# DISCRIMINATION LEGITIMIZED BY TRAGEDY: THE USE OF GPS TRACKING DEVICES FOR INDIVIDUALS WITH AUTISM- A PROTECTIVE SAFETY MEASURE OR UNLAWFUL INVASION OF PRIVACY?

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#### I. Introduction

Approximately 1 in 110 individuals in the United States are diagnosed with Autism each year.<sup>2</sup> Autism includes significant emotional, behavioral, and academic challenges.<sup>3</sup> For instance, elopement, a challenging behavior in which an individual wanders away from safety or bolts from supervision, effects nearly 50% of individuals with Autism.<sup>4</sup> Elopement most often occurs when a person is seeking out an item, for example a toy, or when a person is trying to

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<sup>&</sup>lt;sup>2</sup> See LORI MCILWAIN & WENDY FOURNIER, LETHAL OUTCOMES IN AUTISM SPECTRUM DISORDERS (ASD) WANDERING/ELOPEMENT 1, 3 (Nat'l Autism Ass'n 2012) [hereinafter LETHAL OUTCOMES IN ASD] (explaining elopement and how often individuals with Autism attempt to elope from safe environments).

<sup>&</sup>lt;sup>3</sup> See What is Autism?, AUTISM SPEAKS (2017), archived at https://perma.cc/E4TQ-JRU2 (defining Autism as "a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication."). Autism is defined as a spectrum disorder because there is a wide variation in the severity of challenges that impact a person diagnosed with Autism. *Id*.

<sup>&</sup>lt;sup>4</sup> See LETHAL OUTCOMES IN ASD, *supra* note 2, at 3 (reporting that approximately 48% of individuals with Autism present with elopement behavior). The challenging behavior is amplified by the fact that nearly one third of the individuals with Autism who elope cannot communicate their name, address, or phone number. *Id.* 

escape a task, for example doing homework.<sup>5</sup> It is very important for caretakers, parents, and guardians to be aware of elopement behavior so they can create preventative and responsive plans if the behavior takes place.<sup>6</sup>

As society becomes more aware of the frightening consequences of elopement, parents and educators are advocating for greater protection of their children, including their adult children. GPS tracking is the most recent technology that seeks to improve the response time for when an individual elopes. Although recent legislation and GPS tracking companies typically discuss the positive impact that GPS tracking will have on children with Autism, few discuss the implications that GPS tracking has on adults with Autism. Disability advocates are beginning to push for a greater recognition of the civil rights of individuals with disabilities, yet the creation of technologies continues to push this goal even further out of reach. 10

<sup>&</sup>lt;sup>5</sup> See Valori Berends, Tackling Difficult Behaviors Part 2- Elopement and Autism, SEATTLE CHILD. (June 18, 2014), archived at https://perma.cc/2SCU-4WAF (describing that children engage in elopement for a purpose or "because it serves a function"). For example, children may run away from something or run towards something. Id.

<sup>&</sup>lt;sup>6</sup> See For School Administrators, AWAARE COLLABORATION (Nov. 1, 2017), archived at https://perma.cc/4KJL-HKMW (describing ways schools can take steps in order to prevent wandering and how to react once it is discovered that a student has wandered).

<sup>&</sup>lt;sup>7</sup> See Kerry Magro, Wandering in Adults, AUTISM AFTER 16 (May 23, 2014), archived at https://perma.cc/D62E-8LFR (acknowledging the escalation in society's awareness of elopement). The escalation in acknowledging children wandering stems from the case of Avonte Oquendo, a 14-year-old boy with autism from Queens who eloped from his Long Island City School and was found months later. *Id.* 

<sup>&</sup>lt;sup>8</sup> See GPS Tracking Protects Children with Autism, GPSHEROES (Nov. 17, 2017), archived at https://perma.cc/G5GJ-ZEL7 (suggesting that parents can have peace of mind if their child with Autism is tracked through GPS and that tracking is crucial in minimizing the time it takes to find a child who has eloped).

<sup>&</sup>lt;sup>9</sup> See Critical Safety Legislation Passes U.S. Senate, AUTISM SPEAKS (July 15, 2016), archived at https://perma.cc/UZY6-6T7T (outlining Kevin and Avonte's Law, which aims to protect children with autism and other disabilities who wander); see also Our Mission, ANGELSENSE (Nov. 17, 2017), archived at https://perma.cc/9KTJ-6X8C (specifying that the mission of AngelSense is to create a safer environment and a sense of security for children with Autism).

<sup>&</sup>lt;sup>10</sup> See Massachusetts Office on Disability (MOD), MASS.GOV (Jan. 15, 2019), archived at https://perma.cc/F7Q3-Q99S (explaining that the MOD works to provide services for people with disabilities including health and social services, special needs and accessible living, affordable housing, accessible transportation, and health

This paper examines how AngelSense, a GPS tracking device typically used for children with Autism, creates far-reaching issues for adults with Autism.

## II. Background

#### A. Elopement

One potential behavior that an individual with Autism may exhibit is to leave, or flee from, supervision and safe areas. <sup>11</sup> Elopement is the term associated with wandering or bolting away from a secure area. <sup>12</sup> Elopement typically serves a specific purpose for the individual who is wandering. <sup>13</sup> The purpose of elopement may be goal-directed, a method of task-avoidance, or an escape mechanism due to fear and anxiety. <sup>14</sup> When an individual with Autism wanders,

care). MOD's mission is to ensure that people with disabilities can equally participate in all aspects of life. *Id*.

<sup>&</sup>lt;sup>11</sup> See LETHAL OUTCOMES IN ASD, supra note 2, at 3 (introducing that elopement is a critical issue for individuals with Autism). Elopment presents an increased safety concern for individuals with Autism because they often also experience significant social, communication, and behavioral challenges. *Id.* 

<sup>&</sup>lt;sup>12</sup> See Abby Twyman, What is Elopement?, AUTISM COMMUNITY (June 8, 2012), archived at https://perma.cc/3J8M-QWKU (defining elopement to be whena person leaves an area without permission or notification, which can ultimatlye lead to putting an individual in danger); see also LETHAL OUTCOMES IN ASD, supra note 2, at 3 (projecting that 48% of individuals with Autism attempt to elope four times more often than their unaffected siblings); see also LORI MCILWAIN & WENDY FOURNIER, MORTALITY & RISK IN ASD WANDERING ELOPEMENT 1, 5 (Nat'l Autism Ass'n 2017) [hereinafter MORTALITY & RISK IN ASD] (reporting that although the majority of elopement cases occur with individuals 19 and younger, the 45-49 age group also showed some risk). In addition, 13% of elopement cases involved females, while 87% of cases involved males. Id at 6.

<sup>&</sup>lt;sup>13</sup> See WENDY FOURNIER, AUTISM-RELATED WANDERING: KEEPING OUR KIDS SAFE (Nat'l Autism Ass'n 2013) (recognizing that individuals with Autism are bolting, running, or wandering away for a reason).; see also MORTALITY & RISK IN ASD, supra note 12, at 8 (finding that specific triggers were involved in approximately 40% of cases). Some vulnerable times and triggers occurred during times of transition, commotion or stress, in a disruptive setting, or when they were upset, agitated, or confused. *Id.* 

<sup>&</sup>lt;sup>14</sup> See FOURNIER, supra note 13 (summarizing types of wandering to include wandering for the purpose of getting to a certain place or object, suddenly running to get away from something negative, running away because of fear or stress, and wandering due to confusion or being in an unfamiliar place); see also MORTALITY & RISK IN ASD, supra note 12, at 9 (presenting statistics stating that in instances of

the stark reality that many parents and guardians fear, includes serious bodily harm or death. 15

The National Autism Association reported that between 2009 and 2016, 158 individuals with Autism died after eloping. <sup>16</sup> The report provided that of the 808 individuals with Autism that went missing during that time span, 17% resulted in death, 13% required medical attention, and 38% had a heightened risk of bodily harm. <sup>17</sup> Accidental drownings accounted for 71% of elopement deaths and 18% of those deaths were caused by traffic injuries. <sup>18</sup> Moreover, approximately one third of children with Autism who wander cannot communicate their name, address, or phone number. <sup>19</sup>

However, a 2009 study provided insight into the development of elopement prevention.<sup>20</sup> The research focused on the functionality of elopement, and what types of interventions could specifically

elopement that result in death, 71% in the sample were caused by drowning, 18% resulted from a traffic injury, and 4% occurred due to a train accident); *see also* Berends, *supra* note 5 (reasoning that bolting or wandering is typically done for a specific reason).

<sup>&</sup>lt;sup>15</sup> See MORTALITY & RISK IN ASD, supra note 12, at 1 (stating that wandering presents a substantial risk of serious bodily injury or death); see also Berends, supra note 5 (claiming that elopement is extremely challenging to treat because there is not as much research on it as other behaviors that individuals with Autism typically exhibit).

<sup>&</sup>lt;sup>16</sup> See MORTALITY & RISK IN ASD, *supra* note 12, at 1 (reporting that many deaths have resulted from individuals with Autism wandering away from their homes, schools, public places, group homes, and foster care); *see also* LETHAL OUTCOMES IN ASD, *supra* note 2, at 3 (documenting the amount of deaths and the manner of deaths of individuals with Autism as a result of elopement).

<sup>&</sup>lt;sup>17</sup> See MORTALITY & RISK IN ASD, supra note 12, at 2 (summarizing the results of a study of elopement in students with Autism, based on gender and ehtnicity).

<sup>&</sup>lt;sup>18</sup> See MORTALITY & RISK IN ASD, *supra* note 12, at 2 (analyzing what types of death were the most common in elopement cases as well as the number of non-ftal injuries or traumas suffered by children who eloped).

<sup>&</sup>lt;sup>19</sup> See Connie Anderson et. al., Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders, 130 J. AM. ACAD. PEDIATRICS 1, 1 (2012) (reporting the statistics regarding individuals with Autism who wander after the age of 4); see also LETHAL OUTCOMES IN ASD, supra note 2, at 3 (reporting on the current lethal and non-lethal data of individuals with Autism who wander).

<sup>&</sup>lt;sup>20</sup> See Berends, supra note 5 (specifying a particular literature review that introduced new interventions that were proven to be successful interventions to reduce elopement). For example, teaching the individual to request the desired activity or item that the individual is seeking out, providing the individual with visual schedules, and teaching waiting skills. *Id.* 

address the operative aspect of the behavior.<sup>21</sup> Moreover, the article calls upon parents and caregivers to create elopement intervention treatment plans for home.<sup>22</sup>

In 2016, elopement received national attention through the Senate's passing of Kevin and Avonte's Law.<sup>23</sup> The legislation was created in honor of Kevin Curtis Willis, a 9-year-old with Autism, who drowned in a river after wandering away from home, and Avonte Oquendo, a 14-year-old with Autism, who drowned after wandering away from school.<sup>24</sup> Kevin and Avonte's Law intends to protect children with disabilities who tend to elope, by providing grants to help train law enforcement agencies and school personnel on emergency protocol.<sup>25</sup> At the bills passing, Senator Chuck Grassley stated,

The feeling of dread and helplessness families must feel when a loved one with Alzheimer's or autism goes missing is unimaginable. But with the Senate's approval of Kevin and Avonte's Law, we are one important step closer to increasing the chances of a positive ending to many of these nightmares. This bipartisan bill applies proven community alert systems to help locate people with Alzheimer's, dementia,

<sup>&</sup>lt;sup>21</sup> See Berends, supra note 5 (introducing functional communication training (FCT) as an intervention method to decrease an individual's desire to elope).

<sup>&</sup>lt;sup>22</sup> See Berends, supra note 5 (suggesting that parents and/or caregivers recruit a behavior analyst to work with the individual who is prone to elopement, gather information about what happens before and after the elopement takes place, and tracking the frequency of the behavior in order to understand what the best intervention approach would be).

<sup>&</sup>lt;sup>23</sup> See Critical Safety Legislation Passes U.S. Senate, supra note 9 (announcing that the Senate passed Kevin and Avonte's law on July 14, 2016). S. 2614, Kevin and Avonte's Law, suggests that if enacted, it would help safeguard children with autism from wandering. *Id.* A bipartisan group of Senators, including Senator Chuck Schumer of New York, Senate Judiciary Committee Chairman Chuck Grassley of Iowa, and Senator Thom Tillis of North Carolina, introduced the legislation in the U.S. Senate. *Id.* Further, representatives Chris Smith, co-chair of the Congressional Autism Caucus, and Representative Maxine Waters introduced a companion bill in the U.S. House of Representatives. *Id.* 

<sup>&</sup>lt;sup>24</sup> See Critical Safety Legislation Passes U.S. Senate, supra note 9 (describing why Kevin and Avonte's Law was created). Kevin Curtis Willis drowned in Raccoon River in 2008 after wandering away from his Iowa home. *Id.* Avonte Oquendo drowned in New York City's East River in 2014. *Id.* 

<sup>&</sup>lt;sup>25</sup> See Critical Safety Legislation Passes U.S. Senate, supra note 9 (asserting how the government will allocate the funds provided through Kevin and Avonte's Law to apply community alert systems).

autism, and related disorders who may be susceptible to wandering away from safety. It also supports training for first responders and other community officials to better prevent and respond to cases. By preventing similar tragedies in the future, we can honor the lives of Kevin, Avonte, and others who lost their lives because a medical condition caused them to wander from safety. That's exactly what this bill aims to do.<sup>26</sup>

The law also provides funding for non-invasive tracking technology.<sup>27</sup> However, the passage of Kevin and Avonte's Law has sparked debate about what types of technology should be used to track individuals with Autism.<sup>28</sup>

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<sup>&</sup>lt;sup>26</sup> See Critical Safety Legislation Passes U.S. Senate, supra note 9 (providing that teh purpose behind Kevin and Avonte's Law is to minimize the amount of fatal and non-fatal occurances of when a child elopes).

<sup>&</sup>lt;sup>27</sup> See Critical Safety Legislation Passes U.S. Senate, supra note 9 (explaining how the communities will use the grants provided to them through Kevin and Avonte's law to provide community alert systems and train first responsders and community officials who respond to cases); see also Kenneth Lovett, 'Kevin and Avonte's Law' to Help Track Autistic Kids Passes House, DAILY NEWS ALBANY (Dec. 8, 2016), archived at https://perma.cc/3UXR-ZLJX (reporting that the bill allows parents to apply for a device that will allow them to track their children who have wandered away from care and safety).

<sup>&</sup>lt;sup>28</sup> See Sonia Mastros, Student GPS Tracking: Security and Legal Issues Schools Need to Know, BusBoss (Mar. 3, 2015), archived at https://perma.cc/FDN9-GAYG (describing the privacy rights, data security, and other legal issues that are at risk when students use GPS tracking for their children at school); see also Will Simm et. al., Prototyping 'Clasp': Implications for Designing Digital Technology for and with Adults with Autism, 1 DIS 345, 352 (2014) (addressing that the research of adaptive technology for individuals with Autism has focused on children, young adults, or lower functioning individuals, and there is essentially no research on adaptive technology for high functioning adults with Autism).

### B. Decision-Making

All people, including individuals with disabilities, have the right to make certain decisions about his or her own life.<sup>29</sup> Courts have acknowledged that individuals with disabilities are often deprived of their right to autonomy.<sup>30</sup> When making decisions that eradicate an individual's ability to make decisions regarding their life, liberty, and property, the Constitution guarantees them the right to notice, access, and meaningful opportunity to be heard.<sup>31</sup> Moreover, the Americans with Disabilities Act of 1990 ("ADA") requires that states provide people with disabilities, "equality of opportunity, full participation, independent living, and economic self-sufficiency."<sup>32</sup> Further, the International Covenant on Civil and Political Rights ("ICCPR") provides that all individuals have the following entitlements: (1) the right of self-determination; (2) the liberty of movement including the right to choose a residence, freedom from unlawful interference with privacy; and freedom of association with others; and (3) requirement of periodic review to ensure the rights are properly recognized.<sup>33</sup>

<sup>29</sup> See Shirli Werner, Individuals with Intellectual Disabilities: A Review of Decision Since the Convention on the Rights of People with Disabilities (CRPD), 34(2) PUB. HEALTH REV. NO. 2., 1, 2 (stressing that individuals with disabilities have the basic human right of autonomy and therefore must be given the opportunity to make their own decisions). Autonomy is understood as an individual's ability to take care of himself. Id. at 16.; see also The Right to Make Choices: International Laws and Decision-Making by People with Disabilities, AUTISTIC SELF ADVOCACY NETWORK (2017), archived at https://perma.cc/EVW5-G3P9 [hereinafter The Right to Make Choices] (introducing the freedom to make choices is about how to spend money, where to live, and who to have relationships is a basic human right).

<sup>&</sup>lt;sup>30</sup> See In re Zhuo, 42 N.Y.S. 3d 530, 532 (N.Y. Sur. 2016) (acknowledging the "severe deprivation of individual liberty that results from granting the relief of plenary guardianship."); see also Lyndal Rowlands, People with Autism have a Right to Autonomy Too, INTER PRESS SERVICE NEWS AGENCY (Apr. 2, 2017), archived at https://perma.cc/D8Y4-SW4D (discussing the deprivation of rights that individuals with Autism who are over 18 and under guardianship face throughout their lives).

<sup>&</sup>lt;sup>31</sup> See In re Zhuo, 42 N.Y.S. 3d at 532-33 (explaining that individuals with disabilities have the same constitutional guarantees as individuals without disabilities). When the court is determining potential guardianship of an individual with disabilities, that individual has the right to counsel. *Id.* at 532-33.

<sup>&</sup>lt;sup>32</sup> See Findings and purpose, 42 U.S.C. § 12101(a)(7) (expounding upon the goals of the Americans with Disabilities Act); see also In re Zhuo, 42 N.Y.S. 3d at 533 (recognizing every state's responsibility to adhere to the rights guaranteed by the ADA).

<sup>&</sup>lt;sup>33</sup> See International Covenant on Civil and Political Rights, Dec. 19, 1966, 1976 U.N.T.S. 173 (defining international human rights); see also In the Matter of SCPA

The loss of autonomy becomes especially egregious when the individual reaches the age of 18.<sup>34</sup> When an individual with Autism attains the age of majority, they are legally entitled to make their own decisions.<sup>35</sup> However, through a process called guardianship, the fundamental right is taken away from the individual with Autism, and given to the individual's parents or another court-appointed adult.<sup>36</sup> While this type of supervision is warranted in particular cases, guardianship is often assigned in cases in which the adult has the

Article 17-A Matter of Mark C.H., Ward, 906 N.Y.S.2d 419, 433-34 (N.Y. Sur. 2010) (applying the human rights defined in International Covenant on Civil and Political Rights ("ICCPR") to guardianship issues).

<sup>&</sup>lt;sup>34</sup> See In re Zhuo, 42 N.Y.S. 3d at 535 (dictating the severity of the implications resulting from an individual's loss of self-determination, privacy, and autonomy); see also Rebecca Benson & Catherina Pinnaro, Autonomy and Autism: Who Speaks for the Adolescent Patient?, 17(4) AMA J. ETHICS 305, 306 (2015) (explaining the pediatricians generally expecept parents to make decisions that they believe is in the best interest of their child); see also Rowlands, supra note 30 (contending that adults with Autism do not get to make the same decisions as all other adults and lose the ability to influence their own lives); see also Werner, supra note 29, at 13 (acknowledging that adulthood means an increased ability to control one's own life). 35 See In re Zhou, 42 N.Y.S. 3d at 535 (holding that guardianship infringes on an individual with disabilities right to privacy, right to refuse medical treatment, and right to make decisions about marriage, procreation, contraception, and education); see also National Position Statement on Human Rights, THE AUTISM SOCIETY (Aug. 8, 2017), archived at https://perma.cc/Z4WW-8C84 (asserting that individuals with Autism must be given the opportunity to live independently and fully participate in all aspects of life); see also Dan Baker, Ph.D. et. al., Transition Tool Kit For Famillies on the Journey from Adolescene to Adulthood, AUTISM SPEAKS 18 (2011) (informing parents that their child will have the right to make his or her own decisions even if the individual has significant cognitive or mental health diabilities). <sup>36</sup> See In re Zhou, 42 N.Y.S. 3d at 536 (asserting that guardianships "completely strip the legal authority to make personal decisions over affairs and vests in the guardian 'virtually complete power over such individual""); see also About SDM, CTR. FOR Pub. Representation and Nonotuck Resource Associates (2017), archived at https://perma.cc/XYF3-UCNH (providing that data shows over 1.5 million adults in the United States are under guardianship). However, in actuality, that number may be closer to 3 million due to scarcity of documentation. *Id.*; see also Baker, supra note 35 (defining guardianship as a court-appointed person who is given the authority to make all decisions for the individual with Autism); see also The Right to Make Choices, supra note 29 (explaining that guardianship is a system that grants one person the power to make decisions regarding another person's money, health care, living situation, and relationships); see also Werner, supra note 29 at 13 (alleging that despite advocating for self-determination, parents often become overwhelmed by their son or daughter's dependence, vulnerability, and limited capacity to understand consequences).

capacity to make his or her own decisions.<sup>37</sup> Further, guardianship also creates the opportunity for guardians to abuse their power by making decisions for the individual with Autism that are not truly in that individuals best interests.<sup>38</sup>

Courts have recognized that appointing guardians for people with developmental disabilities directly infringes on their fundamental right of liberty.<sup>39</sup> Under the Fourteenth Amendment, the Disability Convention, and the ICCPR, courts are required to monitor guardianship relationships. 40 As more people grasp the extent that guardianship infringes on the rights of individuals with disabilities, adaptive guardianship and other less intrusive options are beginning to

An individual who for reasons other than advanced age or minority, has a clinically diagnosed condition that results in an inability to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or selfcare, even with appropriate technological assistance.

Id.; see also Vaida v. Vaida, 19 N.E.3d 423 429 (Mass. App. Ct. 2014) (providing an example of individual who has a condition mentioned in the definition of incapacitated, but still had the ability to make decisions about some or all aspects of his life); see also Instructions to Clinicians for Completing Medical Certificate for Guardianship or Conservatorship, MASS.GOV (Jan. 17, 2019), archived at https://perma.cc/N7ZP-4EKM (providing the legal standard for guardianship and conservatorship when a parent is attempting to get legal guardianship).

<sup>38</sup> See In re Guadianship of Moe, 81 Mass. App. Ct. 136, 140 (2012) (holding that a person may be competent to make some decisions and inferring that guardianship must reflect that fact); see also MASS. GEN. LAWS c. 190B, § 5-308(f) (2008) (asserting that a need of temporary guardianship does not lead to a determination that the individual is permanently incapacitated); see also MASS. GEN. LAWS c. 190B § 5-306(c) (2008) (providing for limited guardianship in cases in which a person has the capacity to make decisions about some things, but not others); see also Massachusetts Board of Bar Overseers, Admonition No. 17-06, MASSBBO.ORG (Mar. 13, 2017), archived at https://perma.cc/G7W8-6LVX (cautioning attorneys to be careful of the personal agendas of those allegedly close with the individual with disabilities). In the admonition, an attorney followed directions of his client's adult daughter, who used the guardian to fraudulently transfer her mother's funds to herself. Id.

<sup>&</sup>lt;sup>37</sup> See MASS. GEN. LAWS c. 190B, § 5-101(9) (2008) (providing statutory definition of an incapacitated person). For the purposes of guardianship, an incapacitated person is:

<sup>&</sup>lt;sup>39</sup> See A Guardianship Proceeding for Mark C.H., Ward, 906 N.Y.S.2d 419, 422 (N.Y. Sur. 2010) (holding that an ill-advised and uninvolved guardian may expose an individual with a disability to harm, and portrays why periodic court review and revision of guardianships is required).

<sup>&</sup>lt;sup>40</sup> See id. at 435 (summarizing why guardianships must be monitored by the courts).

be explored.<sup>41</sup> Guardian relationships should not be treated as an all or nothing affair, and parents and courts should ensure that the individual is making as many independent decisions as possible.<sup>42</sup> In addition, over the past few years, advocacy groups have made a push for society to recognize that individuals with Autism should be able to exercise their right to make their own decisions.<sup>43</sup>

One way in which advocates are beginning to make a stronger push for programs for adults with disabilities to have greater control over their lives, is through a system called supported decision

<sup>&</sup>lt;sup>41</sup> See In re Zhou, 42 N.Y.S. 3d at 536 (outlining the ways in which guardianship infringes on a person's liberty and bodily automony); see also About SDM, supra note 36 (explaining the constraints that guardianship puts on an individual's ability to make their own choices). Supported Decision Making (SDM) is a less-restrictive alternative to guardianship. Id.

<sup>&</sup>lt;sup>42</sup> See In re Mark C.H., 908 N.Y.S. at 429 (holding that periodic reporting and court review of guardianships is essential to ensure that and individual's liberty interest is being properly exercised); see also The Right to Make Choices: International Laws and Decision-Making by People with Disabilities Part 5: Guardianship and Supported Decision-Making Law, AUTISTIC SELF ADVOCACY NETWORK (2017) [hereinafter The Right to Make Choices: Part 5] (cautioning parents that although most states have laws stating that guardians should strictly make decisions that the individual is incapable of doing on their own, individuals with disabilities are most often placed under full guardianships without considering their ability to make some decisions on their own); see also Baker, supra note 35, at 18-19 (reminding parents that they should look at what decisions their child can make on his or her own, and ensure those choices are available to the individual through their guardianships). When deciding what decisions should be made by the guardian and which decisions should be made by the individual himself, parents should look at the current level of the individual's educational level, medical problems, self-preservation skills, ability to manage finances, self-care, working status, and living arrangements. Id.; see also Werner, supra note 29, at 13 (presenting research that shows individuals with mild intellectual disabilities have the potential to make their own decisions when caretakers or guardians proactively present them the opportunity to so).

<sup>&</sup>lt;sup>43</sup> See UN calls for Recognizing the Rights of People with Autism to make their own Decisions, U.N. NEWS CENTRE (Mar. 31, 2017), archived at https://perma.cc/K4SN-8QTF (explaining that individuals with Autism should feel empowered to make all decisions that other adults have the privilege to make). Adults with Autism should receive supports and services that allow them to make choices about where they want to live, what job they want to do, and how to manage their money. Id.; see also About SDM, supra note 36 (presenting the recent change in legislation that provides for supported decision making); see also Werner, supra note 29, at 13 (purporting that professionals and advocates have the duty to make individuals with disabilities and their parents aware of the ability for the individual to make guided, informed decisions with as much independence as possible).

making.<sup>44</sup> Supported decision making allows individuals with disabilities to be a part of a team to help with decision making.<sup>45</sup> Unlike guardianship, supported decision making ensures individuals with disabilities to engage in a process that almost every adult does—reaching out to family, friends, and colleagues when making life decisions.<sup>46</sup> While individuals with disabilities may need assistance or advice when weighing decisions, they do not necessarily need someone to make the decisions for them.<sup>47</sup>

A UN pilot project recognizes that individuals with disabilities may need support to make appropriate decisions, but not to the extent that guardianship provides for. <sup>48</sup> In the U.S., the Supreme Court of Oklahoma has acknowledged that mental illness and involuntary commitment are not sufficient to conclude that an individual is

<sup>&</sup>lt;sup>44</sup> See About SDM, supra note 36 (introducing supported decision-making as a way to give individuals with disabilities a greater voice in making life choices). Guardianship acts as a "civil death" because the individual with a disability loses al rights to make decisions about their finances, social life, and health care. Id.; see also The Right to Make Choices: Part 5, supra note 42 (proposing that supported decision making would allow people with disabilities to make their own choices while maintaining supports that help them understand what is required to make informed and appropriate decisions).

<sup>&</sup>lt;sup>45</sup> See About SDM, supra note 36 (explaining the support network concept behind supported decision making). If the individual has a guardian, the individual does not make their own decisions about different matters, including how to spend his or her own money. Id. This provides the guardian with an uncanny amount of power regarding an individual's life choices. Id. However, "supported-decision making allows the person with the disability to make his or her own decisions." Id.; see also The Right to Make Choices: International Laws and Decision-Making by People with Disabilities Part 2: Supported Decision-Making, AUTISTIC SELF ADVOCACY NETWORK (2017) [hereinafter The Right to Make Choices: Part 2] (providing the example that when a person uses supported decision making instead of guardianship, an individual who would like to move can call up someone trusted, like the individual's sister, and have her help the individual go through the process of finding a new place to live).

<sup>&</sup>lt;sup>46</sup> See About SDM, supra note 36 (comparing supported decision making to adults consulting a close network of people to help make their life decisions).

<sup>&</sup>lt;sup>47</sup> See About SDM, supra note 36 (expressing why individuals with disabilities should not use guardianship, but rather need a supportive group or individual that will work with them to guide them through decision making).

<sup>&</sup>lt;sup>48</sup> See About SDM, supra note 36 (proposing that individuals with disabilities need a supportive network of people who care about them to discuss decisions, not one individual who makes all the decisions for them). Many individuals with disabilities can make their own decisions if they have the right support. *Id*.

incompetent to make their own decisions.<sup>49</sup> Moreover, the autonomy rights of an individual with a mental or physical disability should not be treated as less significant than someone who does not have a disability.<sup>50</sup>

Supported decision making has been a major topic of discussion for individuals with disabilities in countries outside of the United States for more than a decade.<sup>51</sup> For example, in 2006, the United Nations signed the Convention on the Rights of People with Disabilities, the first international treaty to specifically address the human rights of individuals with disabilities.<sup>52</sup> A key component of the treaty is that there is a need to "ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances."<sup>53</sup>

In addition, recent studies have acknowledged how important autonomy is for individuals with disabilities, especially for adult who live in a group residential setting.<sup>54</sup> Although individuals with disabilities have the right to make their own decisions about where to live, fewer than half of adults with intellectual disabilities in the United

<sup>&</sup>lt;sup>49</sup> *See* In re the Mental Health of K.K.B., 609 P.2d 747, 751-52 (Okla. 1980) (holding that a patient's mental illness and involuntary commitment does not mean he or she is incompetent to refuse medical treatment and understand the consequences of his or her refusal).

<sup>&</sup>lt;sup>50</sup> See id. at 752 (holding that "[i]f the law recognizes the right of an individual to make decisions about her life out of respect for the dignity and autonomy of the individual, that interest is no less significant when the individual is mentally or physically ill. Because the patient will be the one to suffer the consequences she must have the power to make the decision."); see also Rivers v. Katz, 67 N.Y.2d 485, 492 (1986) (holding that mental illness does not eliminate an individual's fundamental right to make his or her own decisions).

<sup>&</sup>lt;sup>51</sup> See About SDM, supra note 36 (contending that several countries have a long history of believing that individuals with disabilities possess the legal capacity to be a part of the decision making process for themselves); see also The Right to Make Choices: Part 5, supra note 42 (revealing that several Canadian provinces, such as British Columbia, allow people with disabilities to enter agreements in which the person names individuals they trust to help make their decisions).

 $<sup>^{52}</sup>$  See Werner, supra note 29, at 3 (reporting that 153 countries signed the convention and 119 have ratified the convention by 2008).

<sup>&</sup>lt;sup>53</sup> See Werner, supra note 29, at 3 (stressing the importance of Article 12 and the need to supported decision making).

<sup>&</sup>lt;sup>54</sup> See Werner, supra note 29, at 14 (stating that one of the most controversial issues for individuals with disabilities in residential settings was deciding where and with whom to live).

States are given the opportunity to have any say in where they are living.<sup>55</sup> When living in residential placements, many life choices are taken away from those living there, including employment decisions, health care decisions, and sexuality decisions.<sup>56</sup>

Slowly, the United States is beginning to adopt positions similar to the U.K. regarding supported decision making.<sup>57</sup> Texas was the first state to pass supported decision making legislation, signing the Supported Decision Making Act in 2015.<sup>58</sup> In Texas, courts are required to consider supported decision making prior to assigning an individual to a guardian.<sup>59</sup> The only other state that currently has supported decision legislation, is Idaho. 60 Advocates in the United

<sup>&</sup>lt;sup>55</sup> See Werner, supra note 29, at 14 (reporting that individuals with mild forms of disabilities had more of an input about where they live when they are already living on their own or in a sheltered apartment, while those who live in group homes or institutions had less of a say regarding with whom or where they lived). Further, individuals with more severe of disabilities had the least amount of choice regardless of where they were currently living. Id.

<sup>&</sup>lt;sup>56</sup> See Werner, supra note 29, at 15 (explaining that low expectations, funding restrictions, and lack of information were all reasons cited for individuals with disabilities in residential facilities not be provided an opportunity to make their own decisions about employment). Moreover, individuals with severe disabilities have a very limited voice when making decisions about their health care, and essentially never were able to fully exercise their sexual autonomy. Id. at 17.

<sup>&</sup>lt;sup>57</sup> See The Right to Make Choices: Part 5, supra note 42 (explaining that as soon as a family member thinks a person with a disability cannot make good choices, the person with the disability loses his or her right to make life decisions). In the United States the Advance Directive, which is a form that "tells people what you want if you become unable to make decisions or to tell them what you want," has an equivalent form called the Advanced Statement in the United Kingdom. Id.; see also About SDM, supra note 36 (noting the evolving prevalence of supported decision making in the United States).

<sup>&</sup>lt;sup>58</sup> See TEX. PROB. CODE ANN. § 1357 (2015) (granting individuals with disabilities a less restrictive option to guardianship). The Supported Decision Making Act indicates that adults with disabilities can voluntarily enter into a supported decision making agreement with a supporter. Id. The agreement provides individuals with disabilities the ability to help make decisions about where the want to live, who they want to live with, what types of services they will be provided, where the person wants to work, and what kind of medical care the person wants to receive. *Id.* 

<sup>&</sup>lt;sup>59</sup> See The Right to Make Choices, supra note 29 (clarifying that Texas law considers guardianship to be the final option and should be utilized only if supported decision making does not work). In addition, the supported decision making agreement must be signed and understood by the person with the disability. Id.

<sup>&</sup>lt;sup>60</sup> See Health and Safety: Individuals with Disabilities, 16 Del. Code Ann., § 9402A (2016) (providing that all adults should be able to live how they wish so long as they do not do harm and are capable of making their own decisions). The law goes on to

States are beginning to see and acknowledge how choosing where to live, who to be friends with, and how to earn money positively impacts a person's self-confidence and overall quality of life.<sup>61</sup> All individuals, whether they have a disability or not, have the innate desire and right to make their own choices.<sup>62</sup>

#### III. Facts

As more information is learned about Autism and elopement, additional efforts have been made to protect individuals who have the tendency to wander off.<sup>63</sup> One trending piece of assistive technology is a GPS tracking device called AngelSense.<sup>64</sup> The highly invasive tracking device strips a person of his or her right to autonomy while proving to be ineffective in preventing the lethal harm associated with elopement.<sup>65</sup> AngelSense creates an issue regarding the balancing of

state that certain individuals should not be under guardianship, but should simply be provided support to help them make informed and appropriate decisions. *Id.* 

<sup>&</sup>lt;sup>61</sup> See Staci Carr, Quality of Life in Emerging Adults with Autism Spectrum Disorder, 1 VA. COMMONWEALTH UNIV. SCHOLARS COMPASS 1, 35 (2014) (inferring the negative impact that the lack of independence has on individuals with Autism Spectrum Disorder).

<sup>&</sup>lt;sup>62</sup> See id. at 60 (explaining that as children get older, the desire to act independently increases). This is true for all people, including those with Autism. Id. However, children with Autism are not presented as many opportunities to make independent choices. Id. Moreover, the lack of autonomy leads to a lower quality of life. Id. <sup>63</sup> See Rachel Bianco, Family says Gym at Fault for Losing Track of Son, ABC NEWS KGTV SAN DIEGO (June 16, 2016), archived at https://perma.cc/V5AP-KUQ8 (reporting that a GPS locating app allowed a mother to track her child when he wandered away from a babysitting service at the gym); see also Svend Erik Mouridsen, Mortality and Factors Associated with Death in Autism Spectrum Disorders-a Review, 1 Am. J. OF AUTISM 17, 22 (2013) (suggesting increased supervision, maintaining a high standard of care, and having organizational procedures for emergency situations); see also Fox 5 Digital Team, SoCal Mom Wants Approval for Autistic Child to Wear GPS Tracker to School, Fox 5 SAN DIEGO (Apr. 27, 2016), archived at https://perma.cc/CE3M-PFP8 (publishing a story about a mother fighting for her daughter to be allowed to wear a tracking device at school). <sup>64</sup> See Bianco, supra note 63 (revealing that an app called AngelSense is what helped a mother find her lost son by pinpointing his location through GPS services); see also Fox 5 Digital Team, *supra* note 63 (disclosing a mother's desire for her daughter to wear AngelSense to school to give her peace of mind about her daughter's potential to wander away from school).

<sup>&</sup>lt;sup>65</sup> See The Unique Capabilities of AngelSense, ANGELSENSE (2017), archived at https://perma.cc/FT86-9VNR (indicating that the GPS devices are non-removable and actually require a special key for removal by a parent).

the individual's rights, the government's and family's desire to protect that individual, and the new wandering legislation. <sup>66</sup>

After the passing of Kevin and Avonte's law, the Department of Justice now has the power to allocate federal grants to state police departments to buy tracking technologies like AngelSense. Since the discussion of tracking devices for individuals with disabilities began, there has been a struggle between safety and autonomy. Rather than focusing on the individuals who are eloping, the bill focuses on how the family feels when their son or daughter goes missing. In addition, the law requires consent from the individual's parents rather than the individual himself or herself. While this may be appropriate for children with disabilities, it presents alarming intrusion issues for adults with Autism. The lack of consent by the individual being tracked exemplifies the lack of liberty that individuals with Autism face due to the passing of Kevin and Avonte's law. Laws which grant control to someone other than the individual with the disability,

<sup>&</sup>lt;sup>66</sup> See Amy S.F. Lutz, 117 Autistic Children and Adults who Died Deserve Better, PSYCHOLOGY TODAY (Dec. 20, 2016), archived at https://perma.cc/G7D6-USJ6 (describing the hostility between people who only perceive GPS technology to be a device that will save lives and advocates who view GPS as a tool that can lead to the further restraint and seclusion of individuals with disabilities). A group called the Autistic Self-Advocacy Network believes that rather than reacting to the elopement, researchers and parents should focus on why the individual is eloping in the first place. *Id.* 

<sup>&</sup>lt;sup>67</sup> See Kayla Whaley, Want to Track a Disabled Person? Maybe ask them First, THE OUTLINE (Dec. 20, 2016), archived at https://perma.cc/A5YY-SD8W (introducing the power that the Department of Justice has after the passing of Kevin and Avonte's law)

<sup>&</sup>lt;sup>68</sup> See id. (describing the law's potential to help individuals with disabilities while also recognizing the potential for abuse to occur).

<sup>&</sup>lt;sup>69</sup> *See id.* (highlighting the fact that the law failed to take into account the feelings of the individuals with disabilities, and instead focused on the families of the diaabled people).

<sup>&</sup>lt;sup>70</sup> See id. (noting that Kevin and Avonte's law specifically states that the government cannot force a parent or guardian to track an adult or child if the parent does not think the device is necessary).

<sup>&</sup>lt;sup>71</sup> See Vaida v. Vaida, 19 N.E.3d 423, 429 (Mass. App. Ct. 2014) (explaining various intrusions of liberty and privacy that adults with Autism face due to guardianship and other laws intended to protect individuals with disabilities).

<sup>&</sup>lt;sup>72</sup> See Whaley, supra note 67 (comparing the person being tracked to an object). Individuals with disabilities, and more specifically Autism, have a history of losing their autonomy to laws that are supposed to help them. *Id.* Lawmakers assume incompetence and look to a guardian or parent for guidance or consent, rather than asking the person with the disability. *Id.* 

and specifically Autism, fail to consider the "spectrum" of individuals with Autism.<sup>73</sup>

AngelSense is a GPS tracker that attaches to a person's article of clothing, often times sewn into the clothing item, and details the location of the individual wearing the device via a phone application. AngelSense provides application holders the access to see what the person wearing the device is doing throughout the day, updated in 30 second intervals. In addition, whoever has access to the app will receive a text message every time the individual wearing the device arrives at a specific location, departs a specific location, or if they are late to a location where they are expected. The most problematic aspect of AngelSense is the "Listen-In Capability," which allows a person to listen in on the person wearing the device, permitting the app holder to hear any conversation that is taking place with or around the individual being tracked.

Although the app provides great protection to children with Autism and lower functioning adults with Autism, it also creates major problems for higher functioning adults with Autism who are seeking to gain independence from their families and guardians.<sup>78</sup> The website for AngelSense and articles reviewing the product mainly discuss the positive impact that the device has on children with Autism, but it is

<sup>&</sup>lt;sup>73</sup> See Vilma Ruddock, Different Levels of Autism, LOVE TO KNOW (Feb. 19, 2019), archived at https://perma.cc/R4CC-YF8Y (outlining the various functioning levels of individuals with Autism); see also Carr, supra note 61, at 8 (analyzing the variability in symptoms in individuals with Autism); see also What is Autism?, supra note 3 (stressing that Autism is a spectrum disorder, meaning that there is not one set of strengths and weaknesses for every individual with Autism).

<sup>&</sup>lt;sup>74</sup> See The Unique Capabilities of AngelSense, supra note 65 (summarizing the capabilities of the AngelSense GPS).

<sup>&</sup>lt;sup>75</sup> See The Unique Capabilities of AngelSense, supra note 65 (explaining the "Timeline" feature of the app that allows the device to revert back to a parent or guardian where the user is every minute of the day).

<sup>&</sup>lt;sup>76</sup> See The Unique Capabilities of AngelSense, supra note 65 (elaborating on the "ETA" functionality that the application provides to whoever has access to the app, allowing the user to track them throughout the day).

<sup>&</sup>lt;sup>77</sup> See The Unique Capabilities of AngelSense, supra note 65 (describing the listen in feature as a way to make sure the individual wearing the device is safe, especially in emergency situations).

<sup>&</sup>lt;sup>78</sup> See FAQ on Proposed ICD-9-CM Wandering Code, AUTISTIC SELF ADVOC. NETWORK (Mar. 23, 2011), archived at https://perma.cc/23V8-URRE (indicating that a wandering code may allow educators and caretakers to further limit and restrict individuals with Autism).

notably silent of the impact it has on adults with Autism.<sup>79</sup> Advocate groups such as the Autistic Self Advocacy Network recognizes that by allowing GPS tracking devices to be used for adults with Autism, the government is needlessly restricting the freedom of movement for people with disabilities.<sup>80</sup> Although GPS tracking devices are now being used throughout the United States intending to protect individuals with Autism, the question that still remains is what about the self-determination rights of adults with Autism?<sup>81</sup>

Courts must consider the fundamental liberty interests at stake when an adult with Autism is wearing AngelSense because it is well established that mental and physical illness do not alone constitute the forfeiture of all autonomy rights, and therefore, individuals with Autism should have the opportunity to refuse to wear AngelSense.<sup>82</sup>

# IV. Analysis

Although AngelSense intends to address the challenges associated with elopement, the positive aspects of the technology do not outweigh the constitutional violations that result when GPS tracking adults with Autism and other disabilities. <sup>83</sup> Disability and

<sup>&</sup>lt;sup>79</sup> See The Unique Capabilities of AngelSense, supra note 65 (explaining how the product will protect children with Autism who wander); see also AngelSense GPS is MADE for Children with Special Needs, ROWELL FAMILY EMPOWERMENT OF NORTHERN CALIFORNIA, INC. (Sept. 15, 2016), archived at https://perma.cc/PA7S-YEAQ (specifically mentioning that AngelSense is designed for the purpose of tracking children with special needs).

<sup>&</sup>lt;sup>80</sup> See FAQ on Proposed ICD-9-CM Wandering Code, supra note 78 (suggesting that there are less restrictive practices that would address wandering behavior in adults with Autism).

<sup>&</sup>lt;sup>81</sup> See Joint Letter to CDC on Proposed ICD-9-CM Wandering Code, AUTISTIC SELF ADVOC. NETWORK (Apr. 4, 2011), archived at https://perma.cc/759B-28RV (proposing that a code for wandering may lead to the limitation of self-determination rights for individuals with Autism because there is no limit to its application). The Network is concerned that using invasive methods to track adults with Autism will prevent those individuals from willfully leaving an overwhelming and undesired situation. *Id.* 

<sup>&</sup>lt;sup>82</sup> See Rivers v. Katz, 67 N.Y.2d 485, 486 (1986) (holding that mental illness alone is not a justification for detracting an individual's fundamental right to refuse antipsychotic medication). Further, due process requires the courts to balance the individual's liberty interest in relation to the State's compelling need. *Id.* 

<sup>&</sup>lt;sup>83</sup> See Mastros, supra note 28 (publishing the potential concerns that parents and other caretakers may have regarding GPS tracking including various security and legal concerns); see also Rowlands, supra note 30 (asserting that laws intended to

human rights have long been challenging concepts to navigate within the law, and as more intrusive technologies are created, the potential for constitutional violations against a person's liberty becomes even greater.<sup>84</sup>

One issue that concerns opponents of GPS tracking individuals with disabilities is the potential data breach that can give unwanted eyes the access to the individual's location and private information. A tracking device becomes particularly exposed to third party invasions when the GPS device is the host of the data. In order to protect an individual's data from potential breach, the tracking system must ensure that the software is encrypted and has a password enacted, that there is limited allowed third party access including salespeople, the GPS is acting through a private database, and that student information is not attached to the actual card of the GPS. Additionally, when using GPS tracking, parents, guardians, and the individual wearing the GPS should have an understanding of RFID tags and scanners.

Another particular concern regarding the use of AngelSense is whether GPS tracking can sufficiently address the concerns surrounding elopement.<sup>89</sup> Elopement typically serves a purpose,

help adults with disabilities are actually depriving them of their basic Constitutional rights).

<sup>&</sup>lt;sup>84</sup> See Whaley, supra note 67 (noting the contentious nature of balancing the autonomy and safety of individuals with disabilities and GPS tracking).

<sup>&</sup>lt;sup>85</sup> See Mastros, supra note 28 (describing the privacy and data security concerns when using GPS tracking, particularly the unauthorized access to the tracking software database).

<sup>&</sup>lt;sup>86</sup> See Mastros, supra note 28 (identifying how GPS devices that host the information of the individual are at greater risk for the data being compromised).

<sup>&</sup>lt;sup>87</sup> See Mastros, supra note 28 (explaining what steps should be taken to keep an individual's information protected, but cautioning that even the most protective practices cannot guarantee that there will not be a breach).

<sup>&</sup>lt;sup>88</sup> See Mastros, supra note 28 (warning that the only way to protect against data and security breaches is for everyone involved to have an understanding of the complex systems at work when using GPS).

<sup>&</sup>lt;sup>89</sup> See GPS Tracking Protects Children with Autism, supra note 8 (acknowledging that time is crucial when an individual goes missing); see also Magro, supra note 7 (addressing the lack of concern and attention on adults engaging in elopement behavior). The author stresses that society must consider legal, educational, and technological advances that need to be made for adults, not just children. Id.; see also McIlwain & Fournier, supra note 12 (reporting that from 2009 to 2011 the search times for lethal elopements ranged from 15 minutes to 20 hours); see also The Unique Capabilities of AngelSense, supra note 65 (stating the specific

including, but not limited to, achieving a specific goal, task avoidance, or escaping overwhelming fears or anxiety. However, the reason behind elopement is not being appropriately addressed by AngelSense technologies. AngelSense proclaims that the GPS tracking device allows parents, guardians, educators, caretakers, and emergency officials to efficiently and effectively find an individual who is in the process of running away prior to the individual becoming involved in a dangerous situation. However, the accidents that the technology is intending to prevent, such as walking into traffic or drowning, would likely occur before someone using the technology could reach the individual who is bolting from safety.

Additionally, many states recognize the right for individuals with disabilities to determine what is done to his or her own body.<sup>94</sup>

capabilities of AngelSense technology); see also Mastros, supra note 28 (stating that one issue with GPS tracking includes the potential ineffectiveness of tracking people).

<sup>&</sup>lt;sup>90</sup> See Berends, supra note 5 (detailing the reasons an individual may elope is because they are running away from something or running to something, among others). The author compares elopement to pica, in that there is a limited amount of research regarding elopement. *Id.* However, there is a consensus within the educational field that elopement is typically goal-oriented. *Id.* 

<sup>&</sup>lt;sup>91</sup> See The Unique Capabilities of AngelSense, supra note 65 (noting that the observer also receives texts whenever the wearer goes to an unexpected location). AngelSense also allows an individual to listen into the environment in which the wearer is at any time. *Id.* Notably absent is exactly how the device can prevent a death that may occur within minutes of the elopement behavior. *Id.* 

<sup>&</sup>lt;sup>92</sup> See Parents can Worry Less About their Kids Wandering with AngelSense's GPS Device, TECHRADAR (Apr. 4, 2018), archived at https://perma.cc/P2G6-KFFS (inferring that if the device can use WiFi hotspots along with the GPS outdoors, this will be effective in finding children prior to getting involved in dangerous activities); see also First Responder Overview, ANGELSENSE (Jan. 24, 2019), archived at https://perma.cc/BA5F-GGDM (elaborating that the "First Responder Group Alert" additionally gives live updates to first responders when an individual is missing). Further, the specifically chosen group is provided a live feed of the individual wearing the tracker. *Id.* 

<sup>&</sup>lt;sup>93</sup> See The Unique Capabilities of AngelSense, supra note 65 (giving examples of "close call" situations such as, traffic injuries without providing much detail as to how the technology works). Additionally, the app assumes the observer has access to a cell phone at all times, allowing them to react immediately. *Id.*; see also McIlwain & Fournier, supra note 2, at 4 (indicating how often "close calls" with traffic injuries and drowning can occur with elopers).

<sup>&</sup>lt;sup>94</sup> See Rivers v. Katz, 67 N.Y.2d 485, 492 (1986) (introducing New York's long withstanding common law belief that individuals who are "of adult years and sound mind has a right to determine what shall be done with his own body"); see also In re the Mental Health of K.K.B., 609 P.2d 747, 752 (Okla. 1980) (noting that "if the law

Arguably, this recognized right to determine what goes in and on your body also applies to devices being attached to your body, such as AngelSense. When determining whether someone is capable of making his or her own decisions, a mental illness, without more, is insufficient to determine that the person does not have the mental capacity to make decisions regarding his or her well-being. AngelSense impacts an adult's well-being, and therefore, the GPS tracking device should not be attached to an individual with Autism unless they have given informed consent, or if extensive evidence has been presented that the individual lacks the mental capacity to make the decision regarding his or her own body. 97

The most disturbing aspect of AngelSense is the inconsideration of an individual's fundamental right to make conscious choices regarding their own life. 98 Despite individuals with

recognizes the right of an individual to make decisions about...life out of respect for the dignity and autonmy of the individual, that interest is no less significant when the individual is mentally or physically ill.").

<sup>&</sup>lt;sup>95</sup> See Rivers, 67 N.Y.2d at 493 (stating that our system of government places a high grade of importance on individual autonomy, and the right to have freedom from unwanted interference with self is a right that is equally extended to individuals with disabilities).

<sup>&</sup>lt;sup>96</sup> See id. at 493-94 (concluding that mental illness and involuntary commitment, alone, does not prevent that person from refusing medical care). The court stressed that mental illness impacts every person differently, and many individuals with mental illness have the capacity to function idependently in society. *Id.* at 494.

<sup>&</sup>lt;sup>97</sup> See id. at 495 (recongnizing that mental illness does not "ipso factor" warrant a finding of incompetency; and there is evidence that individuals with mental illnesses are capable of making informed and competent decisions about their own bodies).

<sup>&</sup>lt;sup>98</sup> See The Unique Capabilities of AngelSense, supra note 65 (admitting that the AngelSense product constantly allows another person to invade the privacy of the individual wearing the device). For instance, the device provides: 1) full access to the wearer's location and routes taken throughout the day; 2) alerts when the wearer arrives at a specific destination or unknown destinations; 3) Runner Mode, which allows access to the wearer's location every 10 seconds; 4) prevents the wearer from removing the tracker from his or her clothing by required a key for removal; 5) allows the parent, guardian, or educator to listen in the wearer's environment; 6) sends alerts to a specified group of people when it is determined the wearer is missing, and provides a live view of the wearer's location to all members of the group; 7) provides instant alerts at any time the wearer is late to a specified event; 8) enables the wearer to be called at any time without need to "pick-up" the phone, essentially giving the caller access to any oral communication taking place by the wearer or individuals around him or her. *Id.; see also* Werner, *supra* note 29, at 3 (declaring that there are nationally accepted laws ensuring that individuals with disabilities are granted the

disabilities having the right to make decisions regarding their life, liberty, and property, AngelSense takes away those rights from anyone who is using the technology. For instance, the ADA requires that individuals with disabilities have an equal opportunity to participate in society and live as independently as possible, yet AngelSense allows someone else to know and control where a person goes, who a person associates with, and infringes on their right to privacy. For example, AngelSense grants a person access to see what the individual with a disability is every 30 seconds, completely eliminating any sense of privacy. In addition, the parent or guardian using AngelSense has the ability to "listen-in" at any time, infringing on not only the individual wearing the device's right to privacy, but all people around the individual. These two invasive components of AngelSense violate the wearer's right to self-determination and the wearer's liberty of movement.

AngelSense provides additional and different challenges for adults with disabilities than it does for children with disabilities. <sup>104</sup> A

same fundamental rights as all other members of society, including the right to make decisions regarding liberty and property).

<sup>&</sup>lt;sup>99</sup> See In re Zhuo, 42 N.Y.S. 3d 530, 532-33 (N.Y. Sur. 2016) (explaining that there are certain aspects disability law has the potential to infringe on the rights of individuals with disabilities and prohibit to have a say in their life choices); see also Werner, supra note 29, at 2 (stating that the basic human right of autonomy includes making decisions and communicating those decisions to others).

<sup>&</sup>lt;sup>100</sup> See In re Zhuo, 42 N.Y.S. 3d at 533 (describing how the states are obligated to carry out the promises made by the ADA to ensure people with disabilities have equal opportunity); see also The Unique Capabilities of AngelSense, supra note 65 (lacking any regard for the privacy and autonomy rights for individuals wearing the AngelSense device).

<sup>&</sup>lt;sup>101</sup> See The Unique Capabilities of AngelSense, supra note 65 (explaining that AngelSense provides GPS location of an individual at any time the person controlling the device desires).

<sup>&</sup>lt;sup>102</sup> See AngelSense GPS is MADE for Children with Special Needs, supra note 79 (defining the "Listen-In Capability" as the ability to ascertain the whereabouts of your child by listening to sounds you hear). This feature helps validate emergency situations and improves special needs child care. *Id*.

<sup>&</sup>lt;sup>103</sup> See Carr, supra note 61, at 36 (articulating that amount of independence contributes to quality of life, self-confidence, and self-worth); see also The Unique Capabilities of AngelSense, supra note 65 (detailing the various features that take away an individual's opportunity to make independent decisions including who knows where they are, who they associate with, and who hears their conversations). <sup>104</sup> See Mastros, supra note 28 (noting the discrepancy between the constitutional rights of adults and children). Generally referring to a parent's ability to have extensive control over a child's life. Id.

guardian's ability to require an adult with Autism to wear a device like AngelSense presents frightening restrictions of the rights of individual. When an individual with a disability turns eighteen the government stresses that parents should immediately file for a guardian. In guardianships, the adult with a disability essentially loses all authority over his or her own life. The guardian has the power to make all legal decisions and choices for the individual with the disability, including, but not limited to requiring the individual to wear a GPS tracker. Legally, once the guardian and court determine that they believe the GPS tracker is necessary, the adult with the disability has no voice in the matter. The individual with the disability loses all power and ability to make their own choices, and his or her voice is silenced. The restrictions of guardianship paired with the new invasive technologies leaves individuals with disabilities vulnerable to potential abuse.

The Constitution of the United States, the ADA, and the ICCPR all grant individuals with disabilities the right to autonomy, yet AngelSense fails to consider any fundamental right when attaching a

<sup>&</sup>lt;sup>105</sup> See Mastros, supra note 28 (indicating how children are not adults until 21 years old, therefore parents are able to have extensive control over their children and are able to track them with GPS devices). The International Covenant on Civil and Political Rights defines human rights for individuals with disabilities including the right to freely move and make decisions about where they live, who they associate with, and choices regarding family. *Id*.

<sup>&</sup>lt;sup>106</sup> See Rowlands, supra note 30 (asserting that the Guardianship laws are meant to protect people with autism but may actually deprive them of their basic rights and autonomy).

<sup>&</sup>lt;sup>107</sup> See Mastros, supra note 28 (expressing the concerning challenges that come along with GPS tracking, including, but not limited to, unauthorized users obtaining access to the information from the GPS); see also Rowlands, supra note 30 (insinuating that although guardianship laws intend to help individuals with disabilities, the laws often interfere with basic autonomy rights).

<sup>&</sup>lt;sup>108</sup> See Mastros, supra note 28 (reiterating that the guardian may exercise their sole discretion over any legal decisions for their autistic child).

<sup>&</sup>lt;sup>109</sup> See Rowlands, supra note 30 (discussing the extent of guardianship power).

<sup>&</sup>lt;sup>110</sup> See Rowlands, supra note 30 (explaining that guardianship often leads to individuals with disabilities being stripped of their autonomy).

<sup>&</sup>lt;sup>111</sup> See The Right to Make Choices, supra note 29 (explaining that guardianship exposes individuals with disabilities to abuse by the guardian including the guardians refusal to let the individual spend time with friends or family, forcing the individual to live in an institution or group home, making healthcare choices that the individual does not want, stealing money or misusing the money of the individual, not allowing the individual to get married, and neglecting the individual).

GPS tracking device to a person. The individual interest at stake when using AngelSense is the individual's right to make fundamental life choices, while the governmental interest is to keep society and the individual with a disability safe and healthy. <sup>112</sup> Although some instances require that someone make decisions for the adult with the disability, GPS tracking extends beyond the type of decision that one adult should be making for another adult. <sup>113</sup> Each case is unique, which makes the balancing test challenging. <sup>114</sup> However, the constitutional violations against a human being's liberty outweigh the governmental interest in keeping an individual safe if that individual is capable of making safe decisions on their own. <sup>115</sup>

Although elopement complicates the decision making process for individuals with disabilities under guardianship, there are an infinite number of cases in which the decisions can be made through supported decision making or by the individual. Courts have often made decisions regarding where to draw the line on the infringement of rights of individuals with disabilities. Just as courts determined that individuals with mental health diagnoses had a right to refuse medical treatment, individuals with disabilities who have the potential to understand the extent of what GPS tracking would entail should have the right to refuse to wear GPS tracking. Moreover, individuals with disabilities should not be subject to violations of their autonomy and privacy, and caretakers, parents, and government

<sup>&</sup>lt;sup>112</sup> See Werner, supra note 29, at 21 (stressing that individuals with disabilities have an equal right to make autonomous decisions).

<sup>&</sup>lt;sup>113</sup> See Rowlands, supra note 30 (acknowledging the need for laws to address the autonomy rights of individuals with disabilities).

<sup>&</sup>lt;sup>114</sup> See Rowlands, supra note 30 (recognizing the difficulty in making any decisions due to the individualized circumstances of each case).

<sup>&</sup>lt;sup>115</sup> See Rowlands, supra note 30 (questioning where the line must be drawn between Constitutuional rights and the government's interest in safety).

<sup>&</sup>lt;sup>116</sup> See Werner, supra note 29, at 2 (introducing the confines of supported decision making and how the concept allows individuals with disabilities to make informed decisions to the maximum extent possible, while also ensuring that they are remaining safe).

<sup>&</sup>lt;sup>117</sup> See Rivers v. Katz, 67 N.Y.2d 485, 493 (1986) (finding that mental illness does not eliminate a person's right to make their own choices).

<sup>&</sup>lt;sup>118</sup> See Werner, supra note 29, at 2 (stressing the importance of allowing individuals with all types of intellectual disabilities to be informed about all relevant information regarding their life decisions, and enabling the individuals to reflect on what they want in life in order to make intentional decisions about their life). This type of system is defined as supported decision making, and gives power back to individuals with disabilities in order to exercise their basic human rights. *Id.* 

officials should be proactive in addressing elopement, rather than trying to solve the problem reactively. <sup>119</sup> AngelSense should only be used in situations in which the individual with the disability either consents to the device, or the individual truly is not competent to make decisions that may impact his or her health, safety, or welfare. <sup>120</sup>

#### V. Conclusion

Individuals with Autism have the right to make decisions about their own lives. When the individual's disability is of lower severity, the potential for that individual to be in charge of his or her life is completely within reach through supported decision making. However, most individuals with disabilities are under guardianship, and therefore their autonomy is severely limited. As technology continues to improve, and states begin to pass laws about GPS tracking in an effort to protect certain individuals from the dangers of eloping behavior, people with disabilities lose even more of what little autonomy they had to begin with. While the fear of losing an individual

<sup>&</sup>lt;sup>119</sup> See Berends, supra note 5 (advising that elopement is a challenging behavior that can be sufficiently managed by addressing the function behind the elopement, rather than just reacting once the behavior is already in progress). For instance, the author suggests conducting a functional behavioral assessment determine what happened prior to the elopement and what happened immediately after the behavior took place. Id. The author further suggests using the discovered information to create behavioral programs that incentivizes positive behavior and rewards the individual with the function the elopement served. *Id.* For example, if the behavior is to avoid a specific task, teach the individual to ask for a break, or if the behavior is to gain access to a certain object such as food, then the individual should be taught the skills to request the food. Id.; see also Awaare Collaboration, supra note 6 (providing tools to address elopement such as door and window signs, stop signs, social stories to teach the individual to stay with the group or adult, and color-coded systems to provide visual cues to show when it is safe to go to a certain place). Moreover, wandering may be prevented by close supervision, awareness of the individual's tendency to elope by all characters, create a protocol for when wandering occurs, acknowledging known triggers for the individual's challenging behavior, and creating a safe space for the individual to go to if they feel the need to remove themselves from a situation. Id.; see also Werner, supra note 29, at 3 (describing the main contention of Article 12 and the Convention on the Rights of People with Disabilities which is to "ensure that measures relating to exercise of legal capacity respects the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances.").

<sup>&</sup>lt;sup>120</sup> See Werner, supra note 29, at 3 (providing that only when those with autism "are judged to lack decision-making capacity – should be replaced with supported decision-making models and lead the care of people with ID.").

with Autism who is in the process of eloping is a legitimate government interest and laws like Kevin and Avonte's law have good intentions, the danger of GPS tracking is potentially granting too much power to control every single aspect of a person's life. This violation of the U.S. Constitution is discriminatory against individuals with disabilities, and must be reconsidered through the lens of the individual with the disability.