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Andria Bianchi
Janet A. Vogt *Editors*

Intellectual Disabilities and Autism: Ethics and Practice

 Springer

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Editors

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*The editors would like to dedicate this book
to the people we serve, their families, and all
those who support and advocate for them.*

Foreword

Our societies have perhaps never expressed such a clear and strong desire to foster inclusion and participation. The last decades have seen numerous strides in advancing the rights of people belonging to visible minorities, of people living with disabilities, of people with different sexual and gender orientations. There has been progress. More, obviously, needs to be done to foster human practices which allow each person, regardless of their skin color, their physical or intellectual abilities, or other differences to belong, to participate, and to enact who they are.

The ability to enact who we are and to live a life we aspire to live is part of the very meaning of ethics and the cornerstone idea of human flourishing. Human flourishing, historically, was referred to by Greek thinkers as “eudaimonia”. Eudaimonia comes from the Greek “eu” (good) and “daimon” (a spirit or deity). It designated a state and a life where a person was accompanied by a good spirit such that the person made good and wise choices following the advice of this spirit in the form of an inner voice. Socrates famously claimed to be accompanied by a good daimon which he listened to attentively. By extension, eudaimonia came to be considered as a focus of ethical and political thinking. There was an intense and active search to identify what the flourishing life was and consisted of. Accordingly, different thinkers and their followers claimed to find a eudaimonic life in various sets of teachings about, for example, the nature of pleasure (e.g., Epicurus and the Epicureans) or about nature (e.g., Zeno and the Stoics) (Hadot 2002). Aristotle’s teachings on ethics and flourishing are some of the best preserved and best known. Although ethics was much about thinking and enacting a flourishing life during Greek and Roman antiquity, philosophy shied away from these more entrenched considerations as it integrated theology in medieval times. After the Renaissance, ethics soon modeled itself to the emerging new science of Bacon, Descartes Galileo, and Newton such that it tried to identify universal ethical laws and principles. It was also influenced by liberalism and movements toward democracy which made ethics relevant to all, but often at the price of being general and allergic to considering differences as it idealized a universal prototypic individual. Ethics has sporadically come back to the deeper

considerations about the flourishing life. This is starting to change (Racine 2024) following the impetus of contemporary psychology and welfare economics and work led by figures such as Nussbaum and Sen (Nussbaum 1997; Sen 2002).

The imagination of what a flourishing life is has historically been highly constrained, reflecting gender biases, sexual orientation biases, classism, and ableism. This can be seen in much of the Greek and Roman scholarly traditions which were developed by men of the elite and reflected their social position. It is also true of modern academics who reflect some of their own biases and preferences in their theories (e.g., in various instances of colonialism, sexism, and ableism). Only of late have our imaginative capabilities been questioned—mostly by the force of activism and of disability rights movements across the world—because of how excluded groups have called for inclusion and participation. These groups have contributed to expanding our imagination of what a flourishing life is. They have also made everyone realize how our own well-being and flourishing is connected to that of others. To make headway in thinking and enacting a more inclusive society, there needs to be thoughtful consideration given to the various challenges to inclusion such that constrained imaginations are enriched based on the acknowledgement of their limits. And there obviously needs to be resources dedicated to fostering different models of health and social services that afford for different views about what flourishing is and what a flourishing person is.

Such is how I understand the work and contribution of Andria Bianchi and Janet A. Vogt, the editors of *Intellectual Disabilities and Autism: Ethics and Practice*. They invite us to envision in theory and enact in practice how we can create and share opportunities for growth. It is a wonderful effort to carry forth ethics as a quest for human flourishing and human development. The editors are deeply involved in this task on a daily basis. Andria Bianchi is a clinical ethicist at Unity Health Toronto, Surrey Place, and University of Toronto, who specializes on considerations related to sex and sexual consent for people with cognitive challenges. Janet A. Vogt is a manager and senior research associate at Surrey Place, a not-for-profit organization at the service of people with developmental disabilities of all ages for the populous region of Toronto and also of the more remote Northwestern Ontario. In undertaking their volume, they wanted to sensitize, inform, and support dialogue. They need to be commended as well as all their colleagues (numbering over 40) who have delivered a truly impressive and remarkable edited volume of 31 chapters. They have managed to recruit contributors from a wide range of backgrounds, including political science, law, medicine, self-advocacy, nursing, and bioethics. Readers will learn about and reflect on the nature of disability and its moral significance, consent issues, and practices in a variety of contexts such as intimate relationships and minimal-risk research, empowerment strategies based on compelling examples and practices, issues related to health care as well as a strong focus on romantic relationships and sexual education. The feat needs to be underscored since the ability to convene so much talent and diversity implies not only undertaking an impressive amount of work but also a capacity to lead so many people in a common and powerful direction. In

many respects, to flourish is to learn about others and be on a learning trajectory. In this respect and many others, this volume is a major advance in the discussion about ethical aspects of intellectual disability. It is destined to remain a reference for a long time.

Montréal, Canada

Eric Racine, Ph.D., MCAHS

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About the Editors

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Janet A. Vogt is a senior research associate and manager at Surrey Place, with experience on their Research Ethics Board, as a co-chair of their Clinical Ethics Committee, and a founder of their Ethics Education working group. She completed her Ph.D. in Nutritional Sciences and M.H.Sc. in Bioethics at the University of Toronto and enjoys mentoring medical students, engaging them in projects to raise their awareness of bioethics issues arising in the delivery of services for people with developmental disabilities. She is on the Board of Directors for Toronto's Community Ethics Network and has led the development of an organizational ethics framework and toolkit for them. She has presented at local, national, and international conferences;

taught university courses in nutrition and research methods; and given guest lectures in bioethics at the graduate level. Her publications include peer-reviewed articles, book chapters, and tools to support health care access for people with developmental disabilities. Her education in developmental disabilities began in childhood as the sister to an older sibling with a severe developmental disability.

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Abbreviations

AASPIRE	Academic Autism Spectrum Partnership in Research and Education
ABA	Applied Behavior Analysis
ABAI	Applied Behavior Analysis International
ADA	Americans with Disabilities Act
ADAPT	American Disabled for Attendant Programs Today
ASAN	Autistic Self Advocacy Network
AT	Assistive Technology
AU	Alcohol Use
AUD	Alcohol Use Disorder
BACB®	Behavior Analyst Certification Board
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CDS	Critical Disability Studies
CPR	Cardiopulmonary Resuscitation
CRPD	Convention on the Rights of Persons with Disabilities
CW	Child Welfare
DMC	Decision Making Capacity
EPP	Employment Participation Pathway
FASD	Fetal Alcohol Spectrum Disorder
FBA	Functional Behavioral Assessment
FMS	Full Moral Status
HEEDS	Healthcare Education Engages Disability Studies
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
ICE	Initial Clinical Experience
ICF	International Classification of Functioning Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICT	Information and Communication Technologies
ID	Intellectual Disability(ies)
IDD	Intellectual and Developmental Disability(ies)
IQ	Intelligence Quotient

IT	Information Technologies
IUD	Intrauterine Device
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual, and more
MEES	Model of Embedded Employment Supports
OPZ	Openbaar Psychiatrisch Zorgcentrum
OSCE	Objective Standardized Clinical Examination
PAE	Prenatal Alcohol Exposure
PCA	Parenting Capacity Assessment
PECS	Picture Exchange Communication System
PLAN	Planned Lifetime Advocacy Network
PRN	Pro Re Nata
PSID	People with Severe Intellectual Disabilities
PWD	People with Disabilities
RDSP	Registered Disability Savings Plan
SIB	Self-Injurious Behavior
SP	Standardized Patient
STIs	Sexually Transmitted Infections
UN	United Nations
WHO	World Health Organization
YAC	Youth Advisory Council
YES	Youth Engagement Strategy

Chapter 1

Introduction



Andria Bianchi and Janet A. Vogt

Have you ever considered that people with intellectual disabilities have a right to become parents? Have you ever thought about the ways in which healthcare services tend to “treat” autistic people? How do you feel about selective termination of pregnancy based on a gene linked to a condition conferring intellectual impairment? To what extent might your feelings about these—and other questions regarding neurodiverse populations—be based on widespread ableism that pervades our organizations, systems and society? The purpose of this volume is to engage with ethically complex questions relevant to people with intellectual and developmental disabilities (IDD) and/or autistic people, as well as those caring for and working with neurodiverse populations. As editors of this collection, we bring our perspectives as a clinical ethicist and a program evaluation specialist (and sibling of a brother with a severe intellectual disability) who work together in a large developmental service agency in Toronto, Canada. The agency serves individuals of all ages, including autistic people, and those with developmental and sensory-related concerns. As the organization’s ethicist and ethics resource lead, respectively, we hear first-hand and through ethics needs assessments, about the ethical issues our clinicians and leaders encounter in their daily work. Together, we lead the Ethics Education working group in the provision of online events and resources to support the ethics education of staff.

The idea for this book came about when we discussed our respective experiences completing graduate degrees in ethics. Both of us found a paucity of examples and discussion regarding ethical issues arising from the treatment of neurodiverse

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populations and felt the ethics programs with which we were familiar paid insufficient attention to these populations. Relatedly, as an ethicist working in hospital settings, Andria has found that ethical conundrums often arise amongst clinical teams when it comes to working with autistic patients and/or patients with IDD who may present or communicate differently than people considered neurotypical. Thus, the primary reason for developing this collected volume is to give due and deserved attention to ethical issues affecting those we serve—those who are influenced by ableist stereotypes.

Ableism assumes the existence of a perfect kind of human self and body to which “disabled” people are compared unfavorably (Campbell 2001). Consequently, the life of a person with a disability may be deemed as less valuable than the life of a person without a disability (Morris 2023). Ableism involves “... stereotyping, prejudice, discrimination, and social oppression toward people with disabilities” (Bogart and Dunn 2019). Conversely, we take the view that: “... disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal bases [sic] with others, ...” (UN 2006, Preamble). Ableism contributes to the barriers to social inclusion experienced by people with IDD and many autistic people. In fact, such barriers can pervade their lives; some examples being barriers to equitable health care, sexual autonomy, meaningful employment, the necessary technology and the skills to use it, and participation in research and politics.

Starting with a framework encompassing six key areas of ethical tension that have practical implications: moral status (Chaps. 2–5); capacity and consent (Chaps. 6–9); inclusion and empowerment (Chaps. 10–18); sexuality, intimacy, romance, and parenting (Chaps. 19–22); health care (Chaps. 23–26); and ethical responses to ‘behaviours’ (Chaps. 27–31), we approached a range of early-career to seasoned authors who had published recent work in these areas. We encouraged each author to propose a specific chapter topic related to one of the aforementioned areas of tension; this process contributed to the many issues identified and perspectives taken throughout the volume. Our assertion is that in order to effectively understand and analyze ethical issues arising in our work with these populations, we must be aware of, and informed by, the work of our colleagues in other disciplines (Cox 2012). Although principles and values will always be fundamental to the process of ethical deliberation, the perspectives contributed by other disciplines can enrich our understanding of the clinical context in important ways.

In order to capture the multiple perspectives of many disciplines involved in supporting and advocating for neurodiverse populations, we invited not only ethicists, but also scholars and practitioners from various fields (psychology, philosophy/ethics, applied behavior analysis, disability studies, political science/policy, occupational therapy, social work, law, education, rehabilitation sciences, medical anthropology, epidemiology, developmental pediatrics, neurology, genetics, psychiatry, gender and sexuality, public health, and system science) to contribute chapters. Many chapters are written by clinicians and researchers whose work focuses on areas that are fraught with ethical challenges, and who offer practical ways to respond to

such challenges. Other authors turn to philosophical assistance in grappling with ethically complex questions, considering what it means to be a person, to have agency, and to make autonomous decisions. Some authors respond to relatively narrow questions (e.g., what constitutes an ethical response to alcohol use and people with IDD in Chap. 28), whereas others take up more general perennial issues (e.g., consent and capacity in Chaps. 2–5). This blend of theory and practice is intended to empower our readers to: (a) reflect on complex ethical challenges relevant to the developmental sector, each of which stem from ableist structures in our general society; and (b) learn about what people, organizations, and/or disciplines are doing in response to such ethical complexities *in practice*. Overall, each contributor to this volume critically and meaningfully examines how we ought to include and respond to autistic people and individuals with IDD in our ever-changing and ethically complex world; a world that needs to better understand and embrace neurodiversity.

Prior to collating chapters, we hosted online meetings with contributors to discuss our motive for developing the volume and explore overarching topics that relate to it. During these meetings, two particularly impactful discussions occurred. One revolved around the use of person-first language and identity-first language.¹ Several contributors to this volume have expertise in and focus their work on autistic people. As such, it was brought to our attention that neither we—as editors of this volume—nor others were necessarily nor consistently using the language endorsed by the autistic community on a large scale; namely, that of identity-first language (e.g., “Autistic person”). In response to this discussion, authors were encouraged to consider highlighting their rationale for using person- or identity-first language, specifically if their chapters focused exclusively on autistic people. The resulting volume offers some chapters that use identity-first language, with others using person-first language (e.g., people with IDD) and, as such, is fairly representative of the evolving use of language. However, it is worth noting that in our meetings and across the volume, there exists a consensus that it should be up to the person themselves whether they choose to use person- or identity-first language, and others ought to respect their preference.

The second discussion questioned the inclusion of autism spectrum disorder and intellectual (and developmental) disabilities in the same volume and under the same umbrella, as it were. The simple response is that we, as co-editors, work for an organization that supports both groups and consequently, the ethical tensions we identified are applicable, to a greater or lesser extent, to both populations. One reason that the ethical tensions apply to both groups is, at least in part, because we live in an ableist society (Nario-Redmond et al. 2019)—a society that continues not to support neurodiversity in the right kinds of ways. As a consequence, both groups may experience similar kinds of challenges in health care environments, stigma in relation to parenting, questions about their moral worthiness, and require similar accommodations in order to participate meaningfully in day-to-day activities. In addition, recent data suggests that approximately 40 percent of autistic individuals

¹ For a brief overview of person-first and identity-first languages, and the importance of a person-centered approach, refer to Chap. 23, Sect. 3.3.

are likely to have a co-occurring intellectual impairment (Christensen and Zubler 2020). Consequently, readers will find that the focus of individual chapters may be solely on autism, on IDD, or inclusive of people with IDD and/or on the autism spectrum; however, the theme of ableism and the way in which its prevalence pervades the lives of, and workings with, those who are neurodiverse is embedded across all.

With a desire to identify and respond to the many ways that ableism infiltrates our society, subjecting people with IDD and/or those on the autism spectrum to unjust treatment, this book aims to influence bioethicists, ethics students, social justice scholars, and those interested in autism and IDD (e.g., clinicians, service providers, researchers, and policy makers) to learn about and meaningfully reflect upon difficult, timely, and debated ethics questions. Although there exists a range of disciplinary perspectives and approaches to ethics questions across the volume, many of the arguments and discussions put forward in this book resonate with various articles of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006). The purpose of the CRPD is to help protect the rights of people with disabilities worldwide, as guided by eight general principles: respect for the individual's inherent dignity and autonomy; non-discrimination; full and effective inclusion and participation in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; gender equality; and respect for the evolving capacities of children with disabilities (CRPD, Article 3). In spite of the broad range of rights promoted and protected in the CRPD, people with IDD still encounter barriers to accessing these rights and the people who support them may experience significant moral distress as a result (Fisher et al. 2020).

The primary themes explored in this book are what separate each section, though there exists some overlap across sections. By working through this volume, we hope that readers will be better positioned to think differently about and/or respond differently in practice to ethically complex circumstances that arise in their day-to-day work and lives in relation to those who are neurodiverse.

1.1 Moral Status

The first section explores how one might reconceptualize the way we determine the moral status of people with intellectual disabilities. This broad topic is explored in different ways across four chapters, each of which ultimately argues in support of the moral status of people with IDD. In Chap. 2, Jonas-Sébastien Beaudry examines shortcomings of the social contract tradition when considering the moral status of people with severe IDD. He introduces strategies that others have employed to try to include people with disabilities in contractual justice theories. Ultimately, Beaudry demonstrates that none of the strategies can ground a robust moral status for people with severe IDD or, if they do, then their status is merely derivative or contingent. The chapter succinctly presents some key arguments that can be found in Beaudry's book (2021). In Chap. 3, Abraham Graber approaches the debate regarding moral

status and individuals with IDD in an entirely different way. More specifically, Graber introduces a particular quality of love that is sufficient for its object to have full moral status. In the end, Graber's proposal demonstrates that people with IDD have full moral status based on their being loved in this particular kind of way—a way that would not necessarily apply to non-human animals. Similar to Beaudry's opening chapter, Chap. 4 written by Stacy Clifford Simplican, explores the moral status of people with IDD through the lens of the social contract tradition. However, instead of making arguments in relation to the social contract itself, Simplican uses a lens of social contract theory to analyze the 2019 film, *The Peanut Butter Falcon*. Based on her analysis, Simplican argues that the film is important not only because it focuses on a person with an intellectual disability, but also because of the ways that it envisions ethical futures for vulnerable adults in a landscape of neoliberal neglect. Chapter 5 concludes this section of the book, where Chris Kaposy discusses moral progress around the neonatal care of infants born with Down Syndrome during the period from Baby Doe to the present day. In this chapter, Kaposy discusses morally relevant similarities that exist between selective abortion and infanticide/not treating infants with Down Syndrome who have curable conditions, followed by how the Baby Doe case helped make moral progress for people with Down Syndrome. Although Kaposy concludes by saying that moral progress is tangible, he notes that widespread ableism contributes to its fragility. This chapter resonates with Article 10 of the CRPD (right to life).

While the approaches to exploring moral status differ, each chapter in this section acknowledges challenges that exist in thinking about moral status in certain kinds of ways in relation to people with IDD. Furthermore, all authors put forward some possible way to reconceive moral status such that people with IDD would be recognized as moral agents. And insofar as people with IDD have moral status, then they ought to be treated in ways that are exemplified by the CRPD, which are not necessarily reflected in our ableist society.

1.2 Capacity and Consent

The chapters in this section of this volume focus on the perennial topics of consent and capacity. In Chap. 6, Abraham Graber discusses Britney Spears's conservatorship to describe the tension that may exist between the moral obligation to respect a person's autonomy and the legal authority often granted to others who oversee the affairs of a person with IDD. Graber distinguishes between capacity (a clinical property) and competence (a legal property), where it is presumed that Spears had *capacity* to consent to certain medical interventions but lacked *competence* due to her conservatorship. In similar kinds of ways, many people with IDD may be capable of consenting to certain health interventions yet have a guardian in place

who has legal authorization to make all decisions on their behalf. Through his analysis, Graber encourages readers to explore the moral obligations that may exist to respect a person's capable preferences even if they lack competence. In Chap. 7, Marjorie Aunos, Maurice Feldman, and Laura Pacheco present challenges associated with parenting capacity assessments that are frequently used within the child welfare decision-making process for parents with IDD. This area of the developmental sector is fraught with ableist biases regarding who should versus should not parent. In response, the authors present a parenting model specific to the needs of parents with IDD, which may be a more ethically defensible approach to child protection intervention cases involving these parents, particularly insofar as the right to parent is protected by the CRPD. In Chap. 8, Andria Bianchi discusses the value-laden and taboo topic of sexual consent and people with IDD. Bianchi highlights that traditional conceptions of sexual consent may be unhelpful for some people with IDD, which may lead members of our society to inaccurately conclude that they cannot consent in ways that would make the relevant act ethically licit. However, insofar as some people with IDD may want and have a right to engage in relationships that are sexual in nature (as per Article 23 of the CRPD), then it is important to explore different consent mechanisms. Bianchi offers one possible model of consent for consideration, though stops short of necessarily endorsing it. In Chap. 9, Janet A. Vogt examines the informed consent process that is traditionally used for research participation in relation to people with IDD. Vogt argues that there exists an ethical imperative to provide accommodations during research consent processes to reduce the context-specific vulnerability of adults with IDD. Her argument aligns with one of the main messages of the CRPD; namely the importance of reasonable accommodation(s) to support "... the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field" (UN 2006).

Ethical complexities associated with consent and capacity are prevalent in our ableist society. In general, there exists a widespread assumption that people with IDD are incapable of consenting to, or even making rational decisions about important aspects related to their lives. This assumption is inaccurate. The four chapters included in this section speak to a handful of the many areas within which our assumptions about consent and capacity in relation to people with IDD can cause harm and prevent certain rights from being realized. As co-editors, we recognize that the challenges surrounding consent and capacity could fill an entire volume. For example, we recommend Khemka and Hickson's excellent book, *Decision Making by Individuals with Intellectual and Developmental Disabilities: Integrating Research into Practice* for discussion of such topics as supported decision making (Khemka and Hickson 2021). However, we elected to include just four primary topics in this volume to serve as an introduction to this important area.

1.3 Inclusion and Empowerment: Society, Systems, and Ethics

This section includes chapters that focus on inclusion and empowerment within communities, systems, and society. In Chap. 10, Tess Sheldon examines the distance that exists between law and justice for people labelled with intellectual disabilities and calls for a disability-inclusive approach to understanding access to justice. Citing CRPD Articles 12 (equal recognition before the law) and 13 (access to justice), Sheldon critiques the use of clear language judgments as a strategy to improve the understanding of legal information. In Chap. 11, Dora M. Raymaker introduces four ethical tensions in the landscape of autism research (models of disability, definitions of normality, politics of inclusion, and research priorities) and helps us understand the knowledge-power dynamics that contribute to such tensions by applying a critical-systems-thinking lens. Raymaker then describes how Meadow's framework for leverage can be used to intentionally work toward more inclusive and empowered futures. In Chap. 12, Joy F. Johnson and Jacob A. Sadavoy discuss the value of social validity in relation to the field of behaviour analysis. Additionally, they argue that systemic ableism limits a practitioner's ability to provide care that is both meaningful and individualized. In Chap. 13, Parker Gamble and Lorraine Krall McCrary argue that the ability for people with disabilities to participate in local associations and local government is a matter of justice; work that resonates with CRPD Article 29 (participation in political and public life). With this in mind, the authors introduce the principle of subsidiarity as one that would support the empowerment of people with disabilities to participate in local governance while also protecting them against abuse.

The four chapters in this section discuss different parts of our society (e.g., law, research, health care, politics) wherein autistic people and/or people with IDD are neither recognized nor included in meaningful and ethically defensible ways. This failure to treat those who are neurodiverse in ways that are inclusive is, in large part, due to the prevalence of ableist norms. In response, each author presents arguments in support of inclusion and empowerment and offers suggestions of how our society can enhance our inclusion of neurodiverse populations.

1.4 Inclusion and Empowerment: Practical Approaches

While the chapters in Sect. 1.3 discuss inclusion and empowerment from a primarily theoretical perspective, those in this section each provide a robust practical approach to inclusion and empowerment. In Chap. 14, Gabriel M. Ronen and Peter L. Rosenbaum argue for the use of the World Health Organization's International Classification of Functioning, Disability and Health (the ICF) as an ethical framework for working with people with IDD (WHO 2001). Referencing Beauchamp and Childress's Four Principles approach (2013), they argue that the ICF offers opportunities

to contextualize a person with any health “impairment” in terms of their functioning, personal values and preferences, and environments. In Chap. 15, Jane Seale discusses conflicting risk discourses that have influenced the support practices that enable adults with learning disabilities to access and use technologies. In a chapter that aligns with CRPD Article 9 (accessibility), Seale examines the potential of ethical frameworks to offer a way forward, concludes that the ethics literature supports a possibility-focused approach, and argues that ethicists should collaborate with people with learning disabilities and researchers to develop ethically-informed digitally inclusive support practices for adults with IDD. In Chap. 16, Meghan M. Burke, Chak Li, Amanda Johnston, and Adriana Kaori Terol examine parent advocacy and self-advocacy, focusing on the need to balance the two, especially in cases where their respective goals may differ. The authors argue that person-family interdependent planning ought to be used in order to harmonize these advocacy efforts and ensure positive outcomes for the individuals concerned. In Chap. 17, Laura R. Bowman, Carolyn McDougall, and Dolly Menna-Dack consider how employment settings, policies, community supports, and other contextual factors might need to change to meet the needs of individuals with IDD and/or autism. Referencing CRPD Articles 26 (habilitation and rehabilitation) and 27 (work and employment), they advocate for ecologically-based employment pathways to facilitate a more just and inclusive employment context and describe an example of one such approach. In the chapter, a practical example from the authors’ workplace is provided, namely that of the Employment Participation Pathway model, which demonstrates a best practice approach to employment engagement. In Chap. 18, Dolly Menna-Dack and Laura R. Bowman argue for the importance and benefits of empowering youth with disabilities to develop self-advocacy skills for themselves and on behalf of their community. The authors describe their Youth Engagement Strategy which provides opportunities for youth to develop advocacy skills while contributing to the creation of new programs and policies within their organization.

This section of the book offers concrete examples of how we can include, empower, and respond to autistic people and/or those with IDD in our society in the right kinds of ways, i.e., in ways that respond to ableist norms and structures. Although each author focuses on a different area of practice, each practical approach is ethically defensible by virtue of arguments offered within and outside of this section. This section of the book provides various tables and diagrams that may be particularly helpful for readers working on the ground (e.g., clinical staff, program development specialists, etc.).

1.5 Sexuality, Intimacy, Romance, and Parenting

These chapters consider the challenges people with IDD and/or autism may face when trying to express their sexuality, engage in intimate relationships, or have children. Many of these challenges resonate with specific CRPD articles such as the rights: to access education, including sex education (Article 24); to access the same range of

health programs provided to others, including reproductive health services (Article 25); to marry and have children (Article 23); and to be afforded equal recognition before the law (Article 12). In Chap. 19, Robyn M. Powell reviews the profound impacts of ableism on the sexual, reproductive, and parenting rights of people with IDD. Powell offers recommendations to confront and dismantle these impacts by transforming laws, policies, and practices. In Chap. 20, Marina Heifetz provides an overview of how people with IDD conceptualize and experience romantic relationships, discussing the implications of sheltering these individuals from open and informative discussions of romantic relationships and sexuality. Ultimately, Heifetz poses recommendations to mitigate the risks associated with unplanned pregnancies, sexually transmitted infection, and abuse. In Chap. 21, Elizabeth K. Schmidt argues for accessible, inclusive, and comprehensive sexual health education to support the sexuality-related rights of people with IDD. This can be provided by parents, caregivers, educators, health providers, and peers and may utilize a variety of different approaches. Done properly, such education can improve sexual self-advocacy and support the sexuality-related rights articulated in the CRPD. In Chap. 22, Laura Pacheco examines the ways in which dominant and community cultures shape the life story of a parent with IDD. She introduces us to Maria, a resilient woman with IDD who is determined to raise her children in a loving environment. Pacheco explores the implications for socially just ethical practice.

The chapters in this section each discuss a unique aspect related to sex, romance, parenting, and/or intimacy in relation to people with IDD. These topics are value-laden and ethically controversial. As a society, we seldom discuss sex, intimacy, parenting, and romance *in general*, and certainly not regarding those who are neurodiverse. At least part of the reason that we do not give sufficient attention to these matters when thinking about people with IDD is because of ableist stereotypes, which lead members of our society to believe that people with IDD are not sexual, not fit for parenthood, and not interested in relationships. Each chapter in this section responds to the widespread ableist stereotypes by discussing these taboo topics in a manner that accords with the CRPD.

1.6 Health Care

This section includes chapters related to health care, broadly speaking. People with IDD experience a wide range of health inequities (WHO 2022). In Chap. 23, Shay Dawson, M. Ariel Cascio, Meredith Wiles, and Neli Ragina tackle the challenge of diversifying healthcare students' knowledge of disabled patient populations and fostering compassionate practice techniques. To this end, the authors provide an overview of their innovative approach to medical curriculum change—HEED. In Chap. 24, Hilary K. Brown presents data that highlights the many inequities in women's reproductive health, as experienced by women with IDD; data which flies in the face of common assumptions regarding the reproductive status of individuals with IDD. Citing CRPD Articles 23 (respect for home and the family) and 25

(health), Brown advocates for significant changes to health care provision, including reasonable accommodations for people with IDD and specific training for healthcare professionals. In Chap. 25, Julie S. Armin and Heather J. Williamson examine case reports of cancer treatment for people with IDD, including examples of their not receiving standard-of-cancer-care; their exclusion from cancer research; and their limited involvement in decision making about their care. Their chapter concludes with recommendations for ethical treatment practices. In Chap. 26, Tim Stainton and Trudo Lemmens discuss euthanasia and people with IDD, elucidating some key areas of ethical concern, and posing a critical question. With the rapid expansion of euthanasia and assisted suicide, are we heading into an era of quiet, more “subtle” eugenics?

The chapters in this section focus on different areas of health care but take a similar approach. Each chapter acknowledges that gaps exist in our traditional health care system. Our health care system is not built *with* nor *for* autistic people or people with IDD, making it such that those who are neurodiverse can easily fall through the cracks. Each author in this section encourages readers to think hard about how health care is structured, the ways that neurodiverse individuals are/are not treated, and particular kinds of challenges that may exist for those who are neurodiverse given the context within which they live and receive care (i.e., one that is ableist).

1.7 Ethical Responses to ‘Behaviours’

The chapters in this section explore ethical responses to behaviours that may be perceived as “difficult”. In Chap. 27, Elspeth Bradley and Janet A. Vogt argue that organizations ought to broaden their understanding of “patient” safety and embrace practices that contribute to the person’s *felt sense* of being safe. Drawing on Porges’s polyvagal theory and Ramsden’s cultural safety theory, the authors argue that we have an ethical imperative to engender a feeling of safety in service recipients, thereby preventing emotional distress and behaviours that challenge services. In Chap. 28, Brooke Magel and Daniel Z. Buchman introduce the topic of harm reduction as an approach for people with IDD who use alcohol and/or may have alcohol use disorder, highlighting the alignment between the principles of harm reduction and concepts such as dignity of risk, choice, and autonomy. Ultimately, they argue that not only is harm reduction an ethically justifiable approach; people with IDD ought to lead harm reduction strategies to ensure alignment with the community’s needs. In Chap. 29, Peter Sturmey provides an overview of the reduction of restraint and restrictive behaviour management practices. In his chapter, Sturmey points to their widespread use in educational and residential settings for people with disabilities and argues that the use of restraint raises numerous ethical questions for human services. In Chap. 30, Kiruthiha Vimalakanthan and Valerie Temple discuss the many unique ethical challenges for professionals arising in the assessment, treatment, and support of individuals and families living with Fetal Alcohol Spectrum Disorder (FASD), stemming from its link with maternal alcohol consumption. Their chapter closes

with recommendations for improving our approach and support for these families. Finally, in the closing chapter, Nicole Luke and Janet A. Vogt propose an approach to training behaviour analysts in ethical deliberation, informed by the principles of reflective practice, and demonstrated using a case involving behaviours that challenge services. As they point out, this approach can be used to train learners and practitioners in any of the many disciplines who support autistic people and those with IDD.

Although various actions expressed by autistic people and/or people with IDD may be considered “behaviours” of some kind, the chapters in this section each focus on behaviours that may be considered particularly challenging or problematic from clinical perspectives. Value judgments may be placed on many, if not all, of the behaviours discussed in this section (e.g., “bad”, “poor”, “challenging”), and these judgments may influence those on the ground to respond in ways that are ethically concerning (e.g., inappropriate use of restraints). Each of the chapters in this final section encourage readers to question their assumptions about behaviours, which may be rooted in ableist traditions, and offer proportional responses that can be ethically defended.

In conclusion, as editors of this volume, we have aimed to offer a broad-ranging look at some of the ethical challenges experienced by, or in relation to, autistic people and persons with IDD. Although the contributors come from a multitude of backgrounds, each of them shares a common interest in raising awareness of and providing ethical responses to the needs of people with IDD and those on the autism spectrum. The reader will note that the boundaries between sections of the book are not inflexible and similar ideas and arguments will be encountered in chapters residing in different sections. The reader is therefore encouraged to explore the whole book to gain an appreciation of some of the many viewpoints currently occupying this space. That said, we do not claim to have encompassed all important topics related to ethics and IDD and/or autism. There is room for many more volumes of this kind.

We are grateful to have worked with such accomplished and dedicated authors in developing this volume. This book is intended to appeal to bioethicists (and bioethics students) as well as people with an interest in IDD and/or autism, such as researchers, clinicians, service providers, and policy makers. The volume strives to contain materials to challenge readers from undergraduate to post-doctoral levels. Our overall hope is that with more awareness of the issues and challenges, and some exposure to a positive framing of these, the volume may contribute to a better understanding of, and broader advocacy for, the rights and ethical treatment of autistic people and individuals with IDD.

References

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