide have some form of disability, as in those who 'have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'<sup>18</sup> UNICEF posits that identifying and classifying disabilities in children is more complex than in adults, as children develop at varying rates, making it challenging to differentiate between developmental variations and actual disabilities. It is therefore relevant to consider the evolving capacities of children in a broader sense (see Article 5 UN CRC). Small children, for instance, do not have the same capacities as older ones. Making undifferentiated assumptions towards groups of children, such as children with intellectual or other disabilities, potentially encourages or perpetuates discrimination.<sup>19</sup> Hence, considering the capacities of a child based on not only their age but also their stage of development is indispensable in respecting their dignity and individual personality. The role of evolving capacities in relation to the designs of digital products and services will be further elaborated in section 3.2.2.

Furthermore, more instruments are required to accurately assess disabilities among children across various domains during their childhood, including physical, psychosocial, sensory and cognitive functioning. Individual and environmental factors that might hinder children from gaining equal and effective participation in the society should also be considered.<sup>20</sup> In this regard, UNICEF has introduced the Child Functioning Module, focusing on the presence and extent of functional difficulties instead of body structure or conditions. For children aged two-to-four years old, the

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<sup>17</sup> Following Article 1 UN CRC, a 'child' is a person under 18 years of age.

<sup>18</sup> UNICEF, 'Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities' (2021) 152 <<https://data.unicef.org/resources/children-with-disabilities-report-2021/#>> accessed 31 August 2023.

<sup>19</sup> Lansdown (n 13).

<sup>20</sup> UNICEF (n 18) 10.

module classifies the functional difficulties into the following categories: seeing, hearing, mobility, fine motor (ability to pick up small objects), communication and comprehension, controlling behaviour, learning, and playing. Regarding those between five and 17 years old, 'fine motor' and 'playing' were replaced by several other categories including self-care, remembering, attention and concentrating, relationships, coping with change, anxiety and depression.<sup>21</sup>

This article specifically focuses on children with intellectual disabilities, whose cognitive and social functioning has been impaired to varying degrees since childhood, with lasting effects on their future development. Their abilities in understanding new or complicated information, learning new skills, and coping in everyday situations are often considerably reduced.<sup>22</sup> Due to these limitations, they are more likely to encounter challenges in more complex ways compared with their peers, encompassing areas such as accessing education, participating in social activities and enjoying leisure.<sup>23</sup> Social exclusion and bullying are the most common and disturbing realities.<sup>24</sup> In addition, sexual abuse and sexual exploitation present grave issues especially for those children that struggle to navigate everyday social situations.<sup>25</sup> Moreover, their rights are often compromised due to the absence of accessible age and development-appropriate equipment and services aligning with their needs, owing to insufficient understanding and awareness about their functional problems. As digital technologies become increasingly important in children's lives, similar problems arise concerning the suitability of digital products and services.

## 2.2 Specific Challenges in the Use of Digital Technologies

The digital environment is widely perceived to present heightened risks for children with intellectual disabilities.<sup>26</sup> Nevertheless, while there has been a growing amount of research exploring children's experiences online, those with disabilities are often excluded in the discussions of digital youth.<sup>27</sup> Hence, this article will proceed to

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<sup>21</sup> Ibid 12.

<sup>22</sup> World Health Organization Regional Office for Europe, Better health, better lives: children and young people with intellectual disabilities and their families 'The case for change: Background paper for the Conference' (2010) EUR/51298/17/5, 4.

<sup>23</sup> Meryl Alper & Gerard Goggin, 'Digital technology and rights in the lives of children with disabilities' (2017) 19 *New Media & Society* 726, 727.

<sup>24</sup> Donna Koller, Morgane Le Pouesard & Joanna Anneke Rummens, 'Defining Social Inclusion for Children with Disabilities: A Critical Literature Review' (2018) 32 *Children and Society* 1, 4.

<sup>25</sup> UNICEF, 'Children with disabilities: Every child has the right to live in an inclusive world' <<https://www.unicef.org/disabilities#how>> accessed 31 August 2023.

<sup>26</sup> Darren D. Chadwick, Sally Quinn & Chris Fullwood, 'Perceptions of the risks and benefits of Internet access and use by people with intellectual disabilities' (2017) 45 *British Journal of Learning Disabilities* 21, 25.

<sup>27</sup> Amy Jordan & Kate Prendella, 'The invisible children of media research' (2019) 13 *Journal of Children and Media* 235, 236.

analyse the digital risks and challenges specific to children with intellectual disabilities based on previous research work and empirical studies to gain a comprehensive understanding of the adverse circumstances they might encounter.

### 2.2.1 Online Sexual Solicitation

According to Article 34 UN CRC, children should be protected from all forms of sexual exploitation and sexual abuse. Such protection also touches upon the digital environment, especially since online child sexual exploitation and abuse have become increasingly common in this rapidly evolving technological era. Aligned with Article 23 UN CRC, particular attention should be directed towards safeguarding children with disabilities to ensure proper and adequate protection. This is particularly crucial as children and young people with intellectual disabilities might be more susceptible to online sexual solicitation<sup>28</sup> due to their limited cognitive ability and insufficient knowledge of sexuality, as well as the related legal aspects of consent and abuse.<sup>29</sup> In other words, limitations in their ability to assess the risks of online actions (such as sexting) and interpreting others' reactions (such as recognising exploitative conducts) undoubtedly increase their vulnerability to sexual solicitation.<sup>30</sup> In a recent study conducted by the Council of Europe specifically exploring disabled children's online experiences, children with intellectual disabilities reported that they have been exposed to distressing sexual content and behaviours and have trouble developing effective coping mechanisms.<sup>31</sup> What is worse, statistics show that compared with their peers, a higher percentage of children with intellectual disabilities suffer from anxieties and depressive symptoms,<sup>32</sup> largely stemming from interpersonal difficulties offline.<sup>33</sup> Consequently, it is common for them to turn to the Internet to relieve pressure and establish virtual relationships, exposing themselves to the risk of being groomed by predators who pretend to be their friends.<sup>34</sup> Such situations not only harm their mental well-being but also have serious impacts on their right to sexual development and exploration.

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<sup>28</sup> 'Online sexual solicitation' here refers to adults requesting youths to participate in sexual activities, talk about sex, or provide personal sexual information in the online environment. Kimberly J. Mitchell, David Finkelhor & Janis Wolak, 'Risk factors for and impact of online sexual solicitation of youth' (2001) 285 *The Journal of the American Medical Association* 3011, 3012.

<sup>29</sup> Claude L. Normand & François Sallafranque-St-Louis, 'Cybervictimization of Young People with an Intellectual or Developmental Disability: Risks Specific to Sexual Solicitation' (2015) 29 *Journal of Applied Research in Intellectual Disabilities* 99, 100 & 104.

<sup>30</sup> *Ibid* 104.

<sup>31</sup> Council of Europe (n 2).

<sup>32</sup> D. G. Whitney & others, 'Factors associated with depression and anxiety in children with intellectual disabilities' (2019) 63 *Journal of Intellectual Disability Research* 408, 413.

<sup>33</sup> *Ibid* 414-415; Normand & Sallafranque-St-Louis (n 29) 105.

<sup>34</sup> Normand & Sallafranque-St-Louis (n 29) 105-106.

### 2.2.2 Exposure to Misinformation and Disinformation

Article 17 UN CRC sets out state parties' obligations to ensure that children have access to information from diverse sources, especially those aimed at promoting their health and well-being. Among the various sources of information, the Internet has become one of the most crucial, facilitating the participation and inclusion of children with intellectual disabilities in the society.<sup>35</sup> Nonetheless, as highlighted in CRC GC25, children's exposure to misinformation and disinformation has become a pressing issue.<sup>36</sup> Fake news, computational propaganda, inauthentic behaviour, and hate speech are widespread over online networks in different forms and are highly accessible.<sup>37</sup> Studies revealed that with the rapid increase in Internet use among children and young people, the percentage of 14-to-24-year-olds reporting seeing misinformation and disinformation online at least once a week has risen by 50 per cent.<sup>38</sup> As children's cognitive capacities and critical literacy skills are still evolving, they are particularly vulnerable to such information and can suffer disturbing consequences, such as anxieties and unrealistic perceptions of the world.<sup>39</sup> For children with functional difficulties in learning and comprehension, differentiating between authentic and fabricated content is even more challenging due to their limited levels of media literacy skills. Research also indicates that children with intellectual disabilities are largely concerned about being deceived by false information.<sup>40</sup> While not identical, this concern mirrors the difficulty of distinguishing between genuine and misleading content, potentially leading to similar challenges in assessing information accuracy.

### 2.2.3 Trapped by Negative Behavioural Designs ('Dark Patterns')

Aside from misinformation and disinformation, negative behavioural design, also known as 'dark patterns', is yet another area of concern. It is recognised in CRC GC25

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<sup>35</sup> Esther Chiner, Marcos Gómez-Puerta & María Cristina Cardona-Moltó, 'Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers' (2017) 45 *British Journal of Learning Disabilities* 190, 191.

<sup>36</sup> CRC/C/GC/25 (n 6), para 54.

<sup>37</sup> Philip N. Howard & others, 'Digital misinformation/disinformation and children' (2021) 8–9 <<https://www.unicef.org/globalinsight/reports/digital-misinformation-disinformation-and-children>> accessed 31 August 2023.

<sup>38</sup> *Ibid* 13.

<sup>39</sup> National Literacy Trust, 'Fake News and Critical Literacy: The final report of the Commission on Fake News and the Teaching of Critical Literacy in Schools' (2018) 9 <[https://cdn.literacytrust.org.uk/media/documents/Fake\\_news\\_and\\_critical\\_literacy\\_-\\_final\\_report.pdf](https://cdn.literacytrust.org.uk/media/documents/Fake_news_and_critical_literacy_-_final_report.pdf)> accessed 25 January 2023.

<sup>40</sup> eSafety Commissioner, Online safety for young people with intellectual disability (2020) 16–17 <<https://www.esafety.gov.au/sites/default/files/2020-12/Online%20safety%20for%20young%20people%20with%20intellectual%20disability%20report.pdf>> accessed 31 August 2023.



that businesses tend to utilise advertising features that predict and guide children's behaviours towards potentially harmful content for commercial gains.<sup>41</sup> These designs intend to benefit online service providers by manipulating, steering, or deceiving users into making decisions that they would not have otherwise made if provided with sufficient and accurate information along with viable alternatives.<sup>42</sup> Adoption of such interface designs on digital platforms is becoming increasingly common.<sup>43</sup> In this context, children's right to protection from economic exploitation pursuant to Article 32 UN CRC is frequently compromised, as they will have difficulties making purchases of their own free will.

Although dark patterns can influence anyone in general, children and those with intellectual impairments are nevertheless more defenceless against these forms of manipulation.<sup>44</sup> Consequently, children could be subjected to various forms of exploitation, such as excessive screen time, unintended in-app purchases, and the unintentional sharing of personal data.<sup>45</sup> Gaming design serves as a prime example. Empirical studies showed that gaming companies tend to employ personalised advertising strategies and nudge underage users into overspending for game advancement.<sup>46</sup> Moreover, some games might frequently release timed events or intentionally have users engage in repetitive tasks to prolong their playtime and therefore boost profits.<sup>47</sup> Although a direct link cannot be definitely established, it is worth noting that as the gaming revenue model evolves and games with unlimited playtime become prevalent, problematic gaming behaviours have increased. That is, reports of obsessive gaming behaviour and even gaming addiction have become more common.<sup>48</sup>

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<sup>41</sup> CRC/C/GC/25 (n 6), para 40.

<sup>42</sup> Arunesh Mathur & others, 'Dark Patterns at Scale: Findings from a Crawl of 11K Shopping Websites' (2019) 3 *Proceedings of the ACM Human-Computer Interaction* 81:2 <<https://arxiv.org/abs/1907.07032>> accessed 31 August 2023.

<sup>43</sup> Deceptive Design, Hall of shame, <<https://www.deceptive.design/hall-of-shame/all>> accessed 31 August 2023.

<sup>44</sup> Simone van der Hof & others, "'Don't Gamble with Children's Rights'"—How Behavioral Design Impacts the Right of Children to a Playful and Healthy Game Environment' (2022) *Frontiers in Digital Health* <<https://www.frontiersin.org/articles/10.3389/fdgth.2022.822933/full>> accessed 31 August 2023.

<sup>45</sup> Ibid 7; eSafety Commissioner (n 40) 15–16.

<sup>46</sup> Simone van der Hof & others, 'The Child's Right to Protection against Economic Exploitation in the Digital World' (2020) 28 *The International Journal of Children's Rights* 833, 835.

<sup>47</sup> van der Hof & others (n 44) 2.

<sup>48</sup> Ibid.

## 2.2.4 Privacy and Data Protection Issues

As stated in the introduction, children's right to privacy and data protection is protected by the UN CRC. According to Article 16 UN CRC, no child shall be subjected to arbitrary or unlawful interference with his or her privacy. While it does not specifically mention the right to data protection, CRC GC25 indicates that such right is included in the implications of this provision.<sup>49</sup> However, children's right to privacy is constantly under threat. It has been observed in CRC GC25 that besides the use of digital services, children nowadays are increasingly connected via embedded sensors with automated systems, such as smart toys and fitness trackers.<sup>50</sup> Thus, the routine processing of their personal data for digital services, targeted advertising, and personalised content recommendations have become common practice. Continuous tracking of behaviour and subsequent use of those data<sup>51</sup> have given rise to violations of privacy and data protection rights.<sup>52</sup>

The risks to privacy and data protection are especially grave to children with intellectual disabilities. To begin with, the issue of oversharing private information online is a significant concern.<sup>53</sup> Research showed that the borderless nature of cyberspace and the importance of online privacy are not easily grasped concepts for those children.<sup>54</sup> Hence, they might unknowingly disclose excessive personal data,<sup>55</sup> leading to negative consequences such as contact from malicious individuals and becoming victims of online scams or abuse. Furthermore, heavy criticism has been

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<sup>49</sup> CRC/C/GC/25 (n 6), paras 70 & 74.

<sup>50</sup> CRC/C/GC/25 (n 6), para 74; Also see Esther Keymolen & Simone van der Hof, 'Can I still trust you, my dear doll? A philosophical and legal exploration of smart toys and trust' (2019) 4 *Journal of Cyber Policy* 143, 143–144.

<sup>51</sup> See the datafication of children's lives: Deborah Lupton & Ben Williamson, 'The datafied child: The dataveillance of children and implications for their rights' (2017) 19 *New Media & Society* 780–794; Giovanna Mascheroni & Andra Siibak, *Datafied Childhoods – Data Practices and Imaginaries in Children's Lives* (Peter Lang, 2021).

<sup>52</sup> Simone van der Hof, Eva Lievens & Ingrida Milkaitė, 'The protection of children's personal data in a data-driven world: A closer look at the GDPR from a children's rights perspective' in Ton Liefwaard & others (eds), *Monitoring Children's Rights in the Netherlands: 30 years of the UN Convention on the Rights of the Child* (Leiden University Press, 2019) 77–78.

<sup>53</sup> eSafety Commissioner, "'How bad should it be before I tell someone?'" Online abuse experiences of adult Australians with intellectual disability – implications for resource development' (2022) 22 <<https://www.esafety.gov.au/sites/default/files/2022-08/Adult%20Australians%20with%20Intellectual%20Disability%20-%20Online%20Abuse%20report.pdf>> accessed 31 August 2023.

<sup>54</sup> eSafety Commissioner (n 40) 17–18.

<sup>55</sup> Darren David Chadwick, 'Online Risk for People with Intellectual Disabilities' (2019) 24 *Tizard Learning Disability Review* 180, 182; Chadwick, Quinn & Fullwood (n 26) 25.

levelled at the length and unintelligibility of online privacy policies.<sup>56</sup> A certain level of knowledge and proficiency regarding the data economy is a prerequisite to providing meaningful consent.<sup>57</sup> Consequently, children with varying needs and ages often perceive such terms and conditions as non-transparent and beyond their comprehension.<sup>58</sup> For those with particular limitations in reading and comprehending (complex) information, it is even more challenging to understand such terms and to give meaningful and informed consent. Moreover, they might possess a limited awareness of the perils associated with online profiling, including marketing strategies that exploit vulnerabilities and foster discrimination. This is particularly worrisome given that this group is already more susceptible to discrimination and stigmatisation.<sup>59</sup>

In addition, children with disabilities are more likely to be subjected to extensive monitoring due to their physical or mental impairments, even if the intention is benevolent. While some children might find it reassuring to have adults know their whereabouts, others might find such monitoring intrusive and affecting their autonomy. Take wearable technology as an example. Utilising such gadgets can conveniently track locations, provide real-time assistance, and assure child safety.<sup>60</sup> In such cases, however, regulatory oversight and training on effective digital data management are limited. The extent to which children have freely given their consent or understand the potential privacy risks behind those technologies remains in question.<sup>61</sup> What is more, the privacy settings of such devices or applications often follow a 'take-it-or-leave-it' approach, compelling parents and children to accept corporate surveillance defaults for service usage.<sup>62</sup> Consequently, children with disabilities often lack autonomy in managing personal information, as adults may presume their incapability and may directly act on their behalf.<sup>63</sup>

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<sup>56</sup> Eva Lievens, 'Growing up with digital technologies: How the precautionary principle might contribute to addressing potential serious harm to children rights' (2021) 39 *Nordic Journal of Human Rights* 130.

<sup>57</sup> Simone van der Hof, 'I Agree, or Do I: A Rights-Based Analysis of the Law on Children's Consent in the Digital World' (2016) 34 *Wisconsin International Law Journal* 409, 441.

<sup>58</sup> 5Rights Foundation, *Our Rights in a Digital World: A Report on the Children's Consultations to inform, UNCRC General Comment 25 (2021) 46–47* <<https://5rightsfoundation.com/uploads/OurRightsinaDigitalWorld-FullReport.pdf>> accessed 31 August 2023.

<sup>59</sup> Nicole Ditchman & others, 'How Stigma Affects the Lives of People with Intellectual Disabilities: An Overview' in Katrina Scior & Shirli Werner (eds), *Intellectual Disability and Stigma: Stepping Out from the Margins* (Palgrave Macmillan, 2016) 31–47.

<sup>60</sup> Alper & Goggin (n 23) 734.

<sup>61</sup> Reuben Kirkham & Chris Greenhalgh, 'Social Access vs. Privacy in Wearable Computing: A Case Study of Autism' (2015) 14 *IEEE Pervasive Computing* 26, 28.

<sup>62</sup> van der Hof (n 57) 437.

<sup>63</sup> Stacey B. Steinberg, 'Sharenting: Children's Privacy in the Age of Social Media' (2017) 66 *Emory Law Journal* 839, 853.

### 3. Age- and Development-Appropriate Data Protection by Design

#### 3.1 The Concept of Data Protection by Design and its Relevance for Children

The principle of data protection by design is embedded in Article 25(1) GDPR. It requires data controllers, such as tech companies that process personal data in their digital products and services, to take appropriate technical and organisational measures. These measures should be employed both during the determination of means for processing and throughout the actual processing to enhance individuals' rights, including those of children. Various considerations should be considered during this process, including the state of the art,<sup>64</sup> the cost of implementation,<sup>65</sup> the nature, scope, context and purposes of processing,<sup>66</sup> potential risks,<sup>67</sup> and how such processing might impact the rights and freedoms of individuals. The technical and organisational data protection by design measures need to adhere to the principles stipulated by Article 5 GDPR, encompassing fairness, transparency, purpose limitation,<sup>68</sup> data minimisation, storage limitation, integrity, confidentiality and accountability. Codes of conduct established by industry bodies, certification schemes, and advice from data protection authorities can also provide further guidance regarding implementation.<sup>69</sup> Furthermore, as the provision emphasises that these measures should integrate necessary safeguards to protect the rights of data subjects, controllers must acknowledge what rights might be of concern when

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<sup>64</sup> See further: Marit Hansen, Jaap-Henk Hoepman & Meiko Jensen, 'Readiness Analysis for the Adoption and Evolution of Privacy Enhancing Technologies: Methodology, Pilot Assessment, and Continuity Plan' (2015) European Union Agency for Network and Information Security (ENISA); S. Rubinstein & Nathaniel Good, 'The trouble with Article 25 (and how to fix it): the future of data protection by design and default' (2020) 10 *International Data Privacy Law* 37, 42.

<sup>65</sup> See further: Lina Jasmontaite & others, 'Data Protection by Design and by Default: Framing Guiding Principles into Legal Obligations in the GDPR' (2018) 4 *European Data Protection Law Review* 168, 178; Mireille Hildebrandt & Laura Tielemans, 'Data protection by design and technology neutral law' (2013) 29 *Computer Law & Security Review* 509, 517.

<sup>66</sup> See further: Jasmontaite & others (n 65) 179; nature and scope of processing also include, e.g., whether there is automated profiling of users and sharing of personal data with third parties.

<sup>67</sup> Working Party 29 defines it as the 'potential negative impact on data subject rights, freedoms, and interests,' which should be assessed on the basis of the nature of personal data, the category of data subject, the number of data subjects affected, and the purpose of the processing; Article 29 Data Protection Working Party, 'Statement on the role of a risk-based approach in data protection legal frameworks' (2014) 14/EN WP 218, 4.

<sup>68</sup> Identifying purposes also serves as a prerequisite for determining appropriate safeguards during processing, including technical and organisational measures stipulated in Article 25(1), Jasmontaite & others (n 65) 179–180.

<sup>69</sup> Lee A. Bygrave, 'Data Protection by Design and by Default: Deciphering the EU's Legislative Requirements' (2017) 4 *Oslo Law Review* 105, 115.

conducting processing activities and adopt the suitable course of action accordingly.<sup>70</sup> In the case of children and, more specifically, those with intellectual disabilities, it is paramount that not only their data protection rights but also their best interests pursuant to Article 3 UN CRC are a primary consideration when designing digital services. All in all, the principle of data protection by design aims to ensure that privacy is at the core of digital services and empowers users to properly protect their personal data with understandable and accessible tools.<sup>71</sup> To achieve this goal, data protection by design must be part of the design and development of digital services throughout their lifecycle,<sup>72</sup> given that it is likely that privacy-related challenges or harms only arise in the use of a product or service, and specific groups of users might prove to be especially vulnerable.<sup>73</sup>

On the other hand, the risk-based approach<sup>74</sup> underlying Article 25 GDPR necessitates continuous attention to mitigate potential risks and establish safeguards, considering that the state-of-the-art measures to achieve data protection by design and prevent negative impacts on users' rights can change over time.<sup>75</sup> Those risks and safeguards might require specific attention in the case of vulnerable data subjects, such as children. The adoption of this principle is therefore crucial in providing additional safeguards for children in the digital environment.<sup>76</sup> That is, terms such as 'appropriate,' 'effective,' and 'necessary safeguards' in Article 25(1) can have different implications when it comes to addressing children's vulnerabilities regarding personal data processing. Incorporating children's best interests and fundamental rights, such as the right to be heard and the right to information, into technical and organisational measures can be particularly beneficial in mitigating risks and empowering underage data subjects.<sup>77</sup> In fact, a child-centred approach toward data protection by design is not unprecedented. In the European Commission's 2012 Impact Assessment report, it is emphasised that controllers should ensure that digital services provided to children are adapted to their expected capabilities from the very

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<sup>70</sup> Jasmontaite & others (n 65) 175.

<sup>71</sup> Article 29 Data Protection Working Party, 'The Future of Privacy: Joint contribution to the Consultation of the European Commission on the legal framework for the fundamental right to protection of personal data' (2009) 02356/09/EN WP 168, para 46–53.

<sup>72</sup> Bygrave (n 69) 106.

<sup>73</sup> Gianclaudio Malgieri and Gloria González Fuster, 'The vulnerable data subject: A gendered data subject?' (2022) 14 *European Journal of Law and Technology*.

<sup>74</sup> Under the recently adopted EU Digital Services Act (DSA), risk assessment and mitigation will be mandatory for very large online platforms and should specifically also focus on children (see Articles 28, 34 and 35 DSA). We will not elaborate on that in this contribution.

<sup>75</sup> Maria Eduarda Gonçalves, 'The risk-based approach under the new EU data protection regulation: a critical perspective' (2020) 23 *Journal of Risk Research* 139, 142.

<sup>76</sup> Eva Lievens & Valerie Verdoodt, 'Looking for needles in a haystack: Key issues affecting children's rights in the General Data Protection Regulation' (2018) 34 *Computer Law & Security Review* 269, 277–278.

<sup>77</sup> van der Hof, Lievens & Milkaite (n 52).

beginning. The Council of Europe also mentioned in its 'Guidelines to respect, protect and fulfil the rights of the child in the digital environment' that to better address risks in the virtual world, States should incentivise businesses to prioritise safety and privacy by design into their products and services targeting underage users.<sup>78</sup>

Child-friendly interfaces should, moreover, be extended to design functionalities in compliance with GDPR requirements. Age verification and, if legally necessary, parental consent mechanisms serve as prime examples. Data protection by design more generally entails that (excessive) data processing must be avoided to achieve effective verification, and the choice for verification methods must be based on the risks of different processing activities.<sup>79</sup> For low-risk situations, asking new users to the services to disclose their year of birth or solve puzzles that can estimate their age may be sufficient.<sup>80</sup> In cases with higher degree of risks, collaborating with trustworthy third parties to establish a decentralised verification process,<sup>81</sup> preferably based on open-source technologies, should be more feasible than collecting identity cards or even biometric data.<sup>82</sup> Applying a similar risk-based approach is also pertinent regarding parental consent mechanisms. While a double opt-in procedure in which children provide the email addresses of their parents or guardians for authorisation links may be of adequate safeguard in low-risk scenarios,<sup>83</sup> more

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<sup>78</sup> Council of Europe, 'Guidelines to respect, protect and fulfil the rights of the child in the digital environment' (2018) Recommendation CM/Rec (2018) 7 of the Committee of Ministers 20.

<sup>79</sup> European Data Protection Board, 'Guidelines 05/2020 on consent under Regulation 2016/679' (2020) 28 <[https://edpb.europa.eu/sites/default/files/files/file1/edpb\\_guidelines\\_202005\\_consent\\_en.pdf](https://edpb.europa.eu/sites/default/files/files/file1/edpb_guidelines_202005_consent_en.pdf)> accessed 31 August 2023.

<sup>80</sup> Simone van der Hof & Sanne Ouburg, 'We Take Your Word For It' — A Review of Methods of Age Verification and Parental Consent in Digital Services' (2022) 8 *European Data Protection Law Review* 61, 65.

<sup>81</sup> For instance, users may register accounts with OpenID identity providers of their choice. These accounts will then be used as the basis for accessing websites which accept OpenID authentication. In other words, controllers can verify the identity and acquire necessary information of users via the authentication performed by an authorisation server rather than operating their own personal data collection procedure. 'Welcome to OpenID Connect' <<https://openid.net/connect/>> accessed 31 August 2023.

<sup>82</sup> Victoria Nash & others, 'Effective Age Verification Techniques: Lessons to Be Learnt from the Online Gambling Industry' (2013) Oxford Internet Institute Research Project 27 <<https://srn.com/abstract=2658038>> accessed 31 August 2023.

<sup>83</sup> Sonja Kress & Daniel Nagel, 'The GDPR and Its Magic Spells Protecting Little Princes and Princesses. Special regulations for the protection of children within the GDPR' (2017) 18 *Computer Law Review International* 6, 9.

reliable proof would be required when high-risk data processing<sup>84</sup> is involved.<sup>85</sup> Outsourcing such a consent mechanism to trusted third parties as mentioned above is another solution to the challenging task of verifying whether the child's parent is consenting on behalf of the child.<sup>86</sup> However, studies have shown that adults are sometimes less aware of the complex interactions between technology and young people, as well as the positive impacts of the online environment on children's development.<sup>87</sup> Hence, relying solely on parental consent, devoid of adequate information and suitable design, might end up causing unjustified consent request rejections,<sup>88</sup> subsequently restricting children's access to information and effective participation online.<sup>89</sup> In this context, actively involving both children and parents in the design process and incorporating their inputs in the final consent mechanism becomes a crucial consideration.

Finally, data protection by design can effectively address the problem of profiling and automated decision-making concerning children. Children's personal data and online experiences are often exploited for commercial purposes, such as advertising on social media and gaming platforms, in-app purchases, and sponsored content by digital influencers.<sup>90</sup> Marketing as such will then lead to undesirable impacts on children's daily lives and development, including unconscious purchasing, excessive consumption of junk food, smoke and drug abuse, and various health disorders.<sup>91</sup> Consequently, it is recommended that controllers distinguish between child and adult users, as well as various age groups among underage users, to adjust profiling and automated decision-making functions. Moreover, the interface design should allow children to easily opt in and out of those functions.

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<sup>84</sup> For instance, processing activities involving behavioural advertising or enabling children to publicly post information. Milda Macenaite, 'From universal towards child-specific protection of the right to privacy online: Dilemmas in the EU General Data Protection Regulation' (2017) 19 *New Media & Society* 765, 772.

<sup>85</sup> van der Hof & Ouburg (n 80) 65.

<sup>86</sup> European Data Protection Board (n 79) 28.

<sup>87</sup> danah boyd, *It's Complicated: The Social Lives of Networked Teens* (Yale University Press, 2014) 79.

<sup>88</sup> Macenaite (n 84) 773.

<sup>89</sup> Simone van der Hof, 'No Child's Play: Online Data Protection for Children' in Simone van der Hof & others (eds), *Minding Minors Wandering the Web: Regulating Online Child Safety* (Asser Press, 2014) 140.

<sup>90</sup> Pedro Hartung, 'The children's rights-by-design standard for data use by tech companies' (2020); UNICEF Good Governance of Children's Data project Office of Global Insight and Policy Issue brief no. 5 <<https://www.unicef.org/globalinsight/media/1286/file/%20UNICEF-Global-Insight-DataGov-data-use-brief-2020.pdf>> accessed 31 August 2023.

<sup>91</sup> Hartung (n 90) 3.

## 3.2 The Importance of Designing Age and Development-Appropriate Data Protection for Children

### 3.2.1 From Age-Appropriate to Development-Appropriate Data Protection by Design

Data protection by design is closely related to age-appropriate design of digital products and services. ‘Age-appropriate design’ has been on the rise in recent years, a development driven in particular by the Age Appropriate Design Code (now called the Children’s Code) adopted by the UK Parliament in 2021.<sup>92</sup> Since then, similar initiatives have emerged in other countries<sup>93</sup> and, pursuant to the recently adopted Digital Services Act, the European Commission will develop an EU Code for age-appropriate design,<sup>94</sup> which is expected to be finished in 2024.<sup>95</sup> ‘Age-appropriate design’ starts from the notion that while digital services might not be developed specifically for children, they are often used by them, sometimes even on a significant scale. Therefore, the designs and development of digital services should already take children’s rights into account, encompassing both of those providing specific and often higher protection as well as those that ensure meaningful participation of children. To this end, not only must the negative impacts of digital services be monitored and mitigated, but their positive impacts on children must also be amplified.

Data protection by design, while not solely centred on the protection of children and their personal data, offers opportunities to uphold the high level of protection of

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<sup>92</sup> Information Commissioner’s Office, Children’s code: additional resources <<https://ico.org.uk/for-organisations/childrens-code-hub/>> accessed 31 August 2023.

<sup>93</sup> Swedish Guidance on Children’s Rights Online, 2020, <<https://www.imy.se/globalassets/dokument/ovrigt/barn-och-ungas-rattigheter-pa-digitala-plattformar.pdf>> accessed 31 August 2023; Irish Fundamentals for a Child Oriented Approach to Data Protection, 2020, <<https://www.dataprotection.ie/en/dpc-guidance/fundamentals-child-oriented-approach-data-processing>> accessed 31 August 2023; CNIL Recommendations for Protecting Children Online, 2021 <<https://www.cnil.fr/en/cnil-publishes-8-recommendations-enhance-protection-children-online>> accessed 31 August 2023; Dutch Code for Children’s Rights, 2021 <<https://codevoorkinderrechten.nl/>> accessed 31 August 2023; UK ICO Children’s Code Design Guidance, 2022, <<https://ico.org.uk/for-organisations/childrens-code-hub/childrens-code-design-guidance/>> accessed 31 August 2023. Furthermore, there is the still under development CEN-CENELEC Age Appropriate Digital Services Framework, <<https://www.cenelec.eu/news-and-events/news/2022/workshop/2022-03-28-digitalservices/>> accessed 31 August 2023.

<sup>94</sup> See Call for a Special group on the EU Code of conduct on age-appropriate design, <<https://digital-strategy.ec.europa.eu/en/policies/group-age-appropriate-design>> accessed 31 August 2023.

<sup>95</sup> Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, ‘A Digital Decade for children and youth: the new European strategy for a better internet for kids (BIK+)’ (2022) COM/2022/212 final <<https://digital-strategy.ec.europa.eu/en/policies/strategy-better-internet-kids>> accessed 31 August 2023.



personal data envisaged in Recital 38 GDPR.<sup>96</sup> It is important to note that the high level of protection required by Recital 38 GDPR concerns all children. Although the GDPR does not offer a specific definition for children, it can be inferred that children are data subjects under 18 years of age, which is in line with the definition of ‘child’ in the UN CRC.<sup>97</sup> In a single case – the age of digital consent – Article 8 GDPR prescribes a particular age, in principle 16 years but member states can opt for a different age as long as it is not below 13 years. However, it should be made clear that children are not a homogeneous group, meaning that different ages or developmental stages can result in vastly varied capabilities among children.<sup>98</sup> In this sense, the notion of ‘age-appropriate design’ does not necessarily consider the special needs of particular groups of children, as it does not explicitly consider the fact that children’s development can differ significantly regardless of their age. This is particularly, though not exclusively, relevant for the group of children with intellectual disabilities, who are the focus of this article. A glance at initiatives focusing on age-appropriate design shows that this group of children is not – or only to a very limited extent – named and included in the requirements for the design of digital services.<sup>99</sup> We therefore opt here for the broader concept of ‘development-appropriate design’. Given its relevance, the article will now focus on the significance of the concept of the evolving capacities of children pursuant to Article 5 UN CRC, as it plays a central role in shaping data protection approaches in developmentally appropriate ways.

### 3.2.2 The Relevance of the Evolving Capacities of Children

Development-appropriate design must be in line with the central UN CRC concept of ‘evolving capacities’ in Article 5 UN CRC, which provides:

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, *in a manner consistent with the evolving capacities of the child*, appropriate direction and guidance in the exercise by the child of the rights recognised in the present Convention. (emphasis by the authors).

The concept of ‘evolving capacities’ aims to balance protection due to the relative immaturity of children and young people with acknowledging their growing autonomy while they grow up. The concept is inextricably linked to Article 12 UN CRC – a central fundamental principle underlying the Convention – providing that:

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<sup>96</sup> See van der Hof & Lievens (n 14) 35; van der Hof, Lievens & Milkaite (n 52) 114-117; Macenaite (n 84) 770.

<sup>97</sup> Van der Hof, Lievens & Milkaite (n 52).

<sup>98</sup> Lansdown (n 13).

<sup>99</sup> See Codes and Standards (n 93).

State 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, the views of the child being given due weight *in accordance with the age and maturity of the child*. (emphasis by the authors)

Age is not mentioned as the determinative factor in the determination of evolving capacities, and the question of whether children have sufficient competences in a given context will thus depend on their individual development. This specifically leaves room for acknowledging children's intellectual development, which might vary between those with or without intellectual disabilities. Moreover, as we discussed earlier, the concept emphasises the emerging autonomy of children that must be recognised, potentially leading to a reduced parental responsibility over time and possibly established by setting a minimum age for legal capacity. Children can increasingly do more for themselves and must be empowered to make independent decisions. In other words, their evolving capacities must be respected.<sup>100</sup> Of course, it is relevant to consider that some children might experience slower development or remain below the level of development of their peers, meaning they could encounter problems processing new or complex information, comprehending abstract concepts, and coping independently under different circumstances. These children will continue to need guidance from others, such as their parents, when making decisions. Nevertheless, as we will elaborate in section 4, there are opportunities to support them via development-appropriate design in digital services.

'Evolving capacities' is a crucial concept regarding data protection by design for three reasons. Firstly, age – the usual standard for determining suitable design for children – is not always an appropriate benchmark for children with intellectual disabilities. In their case, age and the expected stage of development might not correspond accurately. While age verification technologies might be relevant for GDPR compliance, especially in the aforementioned context and application of Article 8 GDPR,<sup>101</sup> it is essential to note that age verification is not a solution for development-appropriate data protection by design. Clearly, the GDPR does not recognise in Article 8 that children who have reached the age of digital consent might lack the cognitive developmental capacity to provide informed consent. Contract law appears to offer greater flexibility in this respect: many legal systems stipulate that children lack the legal capacity to enter into contracts without parental permission. However, for non-risky contracts, this consent may be assumed if a child, usually a teenager, does have sufficient understanding of the situation to act independently. While age still plays a role, there is potential to consider children's developmental level, even though assessing capacities might be somewhat more feasible in face-to-face interactions than online situations.

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<sup>100</sup> Lansdown (n 13).

<sup>101</sup> See further on age verification and the GDPR, Van der Hof & Ouborg (n 80).

Secondly, the notion of evolving capacities calls for respect to the emerging autonomy of children, as well as the design of digital services that can support them in making independent decisions without running large(r) risks due to reduced intellectual capacities. As data protection by design provides several options and functionalities, it is preferable to set the default settings to the simplest level, where a (very) young age – and thus the stage of early development – is the measure of understandability and accessibility. This approach can be instructive not only for all children but especially also for those with intellectual disabilities. While users of a digital service could be given the option to customise settings, a large group of (minor and adult) data subjects will further benefit from a low-threshold accessibility of digital services. ‘Low-threshold accessibility’ in this context, among other things, means that data protection by design settings are tuned to the most privacy-preserving by default. The language used to indicate and explain the settings is straightforward and preferably provided with visual and auditory information.<sup>102</sup> Some useful measures include using age-specific languages for different age groups<sup>103</sup> and providing appropriate forms of assistance to those with varying needs.<sup>104</sup> It is also important to actively involve children, including those with intellectual disabilities, in the process of developing transparency mechanisms to understand their perceptions and expectations of the dynamics in the digital data economy.<sup>105</sup> More detailed approaches for designing inclusive data protection mechanisms will be provided in the next section.

Thirdly, the direct focus on children's evolving capacities highlights the need for parental support in determining privacy settings. This recognition accounts for situations where children may have reached the age of legal capacity but in practice lack the maturity or intellectual capacity to configure their privacy settings independently. This does not imply constant parental involvement; rather, it introduces the option to activate a parental advisory tool allowing children to proactively enlist the help of adults on their own accord. Incidentally, it is important that these functionalities are developed based on the best interests of the child.<sup>106</sup> For example, children also have a right to privacy vis-à-vis their parents, and as a

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<sup>102</sup> See also Article 29 Data Protection Working Party, ‘Guidelines on transparency under Regulation 2016/679’ (2018) 17/EN WP260 rev.01, 10, stating that ‘the vocabulary, tone and style of the language used’ can clearly convey information regarding the services and data processing practises to children.

<sup>103</sup> van der Hof, Lievens & Milkaite (n 52) 103-104.

<sup>104</sup> Hartung (n 90).

<sup>105</sup> van der Hof, Lievens & Milkaite (n 52) 104; Van der Hof & Lievens (n 14) 37.

<sup>106</sup> See for parents’ and children's views, experiences, and needs with respect to parental control tools: Svetlana Smirnova, Sonia Livingstone & Mariya Stoilova, ‘Understanding of User Needs and Problems: A Rapid Evidence Review of Age Assurance and Parental Controls’ (2021) <<https://euconsent.eu/download/understanding-of-user-needs-and-problems-a-rapid-evidence-review-of-age-assurance-and-parental-controls/>> accessed 31 August 2023.

general rule, constant parental oversight of children's online activities is not recommended, regardless of the child's age or developmental level.<sup>107</sup>

#### **4. Approaches for Designing Inclusive Data Protection**

As mentioned in section 2.1, children with intellectual disabilities usually have difficulty understanding complex information and abstract concepts. Their communication and social skills are also often compromised to varying degrees.<sup>108</sup> Regarding data collection, processing, and various features and information provided by digital services, these children face even more hurdles in comprehending how systems function and managing risks in the digital environment. Such impairments and environmental factors have given rise to various challenges discussed in section 2.2. Hence, it is critical for data controllers to expand the designs of information services to not only comply with child protection provisions in the GDPR, but also accommodate the special needs of underage users with intellectual impairments.

Section 3 discussed how to utilise data protection by design to better safeguard children's personal data under the GDPR in a more general sense. The following sections will now focus on children with intellectual disabilities, aiming to provide them with protection as well as empowerment in the digital environment.

##### **4.1 Accessible Information**

Regarding children with intellectual disabilities, it is essential to adopt innovative approaches in displaying information to enhance their understanding. For instance, according to Working Party 29's guidelines on transparency under Regulation 2016/679, controllers can consider using comics, pictograms, or animations other than plain texts to increase accessibility to children.<sup>109</sup> Various scholars and organisations have also proposed inclusive website design techniques for those with learning disabilities or cognitive impairments.<sup>110</sup> The following sections will discuss

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<sup>107</sup> Van der Hof (n 57) 409.

<sup>108</sup> Keke Wu & others, 'Understanding data accessibility for people with intellectual and developmental disabilities' (CHI Conference on Human Factors in Computing Systems, Yokohama, 2021) 1, 2-3.

<sup>109</sup> Article 29 Data Protection Working Party, 'Guidelines on Personal data breach notification under Regulation 2016/679 (wp250rev.01)' (2018) 11-12.

<sup>110</sup> See Kennedy, Evans & Thomas (n 5); Mark G. Friedman & Diane Nelson Bryen, 'Web accessibility design recommendations for people with cognitive disabilities' (2007) 19 *Technology and Disability* 205-212; Joyce Karreman, Thea van der Geest & Esmee Buursink, 'Accessible Website Content Guidelines for Users with Intellectual Disabilities' (2006) 20 *Journal of Applied Research in Intellectual Disabilities* 510-518; Ben Leach, 'Making your website accessible for those with learning disabilities or cognitive impairments' (HeX Productions, 20 June 2022) < <https://www.horlix.com/how-to-make-your-website-accessible-to-those-with-learning-disabilities-and-difficulties/> > accessed 31 August 2023; and 'How can web pages be

how to apply such techniques to privacy notices and settings in a way that promotes data protection and welfare online to children with impaired intellectual and adaptive abilities.

#### 4.1.1 Child-Friendly Language and Context

One of the most recommended approaches is using clear and easy-to-understand texts to explain data processing-related matters to users. Instead of relying on the same privacy notice like the one for adults, controllers should develop different versions for children with varying literacy levels and comprehension skills.<sup>111</sup> Take Google's Family Link privacy guide for children and teens as an example.<sup>112</sup> It is a document specially compiled for children, displaying data collection and processing information, and has versions for three different age ranges: 6–8, 9–12, and 13–17. Children with intellectual disabilities can thereby choose the information from an age group that matches their understanding rather than their true age. Observing the texts, the controller provides different wordings for each age group. For older age groups, the content is more detailed and involves more complex terms such as 'manage content settings' or 'enforce applicable terms of service.' The choice of examples to clarify specific points also takes children's growing capacities and life experiences into account.<sup>113</sup> Aside from body texts, heading structure is another element to pay attention to; this should categorise content in an easy-to-follow manner.<sup>114</sup> In many child-friendly privacy notices, question headings are frequently used as they can direct children's attention and prompt them to think independently.<sup>115</sup> It is worth noting that while it is important to keep the content concise and understandable, controllers also need to ensure the completeness of the

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made accessible to individuals who have cognitive disabilities?' (DO-IT, 24 May 2022) <<https://www.washington.edu/doit/how-can-web-pages-be-made-accessible-individuals-who-have-cognitive-disabilities>> accessed 31 August 2023.

<sup>111</sup> Kennedy, Evans & Thomas (n 5) 37.

<sup>112</sup> Google Family Link, 'Family Link privacy guide for children and teens' <<https://families.google.com/intl/en-GB/familylink/privacy/child-disclosure/#age-under-8>> accessed 31 August 2023.

<sup>113</sup> For instance, regarding data-sharing with third parties, it listed the reasons why and that Google will take safety measures in simple terms in guides for ages 6-8 and 9-12. For those over 13-year-old, it not only explained the concept of consent and legal reasons for data transfer, but also gave concrete examples such as '*we use external companies to help us with customer support and have to share personal information with the company in order to respond to user questions.*'

<sup>114</sup> Leach (n 110).

<sup>115</sup> See Nottinghamshire County Council, 'Child Friendly Privacy Notice' <<https://www.nottinghamshire.gov.uk/global-content/privacy/child-friendly-privacy-notice>> accessed 31 August 2023.; National Portrait Gallery, 'Child and Young People Friendly Privacy Notice' <<https://www.npg.org.uk/about/gallery-planning-and-policies/child-and-young-people-friendly-privacy-notice>> accessed 31 August 2023.

information and not leave out essential details.<sup>116</sup> Certainly, it is essential to ensure that privacy information is evaluated with children of different developmental levels. Additionally, instead of solely relying on age as the determining factor, one could consider employing a brief assessment, possibly in the form of a game, to gauge the child's ability to comprehend information.

Other than text formats, the structure and flow of the website or application interface should also be made transparent and accessible to underage users with limited cognitive functionalities. In this regard, the Web Content Accessibility Guidelines (WCAG) published by the World Wide Web Consortium serve as a useful guide. The WCAG aims to provide technical standards in enhancing the accessibility of web content<sup>117</sup> and has progressed since 2008. The later versions highlight the barriers people with learning and cognitive impairments often encounter online and further propose multiple technical measures and design recommendations.<sup>118</sup> To begin with, the layout and visual hierarchy should be consistent and utilise common design patterns so that children will not be confused when navigating between different pages.<sup>119</sup> Secondly, since many intellectually disabled children also have deficits in memory, controls and settings should be clearly identified and easily recognisable.<sup>120</sup> For instance, data protection notices and privacy settings should always remain highly visible on the interface, such as in the form of clickable buttons, so that children will know where to seek information and make adjustments.

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<sup>116</sup> Van der Hof, Lievens & Milkaite (n 52) 104.

<sup>117</sup> The scope of web content in the WCAG ranges from 'natural information such as text, images, and sounds' to 'code or markup that defines structure, presentation, etc.' W3C Web Accessibility Initiative, 'WCAG 2 Overview' < <https://www.w3.org/WAI/standards-guidelines/wcag/> > accessed 31 August 2023.

<sup>118</sup> W3C Web Accessibility Initiative, 'Cognitive Accessibility at W3C' < <https://www.w3.org/WAI/cognitive/> > accessed 31 August 2023; W3C Web Accessibility Initiative, 'Cognitive Accessibility Guidance' < <https://www.w3.org/WAI/WCAG2/supplemental/#cognitiveaccessibilityguidance> > 31 August 2023. Though relevant, in this article we will not go into the extensive body of literature regarding how design should take into account how the brain works to be usable and effective. Interesting work, e.g., with respect to gaming has been done by C Hodent, *The Gamer's Brain: How Neuroscience and UX Can Impact Video Game Design* (CRC Press 2017).

<sup>119</sup> W3C Web Accessibility Initiative, 'Use a Familiar Hierarchy and Design' < <https://www.w3.org/WAI/WCAG2/supplemental/patterns/o1p02-familiar-design/> > accessed 31 August 2023.

<sup>120</sup> W3C Web Accessibility Initiative, 'Clearly Identify Controls and Their Use' < <https://www.w3.org/WAI/WCAG2/supplemental/patterns/o1p05-clear-controls/> > accessed 31 August 2023; W3C Web Accessibility Initiative, 'Make it easy to find the most important actions and information on the page' < <https://www.w3.org/WAI/WCAG2/supplemental/patterns/o2p04-page-important/> > accessed 31 August 2023.

#### 4.1.2 Beyond Writing and Assistive Technology

As stated in Working Party 29's guideline regarding transparency, utilising different means other than writing is desirable in establishing a more accessible digital environment. For children with intellectual disabilities, utilising a combination of pictures, icons, symbols, texts, videos, animations and sounds enhances content intuitiveness and better conveys the (often abstract and potentially complex) message.<sup>121</sup> For instance, Data Protection Education, an organisation specialising in improving data protection in schools, has demonstrated a privacy notice animation using comics and text on screen to explain the purpose and usage of children's personal data so as to be easily comprehended by those with lower literacy levels.<sup>122</sup>

Assistive technology is another critical element in facilitating accessibility for children with intellectual disabilities. According to the World Health Organization, such technology enables individuals with functional difficulties to maintain an autonomous and dignified way of living and actively participate in society.<sup>123</sup> While there is an increasing number of people in need of these assistive products globally, it has been estimated that only one in ten people has access to them due to inadequate resources and awareness. Children with impaired intellectual abilities face similar predicaments. In the aforementioned Council of Europe study on disabled children's online experiences, it has been reported that devices essential for their living and learning are either prohibitively unaffordable or lack appropriate adaptations, preventing them from enjoying the benefits of digital technology.<sup>124</sup> Therefore, it is crucial for controllers to actively build specialised accessibility features into their service interfaces.<sup>125</sup> For example, visual reading assistants, such as screen magnifiers, will allow users to adjust the text fonts, sizes, spacing, and background colours to fit their reading habits and abilities.<sup>126</sup> Text-to-speech widgets that can read the content aloud will also benefit those with dyslexia or trouble comprehending large portions of written content.<sup>127</sup>

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<sup>121</sup> Kennedy, Evans & Thomas (n 5) 37-38; Friedman & Bryen (n 110) 208.

<sup>122</sup> Data Protection Education, 'Child-friendly privacy notice: animation' < <https://dataprotection.education/freebies/child-friendly-privacy-notices/> > accessed 31 August 2023.

<sup>123</sup> World Health Organisation, 'Assistive technology – Overview' < [https://www.who.int/health-topics/assistive-technology#tab=tab\\_1](https://www.who.int/health-topics/assistive-technology#tab=tab_1) > accessed 31 August 2023.

<sup>124</sup> Council of Europe (n 2) 11-12.

<sup>125</sup> Friedman & Bryen (n 110) 208.

<sup>126</sup> W3C Web Accessibility Initiative, 'Enable APIs and Extensions' < <https://www.w3.org/WAI/WCAG2/supplemental/patterns/o8p02-apis/> > accessed 31 August 2023.

<sup>127</sup> Leach (n 110).

## 4.2 Inclusive User Interface Design

A specially designed interface should be set up to better accommodate the needs of children with intellectual disabilities and tackle the challenges discussed in section 2. Such an interface design should strive for inclusivity,<sup>128</sup> meaning it should not exclude children due to their specific development, nor should it make it difficult or insurmountable for them to use a digital service. More specifically, user interface design should support them in making choices that optimally respect their rights and enable safe use of a digital service given the challenges they are facing. As children with disabilities are sometimes reluctant to disclose their impairments as they fear it will result in discrimination or rejection,<sup>129</sup> it is crucial to ensure they can freely access and exit the user interface without barriers. Similar to websites that provide both adult and child versions, there should be a clear button displayed on the web page allowing children to choose between different interfaces.<sup>130</sup> This also highlights the importance of applying the transparency and accessibility techniques set out in the previous sections, so that children can navigate through the interface and adjust the settings as independently as possible. Furthermore, services provided in the specially designed interfaces should remain essentially the same as in regular ones so that children opting to use such interfaces will not be disfavoured due to their disabilities.

Inclusive user interface design also means that the design of digital services should provide an age or development-appropriate data protection by design experience for children with intellectual disabilities. Section 3.2 highlighted that there is a growing number of age-appropriate design initiatives aiming to ensure that children can use digital services safely. Although these initiatives generally do not specifically address children with intellectual disabilities, they have offered valuable pre-design measures and design techniques suitable for children's use and to accommodate their development needs. To begin with, similar to what was discussed in section 3.1, controllers are encouraged to take a risk-based approach in the pre-design phase to assess children's capacity, skills and behaviours at different stages of their development when faced with various online risks.<sup>131</sup> A recommended method is conducting the data protection impact assessment (DPIA). As stipulated under Article 35 GDPR, the DPIA requires controllers to evaluate the risks of impact of high-risk processing activities on personal data prior to the processing.<sup>132</sup> While the GDPR does

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<sup>128</sup> Inclusiveness is more generally a requirement given the children's right to non-discrimination, see Article 2 UN CRC.

<sup>129</sup> Council of Europe (n 2) 14-15.

<sup>130</sup> For instance, the German children's TV channel 'Kika' provides users the option to navigate between the adult or the kid's version of their website by clicking on the 'FÜR ERWACHSENE (For Adults)' or 'ZU DEN KINDERANGEBOTEN (Offers for Children)' on the top right corner of the webpage. < <https://www.kika.de/index.html> > accessed 31 August 2023.

<sup>131</sup> Information Commissioner's Office (n 92) 32.

<sup>132</sup> See GDPR Article 35(1) '1. Where a type of processing in particular using new technologies, and taking into account the nature, scope, context and purposes of the processing, is likely to



not explicitly indicate that processing children's data is of high risk, scholars have argued that a DPIA should be carried out in such cases due to children's vulnerabilities stressed in Recital 38.<sup>133</sup> In processing activities involving children with cognitive and developmental deficiencies, performing an extensive DPIA that considers their special needs becomes even more critical. In doing so, controllers will gain a better understanding of children's abilities in dealing with online challenges so that the protective mechanisms installed in the design will be effective without harming children's autonomy, while giving them the opportunities to learn risk management. In this regard, it is essential that children with intellectual disabilities are included as a distinct group in the impact assessment, given that their exposure to specific risks, as previously explained, and the ways to mitigate them, might require specific measures.

Secondly, the age-appropriate design aims for controllers to provide services and take suitable data protection measures based on the age of child users.<sup>134</sup> It is important to note that while age is commonly used to determine a child's abilities and skills, it might not be the most appropriate threshold for those with intellectual impairments since their cognitive development is usually at a slower pace and has certain limitations. Hence, the special interface for these children should be designed in a more flexible and meticulous manner, with a clear and easy-to-adjust opt-in and opt-out mechanism. Take individualised marketing and services as an example. As discussed in section 2.2.3, those with intellectual disabilities are prone to personalisation and micro-targeting of advertising messages since they are less capable of detecting the potentially manipulative nature.<sup>135</sup> Hence, with respect to offering personalised content as well as advertisement based on children's activities online, such a function should be turned off by default when child users opt for this specially designed interface. Should children think they can critically reflect on such content and make good judgement calls, they could choose to opt in to those personalised functions with guidance from their parents and the controllers, which will be further discussed in section 4.4. Regarding personalised advertising within digital services, controllers must comply with regional and domestic regulations on

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result in a high risk to the rights and freedoms of natural persons, the controller shall, prior to the processing, carry out an assessment of the impact of the envisaged processing operations on the protection of personal data. A single assessment may address a set of similar processing operations that present similar high risks.'

<sup>133</sup> Van der Hof & Lievens (n 14) 38.

<sup>134</sup> Information Commissioner's Office (n 92) 32–35. Also see IEEE Standards Association, 'IEEE Standard for Age Appropriate Digital Services Framework Based on the 5Rights Principles' (9 November 2021) 30–31 <<https://app.box.com/s/regblshniri7v7e3ehr8fnz5nwxdp4d>> accessed 31 August 2023; CEN/CENELEC, 'Age Appropriate Digital Services Framework' <[https://www.cenelec.eu/media/CEN-CENELEC/CWAs/ICT/cwa18016\\_2023.pdf](https://www.cenelec.eu/media/CEN-CENELEC/CWAs/ICT/cwa18016_2023.pdf)> accessed 12 October 2023.

<sup>135</sup> Brahim Zarouali & others, "'Do you like cookies?' Adolescents' skeptical processing of retargeted Facebook-ads and the moderating role of privacy concern and a textual debriefing' (2017) 69 *Computers in Human Behavior* 157, 157.

advertising targeted at underage users and ensure that the content will not mislead or harm children in any way.<sup>136</sup> It is also viable to submit advertising content to comprehensive reviews, incorporating input from child specialists, caregivers of children with intellectual impairments, as well as children themselves.

### 4.3 Assistive Tools

Additional assistive tools should be built into the interface for children to learn online risk management and develop coping mechanisms. Besides using assistive widgets to enhance information transparency as explained in section 4.2, support bots equipped with artificial intelligence can further strengthen online safety and independence in using digital services for children with intellectual disabilities. To elaborate, this kind of bot can serve as a buddy for child users and provide reminders and assistance.<sup>137</sup> For instance, when children are going to disclose personal details to strangers online, such as home addresses, credit card numbers, or sexually suggestive images of themselves, the bot can generate warnings to explain the undesirability of such an action and ask them to think twice or check with an adult. When children are unsure of the authenticity of information they see or are confused with interface settings, they can also seek clarification (such as asking the bot to perform a search on the web) or get in touch with human assistants via the bot on the interface. Such a design contributes to addressing the problems of online sexual exploitation and mis/disinformation discussed in sections 2.2.1 and 2.2.2.

### 4.4 Parental Control Tools

Parental control is another crucial tool that should be included in this interface.<sup>138</sup> Research has indicated that compared with other disability groups, parents of children with intellectual disabilities are more likely to restrict children's use of online services as they are under the impression that it will be too dangerous.<sup>139</sup> Consequently, involving those with parental responsibilities in the design will be highly beneficial since they are, besides children themselves, most knowledgeable of

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<sup>136</sup> Simone van der Hof & others, 'Code voor Kinderrechten' (12 March 2021) <[https://codevoorkinderrechten.nl/wp-content/uploads/2021/07/Code-voor-KinderrechtenWordversie\\_EN.pdf](https://codevoorkinderrechten.nl/wp-content/uploads/2021/07/Code-voor-KinderrechtenWordversie_EN.pdf)> accessed 31 August 2023. See on lawfulness of personalised advertising in the European Union, Article 28(2) EU Digital Services Act: 'Providers of online platform shall not present advertisements on their interface based on profiling as defined in Article 4, point (4), of Regulation (EU) 2016/679 using personal data of the recipient of the service when they are aware with reasonable certainty that the recipient of the service is a minor.'

<sup>137</sup> UNICEF, Safer Chatbots Implementation Guide: A safer digital world for children and women, one chat at a time, <<https://www.unicef.org/documents/safer-chatbots-implementation-guide>> accessed 31 August 2023.

<sup>138</sup> See also Smirnova, Livingstone & Stoilova (n 106).

<sup>139</sup> Council of Europe (n 2) 15.

their children's abilities and situations. In this regard, controllers should inform parents of how this specially designed interface operates, as well as how to assist their children to use digital services in a privacy-preserving, meaningful way. For instance, parents should be given the option to customise children's profiles, decide what content to make available, adjust personalised content and individual marketing settings, and supervise their online activities.<sup>140</sup>

Nevertheless, the incorporation of parental control does not intend for increased monitoring of children with intellectual disabilities. Instead, such a mechanism aims to offer an extra layer of protection while they learn to protect themselves in the online environment. Hence, parents are encouraged to observe their children's growing capacities regarding the use of digital services and have regular discussions with them about the extent of parental supervision. Controllers can also develop assessments such as online safety and privacy quizzes for children and recommend the suitable level of parental control based on the results.<sup>141</sup>

## 5. Conclusion

The aim of this article was to explore the challenges children with intellectual disabilities might face in the digital environment and how the implementation of data protection by design can contribute to preventing or mitigating these challenges. To achieve that objective, the article investigates how data protection by design can help in overcoming or at least mitigating some of the challenges in the digital environment for children with intellectual disabilities.

Children with intellectual disabilities include children whose intelligence and social functioning have been impaired to various degrees since childhood and have a lasting effect on future developments. Due to such limitations in capacity, they are more prone to face challenges in the use of digital technologies, which can entail higher risks compared to their peers. These risks include potentially harmful online interactions that can result in abuse, more specifically online sexual exploitation and abuse (section 2.2.1). Furthermore, for children with functional difficulties in learning and comprehension, assessing the reliability of online information and discourse are much more difficult, and they might therefore be more susceptible to disinformation and extreme content (section 2.2.2). This vulnerability also extends to deceptive economic services, where children might be enticed into unintentionally entering economic relationships and/or suffer economic harm (section 2.2.3). A final challenge explained in this article pertains to potential privacy risks, which might be greater for

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<sup>140</sup> Borrowing a page from YouTube Kids' parental control tools that can be helpful for children with intellectual disabilities. YouTube Kids, 'Parental Control Tools & Resources' <[https://www.youtube.com/intl/en\\_us/kids/parent-resources/](https://www.youtube.com/intl/en_us/kids/parent-resources/)> accessed 31 August 2023.

<sup>141</sup> For sample assessments, also see: eSafety Commissioner, Be Secure <<https://www.esafety.gov.au/educators/classroom-resources/be-secure>> accessed 31 August 2023.

children with intellectual disabilities due to the complexity of data-processing activities or the technology itself, making them difficult to understand (section 2.2.4). This heightened complexity could increase the likelihood of potential victimisation and inhibit the children's ability to have some control over data privacy. Such privacy risks are the so-called cross-cutting risks<sup>142</sup> as they can also increase risks in other areas, such as sexual or economic exploitation of children. This is often due to, for example, mishandling of personal information or a lack of proper understanding of safe privacy settings. In other words, if children with intellectual disabilities are better empowered to protect their personal data and privacy, it can contribute to their safer and more informed use of digital services across the board.

A fundamental instrument within the GDPR to better protect individuals, including children, and to enhance control over their personal data is the principle of data protection by design under Article 25(1). Data protection by design offers opportunities to account for children's evolving abilities by tailoring the user experience to match their distinct stages of development. Typically, age serves as the criterion used for adapting digital services to cater to children's needs. However, we elaborated that in the case of those with intellectual disabilities, age is not always the most appropriate indicator of their expected capacities. Therefore, we argue for development-appropriate digital services and, in tandem, data protection by design focusing on the evolving capacities of these children. Incidentally, we do see scope for further research into those evolving capacities in relation to the challenges identified, along with the efficacy of data protection by design strategies intended to address those challenges. Here, we have conducted an initial exploration of possible tools and approaches that can help children with intellectual disabilities to manage their personal information carefully or receive protection by default from certain online practices. Those approaches include four components: disseminating accessible information through diverse formats to enhance comprehension; establishing an inclusive user interface design that avoids exclusion or potential risky online experiences; employing interactive assistive tools, such as AI bots, that support them with advice and assistance; and furnishing parents with parental control tools enabling tailored support aligned with the children's needs and preferences.

While age-appropriate codes and standards have been or are in the process of being developed to create safer and more engaging digital services for children, it is important that equal attention is paid within these initiatives to children with special needs, including those with intellectual disabilities. Embracing data protection by design through the application of the aforementioned tools and approaches emerges as one pathway to turn this attention into actual strategies, fostering a more inclusive

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<sup>142</sup> OECD, 'Children in the Digital Environment - Revised Typology of Risks' (2021)

<<https://www.oecd-ilibrary.org/docserver/9b8f222e-en.pdf?expires=1669644615&id=id&accname=guest&checksum=BE974CB8616DAE4386FF84B93DD64CF8>> accessed 31 August 2023; Sonia Livingstone & Mariya Stoilova, 'The 4Cs: Classifying Online Risk to Children' [2021] CO:RE Short Report Series on Key Topics <<https://www.ssoar.info/ssoar/handle/document/71817>> accessed 31 August 2023.

design of digital services that can effectively mitigate the challenges for children with intellectual disabilities in the digital environment.