Affirming Neurodiversity

Autism is ever more considered an expression of neurodiversity, instead of a disorder. But what does this paradigm shift mean for clinical care for autistic people and their relatives? This doctoral dissertation explores the ethics of early autism detection and intervention. It investigates what good and just early autism care could look like in this era of neurodiversity. The research presented here consists of interview studies with autistic adolescents and with parents of young (potentially) autistic children. It also entails applied ethical reflections inspired by the fields of (feminist) bioethics, disability studies and crip theory. The dissertation concludes with a call to reform, not abandon, early clinical autism care and provides directions towards neurodiversity-affirmative approaches to care.

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Gert-Jan Vanaken Affirming Neurodiversity

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A study on the ethics of early autism detection and intervention

Gert-Jan Vanaken 2023

Supervisors: prof. dr. Ilse Noens and prof. dr. Kristien Hens
Co-supervisor: prof. dr. Jean Steyaert

Doctoral thesis offered to obtain the degree of Doctor of Educational Sciences at KU Leuven and Doctor of Philosophy at University of Antwerp

Parenting and Special Education Research Unit, Faculty of Psychology and Educational Sciences at KU Leuven.
Centre For Ethics, Faculty of Philosophy at University of Antwerp.

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Textual description of the cover design

The cover of this dissertation has been designed by Wout Neirynck (Studio Walter). A bright, blurry and multicoloured rectangular shape depicting a large colour spectrum takes centre stage on the front cover. The variety of colours celebrates the multitude of ways to experience and engage with the world, captured under the banner of neurodiversity. The shape's fading boundaries embrace the impossibility to demarcate neurodiversity neatly and play into the deliberate fluidity of the concept. The rectangle might also remind of a window frame referring to neurodiversity as a framework or a lens through which one can view and investigate the world to make it a better and more just place. The blurry view suggests though that employing this neurodiversity lens is very much an ongoing process, an activity that requires careful focussing.

Summary

Affirming neurodiversity: a study on the ethics of early autism detection and intervention

Autism is ever more considered an expression of neurodiversity, instead of a disorder. But what does this shift mean for clinical care for autistic people and their relatives? This doctoral dissertation explores the ethics of early autism detection and intervention. It investigates what good and just early autism care could look like in this era of neurodiversity. The first two introductory chapters unpack this ethical debate. I provide a state-of-the-art overview of early autism detection and intervention research, and I discuss the neurodiversity movement's critical appraisal of such practices.

Four stand-alone studies make up the main part of this dissertation. In the first study, my colleagues and I analysed the ethics of returning children's individual research findings to their parents in the context of early autism research. For the second and third study, we conducted in-depth interviews to explore the lived experiences and opinions regarding early autism care among autistic adolescents, and parents of a young (potentially) autistic child. In the fourth study, I explored insights from disability studies and crip theory alongside a feminist ethics' understanding of 'vulnerability' to analyse the ethics of early autism interventions.

The dissertation concludes with a final chapter bringing together the main findings of these four studies. Here, I call to reform, not abandon, early clinical autism care. To this extent, I provide three guiding elements towards neurodiversity-affirmative approaches to autism care. First, I suggest carefully reconceptualising autism 'diagnosis' and 'intervention': depathologising autism as such and readjusting interventions to target autistics-endorsed priorities. Second, I call for a careful revision of 'expert knowledge' by including autistic experts by experience in clinical practice. Lastly, I propose that clinical autism practitioners carefully, but explicitly embrace the political dimensions of their work and become active allies in the struggle for autistic emancipation.

Samenvatting

Neurodiversiteit bekrachtigen: een studie naar de ethiek van vroege autisme detectie en interventie

Autisme wordt steeds vaker beschouwd als een uiting van neurodiversiteit, in plaats van als een stoornis. Maar wat betekent deze verschuiving voor de klinische zorg voor autistische mensen en hun familieleden? In dit proefschrift bestudeer ik de ethiek van vroege autismedetectie en -interventie en ga ik na hoe goede en rechtvaardige zorg eruit kan zien in dit tijdperk van neurodiversiteit. In de eerste twee inleidende hoofdstukken geef ik een actueel overzicht van het vroegdetectie en -interventie onderzoek, en bespreek ik de kritische houding van de neurodiversiteitsbeweging hieromtrent.

Vier op zichzelf staande studies vormen de hoofdmoot van dit proefschrift. In de eerste studie analyseerden mijn collega's en ik de ethiek van het terugrapporteren van individuele onderzoeksresultaten van kinderen aan hun ouders in de context van autismeonderzoek. Voor de tweede en derde studie voerden we diepte-interviews met ouders van een jong, (mogelijks) autistisch kind, en met autistische adolescenten om hun geleefde ervaringen en opvattingen over vroege autismezorg in kaart te brengen. In de vierde studie combineerde ik inzichten uit *disability studies* en crip-theorie met een feministisch begrip van 'kwetsbaarheid' om de ethiek van vroege autisme-interventies te analyseren.

In het slothoofdstuk breng ik mijn belangrijkste bevindingen samen met een oproep tot hervorming. Drie richtinggevende elementen zetten ons op weg naar een neurodiversiteitsbekrachtigende autismezorg. Ten eerste stel ik voor de begrippen 'diagnose' en 'interventie' zorgvuldig te herconceptualiseren: autisme als zodanig dienen we te depathologiseren en interventies dienen afgestemd op de prioriteiten van autistische mensen zelf. Ten tweede suggereer ik een zorgvuldige herinterpretatie van de rol van de ‘expert’: autistische ervaringsdeskundigen verdienen hun plek in de klinische praktijk. Ten slotte roep ik clinici op de politieke dimensies van hun werk te omarmen en zich actieve bondgenoten te tonen in de strijd voor autistische emancipatie.

'For sure, everybody is different.
For me, autism, is simply a group of people sharing a similar difference in their brains compared to what society calls the norm.
And those people have more difficulties with certain stuff, for example, filtering background noises or dealing with inconsistencies.
Something which is maybe better known is ADHD or ADD. Autism is a similar disorder.
You function differently, but that does not mean that there is something wrong with you per se.'

Interview quote from a 17-year-old, autistic adolescent

'I have written this book because I desire crip futures: futures that embrace disabled people, futures that imagine disability differently, futures that support multiple ways of being.'

Alison Kafer

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Preface

The field of autism research finds itself amidst a series of structural changes. For decades, autism has been studied in Western countries as an undesirable set of deficits squarely situated within the individual. The agenda of autism research has been determined for the most part by non-autistic scholars. On the top of this agenda were efforts to pin down autism by trying to explain its genetic, neurobiological or psychological causal mechanisms, next to attempts at developing interventions to remedy, treat and even prevent, or cure, autism. Starting in the 1990s, and much more forcefully in recent years, autistic academics, community organisers, self-advocates, activists and their allies have started challenging this conventional, medical approach to autism. Rather than focusing on deficits, autism is considered an expression of neurodiversity. Rather than limiting autistic features to the boundaries of the individual body and mind, social and societal contexts are pointed to as potentially enabling or disabling for autistic people. And rather than staying side-lined, autistic people and autistic-led organisations demand their place at the discussion table in the form of participatory research practices and they advocate for autistics-endorsed research priorities (Pellicano & den Houting, 2022).

It is against the backdrop of these ongoing changes in the autism field that I have investigated the question of whether and how early autism care for young autistic children and their caregivers could be shaped in an ethically justifiable way. Or briefer, what could *good and just* early, clinical autism care look like in the era of neurodiversity?

Overview of the Dissertation

This doctoral dissertation consists of three parts: Part One: Introduction, Part Two: Main, and Part Three: Discussion and Conclusions. In Part One: Introduction, there are two chapters. Chapter 1 introduces autism as such and provides an overview of the current state of early autism detection and intervention research. The chapter concludes with a discussion of emerging ethical reflections on these early autism programmes. Chapter 2 introduces the neurodiversity movement. It will describe the movement both as a social movement and as an academic school of thought linked to the fields of disability and crip studies. At the end of this second chapter, I will provide my working definition of the *neurodiversity paradigm* as this is the critical lens through which I have viewed my research project.

Part Two: Main is a compilation of four, standalone journal articles. In these four articles, I report on the various studies I have conducted over the past years in collaboration with my supervisors and colleagues. These articles have been published or are under review in peer-reviewed academic journals as I will indicate more precisely at the start of each chapter. For reasons of consistency, slight modifications have been made to chapters already published elsewhere to blend in with the choices for British English spelling and APA (7th ed.) referencing style of this dissertation.

Chapter 3 describes a more traditional and applied ethical analysis, on whether and how to return children's individual research findings to their caregivers in early autism detection and similar research. Here, we argue that researchers have a limited, not all-encompassing, responsibility to return only those findings that are clinically significant and actionable. Chapters 4 and 5 report on two in-depth interview studies. In the first study, we interviewed 24 parents whose infant participates in a longitudinal, prospective early detection study with children at an increased likelihood for autism, regarding their experienced benefits and risks of such early detection programmes. In the second

study, we interviewed 18 autistic adolescents between the age of 16 and 18 with diverse intellectual abilities to understand their opinions and experiences regarding the 'right' timing of an autism diagnosis, if such an ideal moment exists at all. Chapter 6 is a theoretical paper where I explored the value of a disability-sensitive interpretation of the concept of vulnerability to reflect on the ethics of early autism intervention. Thinking along with feminist ethicists, I propose that a nuanced understanding of vulnerability can ground a neurodiversity-affirmative approach to autism care in the spirit of solidarity and empowerment.

Part Three: Discussion and conclusions wraps up this dissertation with a final chapter and an epilogue. Chapter 7 returns to my initial research question: what could *good and just* early, clinical autism care look like in the era of neurodiversity? In this last chapter, I will reflect on my research process and formulate three guiding elements which can help us shape neurodiversity-affirmative approaches to early, clinical autism care. The very last pages of this dissertation consist of an epilogue. Here I will present the novel research project my colleagues and I have embarked upon, inspired by the conclusions of this dissertation.

Language Matters

Language is something powerful. The language we choose to describe phenomena often discloses how we understand these very phenomena on a more fundamental level. Language hardly ever describes or represents the world around us in an entirely neutral way. Language choices often involve a certain position-taking and language has the power to influence actions people take or avoid. Even when certain terms and discourses are commonly used, it is still relevant to be aware of the political, cultural, and historical contexts in which these terms have become part of everyday language. Below, I will elaborate on the example of combat metaphors which stem from the era when parent

advocacy groups were the leading force in autism advocacy. Beyond describing what *is*, language can also have the power to generate space for and speculate about what *could be*. Using certain words, terms and discourses, and avoiding others, contributes to shaping the worlds we wish to see (Bottema-Beutel et al., 2021). Therefore, language obviously matters and I find it important to justify some of the language choices I have made in this dissertation.

In Chapter 1, I choose to stick mainly with the terminology, discourse and ways of reasoning prevalent in early detection and intervention research. Here, I intend to give an overview of these lines of research and illustrate the ways autism and autistic people are approached, without immediately calling a value judgement. Hereby, I hope to take and keep all readers of this dissertation on board, irrespective of professional backgrounds and ideological commitments regarding autism. I do realise, however, that some terminology that is (or was) frequently used in the field of early autism science has been flagged as harmful for autistic people because it reproduces a medical autism discourse including its inherent power relations. Early on in my PhD research, an autistic man pointed out to me that much of the early autism terminology has military connotations as if the goal of early autism care is not to help autistic children and their relatives but to fight or eradicate autism (Van Goidsenhoven & Vanaken, 2021). Examples of such words are 'risk', 'red flags', 'surveillance', 'test battery', 'intervention' etc. Some researchers have even described 'social interaction as the *battlefield* [emphasis added] of neurodevelopment' (Klin, 2019). As Anne McGuire (2016) points out forcefully in her book *War on Autism*, these combat metaphors have roots in autism's parental advocacy history and have real impacts on the way people with autism are treated[1]. It is tempting to judge the choice for these kinds of metaphors negatively anno 2023. Especially names

[1] I admit that some combat metaphors will pop up below, be it however to discuss the neurodiversity movement's 'struggle' for emancipation and its 'fighting against' injustices. I realise that using such language lightly might promote a certain (perhaps toxic) masculinity and idolising conflict over compromise. Yet, my point here is that I am not opposed to this in general but that we should only mobilise such combat metaphors when we have convincing reasons to put up a fight which I believe we have as neurodiversity proponents and allies.

such as ‘Defeat Autism Now! (DAN!) are provocative. These metaphors and phrasings are provocative since autism is experienced by many as part of their identity nowadays. In this line of thought, ‘defeating autism’, therefore equates to denying’ autistic people’s right to be in the world. Yet, as I will touch upon briefly in Chapter 2, parent advocacy groups’ historical struggle for treatments, cures and prevention of autism, has to be understood against the backdrop of psychogenic mother-blaming theories, systemic institutionalisation of ‘feeble-minded’ children and an enormous lack of adequate clinical support for autistic children and their caregivers (Eyal, 2010; Silberman, 2015). This historical information does not justify the ongoing use of anti-autistic, combat metaphors but it gives some contextualisation of their origin at least.

So, in the opening Chapter, I will balance two aims: (1) to provide a fair representation of the field of early autism detection and intervention research, and (2) to avoid additional harm to autistic people by using offensive language. To this extent, I have chosen to continue using certain terms such as ‘risk’ in this first chapter, be it always between quotation marks (‘’). In subsequent chapters, I have diverged more from the jargon in the field of clinical autism research. Here, my choices have been guided in the first place by reported preferences of autistic communities rather than by conveniences in mainstream clinical autism research.

As mentioned, language can also have the power to shape and reshape reality (Bottema-Beutel et al., 2021). Therefore, for me, it is a matter of doing good research to choose language that is accurate, inclusive and where possible emancipatory[2]. For example, I have opted to use ‘autism’ as an umbrella term rather than ‘autism spectrum disorder’ or ‘ASD’. The latter two terms represent a more narrow clinical operationalisation of the phenomenon ‘autism’. This is often useful in clinical settings, although it was less appropriate for my research project as ‘ASD’ implies a direct coupling of autistic characteristics to distress

[2] For a more elaborate argumentation on how accurate, inclusive and emancipatory language contributes to better research, I refer to a presentation on language use in autism research I gave a few times to fellow autism researchers (Vanaken, 2022a).

and disfunction. ‘Autism’, then, is not only preferred by many autistic people and therefore more inclusive (Keating et al., 2022), this term also offers me more space to capture and highlight the ‘many meanings of autism’ (Hens, 2019), including experiential, social, cultural, political dimensions of the phenomenon. For reasons of accuracy and specificity, I will sometimes use ‘autism spectrum disorder’ to refer to autism as a clinical diagnosis operationalised in handbooks such as DSM 5. Lastly, writing about ‘autism’ instead of ‘autism spectrum disorder’ has a speculative, emancipatory function. By using this term, I aim to contribute to a future where autistic characteristics can be recognised, accommodated for and squarely welcomed, rather than pitied, feared or opposed by default. In Chapter 7 I continue this speculation on reconceptualising ASD to autism.

In this dissertation, I have chosen to use mainly *identity-first* language, rather than *person-first* language. This was, however, a slightly less evident choice than it might seem. In Dutch-speaking contexts, most autistic people currently prefer to describe themselves as people with autism (Buijsman et al., 2022). This is the reason that we, in our research groups, often alternate between identity-first and person-first language in our publications and presentations, especially when communicating in Dutch. Yet, in this dissertation in English where I am explicitly exploring neurodiversity approaches to early autism care, it feels more appropriate to stick with identity-first language. In Chapter 3, the first journal paper I wrote during my PhD research, I deviated from what I am saying here. My insights with regards to language matters have changed (for the better, hopefully) over the past years. The contrast between my claims in this Preface and the choices I have made in that paper illustrates this change. I hope readers will bear with me there. Also, I am convinced that some of the deliberate language choices I have made in more recent work might come under pressure in the future as (my) ideas continue to change. One such example might be the word ‘interventions’. This term is commonly used in psychiatric, psychological and educational practices to refer to a wide range of support, counselling,

training and therapies. Some neurodiversity scholars have also used it in this broad sense (Kapp, 2020b). However, the word seems to suggest that a certain spontaneous process, development or behaviour needs to be halted and altered by an external party, like a military intervention by a foreign nation to force a regime change. Also, when I talk about 'early interventions' to an audience of autistic people, this sparks immediate thoughts on strictly behavioural interventions such as Applied Behavioural Analysis (ABA) which then overshadow the conversation. Terms such as early support or early (clinical) care might be better alternatives. I will explore this further in my final chapter.

Positionality

Next to justifying language choices, I find it important to dedicate some words to my position as a researcher, to the academic settings and to the societal context that set the stage for this research project. All research questions and answers are, indeed, embedded in and influenced by a specific context. By sharing the most relevant aspects of this personal and social context, I hope to give readers of this dissertation the necessary insight to evaluate my work in general, and more value-laden claims and suggestions in particular.

Who am I?

When I started this doctoral research project, I was a freshly graduated medical doctor and for three years, I combined my PhD research with clinical practice as a resident in child and adolescent psychiatry. In this position, I mainly conducted diagnostic and counselling work at the Expertise Centre for Autism at the University Hospital in Leuven, one out of four reference centres for autism diagnostics in Flanders. I mainly worked here with infants and toddlers on the autism spectrum, and their parents. This gave me a relevant insider's view in current early autism diagnostic and support practices in our region.

Beyond my professional commitments, I am engaged in the Belgian climate movement, as an organiser, writer and activist in several grassroots, non-institutionalised groups. I feel affiliated with concepts and methodologies of degrowth, climate justice, deliberative democracy and (mass) direct action. Before starting my doctoral research I was not familiar with disability and autism rights groups and movements, but I quickly started to feel an affinity with the struggle for disability justice, recognising many societal power dynamics that come about when mainstream ideas are being challenged from the margins, including the much needed and fragile roles of being a reliable and committed ally to a movement. So, I think it is clear that my activist commitments in struggling for a more just society against the backdrop of climate breakdown, have coloured my affinities and choices in studying the ethics of early autism care.

Also, my partner, Kaat, lives with an inborn metabolic disease. Co-experiencing the consequences of such a chronic illness, was however not what drew me into disability research in the first place. While studying medicine I mainly tried to understand her condition by familiarising myself with metabolic pathways, and I was fascinated by developments in gene therapy as ways to treat 'single-gene' diseases such as hers. Yet, throughout these past four years, the two of us became more interested in the societal dimensions of chronic illness. Together, we developed more critical understandings of 'work' and 'productivity', of the administrative burden and government gatekeeping of disability allowance systems, and of the unsettling dualisms that dominate mainstream thinking about dis/ability. The concept of 'crip time' (Kafer, 2013) helped us reflect on how taking more time, doing things slowly on purpose, and deliberately disengaging with dominant schemes of time can be very fulfilling. Last year, we pulled together some of these experiences and ideas in an opinion article for the Flemish magazine *Knack* published on Rare Disease Day 2022 (Winters & Vanaken, 2022).

Myself, I identify as non-autistic and at the start of my research I would have probably added 'healthy' and 'able-bodied' here as well, but some health issues along the way have shown me in very bodily ways how leaky the borders of these identity categories actually are. I have to say, though, that 'identifying as' does not entirely capture what happens when one realises they are temporarily or chronically ill, disabled, or neurodivergent. In the aftermath of a viral infection in the spring of 2020, I simply had to admit that my body and mind were no longer functioning the way I was used to, whether I wanted this or not. Irrespective of my preferences, choices or identifications, I had to relate to living with chronic fatigue, having significantly less energy, requiring more rest and sleep, and dealing with secondary impacts on my mood. This meant that significant parts of my research have taken place at inconvenient hours of the day and at inconvenient places such as in bed and on the couch. Overall, the bodily and mental differences I experience forced me to relate to the (im)material contexts that are often not fit to accommodate these differences. This experience made me understand a whole lot better how Robert Chapman (2020a) defines neurodivergency. They describe it not merely as a biological essence, nor as choice or self-identification, but as a 'serial collective', defined in light of 'shared external material factors that mutually affect each member of the collective, regardless of whether they actually identify or not' (ibid, p. 810). I will get back to this in Chapter 2.

This might also be the right moment to acknowledge the limitations of doing autism research as a non-autistic person. I do not have direct access to first-hand, autistic lived experiences, but I am always reliant on other people's stories and writings. For example, I have collected qualitative data with autistic adolescents, but my research design, the data analysis, the dissemination of findings, and all steps in between are inevitably coloured by my non-autistic ways of thinking (Thompson-Hodgetts, 2023). Also, as a non-autistic autism researcher, I do not have immediate access to autistic spaces where relevant experiences are exchanged and theorised (Bertilsdotter Rosqvist et al., 2019). I

think that recognising and critically reflecting on these limitations is already valuable, but luckily I am also surrounded by some wonderful and talented, neurodivergent colleagues and by representatives of the autistic-led LAVA group (Lees- en Adviesgroep Volwassenen met Autisme, Autistic Adults' Reading and Advisory group) with whom I have had multiple discussions on my research over the past years. So, indeed, my access to non-mixed, neurodivergent spaces is limited, but I have been contributing myself as well in generating and sustaining neuro-mixed academic spaces which have proven to be very productive sites for exchange and critical reflection. In this same vein, I am convinced that emancipatory struggles always benefit from reliable and committed allies. Evidently, it is not up to me to define whether I am a good ally to the neurodiversity movement, but at least it is my ambition to be one, and I believe that my experiences as a researcher in academia, as a doctor in the clinic and as an activist in the streets, help me in this ambition.

In addition to these reflections, I have been made aware by colleagues across neurotype boundaries, that disclosing one's identity in terms of neurodivergency/neurotypicality has its limitations too. Being autistic does not automatically make one a good autism researcher, and vice versa, nor does identifying as neurodivergent necessarily lead to positions that can be considered neurodiversity-affirmative. Some of the autistic adolescents I have interviewed in my research, for example, strongly supported the position that an early autism diagnosis is key because it could help autistic youth to mask their autistic features as soon as possible with the goal of passing as normal. There is much to say about such positions[3] but at first sight, it is clear that this does not straightforwardly reflect a neurodiversity perspective on diagnostic practices. Therefore, next to disclosing my *identity* affiliations, it is important to point out my ambition to take a neurodiversity *approach* to my research questions. Here,

[3] I do not want to claim that camouflaging autistic features in a neurotypical-dominated social context is something bad per se, or that this implies dismissing neurodiversity ideas. But in the context of this interview, camouflaging was discussed as a systematic strategy to hide autistic features as the adolescent in case felt ashamed to be autistic and to have others know about this.

the distinction plays out between the neurodiversity movement as a social movement and as an academic school of thought. As a social movement, the neurodiversity movement is organised, at least in part, around the political identities of being neurodivergent. Academically, deploying the neurodiversity paradigm implies that a researcher examines phenomena through a specific, critical lens. This paradigm can be employed irrespective of the researchers' identity affiliations (Bertilsdotter Rosqvist, Stenning, et al., 2020). In Chapter 2, I will describe my take on the neurodiversity paradigm as a research paradigm.

Which context am I situated in?

Beyond my own positionality, there is also an academic and societal context in which this research takes place. In this joint PhD, I have had the privilege to navigate between two fairly different research teams, in two different faculties, at two different universities. First, there is the team supervised by prof. Ilse Noens at the Parenting and Special Education Research Unit (Faculty of Psychology and Educational Sciences, KU Leuven). Here, we conduct both quantitative and qualitative autism research focused on topics such as parenting, language development, adaptive behaviour, and quality of life. Over the past years, participatory research methods became ever more central to this group's work. This is perhaps best exemplified by the Academic Collaborative Centre for Autism (2022) where my colleagues conduct practice-based research. Here, 'researchers, autistic individuals and their family members, professionals and policymakers collaborate in prioritising, designing and carrying out research projects focusing on support to improve participation of autistic children, adolescents and adults in society' (ibid).

Second, there is the team supervised by prof. Kristien Hens at the Centre for Ethics (Faculty of Philosophy, University of Antwerp). Here, some of us work on the ERC-funded project NeuroEpigenEthics investigating 'how dynamic concepts of human biology influence the ascription of responsibility, specifically in the context of neurodevelopmental disorders'. We use a

combination of theoretical and empirical methods, with a special focus on the importance of experience stories (NeuroEpigenEthics, 2022). The group holds particular expertise in disability and neurodiversity theory, feminist and posthumanist ethics, and qualitative methodologies.

Lastly, it is relevant to say that the autism field in Flanders differs from North American and UK settings which are discussed most frequently in the autism literature. At the start of my PhD, autism rights and neurodiversity discourses were almost inexistent in advocacy groups, academia and public opinion in Flanders. The LAVA group I mentioned had just been founded and the Flemish Autism Association (VVA) was still largely run by non-autistic relatives of autistic people. It is good to know as well that Flanders has no history of ABA interventions and also complementary and alternative autism interventions (e.g. hyperbaric oxygen therapies etc.) have always been marginal in our region. Starting from this fairly unpolarised state of affairs, my supervisors have seized the opportunity to establish and maintain strong relations with the emerging autistic community in Flanders. These engagements are reflected, for example, in the structural embedding of LAVA representatives in the monthly meetings of the Leuven Autism Research (LAuRes) consortium, and in the participatory methodology of the Academic Collaborative Centre for Autism. Altogether, these societal circumstances have allowed me to explore the perspectives of both the neurodiversity movement and of clinical autism practice and research, in a sphere of constructive dialogue.

Part One: Introduction

1. Early autism detection and intervention research

Clinical practitioners and researchers generally describe autism as a neurodevelopmental disorder. Following DSM-5, it is characterised by deficits in social communication and interaction, and by restrictive and repetitive behaviours and/or atypical sensory sensitivities. When we unpack the term 'neurodevelopmental disorder' in the context of autism, we arrive at the full definition as proposed by DSM-5. The 'neuro'-aspect refers to autism's strong neurobiological underpinnings and fairly high heritability. 'Developmental' indicates here that autism's first signs appear as a deviation from typical developmental sequences early in life. Lastly, autism is seen as a 'disorder' when the aforementioned autism characteristics cause clinically significant impairments in social, occupational or other important areas of functioning (APA, 2013).

Despite these efforts to describe autism with a single definition, it remains important to recognise the great variety of experiences among autistic people. This variety is captured in terms such as the autism *spectrum* or autism's *heterogeneity*. These terms refer to the difference in the presentation of autism characteristics between individuals, cultures, and genders, but also to the various manifestations of autism in the lifespan of a single person. Autistic people also differ in terms of the support they need in daily life and in order to participate in society, and there is significant variety in the presence of co-occurring (neurodevelopmental) conditions in the domains of cognition and learning, language and speech, motricity and coordination, attention and hyperactivity etc. (Lord et al., 2022). In this dissertation, I will steer away from pathologising descriptions of autism. However, and this is important to me, this does not imply at all that I assume that autistic people cannot experience pathology. Autistic people are people, obviously, and like all people, autistics can also be ill, get traumatised or require (extensive or sustained) care. Moreover, as a group, autistic people in Western societies do experience more physical and mental health problems than the general population (M.-C. Lai et al., 2019; Sala et al.,

2020), they have lower quality of life scores (Evers et al., 2022)[4], live shorter lives and are significantly overrepresented in suicide prevalence numbers (South et al., 2021). The latter finding plays out particularly strongly for autistic women and non-binary people, and those with co-occurring mental health problems (South et al., 2021). Rather than dismissing these disadvantages or sugar-coating them by proposing non-pathologising language, neurodiversity proponents take these experiences as starting points for theorising and advocacy. It is out of question that autistic people experience issues in life that require ameliorative action: action to change the state of affairs for the better; action which might involve clinical care in early life as well. The real questions neurodiversity proponents, including myself, are interested in are therefore how to understand the emergence of these disadvantages and how to respond to them in good and just ways. I will dive deeper into these questions in Chapter 2.

On a slightly lighter note, I also find it important to wrap up these general remarks on autism by noting there is more to tell about autism and autistic people than the *clinically* relevant aspects, although this is not core to my research work. Autism's heterogeneity, for example, does also apply beyond co-occurring conditions. For every straight, white, tech-savvy autistic man striving to colonise space as he already became the richest person on Earth, there are plenty of other autistic folks who could not differ more in their passions, interests and ambitions (including struggling for socially just societies embedded in a liveable planet Earth).

So much for these general remarks on autism. In the next two sections, I will introduce two key lines of autism research which are core to my research questions: early autism detection and early autism intervention.

[4] My colleagues and I looked into some of the conceptual problems of quality of life measurements in autistic populations which partly explain these lower group average scores, for more information see Evers et al., 2022.

Early autism detection

In Flanders, as in many regions worldwide, an autism diagnosis is most often established in childhood, while sometimes autism is only formally recognised in adolescence or even adulthood (Shattuck, 2009). Often there is a significant time gap between the first experience of autism-related difficulties, or concerns regarding a child's development, and actual access to clinical assessment and intervention. Parents' first concerns often predate the child's second birthday (Bölte et al., 2013; Chawarska et al., 2007). But a recent meta-analysis estimated the global average age at autism diagnosis at around five years, based on studies published in the past decade. Calculating such global averages is a complicated task, though. Estimations are influenced by differences between national healthcare systems and get skewed by 'late' adult diagnoses. When childhood diagnoses (under the age of ten) were considered separatedly, the mean age at diagnosis dropped to 43 months (van 't Hof et al., 2021). Moreover, also within countries, there are significant differences in the age at diagnosis. There is no entire consensus on the determinants of this variety, but findings suggest that growing up in an ethnic minority and/or working-class family (Hosozawa, Sacker, Mandy, et al., 2020) delays a diagnosis, just like being a girl, having fewer autistic features and demonstrating more typical language development (Salomone, Charman, et al., 2016).

A systematic, preventive approach to detecting autism in infancy could speed up access to services such as psycho-education, parenting support, clinical rehabilitation, educational accommodation, access to self-help groups and financial allowances (Pierce, 2016). For these reasons, there is significant academic and public health interest in detecting and diagnosing autism early in life.

To screen or not to screen?

Typically, research on detecting autism in infants and toddlers has focused on observable developmental and behavioural features. The American Center for Disease Control summarised the most common of these features in their list of so-called 'red flags'. This list includes characteristics such as non-responsiveness to the own name, no or limited pointing to objects to show interest, limited playing of pretend games, avoidance of eye contact, preference to be alone, atypical use of objects such as lining up or spinning them, getting upset by minor changes in routines and unusual reactions to the way things sound, smell, taste, look or feel (Center for Disease Control and Prevention, 2022). This kind of list can be seen as a more specific operationalisation DSM criteria for this young age group. Nevertheless, there is no single feature that can ultimately rule out or confirm an autism diagnosis. Potential autism characteristics should therefore always be considered within the wider context of the child's development across different domains. Skilled and multidisciplinary teams of diagnosticians can establish a reliable autism diagnosis starting from 18 and especially from 24 months of age in case sufficiently different and pronounced autism characteristics are present (Ozonoff et al., 2015). But the need for such a careful and extensive assessment generates a bottleneck in large-scale early autism detection. Up to now, easy-to-use screening tools cannot replace the work of multidisciplinary diagnostic teams.

When it comes to autism screening, there is no consensus in Western countries over whether and how such strategies should be implemented in practice. In the United States for example, the *US Preventive Services Task Force* (USPSTF), an advisory body to the Health Ministry, concluded in 2015 that the evidence was insufficient to assess the benefit/harm balance of *universal* autism screening (see Table 1 for a glossary of strategies for early autism detection) (Siu, 2016). The USPSTF's main argument for this conclusion was that existing early intervention studies have mainly included children referred from specialist clinics, while it might be the case that children identified by

screening would be 'younger and possibly less severely affected'. The Task Force concluded that evidence of the beneficial effects of early interventions for this latter group was insufficient. Therefore, they called on the autism research community to conduct more intervention research including children aged 18 to 30 months referred from screening programmes in the general population. A more recent review of the literature by Levy and colleagues (2020) indicated that the evidence base has not changed significantly in the meantime in this particular respect. Therefore, recommendations on screening will have to continue dealing with the uncertainties that many but not all children will get picked up by universal screenings and that there will be substantial variation in responses to early interventions.

Table 1: Strategies for early autism detection

Terms		Description
Autism Screening		Standardised testing in an attempt to demarcate groups of children at a higher likelihood for autism from this with an average likelihood.
	Universal	Screening of the general population of children without any differentiation in their pre-screening likelihood for autism.
	Selective / Targeted	Screening of subgroups at an increased likelihood for autism based on so-called 'risk factors' such as preterm birth and family history of autism.
	Indicated	Screening of subgroups who present early, subclinical or subthreshold characteristics associated with autism such as otherwise unexplained feeding difficulties, and difficulties in language development.
Developmental Surveillance		Unstandardised observation of behavioural and developmental characteristics, and interviewing of parents during preventative healthcare visits, guided by the clinical intuition of the practitioner.

Several commentators in the autism field have criticised the USPSTF's recommendation as overly cautious. Mandell and Mandy (2015) for example, argued that children identified by screening would not be much younger than the ones currently involved in intervention studies, because of waiting lists. They

also claimed that doubting the benefits of early autism interventions for children with fewer autistic characteristics is counterintuitive. A recently published paper indeed supports the claim that those infants at an increased likelihood for autism with the fewest autism characteristics benefit most from a parent-mediated early intervention (Yoder et al., 2021a). Adding up to the debate, the American Academy of Pediatrics (AAP) recommended a few years later that 'all children be screened for autism at 9 months, 18 months, and 24 or 30 months, with standardized autism spectrum disorder–specific tools used at the 18- and 24-month screenings' (Hyman et al., 2020). Ongoing surveillance after the age of 24 to 30 months is however recommended according to the AAP, since 'early screening does not identify many children with milder symptoms and typical cognitive ability as at risk for ASD'.

In their recommendation, the AAP does not point to one particular screening instrument. But the instrument which is most discussed in the academic literature for early autism detection is the Modified Checklist for Autism in Toddlers (M-CHAT). This checklist is a freely available, caregiver-reported questionnaire applicable to children between 16 and 30 months of age. In its Revised form, the M-CHAT-R/F contains 20 questions on the child's development and behaviour, leading to a classification of 'low, medium or high risk for ASD'. The tool is designed to have a relatively high sensitivity in order to detect as many children with autism (and developmental delays of other kinds) as possible. This tool's high sensitivity does lead, however, to a high amount of false positive screens (for autism) as well. More precisely, a positive screen is estimated to predict an autism diagnosis in a bit less than half of the cases from the general population, yet, it does predict developmental delay of any other kind in 95% of the cases (Zwaigenbaum et al., 2019). A recent systematic review and meta-analysis points to the benefit of deploying the Follow-up portion of the M-CHAT for those children scoring in the medium range at initial screening. This way false positive screens can be reduced, limiting the case load for diagnostic centres (Wieckowski et al., 2023).

Fewer data are available on the number of children who are not picked up by screeners such as the M-CHAT, although it is commonly accepted that not all children who later receive a diagnosis screen positive (Øien et al., 2018). More recently, evidence from the implementation of near-universal autism screening in community settings has introduced some doubts over the accuracy of administrating the M-CHAT with sensitivity dropping below 40% and a positive predictive value of around 15% (Guthrie et al., 2019).

Based on these uncertainties, advisory bodies in other Western countries and regions have chosen to be more conservative in their recommendations on autism screening. The European Society for Child and Adolescent Psychiatry (ESCAP) for example, subscribes to the importance of a timely autism diagnosis, yet they have steered clear from a concrete recommendation on screening for autism. The Society rather suggests taking a developmental surveillance approach, by reinforcing awareness of atypical development among practitioners at well-child visits and for childcare workers such as kindergarten teachers (Fuentes et al., 2020). In contrast to developmental screening, surveillance is a less structured and delineated, but more flexible and continuous process where caregivers collect information through observations and specific questions. While such surveillance is key to current developmental check-ups in many countries, the ESCAP guidelines provide little empirical backing to promote developmental surveillance for autism. Since its publication however, new supporting evidence emerged. A large scale community-based surveillance and diagnostic assessment study in Australia highlighted the high diagnostic accuracy of the SACS-R tool (Social Attention and Communication Surveillance-Revised) (Barbaro et al., 2022). This observation-based, early developmental surveillance tool for autism consists of 12 to 15 early social-communication behaviours observed at 12, 18, and 24 months of age, and can be administered by trained nurses during well-child visits. The Preschool variant (SACS-PR) can be used at 42 months.

Compared to community-setting, universal screening with the questionnaire-based M-CHAT-R (Guthrie et al., 2019), the observation-based universal surveillance/screening with the SACS-R resulted in both a higher positive and negative predictive value (respectively 83% and 99%). When adding an observation at 42 months with the SACS-PR, sensitivity rose from 62% (based on observations between 12-24 months) to 96% for an autism prevalence of 3,3% at 42 months of age (Barbaro et al., 2022).

Up to now, in Flanders, the Taskforce Autisme (Noens et al., 2016) explicitly advised against the implementation of universal autism screening. At the same time, the authors of this Flemish Taskforce recommended increasing autism awareness among primary childcare practitioners, particularly those working at well-child visits, for example regarding so-called 'red flags' mentioned before. In addition to this surveillance approach, the Taskforce also advised paying special attention to children at an increased likelihood to develop autism, such as those with an autistic sibling or parent, prematurely born children and children with other developmental conditions such as an intellectual disability, or a language development disorder. For these so-called 'high risk' groups, the Taskforce did recommend using an autism screening instrument as an imperfect (Wieckowski et al., 2023), but fairly easy and quick tool to estimate the need for a full-fledged diagnostic assessment (Hellemans et al., 2018).

What are the odds?

Against the backdrop of this discussion on questionnaire-based early autism detection, potential new markers of autism have come under more intense investigation. Examples of such markers are genetic and metabolic indices, MRI images, EEG patterns, pupillometry and eye-tracking measures. Up to now, no such diagnostic biomarkers have been found, not for autism nor for other neurodevelopmental conditions. Moreover, the odds that truly diagnostic biomarkers will be found are rather low as the relation between biological measurements and behavioural manifestations of neurodevelopmental conditions is a complex one (Cortese et al., 2023). Rather than serving diagnostic purposes, the current, prevailing hope around such biomarkers is that these could help to detect autism accurately and objectively in an earlier, 'prodromal' or 'presymptomatic' phase when behavioural features are not yet (easily) observable (G. Dawson, Rieder, et al., 2022; MacDuffie et al., 2021).

Over the past decade, prospective, longitudinal studies with infants have become a preferred way to examine the predictive value of such new markers in combination with more traditional, behavioural features of early autism development. As the prevalence of autism in the general population is estimated between one and three percent the efficacy of such studies is often increased by recruiting so-called 'high risk' infants. These are children at an increased likelihood to develop autism, for example, infant siblings of children with autism and prematurely born children. Siblings have between a 10 and 20% chance of receiving an autism diagnosis themselves (Bölte et al., 2013), while this chance is situated around 7% for preterms, with higher odds for lower duration of gestation (Agrawal et al., 2018). Some of the lessons learned from the first generation of longitudinal, early autism studies are that an autism diagnosis established by clinical experts between the age of 18 and 24 months is very stable upon re-evaluation at 36 months. These studies suggest, however, that at 18 months up to 60% of siblings who later receive an autism diagnosis are still missed based on their behavioural profile. On average, these 'missed cases' do

not only present fewer autism characteristics but also seem to show higher levels of verbal and nonverbal skills (Szatmari et al., 2016). To put it differently, the way autistic children develop in their first years seems to be heterogenic as there is variety in the timing and profile of the expression of autism and related developmental characteristics. This seems to confirm some of the epidemiological data on determinants of the age at diagnosis discussed before. Another finding stemming from this line of research is that a significant proportion of these infant siblings who do not go on to be diagnosed autistic, still show atypical developmental features. These features involve autistic characteristics that do not add up to a categorical autism diagnosis, sometimes referred to as the 'broad autistic phenotype', but also language and cognitive delays occur here (Szatmari et al., 2016).

Also in Flanders, such early autism detection research is conducted. The Tracking Infants At Risk for Autism study, or shortly TIARA (http://tiara-onderzoek.be/) is a multi-centre, prospective, longitudinal cohort study on infant development between the age of 5 and 36 months, co-led by Ghent University and KU Leuven. TIARA aims to identify and understand the interplay and the predictive value of a wide range of parameters in the early development of autism, including developmental, behavioural and neurological parameters. The study goal is to develop an easy-to-use and affordable two-step early detection programme which can be implemented in clinical practice. Children participating in TIARA belong to one of three groups, each with an increased likelihood to develop autism, i.e. siblings of children with an established autism diagnosis, infants born prematurely under 30 weeks of gestation and infants with persistent, medically insufficiently explained feeding problems. As such, TIARA is part of a wave of prospective, early autism research in Europe (Magán-Maganto et al., 2017). This TIARA study was a starting point for the research groups involved to reflect on the ethics of early detection and intervention for autism, giving rise to my PhD project. In Chapters 3 and 4, I will provide more details on the TIARA study and its connections to my work.

Early autism interventions

Talking about early autism detection easily leads to talking about early autism *interventions* and their acclaimed benefits. In the field of early autism interventions, infancy is regularly depicted as a window of opportunity during which interventions can be optimally effective in changing the behavioural and developmental outcomes of autistic children (G. Dawson, 2008). The rationale here is that such early interventions would 'capitalize on experience-dependent neuroplasticity' and would enrich the 'diminished, unelaborated, and truncated [sic] social and communication learning opportunities' of autistic infants (Landa, 2018, pp. 25–26). As such, it is often argued that interventions for autistic children are optimally provided as early as possible, possibly even before a full autism diagnosis can be established (ibid).

Behavioural, developmental and mixed early intervention approaches

The term 'early intervention' is an umbrella term that captures various practices, target groups, timings and intervention strategies. In terms of timing, there is currently no clear consensus on what *early* exactly means in this context. Recent systematic reviews have set an upper limit of respectively six and eight years of age for so-called *early* interventions (French & Kennedy, 2018; Sandbank et al., 2020). However, in reference to the previous section on early detection programmes, it would probably be more consistent to consider early interventions as interventions offered between birth and three to four years of age[5].

[5] For the scope of this dissertation, I restrict myself to postnatal autism detection and intervention, and to psychosocial interventions, rather than biomedical ones. For discussions on the ethics of prenatal autism screening and interventions, I refer to Virginia Bovell's book chapter in *Neurodiversity Studies* on the ethics of preventing and curing autism (Bertilsdotter Rosqvist, Chown, et al., 2020). I can also point to the Commentary by my supervisors on the ethics of patenting autism genes for the sake of prenatal autism screening (Hens et al., 2018), and to the scoping review on the ethics of autism biomarker research by Walsh et al. (2011).

Also in terms of types of practices and intervention strategies, there is a variety of approaches circulating in research and clinical practice. In this dissertation, I understand 'early psychosocial interventions' deliberately in a broad sense. For me, the denominator of early autism interventions entails clinical, parental and educational efforts supporting the autistic child and its caregivers. This can involve practices such as psychoeducational sessions, pedagogical home guidance, psychotherapy, behavioural and developmental interventions, and kindergarten and classroom accommodations. In combination with early autism detection programmes, I will regularly refer to this set of practices as 'early (clinical) autism care'.

In much of the literature though, early interventions are more narrowly understood as structured forms of psychosocial therapy addressing parents and/or children, following a predefined manual and clear intervention goals to impact the child's behaviour and/or development. Early autism interventions exist in many forms and shapes, yet the most researched types are behavioural, developmental and combined approaches.

Behavioural approaches

Time-intensive, behavioural approaches have long been recommended as the golden standard of early autism interventions, particularly in Anglo-Saxon parts of the world (National Autism Center, 2015). The key example of such behavioural interventions is Applied Behavioural Analysis or ABA. Currently, ABA entails a variety of practices in itself, but in its prototypical shape, it relies on operant learning theory. A certain desired behaviour is broken down into discrete components and learned one step at a time using prompts, positive reinforcement and many repetitions (Schreibman et al., 2015). This element of ABA is referred to as Discrete Trial Training (DTT). A classic example of such target responses is learning to make eye contact, yet target behaviours can be basically anything, chosen according to individual needs. Typically, ABA is conducted in highly-structured environments where such stimulus-prompted

behaviour-reinforcement series are exercised in one-on-one clinical settings between the child and the therapist (Leaf et al., 2021). Important limitations of this kind of behaviourist approaches are that learned behaviour does not easily generalise to less-structured, real-life settings, that showing target behaviour becomes a fairly unspontaneous act heavily reliant on prompting, and that (some) children have a tendency to avoid being steered so explicitly in a certain behavioural direction (Schreibman et al., 2015). Beyond these clinical limitations, many autistic people view ABA as a key example of trying to *normalise* autistic children or to train autism away (M. Dawson, 2004; Kirkham, 2017). Consequently, there is currently a fierce debate on whether ABA's sharp edges can be softened, or whether this form of therapy should be left aside entirely (Chapman & Bovell, 2020; Leaf et al., 2021). But at least discursively, it seems that there will not be much room in autistic communities to endorse an *ABA 2.0*, as the term has come to embody all that is wrong with medical approaches to autism. As said, my ambition for this first chapter is to hold my horses in terms of making value judgements or overtly taking a position in the debates on early detection and intervention. Therefore, I do not engage in more detail with the ABA discussion here. Importantly, in Flanders, ABA has also never been institutionalised as a golden standard. Of course, a significant amount of clinical practitioners in childhood autism care are trained as (cognitive-) behavioural therapists, but strict and systematic applications of ABA have been scarce in our region. Compared to some neighbouring countries and the Anglo-Saxon world, there is more space in Flanders to move beyond a mere pro- or contra-ABA debate and discuss early autism interventions in their broad sense, which is what I aim for in this dissertation.

Developmental and mixed approaches

Next to ABA, a wider range of early intervention programmes has been developed and tested over the past 20 years, including developmental and mixed behavioural-developmental approaches (French & Kennedy, 2018). These more recent approaches mainly arise in the context of new insights into child development theory and in response to the limitations of behaviourist approaches. Moreover, Sandbank and colleagues (2021) recently formulated a piece of advice to clinical practitioners in favour of such developmental and mixed approaches. This advice was based on their systematic review and meta-analysis of the early intervention literature taking into account randomised control trials of early interventions offered to children up to eight years of age (Sandbank et al., 2020). This meta-analysis only found significantly positive intervention effects for developmental and so-called Naturalistic Developmental Behavioural Interventions (NDBIs). No such positive effects were found for strictly behavioural or other approaches. Also, in contrast to earlier practice recommendations, Sandbank et al. no longer recommend highly time-intensive interventions (of up to 40 hours per week), over less time-intensive ones.

> *First, heavily structured, high-intensity interventions may not be developmentally appropriate for very young children and may contribute to family stress, which could negatively affect children's development. Second, highly intensive interventions that separate children from their siblings, peers, and family members for extended periods may have unintended adverse developmental and social consequences.* (Sandbank et al., 2021, p. 342)

In contrast to strictly behavioural interventions, developmental approaches are based on more interactive theories of skill acquisition and learning. Here, it is posited that children's development is fundamentally dependent on the interaction and active engagement with their physical and social environments - and vice versa. Research shows that children learn best when they are engaged

as active participants in developmentally appropriate learning experiences and in contexts meaningful to the child. Children learn most easily the skills that are just beyond their current abilities and they follow regular developmental sequences in virtually all developmental domains. Oft-cited examples concerning autism are joint attention and imitation. These skills are viewed as important precursors of later socio-communicative development and language (Schreibman et al., 2015). Often, autistic children differ from their peers in showing fewer manifestations of joint attention and imitation. It has been reported that these early developmental characteristics are associated with 'perturbations' in the parent-child interaction which further reduce skill acquisition in the socio-communicative domain. Parent-child interaction dynamics are thus not viewed as the cause of autism, but rather as a factor which can 'maintain or amplify pre-existing (neurodevelopmental) vulnerability' of the child (Green et al., 2015, p. 133).

By fostering synchrony, reciprocity and duration of parent-child interactions, developmentally-based early autism interventions aim to remedy such skills and therefore positively impact cascading language and socio-communicative development. Typically, developmental approaches are set in daily, play-based contexts where parents are significantly involved in delivering the intervention by practising with their child at home (Sandbank et al., 2020). The rationale here is that all social interactions that infants engage in are potential learning moments. As such, training parents to apply certain approaches and techniques of an early intervention programme in the home context offers a significant increase in intervention time, compared to clinician-led programs, while healthcare costs for paid labour and infrastructure are significantly lower (Wainer et al., 2017). Examples of such developmental approaches to early intervention are the Paediatric Autism Communication Therapy (PACT) (Pickles et al., 2016) and the iBASIS-VIPP, an autism-adapted version of the Video Interaction to Promote Positive Parenting (VIPP) developed in the context of the British Autism Study of Infant Siblings (BASIS) (Green et al., 2015).

Several recently developed intervention protocols also combine behavioural and developmental elements. These interventions came to be categorised as Naturalistic Developmental Behavioural Interventions or NDBIs. Operant learning principles still play an important role here, yet, a change in terminology was deemed necessary as ABA became nearly equated with DTT and its limitations and controversies (Schreibman et al., 2015). The rationale and setting of NDBIs largely resemble those of developmental approaches in the sense that they are conducted in 'natural' settings, i.e. in the context of play. Parents often have an important mediating role and the intervention targets developmental sequences. Compared to developmental intervention approaches, the add-on here is that operant learning principles are mobilised to reinforce skill acquisition. Operant learning principles aim to improve skills that are considered key in a developmental sequence, be it in a less discrete and clinical setting but in a more everyday, naturalistic way that follows the child's cues and interests. For example, in a parent-child free play setting, the parent could hand over a preferred toy to the child right at the moment the child joins the parent's attention towards that toy. This way receiving the toy serves as a contextually-relevant, naturalistic reinforcement of behaviour which is deemed developmentally valuable, in this case engaging in joint attention. Examples of NDBIs are Early Start Denver Model (ESDM), Joint Attention, Symbolic Play, Engagement and Regulation (JASPER) and Improving Parents as Communication Teachers (ImPaCT).

Do they work? The complexity of measuring interventions' effectiveness

As mentioned before, current evidence for effectiveness points mainly in the direction of developmental and NDBI approaches. Of course, when we discuss effectiveness, we have to ask: effective in doing what exactly? What are desirable goals of early interventions? Do we want to increase children's results on an IQ test, make them score lower on an autism characteristics questionnaire,

enhance adaptive behaviour, address secondary problems such as behavioural difficulties and self-injury, or improve the quality of life of the child and/or its family? These are of course key questions to be answered in this study on the ethics of early autism care, and I will get to those in the next chapters. Yet, in this introductory chapter, I want to stay closer to the debates as they are most commonly held in the early intervention literature. These current debates are largely methodological and call for a cautious interpretation of claims of effectiveness. At least three methodological issues are important to consider here.

First, intervention outcomes might be bound to the intervention context itself, rather than generalise to other settings too, and they might be proximal to the intervention exercises, rather than having a more downstream impact on the child's development, behaviour or well-being (Sandbank et al., 2020). For example, an NDBI might increase parent-child synchronicity, without provoking an effect on socio-communicative behaviour as measured by the Autism Diagnostic Observation Scale (ADOS). Second, early intervention trials are vulnerable to detection bias. Positive effects might be unduly reported when outcome assessors are not blinded. This is particularly difficult for interventions offered to children since parents are often very valuable informants, while at the same time, they are also nearly always aware of, or even actively involved in the intervention.

Adding to this 'placebo-by-proxy' effect, parents might also elicit a stronger outcome when they are taking part in the interaction that serves as an observation occasion to measure the intervention's outcome. A positive outcome might not just reflect the child's increased ability to demonstrate a certain skill or behaviour, but the ability of parents who have become more skilful in eliciting this skill or behaviour as they have been trained to do so themselves. The risk of this type of bias was so prevalent in Sandbank et al.'s meta-analysis, that they came to the sobering conclusion that no single intervention approach yielded

positive results after excluding the studies with a risk of detection bias (Sandbank et al., 2020).

Lastly, it has been shown recently that conflicting interests in early intervention research are remarkably underreported. Conflicts of interest might arise for example when researchers are also the developers of a given intervention. Bottema-Beutel et al. (2021) showed that conflicts of interest could be detected in 70% of the 150 early autism intervention papers they studied, while only 6% explicitly mentioned all conflicts adequately. The most commonly detected conflict of interest was when researchers were also the developers of the intervention they studied. It is probably exaggerated to state that such conflicts of interest systematically influence study findings in every case. It seems fair though to remain alert and to call for replication studies by unrelated research teams to verify earlier findings. Interpreting the body of evidence for early autism intervention, thus, requires some cautiousness. Also, it is not self-evident to conduct high-quality studies with enough participants, blinded assessment of outcomes, measuring both outcomes proximal to the intervention and more distal outcomes which might be more clinically relevant and potentially more valuable for children and families involved, and a sufficiently long follow-up in time. At least when it comes to these methodological issues, some examples have lighted the way. One such example is Pickles et al.'s study following children up to six years after the end of the PACT, a parent-mediated socio-communicative intervention, measuring both proximal and distal outcome measures. The authors reported that reductions in core autism characteristics at the end of the intervention in toddlerhood were sustained until mid-childhood, even while effects on more synchronous parenting interaction styles had waned over time (Pickles et al., 2016). A recent mechanistic study of these long-term effects points out that an increase in the autistic child's communication initiations is largely responsible for the reduced autism characteristics and increased adaptive behaviour outcomes (Carruthers et al., 2023). This kind of findings further spurs the idea that it is key to target

developmental precursors of social communication in an early timeframe, potentially even before a formal autism diagnosis can be established.

Intervening before diagnosing?

In the past few years, researchers became increasingly interested as well in interventions delivered to infants and toddlers in a pre-diagnostic phase. Such 'pre-emptive interventions' aim to target autism characteristics and related developmental domains at a moment before an autism diagnosis can be fully established for the children involved. Here, it concerns children between approximately six months and three years of age who show emergent features related to autism without meeting diagnostic criteria (indicative intervention) or who have a heightened familial chance of being autistic since they have an older sibling on the spectrum (selective intervention).

Pre-emptive interventions largely rely on developmental theories of learning and generally also include elements such as promoting responsive parenting behaviour and fostering joint attention in everyday and play-based settings. These pre-emptive interventions can be considered transdiagnostic approaches, in the sense that they are not strictly targeted to children with a categorical diagnosis of autism nor to specific autism characteristics. Therefore, interventions aim to target language and cognitive development as well. This way, pre-emptive interventions take into account the facts that autistic children often present co-occurring conditions in these domains, or go on to develop other developmental disabilities without receiving an autism diagnosis.

In a recent meta-analysis of 13 pre-emptive intervention trials conducted between 2011 and 2021, Hampton and colleagues (2021) could not detect a significant association between the early interventions and child developmental outcomes in terms of receptive or expressive language, social communication or autism characteristics. Parents did show significant increases in implementing the intervention strategies and became more 'responsive' to their child, although

these interventions are labelled ‘low-dose’, meaning they require a maximum of 2 hours per week.

This finding does not have to imply per se that pre-emptive interventions are ineffective. In a follow-up study, Green et al. (2017) showed for example that child-centred, fairly distal outcomes such as autism characteristics might still be impacted up to 24 months after finalising an intervention offered to parents of children around 9 months of age with an autistic sibling. Immediately after finishing the intervention, though, only effects on parenting behaviour were found, while children’s outcomes remained unchanged (Green et al., 2015). This finding provides further corroborates the hypothesis that attuned parenting behaviours are an important mediator of their child’s development cascade over time (and vice versa, children probably also do impact their parents’ behaviours to a significant extent). In the same vein, Yoder et al. (2021b) provided evidence of such mediating effects in a pre-emptively delivered ImPACT intervention.

Pre- and post-diagnostic services are not necessarily mutually exclusive. Jonathan Green (2019; 2022) suggested, for example, to reframe autism interventions from a one-off act towards ‘an integrated sequence of developmentally orientated, evidenced approaches’(Green, 2019, p. 1353) given the developmental and lifelong nature of autism as a condition. In his words, this could include both pre-diagnostic, parent-mediated interventions for so-called ‘at-risk’ groups. Succeeding an autism diagnosis, psycho-educational and adaptation support should be offered, followed by post-diagnostic interventions targeting socio-communicative development. Later, more individualised step-up care for secondary issues could then be offered if needed.

Current early intervention practices

To conclude this section, it seemed relevant to describe briefly how early autism interventions are actually implemented already in clinical practice nowadays. In European clinical contexts, there is a variety of interventions on offer. Following a questionnaire in 18 European countries, speech and language therapy (64%)

was the most frequently reported type of intervention according to parents of autistic children up to seven years of age. Behavioural, developmental and relationship-based interventions were reported for a bit over half of the children (55%) (Salomone, Beranová, et al., 2016). Specifically in the Flemish context, autism diagnosis and intervention for children under the age of three is not uncommon. Yet, there are no systematically combined early detection and intervention programmes in place so far. Toddlers who are suspected to be on the autism spectrum are generally referred to the provincially organised Centres for Developmental Disabilities (COS) and the Reference Centres for Autism (RCA) for a diagnostic assessment. Based on the assessment, an individualised set of services is recommended to parents. Often these include autism-specific home guidance services. In case multidisciplinary therapy is needed, children are referred to an ambulatory rehabilitation centre offering for example speech and language therapy and psychomotor therapy. In Flanders, there is no history of widespread ABA therapy in contrast to the USA or some other European countries. One more structured early intervention which is more commonly available and referred to in Flanders is the *Improving Parents as Communication Teachers* (ImPaCT), an NDBI. In this training programme offered by the home guidance and rehabilitation services, parents are trained for approximately three months, both in a group and individually. The goal is to improve functional communication between parents and their child. The programme is available for parents of children between 9 months and 6 years of age (Limburgse Stichting Autisme, 2022).

Emerging ethical reflections

When summarising the past two sections, we see that current discussions on early autism detection and intervention are mainly centred around issues of optimising these programmes' efficacy in clinical terms. Autism screening tools are debated in terms of potential *classification errors* and *overdiagnosis*, referring to the risk

of false negative and false positive screens, and to the presumption that some 'mildly affected' children might be diagnosed autistic without actually requiring early intervention (Hickey et al., 2021; Siu, 2016). Early interventions, in their different forms, are debated in terms of their effectiveness given some risks of bias and in terms of the clinical significance of the measured outcomes. Moreover, early interventions can imply so-called opportunity costs. The time, energy and means dedicated to an early intervention obviously can only be expended once. The more intensive the intervention is, the higher this cost obviously becomes. This applies to practitioners, and parents, but obviously also to children. A child who spends over 25 hours per week practising a certain skill in a clinical setting, cannot spend this time learning and playing with peers in an inclusive day-care setting (Hickey et al., 2021; Øien et al., 2021; Sandbank et al., 2021; Zwaigenbaum et al., 2019).

When I look at these debates from a certain distance, it appears to me that the questions that are asked, the means that are used to answer them and the people involved in the process are rather technical. Questions are asked about accuracy and effectiveness, and we expect clinical researchers, methodologists and public health bodies to answer them armed with *p*-values and Cohen's *D*'s. Of course, this is relevant for an ethical consideration of the implementation of early autism care. It would of course not make sense to argue in favour of a programme that does not have the effect it claims. However, when we assume that these questions, methods and people are the only relevant ones, we would not see the full picture. At the risk of generalising here, my impression is that the most vocal participants in this academic debate have been silently taking for granted a set of assumptions which are actually worth questioning. For example, it is regularly assumed that autism should be diagnosed as soon as this is reliably possible. Moreover, autism is seen (implicitly) as a condition that needs intervention by definition, particularly in the socio-communicative domain, to have a chance at living a flourishing life. Lastly, for a long time, it has been assumed that tightly defined experts are the right ones to call the shots when

developing and approving early autism programmes. This interpretation on my side is also supported by some recent empirical findings (Botha & Cage, 2022). Formulating this differently, I believe the debate on early autism care has been confined largely within a medical paradigm, presenting autism strictly as a disorder in need of remediation by professional experts.

Interestingly, some commentators are increasingly recognising the limits of this confinement and have called for a broader ethical reflection on the topic, moving beyond this medical paradigm towards neurodiversity approaches to autism. Meng Chuan Lai and colleagues (2020) for example point out in a review article for *The Lancet* on autism interventions across the lifespan that ethical analysis of early clinical engagements with autistic children is urgently needed.

> *(It) requires an examination of the consequences of treatment, from the perspectives of all stakeholders, in both utilitarian (e.g., pros and cons of an intervention) and deontological frameworks (e.g., individual values vs. societal values). (…) merging the neurodiversity framework with an early intervention paradigm can be a significant innovation* (M. C. Lai et al., 2020 Annex 1).

In their agenda-setting review 'The ethics of autism', the philosophers Hens, Schaubroeck & Robeyns (2019) identify key clusters of ethical questions related to autism. One of those clusters, as they mention, concerns questions on parental rights and duties with regard to obtaining an early autism diagnosis and pursuing interventions for their child. They raise the question of whether parents can decline a diagnostic assessment. Is it the parents' duty to aim for optimal (or 'normal'?) functioning of their child through interventions? Or, should parents rather accept and accommodate their child's autism as a neutral, neurological difference (Hens et al., 2019)?

Walsh, Elsabbagh, Bolton, and Singh reviewed some of the ethical questions related to early autism biomarker research. A key question they identified at the heart of this research field, is that of autism's value:

> *The question of value -of whether to focus on the positive or the negative aspects of autism symptoms and profiles- has current political, as well as ethical, implications. (…) On one side of the debate is a group that includes proponents of 'neurodiversity', who claim that autism is best understood as 'cognitive difference' that requires no treatment or intervention but rather social acceptance and support. (…) On the other side of the debate are those who regard autism as a serious disability and those who fund scientific research into the condition with the hope that it will lead to a cure for autism or to a means of preventing autism(…). The current research emphasis on the desirability of early identification and (potentially) prevention of autism has further stimulated this debate (…). Clearly, the challenge is to achieve and communicate as much clarity as possible on the goals and rationale of a particular research and intervention strategy, and on the crucial question of whether the perceived desirability of the outcome is based on something more objectively important than 'fitting in' with contemporary cultural norms* (Walsh et al., 2011, pp. 607–608).

Overall, I think it becomes clear that implementing early autism programmes definitely requires thorough ethical reflection. The technical input from autism researchers developing these programmes is indispensable to this extent. Yet, the discussion cannot be limited to this. Both the scope of questions and contributors to the discussion needs broadening. So far, this broadening-up has largely remained stuck at formulating new questions (Graf et al., 2017), while less work has been done to actually try and provide some answers.

When I started my research, the literature on the topic was thus rather scarce (e.g., M. Dawson, 2004; Fletcher-Watson, 2018; Mottron, 2017), and I did not find it an easy task to find a proper entry point into the discussion back then. Luckily, as my own research and thinking evolved over time, a handful of publications started to come out in the course of 2021, in my 3rd year as a PhD student, imagining the contours of neurodiversity-affirmative approaches to

early autism care (Brown et al., 2021; Leadbitter et al., 2021; MacDuffie et al., 2021; Manzini et al., 2021; Schuck et al., 2022). This strengthened me in pursuing the road I was on. Rather than discussing these papers here as if their contributions were already a given at the start of my work, I will discuss them in my final Chapter 7 where I will put their ideas into dialogue with my own findings.

Now, I will turn to this term which already passed by a few times, but which I did not introduce properly yet: neurodiversity.

2. Neurodiversity, disability, crip

The concept of neurodiversity recognises the significant human diversity regarding cognitive, sensorial, behavioural, emotional, communicative ways of experiencing and engaging with the world. In recent years, both a social and an academic neurodiversity movement have emerged around this concept. As a social movement, it strives for acceptation of diversity and emancipation of neurodivergent people. In academia, the neurodiversity paradigm equips researchers with a critical lens to analyse existing autism research and practice and explore alternatives, including for early autism detection and intervention (Walker, 2014).

Neurodiversity activism, advocacy and theory did not emerge in a vacuum. There are clear links, and obviously also some differences, between the neurodiversity movement and disability and crip studies (Ne'eman & Pellicano, 2022). The second part of this Chapter introduces these latter two fields, their relations to neurodiversity thought, and it clarifies my take on the neurodiversity paradigm as a research paradigm.

The neurodiversity movement

The term neurodiversity has been coined in the late 1990s by the autistic sociologist Judy Singer (1998) in collaboration with *The Atlantic* journalist Harvey Blume (1998). The term emerged from conversations among autistic individuals and community organisers who connected via mailing lists, newsletters and online support groups in the early days of the internet. Informally, autistic people shared experiences and increased their critical awareness of societal norms and barriers obstructing them to live their lives as they wish. From the very start, these conversations welcomed and included ADHD folks, Tourettics, dyslexic people and others. Together, these pioneers moved away from understanding their conditions as disorders. Instead, they found a shared sense of community and belonging, despite internal

heterogeneity, in the affirmative notion of embodying *differently* wired, not disordered, brains (Dekker, 2020).

Emerging from the grassroots up

The wave of online neurodiversity community-building in the 1990s came at a time when some autistic people in North America[6] started to speak out publicly as well, as *self*-advocates, in favour of their own interests and priorities. Indeed, up to that point in time, parents' organisations were the leading force in autism advocacy. These parents' organisations tried to break away from earlier, psychogenic and mother-blaming theories of autism, and from the systematic institutionalisation of autistic children. In this breakaway effort, many parent groups aligned themselves in the 1980s and 90s with medical views on autism and advocated biomedical interventions to treat, cure or prevent autism. 'Defeat Autism Now!' is the very telling name of one such former parent group (which also had a modest Belgian branch) (Eyal, 2010; Silberman, 2015). As mentioned before, combat metaphors are indeed always lurking around the corner in (parental) autism advocacy.

In 1993, while the term 'neurodiversity' had not been coined yet, one of the pioneers of autistic self-advocacy, Jim Sinclair, already captured the complex dynamics between non-autistic parents and their autistic children in their now famous speech 'Don't mourn for us'. The speech is as old as I am, but I believe Sinclair's core message is still relevant for our discussions on early autism care today. At the International Conference on Autism in Toronto, they addressed parents as follows.

[6] My description of the neurodiversity movement relies dominantly on the dynamics and writings taking place in Western countries. Comparable things happen indeed globally (see for example Pukki et al. 2022). However, I cannot claim that my discussion of the movement is a universal one, as I did not engage in sufficient detail with its manifestations in other parts of the world.

> *Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you. This is what I think autism societies should be about: not mourning for what never was, but exploration of what is. We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it--and then do something about it. The tragedy is not that we're here, but that your world has no place for us to be. How can it be otherwise, as long as our own parents are still grieving over having brought us into the world?* (Sinclair, 1993)

Sinclair formulates here a sharp critique to tragic views of autism and appeals to unaccommodating, unwelcoming societies as determinants of experienced difficulties of autistic people. Although they squarely addresses parents' problematic attitudes, Sinclair also calls upon parents to become allies in the struggle to create more accommodating, welcoming worlds. Next to their message itself, I mention Sinclair here as well to acknowledge that neurodiversity advocacy and theorising did not emerge out of thin air at the point that an academic coined the term. Rather, the neurodiversity movement built on the fundaments laid down by the autism rights movement, spearheaded by people such as Jim Sinclair in North America and Martijn Dekker, Leneh Buckle, Heta Pukki and many others in Europe. One of the key struggles the autism rights movement embarked upon, was opposing autism 'cures'. Behaviour-modification therapies, such as Applied Behavioural Analysis, became a core antagonist for autism rights advocates. Autistic scholar Michelle Dawson for example, spelled out this anti-cure perspective already in 2004 in her extensive blogpost 'The Misbehaviour of the Behaviourists: Ethical Challenges to the Autism ABA-Industry' (M. Dawson, 2004).

Since the turn of the century, then, the term neurodiversity started to spread from the grassroots upwards. By the late 2000s, it began to feature in more mainstream academic publications (e.g. Fenton & Krahn, 2007; Ortega, 2009). Since the start of my PhD in 2018, the attention for and discussions about neurodiversity have absolutely boomed. In the past few years, I have witnessed how neurodiversity-related discussions have been shifting from the margins towards the centre of autism research. At first, neurodiversity claims were only discussed in a dismissive way as an inadequate (or more ironically phrased: deficient) theory which would discredit the real-life problems of autistic people with higher support needs than the ones proclaiming neurodiversity views (e.g. Jaarsma & Welin, 2012; Lord et al., 2022). Or, neurodiversity approaches were mentioned only in passing as an 'alternative' to dominant, medical views on autism, without addressing the incoherence and tension of accepting two entirely different views on autism at the same time (M. C. Lai et al., 2020). Over the years, more affirmative publications, most notably by autistic academics, have expanded on initial neurodiversity theorising and kickstarted fruitful discussions within the emerging academic branch of the neurodiversity movement (e.g. Bertilsdotter Rosqvist, Chown, et al., 2020; Chapman, 2019; Kapp, 2020a; Milton et al., 2020). Academic allies, who do not (choose to) identify explicitly as autistic -although some do as neurodivergent-, have joined in as well to play their part (e.g. Bottema-Beutel et al., 2021; Fletcher-Watson et al., 2019; Hens et al., 2019; Leadbitter et al., 2021; Nicolaidis et al., 2019; Pellicano & den Houting, 2022; Russell, 2020).

In summary, community building and theorising around the concept of neurodiversity started back in the 1990s. Right now, we can speak of a proper social and academic *neurodiversity movement.* Activistic and academic neurodiversity work obviously interact with one another. Yet, for the sake of clarity, I will first zoom in on its manifestation as a social movement by discussing some key assumptions, claims and tactics. Thereafter, I will situate the academic, neurodiversity movement in relation to the associated fields of

disability and crip studies and provide a description of how I understand the neurodiversity paradigm as a research paradigm.

Assumptions, claims and tactics

Anno 2023, the neurodiversity movement as social movement is an emancipatory movement grounded in grassroots socio-political practices such as self-help and community building activities, advisory, advocacy and activist work. The movement's shared ambition is to forge a more just society by opposing the systematic pathologisation of neurodivergent people and the structural injustices experienced by neurodivergent people. Neurodiversity proponents aim to contribute actively to social change by advocating and creating more inclusive spaces, practices and interactions that decentre neurotypical norms and support people to thrive irrespective of their neurotype (Bertilsdotter Rosqvist, Chown, et al., 2020).

The movement's core concept is obviously that of 'neurodiversity'. The way I have come to understand and present this concept is that it is 'a recognition of the significant human diversity regarding cognitive, sensorial, behavioural, emotional, communicative ways of experiencing and engaging with the world' (Vanaken, 2022b). This is no consensus definition and to my knowledge no such consensus exists. For now, I stick with this description of the concept.

The concept of neurodiversity is a population feature and therefore it applies to every one of us. No single individual is *neurodiverse* in themselves as neurodiversity is a group characteristic (Walker, 2014). Within our human populations, there are obviously dimensional distributions of attention and concentration skills, of preferred forms of sociality, of the occurrence of tics, of intellectual abilities, of sensory profiles, of reading, writing and mathematical proficiencies etc. The set of 'ways to experience and engage with the world' that neurodiversity captures, extends thus beyond autistics and, indeed, also ADHDers, Tourettics, dyslexics and many others tend to find their place under

the umbrella of the neurodiversity movement[7] (Kapp, 2020b). Of course, choice of words can be debated, but it should be fairly uncontested to acknowledge that kind of heterogeneity in experiencing the world is a given. When we look at the assumptions and political claims of the neurodiversity movement though, things get more value-driven, and therefore contestable by opponents. In my understanding, neurodiversity proponents make two basic assumptions which lead to two political claims.

First, they state that all neurotypes are intrinsically of equal value. Autistic people for example, are not inherently inferior, nor superior to their neurotypical peers, and have as much right to live their lives in ways they see fit, just like non-autistics do. This assumption leads to a political claim of *acceptance of diversity*, of *embracing diversity as the norm*. Diversity is not something to combat or cure, but something to cherish, value and take care of. Applied to autism, this claim materialises in anti-cure positions. Examples are opposition to (the potential development of) prenatal diagnostics and selective abortion (Bovell, 2020; Hens et al., 2018). As said, behavioural modification therapies that aim to 'unlearn' (harmless) autistic behaviours and teach specific neurotypical behaviours instead are also an important focus of anti-cure efforts (Chapman & Bovell, 2020). Applied Behavioural Analysis is the most-cited target in this context, but interventions such as social skills training have come under fire as well as they would disvalue autistic ways of sociality and induce potentially harmful camouflaging behaviours (Roberts, 2021). As touched upon in the Preface, much of the language and discourse in the autism field clearly positions autism as something undesirable-per-se which should be avoided or remedied. The claim for acceptance of diversity therefore also manifests in the struggle for inclusive language and discourse (Bottema-Beutel et al., 2021).

Second, neurodiversity proponents politicise the problems and challenges experienced by neurodivergent people. They state that many experienced

[7] The boundaries of neurodivergency are a hotly debated topic. Who can claim to be neurodivergent? I will get back to this question below, making a parallel with terms that found a way to deal with similar dynamics, i.e. 'queer' and 'crip'.

problems, such as mental health and behavioural problems, educational and occupational dysfunction, victimisations of bullying and other types of violence, cannot be reduced to individual, autistic characteristics (den Houting, 2019; Dwyer, 2022). Rather, such problems emerge in close interaction with the micro and macro settings of a society which is primarily shaped to meet the 'normal' needs of neurotypical people, and which often fails to meet neurodivergent needs (Chapman, 2019). Needs of neurodivergent people repeatedly go unseen and remain therefore unmet. When needs *are* seen, these are often viewed through a medical lens implying a tendency to 'fix' neurodivergent people, or through a compassionate lens, implying pity and a tendency for charity work, patronising neurodivergent folks. According to neurodiversity proponents, both these 'fix' and 'pity'-approaches strengthen problematic power relations relying on an inferior position of neurodivergent people compared to neurotypicals (Kapp, 2020b). In other words, these approaches reproduce the same political background conditions which are deemed problematic in the first place. In contrast, neurodiversity proponents politicise the needs of neurodivergent people by claiming they arise from the interactions between bodyminds[8]-diverging-from-the-norm and a society failing to accommodate adequately (Bertilsdotter Rosqvist, Chown, et al., 2020).

This societal failure to accommodate divergent needs adequately can be framed as a structural injustice. The late feminist philosopher Iris Marion Young helpfully defined structural injustice as a kind of moral wrong that stems from many people and institutions' contributions. Structural injustice emerges from conscious and unconscious behaviours which are often not illegal and are even within the limits of accepted rules and norms of a given society. The consequences of such structural injustice are that

[8] I use the neologism bodymind in alteration with 'bodies and minds' to complicate the body/mind dualism (Price, 2015). This neologism also helps me to position autism and neurodiversity studies squarely within disability studies, even though the latter field is often associated to research with physically and sensorially disabled people.

large groups of persons are put under systematic threat of domination or deprivation of the means to develop and exercise their capacities, at the same time that these processes enable others to dominate or to have a wide range of opportunities for developing and exercising capacities available to them (Young, 2011, p. 52).

This assumption about neurodivergent people facing structural injustice serves as the basis for the neurodiversity movement to be an *emancipatory* movement. Neurodiversity advocates aim to redress these structural injustices by decentring and diversifying neurotypical norms in different societal domains. Lived autistic experiences can give rise to knowledge that is less obviously available to non-autistic relatives, researchers, practitioners and policy-makers. Therefore, neurodiversity advocates demand to be heard and taken seriously (Bertilsdotter Rosqvist, Chown, et al., 2020).

As we have seen, the neurodiversity movement has its roots in the digital sphere[9] and also today much of its activity takes place online. Neurodiversity advocates have used their reach on social media, for example, to talk back at certain research projects and publications. Recent and remarkable examples are the critical responses to a large scale study in genetics, the Spectrum10K trial (Askham & Dattaro, 2021), and to the Lancet Commission report on the Future of Care and Clinical Research in Autism (Pukki et al., 2022). In Flanders as well, autistic adults voiced directed critical remarks at autism research. The LAVA group (Autistic Adults' Reading and Advisory group, cf. supra*)* spelled out their disagreement with certain aspects of the early autism detection study TIARA (Tracking Infants At Risk for Autism, cf. supra), which got framed in the media as a way to 'unravel the mystery of autism' (Cools, 2018). Also, a group of Australian neurodiversity advocates launched a petition in response to a research paper[10] on a very early, pre-emptive autism intervention, in which the authors

[9] In-person events such as Autreat and Autscape, however, play(ed) an important role in neurodiversity and autistic self-advocacy organising.

[10] The paper under discussion is the one by Whitehouse et al. (2021) which I will discuss in some more detail in Chapter 6.

claimed autism could be prevented in some 'high-risk' infants (Neurodiversity Advocates, 2021).

Some progressive autism researchers and research groups have picked up on the more general claims of the neurodiversity movement without being antagonised in particular. Yet, it seems like this more specific 'talking back' to certain projects and publications is an effective tactic to provoke change in academia. The critique at the Spectrum10K trial led to halting this project temporarily to undertake a novel ethics procedure with significant autistic participation (Askham & Dattaro, 2021). The LAVA response to the TIARA study also fostered a more intense collaboration between this advocacy group and the research consortium. Concretely, LAVA representatives invited me in the early days of my doctoral research to give an introduction to the ethics of early autism detection and intervention and to be part of an internal LAVA discussion on the topic. Conclusions of this discussion were presented afterwards to TIARA researchers[11].

As a social movement, the neurodiversity movement strives, thus, for acceptance of diversity and emancipation of neurodivergent people. In contrast to previous movements, such as the 20th century anti-psychiatry movement, it does not so by dismissing clinical research and practice altogether. Rather, the neurodiversity movement took a 'scientific turn' aiming to be a critical, but constructive partner in developing new knowledge that can ameliorate the lives of neurodivergent people (Arnaud & Gagné-Julien, 2023). This commitment of the neurodiversity movement to contribute to *better* science by being part of it, brings us to the next section on the neurodiversity paradigm as a research paradigm.

[11] LAVA representatives proposed adopting depathologised terminology such as 'at increased likelihood of autism' instead of 'at risk for', and avoiding harmful and stereotypical metaphors such as 'solving the autism puzzle'. Also, they suggested it should be possible to recognise autism early in life without having to see it as a disorder. Moreover, early detection efforts should ideally be early detection of experienced difficulties of children, parents and the relations between them. In Chapter 7, I elaborate on those suggestions.

The neurodiversity paradigm

When it comes to the neurodiversity paradigm as an academic school of thought, I have to underscore that I was only drawn into this direction in the second part of my PhD research. At the start, the academic neurodiversity literature was not as extensive as it is at the time of writing this chapter (or I did not yet understand the existing literature sufficiently well). Therefore, in the first two years of my PhD, I was attracted more towards the fields of disability and crip studies, and I framed my research initially as a 'disability bioethics approach' to early autism detection and intervention. The influences from disability and crip studies are present throughout this dissertation but particularly in Chapter 6.

My colleague Leni Van Goidsenhoven, a disability and cultural studies scholar, helped me very generously in exploring disability and crip studies. Together, Leni and I wrote two narrative review articles in Dutch: a first one on how disability studies help understanding autism as a polysemous and political phenomenon; and a second one on the term 'crip' and the field of crip studies (Van Goidsenhoven & Vanaken, 2021; Vanaken & Van Goidsenhoven, 2021). Also, I wrote a book review of Alison's Kafer seminal work in crip studies *Feminist, queer, crip* (Kafer, 2013; Vanaken et al., 2022), and I contributed to a review of the first crip studies conference in Belgium (Meinen et al., 2022).

In hindsight, these explorations of disability and crip studies do not feel as a detour. Like others have pointed out as well (Bertilsdotter Rosqvist, Stenning, et al., 2020; Ne'eman & Pellicano, 2022), the academic branch of the neurodiversity movement bears much resemblance with disability and crip studies. Based on these previous publications I contributed to, the next paragraphs will introduce disability and crip studies, and their links to neurodiversity. I wrap up this chapter with my take on the neurodiversity paradigm as a research paradigm.

Disability studies

Disability studies is an interdisciplinary academic field that is mainly grounded in the social sciences, humanities and educational sciences. The field is centred around critiques of medical approaches to disability and commits to adjusting unequal power balances between disabled and non-disabled people both in society at large and in research practices in particular. To this extent, many disability scholars consecrate their work to destabilising oppressive norms of the ideal and desirable body and mind (Adams et al., 2020; Mollow, 2017). In the opening chapter of the much referred *Disability Studies Reader*, editor Lennard Davis characterises the field as follows: 'If anything, [disability studies] serve to render complex the simple fact of impairment while rendering simple the ideological screen of normality' (L. J. Davis, 2016, p. 13). As such, the field contributes to understanding disability in a multitude of ways, rather than holding on to one-dimensional, reductive views of disabilities as disorders to be treated, costs to be prevented or tragedies to be pitied.

When I first learned about disability studies, two of its key elements stood out for me. The clarion call 'Nothing about us, without us' is a first one. Its origins date back to South African disability rights groups in the 1990s (Charlton, 1998). I learned that many disability studies scholars have turned this slogan into an ethos of research practice. The phrasing refers to the importance of working *with* instead of *on* disabled people, as is often the case in biomedical disability research. Consequently, participatory and emancipatory research practices are core to disability studies, and so is studying lived experiences by means of accessible and creative qualitative research methodologies (Goodley, 2016b).

A second key element that stood out to me in the field, perhaps unsurprisingly, were the 'models of disability'. These models reconceptualise disability and the challenges experienced by disabled people. The social, minority politics, cultural-discursive and interactional models of disability are probably the most frequently cited ones (Goodley, 2016a). Despite relevant differences, these various models share a common intention: to move away from

the dominant focus on individual, deficient bodies and minds as the locus of experienced problems and as the target of interventions. Instead, these alternative models shift the gaze towards disabling social barriers, laws, ableist discourses and representations, and mismatches between individual needs and common societal practices (Van Goidsenhoven & Vanaken, 2021).

Despite my initial excitement about these models of disability, I have also realised that they are no silver bullet to understand neurodiversity, to respond to neurodiversity's critics or to develop good and just early autism care. Below, I will discuss two sets of issues which I find relevant for my research, focussing on the social and minority politics model. Thereafter, I will turn to the subfield of crip studies where I have found complementary insights in thinking about neurodiversity and clinical autism care.

Impairment v. disability

A first set of issues stems from the social model's strict distinction between *impairment* and *disability*. In the social model's classical example, a wheelchair user is confronted with an inaccessible building and the definitions go as follows. The person's paraplegia is what constitutes their *impairment*. The fact that the building is not equipped with a ramp, escalator, wide hallways and doors, and wheelchair accessible toilets is what causes the spatial exclusion. This exclusion is based on material obstacles (within a given political, cultural, historical etc. context) and constitutes the *disability*. The ethical imperative of this model is fairly clear then: remove the barriers in society, for example by applying Universal Design principles, and consequentially, disabled people will be able to participate equally, without having their impairment itself touched upon (Shakespeare, 2006).

The social model has been useful to politicise disability and to support a move away from mere medical approaches. But for many disabilities and neurodivergent conditions, the model's neat separation of impairment and disability obviously represents an oversimplification of people's actual

experiences. Therefore, it remains important to acknowledge that disabilities and neurodivergent conditions can also entail experiences which cannot always be accommodated in the same way a building can accommodate wheelchair users. We can think, for example, about chronic pain and fatigue (Wendell, 2001), and more autism-specifically: sensory overload, autistic inertia, social exhaustion after (deliberate) participation in neurotypical-dominated social encounters, etc. (Leadbitter et al., 2021). This is not to say these experiences do not have any socio-political dimensions, yet, these examples serve to show that such bodily experiences should be kept in mind when theorising disability and neurodivergency.

In this same vein, the social model's impairment/disability distinction presumes a hard separation between the bodily and the social sphere. This presumption relies on a conception of biology that is static, rather than dynamic. Especially when thinking about developmental conditions, it is crucial to realise that the environment gets 'under the skin' in many ways, and vice versa (Hens, 2022). Children's developmental pathways, including autistic ways of developing, are fundamentally processes where biological and environmental factors are woven together. Therefore, it is complicated, and perhaps even simply wrong to understand neurodivergent conditions as fixed identities which can be traced back entirely to innate and static characteristics grounded in one's neurobiology (Hens & Van Goidsenhoven, 2023).

I definitely do want to acknowledge that the idea of sharing a similar brain wiring can feel as homecoming for some neurodivergent people. Also, I am sympathetic to claims to 'change the environment' and stay away from attempts to change the autistic person's identity and authenticity (Kapp, 2020b). Yet, from a dynamic view on biology, claiming that one's autistic identity cannot be touched upon, runs into conceptual trouble. For example, we can be fairly sure that when parents adopt autism-adapted parenting techniques over an extended period of time (which can be seen as an environmental intervention), this will always impact the development of their child, and possibly as well the expression

of so-called core autism characteristics, even when this is not the primary goal of such an intervention (see for example Pickles et al., 2016). Or, to use the social model's jargon, disability accommodations may also change the 'underlying' impairment. Therefore, I think that the social model's ethical imperative to address disabling societal structures, not bodily impairments, is a less straightforward one than it seemed at first sight. I will get back to this in Chapters 6 and 7, but I can already disclose that I believe that the task to develop good and just autism care, is not a task of preserving and protecting some sort of pristine, untouched autistic identity. Rather, it will boil down to finding ways to care for one another on an equal footing, within and across neurotype boundaries, and accepting that changing how society functions inevitably also changes who we are ourselves.

Disability identity politics

A second set of issues I came across in the disability literature revolves around the disability movement's focus on identity politics, rights-based discourses and demands for independent living. This approach draws mainly from the minority politics model of disability and is situated in liberal political thought (whereas the social model has roots in Marxist theory). Clearly, this liberal approach has secured some significant wins. The Convention on the Rights of Persons with a Disability (United Nations, 2006), for example, brought disability rights within the sphere of universal human rights, and funding for Personal Care Attendants in certain countries vastly improved some disabled people's participation in society (despite the policy's limitations).

However, new questions arise due to this organising around a well-defined political identity (Botha, 2021a). Who can claim these identities and who does the gatekeeping? For example, does one need an official autism diagnosis to be part of the neurodiversity movement, or to make use of autism-specific accommodations and services? When is one 'autistic enough' to speak from an autistic perspective? Where are the boundaries of these categories? For example

can bipolar people, people with psychotic experiences, or with a borderline personality identify as neurodivergent? How can the neurodiversity movement work towards societal acceptance of diversity as the norm, while it also seems (at first sight) to rely on a new dualism of neurotypical/neurodivergent? And is the ablebodied and neurotypical ideal of living independent and productive lives actually an ideal worth fighting for at all (Chapman, 2020a; den Houting, 2019; Kittay, 2015; Runswick-Cole, 2014; Van Goidsenhoven & Vanaken, 2021)?

Obviously, there are no easy answers here, but the field of crip studies gave me inspiration to continue moving forward, rather than to get stalled by these questions. Also, I will take some space to talk about crip studies because I am convinced that it has a range of valuable contributions to make to neurodiversity theorising which can help defining what a neurodiversity approach to research and clinical care actually entails.

Crip studies

Crip studies, also referred to as crip theory, is a fairly young, interdisciplinary academic field at the intersection of disability and queer studies. The field has strong roots in activist and artistic practices. 'Crip' is/was a derogatory term, short for 'cripple', that has been reappropriated by disabled people over the past few decades (McRuer & Berube, 2006). Towards outsiders, the harshness of this term is purposively provocative. It captures the 'urge to shake things up, to jolt people out of their everyday understandings of bodies and minds, of normalcy and deviance' (Kafer, 2013, p. 15). The in-group meaning of the term, i.e. within (certain) disability communities, is rather infused with pride, self-irony and solidarity (Vanaken & Van Goidsenhoven, 2021). The term crip gained currency against the backdrop of increased governmental gatekeeping in Western countries on who deserved the label 'disabled' and on who was granted access to specific disability rights and accommodations. Some people who did not find their place under the disability banner, did so in crip communities (Lewis, 2015).

The term 'crip' is notoriously hard to define as it resists being pinned down by outsiders, by formal criteria or by government policies. 'Claiming crip' is therefore best understood as taking up a critical position and an attitude of resistance towards dominant societal norms that exclude non-normative bodyminds (Vanaken & Van Goidsenhoven, 2021). This way, the term crip functions similarly to the term 'queer'[12]. Just like claiming queerness, claiming crip does not refer to a well-defined, fixed or essential identity. Crip's boundaries are open to be contested and to be shifted over time. When societal norms swing, the group who continues to fall outside these norms, could claim crip in turn. In a seminal publication in crip studies, Carrie Sandahl clarifies crip's fluidity as follows.

> *(…) the term cripple, like queer, is fluid and ever-changing, claimed by those whom it did not originally define. As a pejorative, the term queer was originally targeted at gays and lesbians, yet its rearticulation as a term of pride is currently claimed by those who may not consider themselves homosexual, such as the transgendered, transsexuals, heterosexual sex radicals, and others. The term crip has expanded to include not only those with physical impairments but those with sensory or mental impairments as well* (Sandahl, 2003, p. 27).

Neurodiversity theorists such as Robert Chapman (2020b) have argued that similar dynamics are at play for the concept of neurodiversity. Chapman refers to neurodiversity as a 'moving target', a phrasing they borrow from the philosopher Ian Hacking, 'meaning that the concept will continue to change and

[12] In a similar vein, a few authors came up with the term 'neuroqueer', referring to the intersections of identifying as queer and neurodivergent. Similarly to crip and queer, neuroqueer is not only employed as an adjective, but also as a verb (see below). Here, neuroqueering implies reading practices against the grain to expose and alter neuronormative and heteronormative assumptions (Walker, 2021). I have chosen not to engage in more depth with the term neuroqueer as my study does not deal with aspects of gender and sexuality, which makes the term less apt for me than the term crip. Also, as a verb, it did not offer me additional analytic tools compared to crip theory. Arguments to reconsider my position in future work are that neuroqueer theory has been developed by neurodivergent scholars and it maybe holds more face validity than crip theory in the context of autism-related discussions.

'move' due to complex interactions between those who are categorised by it, as well as the various relevant institutions it challenges and responds to (psychiatry, education, etc.)' (Chapman, 2020b, p. 219).

In parallel to claiming queerness, the move to reappropriate the harsh word crip, expresses an underlying conceptual shift. This shift resembles the way that autistic people are reclaiming 'autistic' as an adjective and as a noun to refer to themselves with pride. Instead of reproducing the idea that disabled and atypical bodyminds are undesirable by definition, people claiming crip (and I'd add 'autistic' here as well) explicitly embrace their deviant bodymind as a *desirable* one (despite the many struggles of living disabled and neurodivergent lives). Crip theorist Alison Kafer elaborates on this aspect of desirability in her book *Feminist, queer, crip* (2013)[13].

> *I have written this book because I desire crip futures: futures that embrace disabled people, futures that imagine disability differently, futures that support multiple ways of being. I use this language of desire deliberately. I know how my heart can catch when I see a body that moves oddly or bears strange scars. I know how my body shifts, leans forward, when I hear someone speak with atypical pauses or phrasing, or when talk turns to illness and disability. Part of what I am describing is a lust born of recognition, a lust to see bodies like my own or like the bodies of friends and lovers, as well as a hope that the other finds such recognition in me. Perhaps most important to this examination of disability futures, it is a desire born largely of absence. We lack such futures in this present, and my desires are practically inconceivable in the public sphere. There is no recognition that one could desire*

[13] I am well aware that I draw quite extensively on the work of Alison Kafer in this section. In general, I would avoid such a reliance on a single source. Yet, Kafer's work had a large impact on me, both academically and personally. Therefore, it feels right to make that impact visible by citing and quoting Kafer several times here and in the upcoming chapters.

> *disability, no move to imagine what such desire could look like* (Kafer, 2013, p. 45).

Kafer writes here about how she desires 'crip futures'. This ties in with her overall project, i.e. to challenge the idea that 'that a future with disability, is a future no one wants'. Kafer's counterproposal here is to actively envision different futures. This forward-looking exercise imagines political futures that actually welcome and desire disability, rather than marginalise, normalise or even deliberately brush it away. This kind of activity is what Kafer calls 'cripping futures'. In my review of Kafer's book, I suggested that this speculative approach to inclusive futures also offers a way to think differently about early autism care practices (Vanaken et al., 2022). Instead of seeing these practices as spaces where autism is managed or controlled, we could also try to turn these spaces into spaces of political contestation; spaces where researchers, practitioners, parents and autistics come together to shape more desirable futures for autistic people (but more about that in Chapter 7).

If we return to the issues I described before related to the impairment/disability distinction, and to identity and rights-based disability politics: how could crip studies help here? I think there are (at least) two clusters of ideas in crip studies that can complement our understanding of neurodiversity and neurodivergency. The first cluster relates to 'cripping as a verb' (Sandahl, 2003). The second one relates to crip studies' approach of working both 'with and against [group] identities' (McRuer & Berube, 2006).

To crip, as a verb

Mobilising crip as a verb, is one of the theoretical tools developed in crip studies. 'To crip' or 'cripping' a certain practice, object, text, or concept refers to reading it against the grain, to put it to work in favour of disabled people's interests and to reappropriate it in a whimsical, creative or confrontational way with the aim of critically questioning the exclusion of disabled people (Vanaken & Van Goidsenhoven, 2021). Or, in the words of disability arts scholar Carrie Sandahl:

> *Cripping spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects. (…) cripping expose[s] the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity, and both disarm what is painful with wicked humor, including camp (Sandahl, 2003, p. 37).*

An example might help to grasp this better. In writing about the accessibility of cultural institutions for physically disabled spectators, Fien Criel (Criel & Fierlafijn, 2022) argues that it does not suffice to have an elevator that can be reached via a side entrance or to have dedicated stewards guiding you to your reserved, special seat. 'The mere fact that we need these exceptions to be part of the audience are proof of the inequality which I do not applaud' (ibid, own translation, p. 4). In Chapter 5, I will present an anecdote of an autistic adolescent describing a similar experience with well-intended, but problematic accommodations offered to her during an internship. Crip interventions, Criel claims, are forms of creative resistance. Resistance against the pressure to assimilate oneself to participate, and resistance against the dis/abled binary that some accommodations reproduce (such as elevators that can only be reached via separate entrances). To crip the accessibility of a building might involve, for example, 'installing colourful, eye-catching wheelchair ramps squarely at the main entrance' (ibid, p. 5). In this sense, crip interventions are not just a juridical obligation (as in the minority politics model), nor an accommodation that resolves disability (as in the social model), they are, as crip theorists speculate, caring acts filled with pride, joy and political contestation (Piepzna-Samarasinha, 2018).

Crip identity

The second cluster of ideas I want to discuss, is crip studies' approach to identity. Compared with disability scholars, crip theorists resist one-dimensional, medical approaches to disability but they occupy more fluid, intersectional and

contestatory positions (Vanaken & Van Goidsenhoven, 2021). These positions are not easily pinned down into a neat description such as a 'model of disability'. Crip scholars even tend to stay away deliberately from such fixed definitions of disability. They rather suggest that what constitutes disability is always open for debate. The rationale here is that crip theorists are convinced that no matter how society is organised, there will always be bodyminds that are situated more in the margins. To buffer this, crip theorists rather opt for a description of disability which is open for change. Disability is positioned as a political phenomenon, as 'a set of practices and associations that can be critiqued, contested, and transformed' and which is 'implicated in relations of power (…) that are contested and contestable, open to dissent and debate' (Kafer, 2013, p. 9).

Yet, when pinning down a well-delineated disability identity is so actively avoided, is there then still something that binds disabled (and neurodivergent) people together? According to Kafer, it is not so much 'any essential similarities' that disabled people share with each other, but rather a sense of 'collective affinity' that ties disabled people (temporarily) together as a group. Borrowing from Donna Haraway, Kafer describes this collective affinity as the fact that all members 'have been labelled [explicitly or implicitly] as disabled or sick and have faced discrimination as result' (ibid, p. 11). In other words, Kafer suggests that what brings disabled and neurodivergent people together, is not any similar traits or diagnoses, nor the active choice to identify as disabled or neurodivergent. Instead, she suggests that what forges the group identity is the shared experience of being situated in society's margins and facing the disadvantageous effects of mainstream norms defining what the desirable bodymind looks like. This nuanced approach is what I referred to before as 'working both with and against' group identities.

Kafer's suggestions relating to crip identity have been echoed more recently by neurodiversity thinkers as well. Robert Chapman (2020a), for example, suggests conceptualising neurodivergency as a 'serial collective', a concept borrowed from Iris Marion Young. 'What binds members of [such a

serial collective] is their shared relationship to material and social conditions, rather than their shared identification with the classification', which allows to conceptualise neurodivergency 'in an intersectional and anti-essentialist way that is useful for organizing political resistance' (ibid, p. 811). Interestingly, this conceptualisation of neurodivergency also opens up the possibility to claim a neurodivergent identity without having a formal diagnosis. Also, claiming neurodivergency as an identity should not so much be understood here as reflecting a fixed, unchangeable identity merely for the sake of indicating one's difference from the norm. Rather, as my colleague Lisanne Meinen suggests, claiming neurodivergent identity can be seen as 'a caring and political action' with the goal of resisting the norms of a non-ideally organised society (Meinen, n.d.).

These two clusters of ideas from crip studies, 'cripping as a verb' and 'crip identity', certainly do not simplify our understanding of disability and neurodiversity, nor can we easily distillate ethical advice on how to organise early autism care. Yet, they do help to formulate how I have come to understand the neurodiversity paradigm as a critical lens to look at research and practice. To finalise this chapter and thereby this Introduction, the upcoming section describes my understanding of a neurodiversity paradigm as a research paradigm.

A neurodiversity approach as research paradigm

As touched upon in the Preface, I cannot claim to *be* neurodivergent, however as a researcher I can approach my research questions through a neurodiversity lens. But what does that mean exactly? And also, how can researchers across neurotype boundaries take a neurodiversity perspective without watering down or reappropriating this approach[14]? Again, I borrow here from Kafer and I build

[14] Some authors have claimed to embrace neurodiversity as concept, and changed certain terms (for example moving to 'Autism Spectrum Condition' instead of 'Disorder') accordingly, but without changing their underlying assumptions about autism as a set of individual deficits to be

on the parallel between mobilising a neurodiversity approach in research and 'claiming crip'. Kafer asks: 'Can claiming crip be a method of imagining multiple futures, positioning "crip" as a desired and desirable location regardless of one's own embodiment or mental/psychological processes?' She suggests the following answer: 'To claim crip critically is to recognize the ethical, epistemic, and political responsibilities behind such claims' (2013, p. 13). The way I interpret this suggestion, is that indeed, yes, it is possible to take up a neurodiversity approach as a (neurotypical) researcher, yet, this comes with certain responsibilities. My way of taking up these responsibilities is to be transparent about how I understand the underlying assumptions of such a neurodiversity approach qua research paradigm.

According to neurodiversity proponent Nick Walker, the neurodiversity paradigm is a 'specific perspective on neurodiversity'. This perspective assumes the intrinsic equality of neurotypes and the politicisation of neurodivergent experiences in an ableist society. The neurodiversity paradigm, Walker writes, provides the 'philosophical foundation for the neurodiversity movement' (2014).

A research paradigm[15] is a theoretical framework that articulates researchers' beliefs about how they view reality and how they think this reality can be studied. A research paradigm provides indeed the essential philosophical groundwork for any research activity, although it often only functions tacitly in the background. A research paradigm entails assumptions about *ontology*, or the nature of beliefs about reality, about *epistemology*, or the nature of beliefs about knowledge acquisition and transfer, about *methods* and *methodologies*, and about *axiology*, or the role of values in research (Botha, 2021b; Rehman &

remediated. 'Endorsing' neurodiversity approaches in this way actually undermines its innovative contestatory elements (e.g. Baron-Cohen, 2017; M. C. Lai et al., 2020).

[15]I use the term 'paradigm' here mainly because it has gained currency over the past years (Pellicano & den Houting, 2022; Walker, 2014). I realise that philosophers of science rely on more restrictive uses of the term paradigm and paradigmatic change, which is a discussion I will sidestep. For this thesis, I will simply define how I understand 'research paradigm' and 'neurodiversity paradigm' and stick to those definitions.

Alharthi, 2016). In the next paragraph, I clarify which assumptions make up my take on the neurodiversity paradigm, applied to autism. More specifically, I spell out my assumptions on what neurodiversity *is*, how relevant autism *knowledge* comes about, and which (relation to) *values* are involved in this paradigm.

A working description of the neurodiversity paradigm

Regarding the ontological question of what neurodiversity *is*, my working description is as follows.

> *Neurodiversity reflects the diversity of cognitive, sensorial, behavioural, emotional, and communicative ways of experiencing and engaging with the world. Neurodivergent experiences are rooted in, but not entirely reducible to neurobiological differences. Yet, they emerge from bidirectional interactions between individual factors on the one hand, and normative and contestable environments and societies on the other hand* (Vanaken, 2022b).

On this account, problems experienced by neurodivergent people, such as autistic people, are not entirely attributable to the individual (as in the medical model of disability), nor to the environment and society (as in the social model of disability). Instead, such experiences emerge from interactional mismatches between these two spheres, all while keeping in mind that the boundaries between nature and nurture, the individual and the environmental are porous.

For this description, I draw from Walker (2014), who defines neurodiversity as 'the diversity of human minds, the infinite variation in neurocognitive functioning within our species'. However, the phrasing 'neurocognitive functioning' feels too narrow to capture neurodivergent lives in all their aspects, including emotional, behavioural, interpersonal, and socio-political ones, which is why I choose 'experiences and engagements'. Also, I build on Chapman & Botha's (2022) suggestion to conceptualise neurodivergency in the framework of the interactional model of disability because experienced problems are 'relational rather than intrinsic to

neurodivergent people'. In the context of autism, this interactional take on disability also matches well with Damian Milton's (2012) description of the Double Empathy Problem. Milton posited that cross-neurotype socio-communicative mismatches are not solely due to the autistic person having difficulty empathising with their non-autistic interlocutor. Rather, the 'success of an interaction partly depended on two people sharing similar experiences of ways of being in the world'. In other words, non-autistic people might have as much difficulties understanding autistic people's engagements with the world, as goes the other way around. By consequence, fruitful, cross-neurotype communication requires efforts from both sides (Milton et al., 2022). At the same time, the interactional model of disability originated in Scandinavian countries in the context of radical inclusive practices designed for intellectually disabled people. As consequence, this model tends to focus strongly on the 'normalisation' of disability. Normalisation here refers to bringing disability and disabled people into the mainstream of society, including in educational, housing and work contexts (Goodley, 2016). While there is much to say in favour of such approaches, I prefer not committing entirely to these implications of the interactional model of disability. My rationale here is that next to mainstreaming disability and neurodiversity, I believe there is *also* a need to keep space for self-determined disabled and neurodivergent niches in the margins, without the pressure to fit into the needs of this mainstream, and from which the mainstream itself can be criticised[16]. Therefore, as a third element of my working definition I rely on Kafer's description of disability as a political phenomenon, as 'a set of practices and associations that can be critiqued, contested, and transformed (…) implicated in relations of power (…) that are contested and contestable, open to dissent and debate' (Kafer, 2013, p. 9).

So, if we view autism as a phenomenon that takes place at the level of experiences that emerge from interactions between biological and social factors,

[16] At least one argument to favour the such non-mixed, deliberately 'marginal' spaces is that it is an illusion that mainstream can be accommodating for everyone, at all times. Having spaces to retreat among people with similar experiences can buffer this in part.

then, indeed, autistic lived experiences become an important source of information in producing relevant knowledge on autism. Within the wider fields of medicine and psychiatry, similar turns towards including the perspectives of 'people with lived experiences' are obviously taking place as well (Voronka, 2016). However, what sets this turn apart in the autism field are the long-standing claims that autistic people would be untrustworthy knowledge producers as they would have unbridgeable deficits in taking another's position or to coherently understand their own experiences (Hens, 2021)[17]. Such explicit claims are already less dominant in contemporary autism research, but they are still part of the (unconscious) background conditions against which autistic self-advocates and autistic scholars struggle to be seen as rightful experts in living autistic lives.

Borrowing from feminist philosophers, we could rephrase this as the assumption that knowledge is 'situated', rather than absolute and universally applicable. Relevant knowledge cannot be produced (only) from a disengaged, outsider perspective but requires active engagement with those people living the phenomena under study on a daily basis. In this view, occupying marginal positions in society and having lived through certain experiences, generate an epistemic advantage compared to non-autistic knowledge producers. Doing relevant research without including the richness of such experiences would therefore lead to partial, suboptimal knowledge acquisition (Harding, 2015; Kourti, 2021)[18]. There are at least two risks here, though. A first one is to conceive autistic lived experience as one homogenous block, effacing heterogeneity among autistic people, for example, regarding intersecting

[17] The exclusion of autistic voices on grounds of their deficits to interpret their own or other's experiences properly is a clear example of what philosopher Miranda Fricker coined as 'testimonial epistemic injustice', i.e. a harm done to a knower by discrediting their inherent capacity to contribute to knowledge production (Fricker, 2007)

[18] I admit that discussing feminist standpoint epistemology here would be sensible. Although I much agree with its presumptions, I have decided not to include it explicitly in this Dissertation. The main reason is that I am not convinced that my empirical studies (Chapter 4 and 5) actually deploy standpoint epistemological values. I have interviewed parents and adolescents, irrespective of whether they had gained a critical perspective (or standpoint) regarding autism. If I had to redo the studies, I might make different methodological choices and engage principally with participants who did acquire a critical standpoint (in the technical sense).

identities and co-occurring disabilities (Botha & Gillespie-Lynch, 2022). A second risk is seeing autistic people merely as sources of extractable information without guaranteeing that such knowledge extraction actually ameliorates the state of affairs for autistic people (Bertilsdotter Rosqvist et al., 2019). When one claims to take a neurodiversity perspective to research, it is important to connect this epistemological commitment to engage with lived autistic experiences to the ethical commitment of contributing to social justice for and emancipation of autistic people (Stone & Priestley, 1996). This brings us to a third aspect of the paradigm, i.e. its axiology or underpinning values.

The neurodiversity paradigm is explicitly value-driven. As such, it differs from and actively contests so-called value-neutral research paradigms such as positivism, which underpin much of the medical model-type of autism research (Botha, 2021b; Kourti, 2021). Rather than hiding values behind a veil of supposed 'neutrality' or 'objectivity', researchers mobilising a neurodiversity paradigm make their values explicit and take them as a starting point for their research. The most cited values here are social justice for and emancipation of neurodivergent people (Botha, 2021b; Kourti, 2021). In this sense, doing research from a neurodiversity perspective means taking up part of the shared responsibility to combat the structural injustices that contribute to the experienced difficulties of neurodivergent people (Young, 2011).

Implications for this study

This take on the neurodiversity paradigm has three implications for my own research.

First, I acknowledge that young autistic children and their caregivers can experience tangible difficulties and problems in their lives for which they might ask (clinical) support. Chapters 4 and 5 of this dissertation zoom in closely on these experienced difficulties of parents and young autistic people. For me, however, claiming a neurodiversity perspective means looking at these difficulties from an *interactional and politicised* perspective. This means that I

assume that such difficulties arise from an interaction between individual differences and contestable environmental and societal factors. This conceptualisation underpins the discussion of my empirical findings in Chapters 4 and 5, and it is a core aspect of the theoretical Chapter 6.

Second, I believe it is key to engage with autistic people and their relatives directly to formulate ethical recommendations that are relevant for and grounded in the daily lives of people concerned. I tried to do this formally in two interview studies, but also informally by discussing my ideas and findings with neurodivergent colleagues and self-advocates as touched upon in the Preface.

Lastly, this research project is guided by the drive to emancipate autistic people and work towards a society that is more just for all, irrespective of our minds and bodies. In Chapter 6, I will return to this question of values. There I will rephrase things a bit and propose that potential values to develop a neurodiversity-affirmative autism care are those of solidarity and empowerment.

Here, we arrive at the end of the second chapter, and therefore at the end of this *Part One: Introduction.* Up next is *Part Two: Main* consisting of four stand-alone journal papers. The justification of why I chose to do these specific studies is embedded in the chapters themselves. Therefore, I will not take up more space here for introductions. As said, Chapter 3 might feel as an odd one out as the study is not directly about imagining good and just autism care from a neurodiversity perspective. Instead, it is a traditional, applied bioethical analysis. We explored whether and how to return children's individual research findings to their caregivers in early autism detection and similar research. Initially, I doubted whether to include this paper in this dissertation. But now I think it deserves its place as it does make a contribution to the ethics of early autism care. The chapter highlights diverging interests between children and their parents, and deals with the ethical non-neutrality of communicating 'objective' findings of a child's development and behaviour to its caregivers. Moreover, assessing this Chapter 3 (written early in my PhD research) in parallel to the

other chapters might give a feel of how my own views of autism have changed over the course of these past four years.

Part Two: Main

3. Ethics of returning children's individual research findings

from principles to practice

This chapter has been published elsewhere before.
Vanaken, G.-J., Noens, I., Roeyers, H. , van Esch, L., Warreyn, P. Steyaert, J., Hens, K. (2020). Ethics of returning children's individual research findings: from principles to practice. *Eur Child Adolesc Psychiatry* https://doi.org/10.1007/s00787-020-01606-4

Abstract

Little ethical recommendations on returning children's individual research findings are available for researchers in behavioural sciences, especially when compared to genetic research. Anecdotic evidence suggests that since parents are often interested in their child's individual research findings, researchers tend to offer this information as a form of compensation for research participation. Despite good intentions, these practices are not without potential harmful consequences for children. We were confronted with these difficulties and with the paucity of available guidance on this topic, being involved in a longitudinal, infant development study, i.e. Tracking Infants At Risk for Autism (TIARA). First, we review current ethical recommendations and discuss their limitations in the light of the TIARA-study. Second, we will suggest to revise these recommendations, by identifying and applying the relevant bioethical principles and concepts at hand. Third, as an example of practical implementation, the adopted 'return of research findings'-policy for the TIARA-study is presented. The principles and concepts we engage with are the ancillary care responsibilities of the researcher, non-maleficence and beneficence, the right to an open future of the child, and the avoidance of therapeutic misconception. Ultimately, we present the concrete return of research findings policy implemented in the TIARA-study. Here, we suggest restricting the systematic return of children's individual research findings to cases where findings are considered clinically significant and actionable for the child. We discuss the broader implications for designing and conducting research in behavioural sciences with children.

Introduction

Much has been written regarding the ethics of returning individual research findings to study participants and their relatives with regards to biomedical research, and especially genetic findings (Hens et al., 2011). However, significantly less has been published about communicating individual findings in behavioural sciences, e.g. in the fields of psychological, educational and developmental research, particularly when minors are concerned. While it is not our aim to frame parents as potential liabilities to their children, we believe that particular attention and care towards children in research settings is relevant, as their interests do not always converge entirely with those of their parents. Below, we will highlight some of these diverging interests between children and their parents, as we believe that these are often interpreted as one and the same.

To our knowledge, very little recommendations are available for researchers in this field with regards to the duties they owe their underage research participants and their parents (Lefaivre et al., 2007). In contrast to genetic research where researchers previously tended not to inform their participants about individual research findings (Kostick et al., 2018), anecdotal evidence from the field of behavioural sciences suggests that these researchers do often return children's individual research findings to parents. Such results may range from a description of how well a child has performed on a certain psychological task, visual material of brain imaging or the results of an intelligence test conducted as part of a research protocol. It is often assumed that parents have a right to this information about their child, and thus, that it is the duty of researchers to return these results. Previous empirical work showed that parents value receiving such individual feedback (Cox et al., 2011). As such, both parents and researchers might consider this information a kind of compensation for research participation. To our knowledge, often, researchers already make a nuancing distinction between returning findings based on standardized instruments for which norm or cut-off scores are available, as

compared to findings from experimental instruments for which interpretation of the results is less straightforward. However, despite this valuable distinction, we will argue below that more criteria need to be fulfilled in order to justify returning children's individual research findings in behavioural research. As such, our position is that returning information from the child that is being collected during research should rather be the exception than the rule, especially when young children are involved.

Before outlining the set-up of this argument, some conceptual clarifications with regards to terminology seem to be relevant at this point. The concept 'return of research findings' might refer both to communicating the *general* findings of a study (or 'aggregate findings') to all participants, as to providing individual participants and their caretakers with personal feedback on the outcome of the instruments that were administered. It has been argued before extensively, that the return of general research findings to all participants willing to receive them, should be common practice acknowledging that participants do not merely act as a mean to a scientific end, but should be respected in their dignity as person as such (Fernandez et al., 2003; Partridge & Winer, 2002). Additionally, empirical studies repeatedly highlighted participants' interest to be informed of these general findings (Shalowitz & Miller, 2008).

Here, we focus on the ethics of returning *individual* research findings, in the case of underage research participants. Individual research findings are the *interpreted* outcomes of a given assessment of a single participant obtained within a research study setting. These may be *intended* results (results that straightforwardly come out of the instruments administered) or *incidental* findings (results that come out of an instrument but where not intended, think for example about the detection of a tumour during brain imaging research). For the purpose of this paper, we will not make the distinction, since our argumentation and conclusions apply to a same extent to both intended and incidental findings.

First, we will review existing ethical recommendations on this topic. Second, we will introduce the TIARA study (Tracking Infants At Risk[19] for Autism), a longitudinal infant development study in which we are involved concerning the research ethics. We will describe the limitations we were confronted with when applying the existent recommendations in practice. Third, we will attempt to revise existent recommendations, building on the principles and concepts that have been successfully applied to the question of returning individual findings in the case of genetic research on minors. These principles and concepts include the *ancillary care responsibilities* of the researcher, *non-maleficence* and *beneficence*, the *right to an open future of the child*, and the avoidance of *therapeutic misconception*. Lastly, we will describe the practical implementation of these revised recommendations in the TIARA study.

Existing ethical recommendations on returning children's research findings

To our knowledge, only Lefaivre, Chambers and Fernandez (2007) examined, from a theoretical perspective, the ethics of returning children's individual research findings in the field of psychology[20]. Before providing a set of recommendations, the authors highlight several relevant issues to be taken into

[19] Although the phrase 'at-risk for autism' is widely used in research settings, we understand that the use of the word 'risk' when referring to autism is controversial. At-risk language frames autism as a threat, as a medical condition to be prevented as such. More neutral use of language replacing 'risk' by 'likelihood' or 'chance' could function as a less pejorative alternative (Fletcher-Watson et al., 2017).

[20] In order to identify earlier ethical recommendations on returning children's individual research findings, we carried out a literature review. Papers were included for review if they (a) prescribed ethical recommendations on whether and how (b) individual research results of (c) minors (<18y) should be (d) returned to parents (e) within the field of psychological and psychiatric sciences. Papers were excluded if they merely (a) empirically researched the effects of returning such findings or stakeholder preferences on the topic, or (b) when they only addressed genetic or biological findings. To this extent we searched Web of Science using the following search terms (ethic* OR recommendation*) *AND* (result* OR finding*) AND (return OR feedback OR communication OR disclosure) *AND* (psycholog* OR psychiatr*) *AND* (child* OR infant OR youth OR adolescen* OR parent*). This search yielded 379 results. Based on title and abstract, 6 results were selected for full-text review. Three papers were excluded for only addressing genetics or neuroimaging findings. One paper did not discuss individual research findings, while one did engage with our precise research question, but addressed the issue in an empirical-descriptive way (Cox et al., 2011). Ultimately, one paper could be included, i.e. Lefaivre et al. (2007).

account, both in favour as opposed to returning children's individual research findings. Here we give an overview of those issues as formulated by Lefaivre et al., which we have categorized as related to: (a) the impact on participants and their parents; (b) the impact on the research project; and (c) the qualitative aspects of the research findings.

(a) With regard to issues impacting underage participants and their parents, Lefaivre et al. (2007) argue, in line with arguments on returning general research findings, that 'one of the strongest arguments in favour of offering individualized feedback is that this procedure obligates researchers to treat each of their participants primarily as persons or an end in themselves rather than a means to an end' (p.245). Adding up to this, 'the opportunity to gain knowledge[21]' (p.245) is presented as a benefit of research participation for both the child and the parent. They also present caveats regarding individualized feedback, such as the child's right to privacy, the potential of disagreement between the minor and the parent on whether and how the research results should be dealt with, the risk for the child of being labelled unwantedly and for installing a self-fulfilling prophecy. For example, merely returning research results of a child scoring below average on a test measuring receptive language skills, might, hypothetically, incite parents to simplify their language or read less to their child, as they might believe is best. In result, the amount of language on offer reduces and the child's receptive language competences are granted less opportunities to develop. This way, the prophecy fulfils itself.

(b) From the perspective of the researchers and their study, Lefaivre et al. suggest that returning individual findings to participants as compensation for their efforts may encourage participants to take part in research in the first place, and may keep participants involved when longitudinal research is concerned (2007). However, the authors equally mention concerns on how the promise of individual results as recruitment strategy in some cases can be considered an 'excessive enticement for research participation' (p.246). Especially in

[21] Lefaivre et al. refer here to the potential benefits of gaining *individual* knowledge

healthcare contexts where clinical access to the assessments in case might be limited, e.g. due to financial limitations or waiting lists, research participation carries the risk of compromising the autonomous consent procedure of participants to take part in the study without any form of coercion. This way, the authors argue, theoretically, a sample bias could be introduced 'limiting the generalizability of the study's results' when 'parents and youths falsely report difficulties or signs of psychopathology simply to meet the eligibility criteria' (p.246). Furthermore, and especially when results are returned during ongoing longitudinal research, 'the timing of the feedback and subsequent need for additional assessment could compromise the integrity of the research design' (p.248).

(c) As a third category of issues, Lefaivre and colleagues (2007) highlight the point that instruments that are administered in research settings regularly differ from those used in clinical circumstances in terms of 'reliability, validity and clinical utility' (p. 247), qualities on which the justification of returning individual research findings depend. If the instruments at hand lack good psychometric properties, or if the findings do not evidently correlate to diagnostic or therapeutic practice, returning findings based on those instruments is of limited value.

In an effort to translate these theoretical issues into practical guidance for researchers in psychology and related fields, Lefaivre and colleagues listed a set of ethical recommendations. In these recommendations, the authors define which kind of individual findings could be returned, and when and how this could be done. In practical terms, the authors recommend returning individual findings if these rely on 'well-validated psychological measures' and if they include 'normative data or empirically-derived cut-offs' (p.248-249). Furthermore, the authors formulate extensive recommendations on how to approach this individual feedback. They suggest explaining the opportunity for returning findings during the consent procedure, to engage underage participants in the choice to obtain the findings and to provide written feedback in lay-language

combined with percentile ranks or a description comparing the results with the average outcome range. The authors advise to have a face-to-face conversation led by a clinically experienced professional when complex, ambiguous or impactful findings need to be communicated.

Taken together, these suggested practical recommendations focus first of all on the principle of beneficence by providing valid and reliable individual research findings to participants that are considered of interest to them and their parents. Seconds, the recommendations highlight the underage participant and parents' autonomy in having their voice heard on whether or not individual feedback is to be welcomed.

However, it is remarkable that these practical recommendations do not integrate all the theoretical reflections the authors raised before. Most prominently, attention to prevention of harm to both the participant and the study itself, and to the aspect of clinical utility appears to be left out in the recommendations. Furthermore, while the authors stress parents' autonomy on whether they want to be informed on the research findings of their child, the recommendations seem to imply that parents can opt-out of all findings. While this is a valuable position in many cases, it can be problematic when the findings indicate a severe or life-threatening condition. A critical appraisal of parents' apparent right of not knowing certain findings seems to be lacking.

In what follows, we will illustrate how we were confronted with these gaps in the practical recommendations when reflecting on the return of individual findings during the TIARA-study in which we are involved. We start by describing the goals and methods of TIARA as such, moving over to the relevant ethical principles and concepts to consider and finalize by giving insight in the return of research findings policy that we eventually adopted.

From ethical principles to practice: the case of TIARA

The TIARA-study (Tracking Infants At-Risk for Autism) is a multi-centre, longitudinal cohort study on infant development between the age of 5 and 36 months, co-led by two Belgian universities, Ghent University and KU Leuven. (http://tiara-onderzoek.be/). TIARA aims to identify and understand the interplay and the predictive value of a wide range of parameters in the early development of autism spectrum disorder (ASD, or shortly autism). Children participating in TIARA belong to one of three groups, each with a suspected increased chance for developing ASD, i.e. siblings of children with an established ASD diagnosis (Szatmari et al., 2016), infants born prematurely under 30 weeks of gestation (Agrawal et al., 2018) and infants with persistent, medically insufficiently explained feeding problems (Field et al., 2003). These children are being assessed at 5, 10, 14, 24 and 36 months of age. At these ages, children are assessed in a variety of ways including via developmental (e.g. Bayley Scales of Infant Development (BSID-III)) and behavioural assessments (e.g. Autism Diagnostic Observation Scale (ADOS-2), mother-child interaction, eye-tracking), and genetic, metabolic and neurophysiological tests (e.g. EEG). At the age of 36 months, a best-estimate categorical research diagnosis of ASD, non-ASD or atypical development is established.

Within the TIARA study, parents prove to be particularly interested in the individual research findings of their young child, a dynamic which has equally been reported in a similar Swedish study (Achermann et al., 2020). This should not be a surprise knowing that the participating child has been described as 'being at-risk for autism' even before the first study assessment took place. Additionally, parents are in some cases confronted with the fact that their child has difficulties with specific tasks since they are present at the research assessments. As such, it can be understood that parents have a particular interest to be informed of the findings of their child. Another factor is that over the course

of the different assessments a more familiar bond is established between parents and researchers, leading parents to ask more questions and researchers to intuitively lean towards discussing more individual findings. Most of the TIARA researchers have clinical degrees in psychiatry, psychology and educational sciences, and because of this clinical training, they also may be more inclined to discuss results with parents, as they would do in a clinical setting. This reciprocal give-and-take dynamic where borders between research and care are partly blurred, has been described in ethnographic research before as a noteworthy characteristic of performing early autism studies (Lappé, 2014).

However, TIARA is a research protocol, not clinical care. Therefore, the TIARA team developed a return of research findings policy, which, in our view, respects the principles and concepts of *ancillary care responsibilities of the researcher*, *non-maleficence* and *beneficence*, *the right to an open future of the child*, and the avoidance of *therapeutic misconception*. We are convinced that these principles and concepts can help guiding similar policies in other studies too. However, their application will necessarily depend on the concrete circumstances at hand.

Implementing researchers' ancillary care responsibilities

To start with, one can ask if researchers do have any responsibility at all to be occupied with returning individual research findings and if so, how far such responsibility would reach. In this respect Richardson and Belsky helpfully conceptualised the *ancillary care responsibilities* for researchers (Richardson & Belsky, 2004). These authors argue that there is indeed a minimal set of responsibilities for researchers to care for their participants, be it only if two criteria are fulfilled based on the scope and strength of the findings. Ancillary care is defined here as care 'which goes beyond the requirements of scientific validity, safety, keeping promises, or rectifying injuries' (p. 26). Ancillary care can thus entail returning individual research findings and providing –directly or indirectly via a referral- clinical care, if needed.

Hereby Richardson and Belsky find a middle ground between two polar positions, i.e. the researcher as personal physician for the participant as patient on the one hand versus the researcher as pure scientist and the participant as mere volunteer on the other. Research participants do not hand over permission to researchers to promote their health in the same way as in a clinical patient-physician relationship. However by taking part in research, participants (or when minors are concerned: their parents) do give limited authorizations to the researchers to collect health information about them or to conduct a certain intervention. This happens however within a pre-defined scope. As such, a certain vulnerability is generated between participant and researcher in which the participant's well-being is partly dependent on the researcher's decision-making. Together, this is what Richardson and Belsky describe as the *partial entrustment model* of the researcher-subject relationship.

From this model, two criteria come forth that justify and limit ancillary care responsibilities. First, the care should fit within the health *scope* of what participants have entrusted the researchers. Clearly, this means that there are significant differences in scope between studies relying on a simple once-only online questionnaire versus those using a longitudinal approach with many different contacts between participant and researcher and using a variety of instruments. Second, based on the participant's vulnerability in the concrete case, the rationale to provide care should be sufficiently *strong.* To this extent, Richardson and Belsky, point to the following three elements: How much difference would the provided care make (i.e. clinical significance of the finding and the associated act), how much risk did the participant take to participate and how dependent is the participant to the researcher to provide the care needed (Richardson & Belsky, 2004)? For example, the authors argue that in brain imaging studies, researchers have a responsibility to undertake a diagnostic reading of the brain scans to screen for tumours and aneurisms. These findings are clearly within the scope of the brain imaging research and their potential life-

threatening character makes participants strongly vulnerable to the researcher acting upon the findings.

This concept of ancillary care offers some guidance on whether researchers should consider providing care, such as returning individual findings and referring to clinical care. Besides the *scope* and *strength* criteria, we also believe the consequences of returning individual research findings are to be considered. Below we outline the consequential principles of non-maleficence and beneficence.

Considering non-maleficence and beneficence

The principles of non-maleficence and beneficence are two of the four basic principles of biomedical ethics, as laid down by Beauchamp and Childress (2019). Both of them point to the consequences of a given act to judge whether this act can be justified. Non-maleficence refers to the duty of medical personnel and biomedical researchers to avoid harm from happening to their patients and participants, either by the professionals' interventions or by negligence. Beneficence on the other hand refers to the duty to be of a benefit for patients and participants by taking active steps to promote health or to prevent and remove harm. Clearly, these two principles are partly entangled. Furthermore, absolute interpretations of either of them set a practically unfeasible standard. Therefore, the application of these principles often comes down to finding a reasonable balance between minimizing harms and maximizing benefits. We believe this also applies to psychological, educational and developmental research, although the possible 'harm' and 'benefit' may be not so straightforward here. Importantly to note here is that definition of benefits and harms are often not merely objective facts. Making up the balance depends on whom the consequences of an act occur to and how these consequences are interpreted. In other words, the principles of non-maleficence and beneficence are value-laden.

The recommendations by Lefaivre et al. would support returning all findings based on standardized instruments for which norm or cut-off scores are available, suggesting that they consider these findings as neutral or not harmful. In the case of TIARA, this would imply for example returning findings regarding the child's cognitive development obtained via the BSID-III, or the results on the ADOS-2. Parents might be interested to know at which percentile their child situates herself, or whether she scores above, below or on average for these measures. We believe however that giving parents systematically access to all of this information, even if this relies on a standardized instrument, entails a couple of risks. In our view, Lefaivre et al.'s practical recommendations do not sufficiently take into account potential negative implications for the child, i.e. the principle of non-maleficence. Such potentially negative implications for the child, as exemplified below, may trump the benefits that these findings may have in satisfying parental interest. Indeed, as we are dealing with research on minors, it is important to keep in mind that, strictly speaking, the child is a participant, and not her parents.

Potential negative implications of returning any and all findings may imply unasked for and potentially unnecessary labelling, i.e. applying classificatory terms associated with sticky stereotypes or a self-fulfilling prophecy. For example, returning findings of a child scoring above the clinical cut-off on the ADOS, an observation schedule of autism characteristics, might lead the child's environment to start seeing the child as 'a little autistic', even when in se, this result by itself does not imply that a clinical diagnosis of ASD could nor should be established. Another example, this time not drawn from the TIARA study, could be returning an average result on an intelligence test (e.g. IQ 100). Especially when interpreted statically, as in the implicit entity theory of intelligence (Dweck, 1999), the perspective of parents on their child and possibly the expectations they hold for her may be altered (e.g. 'an average intelligent child shouldn't strive for going to university'), all while there might be no clear

clinical argument that this practice would benefit the child[22]. As mentioned before, applying non-maleficence and beneficence involves finding a balance between potential harms and benefits. In research settings the primary goal, and thus benefit, is a scientific one, i.e. to gather generalizable knowledge. Individual benefits for participants are definitely not excluded, but are not on the forefront. This is a sharp difference compared to clinical care. Therefore, we believe that minimizing harm warrants a stringent interpretation in research settings. We understand that this is an ideal that is hard to attain and that in one way or another, participation in research may alter the child's life course. The aim of policies is however to avoid that such alteration is actively enabled if it potentially implies harm to the child.

When it comes to the consequences of returning individual findings, we believe that the child in case should clearly benefit from this act to justify it. This judgement on the beneficial consequences of feeding back certain findings should be based on the best available clinical evidence. At this point in our argumentation, we feel however that it is important to stress that this a clinical judgement specific to the given case and its context, including parents' view on the matter. Therefore, the decision-makers at hand will often need to deal with various layers of uncertainty. Examples of such uncertainty are the notion that findings often only capture a snapshot of a child's development, which is a dynamic process; and that often evidence-based clinical interventions are not directly applicable to the particular, individual case at hand. As such, researchers in this field of inquiry will benefit from having close ties with clinicians experienced in working with the relevant instruments and research population.

[22] User guidelines of instruments like the ADOS-2 and BSID-III highlight these risks of overinterpreting results of a single test at one point in time as a definite diagnostic assessment, especially during early development. The ADOS-2 for example, does not use clinical cut-offs in the toddler version of the instrument, while BSID-III mobilizes the terminology of *developmental index* and acknowledges limitations to its stability over time, when compared to intelligence tests administered at school age or later in life. We are however concerned that such strong interpretations might still take place when feeding back findings to parents in a research context, despite efforts of the developers of these instruments to apply the necessary nuances.

As is often the case in bioethical analyses, this interpretation of the principles of non-maleficence and beneficence heavily relies on professional judgement. Defining what is beneficial or harmful undeniably depends on who is judging and what their priorities and values are (Kohler et al., 2017). Respecting autonomy rights of the participant, i.e. the child, is therefore a key element, besides respecting the views of parents who are the primary caregivers of the child. In our practical implementation below, we will discuss how this approach differs from full-fledged shared decision-making processes in clinical care.

Respecting the right of the child to an open future

In bioethics, making a decision autonomously refers to judging a situation voluntarily, i.e. without external pressure, and in an informed way. Since this capacity for autonomy develops over time, parents initially make decisions for their children, granting them more voice when they grow older. When doing research with young children, such as in the TIARA study, respecting autonomy does however not merely boils down to acquiring parents' informed consent. Here, the *right of the child to an open future* provides useful guidance. Legal scholar Joel Feinberg defined this as a right, derived from adults' rights on autonomy, which protects the child against having important life choices determined by others before she has the ability to make them for herself (Feinberg, 1980). In the context of genetic research, this *right to an open future* has been taken to imply that unless a result of a genetic test is clinically actionable while the child is still underage, the choice to undergo such an action should be left to the child. The rationale behind this right is that she may have or develop a different opinion about what she wants to be known about her genes (D. S. Davis, 1997). Although results of psychological, behavioural and developmental assessments usually contain information that will change throughout a lifetime, unlike genetic information, we believe that some analogy can be drawn here. This is particularly the case when the research involves e.g.

intelligence correlates or an assessment of autistic characteristics that are frequently interpreted as being stable over the lifetime. In other words, the application of long-lasting diagnostic labels or the use of interventions with long-term effects pose a potential threat for the future autonomy of the child. However, such actions can be justified when weighed against the other principles here at stake, namely the ancillary care responsibilities of the researcher, beneficence and non-maleficence. The added value of considering the child's right to an open future is rather that actions with long-term effects for the child, should not be undertaken lightly as if there were no autonomy rights of the child in case at stake.

Avoiding therapeutic misconception

Returning individual findings to parents of participating infants may be considered as a form of compensation for research participation, especially in cases where such compensation is otherwise not foreseen. Apart from the above mentioned reasons, such situations must be avoided since it increases the risk of *therapeutic misconception* (Appelbaum & Lidz, 2008). Especially in research studies where the instruments administered are similar or identical to those taken in the context of a clinical assessment, there is a risk that participants or, in the case of TIARA, their parents, mistake the research for clinical care or for research that is primarily oriented towards the care of their child, rather than to generate new knowledge about child development in general. For example, they may interpret early findings as a definite diagnosis of autism or of another developmental condition. As in Belgium the waiting lists for a clinical assessment are long, they may have the expectation that by participating in the research an earlier diagnosis can be obtained, even if this cannot be guaranteed. Such misconceptions about the aim of the study may also include a sample bias: those participating may not be representative for the population of parents of a child at increased chance of a developmental condition, but rather be a subgroup of parents with a certain vigilance toward possibly deviant behaviour of their

child or who are already actively looking for clinical care for their child. Although we feel it is important to make clear from the outset to participating families that they engage in research, and not a clinical trajectory, this does not mean that when beneficial clinical consequences can be obtained from research participation this should be blocked off. This might be especially beneficial for less privileged families who face on average more obstacles in obtaining access to clinical care. This notion of therapeutic misconception is further developed below when describing the concrete policy that we have adopted.

Practical implementation

Clinical significance and actionability

We consider the above-mentioned principles and concepts as building blocks for designing a respectful return of findings policy when doing research with children in our field of inquiry. The concrete application of these theoretical considerations depends however on the particularities of the research setting at hand. With regards to the TIARA study, the following particular elements shaped the design of the policy. This study has a longitudinal design, with five daylong contacts during which a wide variety of developmental, behavioural and biological parameters are assessed. When reflecting on ancillary care responsibilities, these aspects result in a fairly wide scope of well-being domains entrusted to the researchers, i.e. the physical, social and emotional development of the child. Furthermore, there is a significant vulnerability in the relationship with participants since this kind of in-depth assessment with clinically relevant instruments is not easily available in clinical settings at such a young age, and since it is generally accepted that infancy is a critical period for development. Following the concept of ancillary care, these two elements make that in the setting of TIARA there is a significant responsibility for researchers to provide care beyond what is merely necessary to keep the study running. However, as we have discussed returning individual research findings might also have

potential harmful effects for the child and can thwart their future autonomy especially when long-term labels are considered. When reflecting on whether or not individual research findings should be returned to parents, we believe a case-by-case analysis should be made defining if the beneficial consequences outweigh the potential harms and limits to future autonomy. In the context of TIARA, we practically translated these theoretical considerations into the following baseline of our return of research findings policy. We have chosen to limit the systematic return of individual findings to *clinically significant and actionable findings*. As laid out below, we refer here to significantly deviating findings that stem from validated instruments within the behavioural, developmental and biological scope of the research and for which the estimated benefits of clinical action (such as clinical follow-up, further diagnostic assessment or therapy) are considered to outweigh potential harmful effects to the child in its particular context.

Return of research findings policy in TIARA

As an element in the informed consent procedure, parents can indicate if they want to obtain individualized feedback. If parents give their consent, they receive a feedback report in understandable lay language after each round of testing in this longitudinal protocol. This report either states that the child's performance on the administrated instruments warrants no clinical follow-up at that stage or either that it does.

Findings based on validated instruments, such as well-established questionnaires and observation scales can be communicated to parents if a multidisciplinary team of researchers supplemented with experienced clinicians agrees that the findings are both clinically relevant and actionable from a professional perspective, as defined above. If this is the case, a concrete referral towards a clinical practitioner is proposed to parents, depending on the developmental domain concerned. For example, when a child scores significantly low on gross motor skills, we suggest the parents to consult a

paediatrician for follow-up of this developmental domain. Due to the longitudinal design, researchers often have come to know parents' views on their child's development. As such, it is possible for the multidisciplinary team to consider this input when making the decision on returning individual findings and on the concrete referral that is proposed. In principle when such contextual factors differ considerably, a similar finding can result in a different decision on whether to return it or not.

When clinical follow-up is advised, parents receive information on the research findings that are relevant for this follow-up. As such, parents only receive the concrete, individual findings of their child if these findings are considered clinically significant and actionable. If not, we aim to reassure parents that based on the administered instruments and to the best of the team's knowledge, no clinical guidance is warranted for their child. We consider it our responsibility as researcher to deliver this minimal, reassuring feedback as a form of ancillary care towards parents. This policy rules out returning findings based on instruments for which at the point of data collection in this study, no validated norms or cut-off values are available, such as for eye-tracking and explorative EEG paradigms. These findings offer too limited guidance in terms of clinical significance and actionability, while they might have harmful effects when interpreted as deviant.

For a child with feeding problems or a child in follow-up due to prematurity, with permission of the parents, findings may be communicated to the clinical team in order to offer clinical guidance directly, or to avoid unnecessary duplication of an assessment, which in itself may be burdensome for the child.

In case no consent is given by parents to receive individualized feedback, this position is evidently respected, except when findings are obtained where the parents' choice not to know would very significantly harm the child, such as in case of detection of a life-threatening condition. It is clear that the bar for

returning findings in this case is set higher compared to the standard of mere clinical significance and actionability discussed above.

Early on, during the design of the TIARA research protocol, different clinical referral pathways were reflected upon and discussed with clinical practitioners in the surroundings of the study centres, in order to make sure that children in need would have effective access to clinical follow-up. In order to set the right expectations from the start, this policy is communicated to parents during the informed consent procedure. Additionally, to avoid therapeutic misconception, during promotion of study participation, arguments that stress clinical benefits are avoided (e.g. 'Is your child autistic? Know it early on by participating in this study!'). When parents explicitly express their worries about their child's development during the study, despite findings that are not clinically significant, we offer parents a discussion with a senior researcher with clinical experience. In this conversation, we discuss the rationale behind this policy, and we consider whether parents should be oriented to a clinical setting to explore their concerns further.

We believe that this policy which restricts systematic return of individual research findings but explicitly argues in favour of returning clinically relevant and actionable findings, is respectful for the infants in the study, and ultimately also their parents. Even though this policy does not eliminate parents' interest in the individual findings, we can reassure them that they will have access to this information if clinical action is needed. As such, we believe that we have centred the fact that at its heart, TIARA is a research protocol and not clinical care, while also not forgetting that vulnerable research participants such as infants need specific care.

Strengths, limitations and future research

Ethical guidance on returning individual research findings of children in the field of behavioural sciences is scarce. As we have pointed out, in our view earlier recommendations lacked a critical approach to possible harmful effects of

returning findings for the child, including thwarting of their future autonomy. By discussing the different ethical principles and concepts, we aimed to fill this gap and provide the theoretical building blocks that can inspire other return of research findings policies in our field. The novelty of this work lies in the unique collaboration of researchers from the fields of child psychology and psychiatry, educational sciences and ethics. Hereby, we have been able to ground our recommendations both firmly in ethical theory as in the daily experiences of conducting clinical research with children.

We acknowledge however that a different research setting would have led to a different integration of the principles and concepts discussed. For example, when research participants are adolescents, the autonomy principle might play a larger role in deciding which findings are returned to them and beneficial outcomes might also entail satisfying personal interest of the adolescent, going beyond the more restrictive approach of only returning findings that are clinically actionable. We did not argue however for a case-by-case full-fledged shared decision- making process (with parents) on deciding which findings are to be returned, as is this is typically the case in clinical settings. As discussed for the TIARA study, parental views are taken into account, but we believe that –at least in settings like ours- individual discussions at the time of giving consent would stretch beyond the ancillary care responsibilities of the researchers. Instead, we have opted to install and communicate clearly a policy to which parents can agree if they want to join the study, thereby entrusting the researchers in making a justifiable decision on returning individual findings of their child.

Furthermore, as we touched upon, clinical significance and actionability might be less straightforward concepts than they appear to be. Despite the weight of evidence-based medicine and best practices, there will be differences in judgements between centres regarding the conditions that require or are amenable to clinical action. Although we argued for having close ties to experienced clinical practitioners when deciding on this aspect, we understand that this is not self-evident for all research groups.

Lastly, it should be mentioned that besides a discussion based on ethical principles and concepts, also from a legal perspective arguments can be drawn. Most importantly, we can think of the child's right to privacy as defined in Article 16 of the United Nations Convention on the Rights of the Child (UNCRC), protecting children's personal information, even from caretakers. On the other hand, data protection regulations such as the EU's GDPR could, arguably, also provide parents with a right to access and verify data from their children that have been collected, processed and stored within research contexts. Exemptions to this right however exist; therefore, we consider the interpretation of the GDPR in light of the right of parents to access their children's data and the rights of children to be protected from such access to be valuable matters for future legal research.

Conclusion

Deciding on the returning individual research findings of children is a point of ethical discussion, also in the behavioural sciences. We introduced a set of principles and concepts that can inspire a concrete return of research findings policy. As a matter of example, we presented the practical implementation of such a policy in the longitudinal child development study TIARA. Here we decided to restrict systematic return of individual findings to those considered clinically significant and actionable. Hereby, we refer here to significantly deviating findings that stem from validated instruments within the scope of the research and for which the estimated benefits of clinical action are considered to outweigh potential harmful effects for the child in its particular context.

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4. The earlier, the better?

an in-depth interview study on the ethics of early detection with parents of children at an elevated likelihood for autism

This paper is currently under review. A pre-print version can be found here:

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Abstract

Autism is increasingly viewed as an expression of neurodiversity deserving accommodation, rather than merely as a disorder in need of remediation or even prevention. This reconceptualization has inspired calls to broaden the ethical debate on early autism care beyond matters of efficient screenings and effective interventions. We conducted 14 in-depth interviews with 26 parents of infants at an increased likelihood for autism (siblings, preterms and children with persistent feeding difficulties) to understand which benefits and risks these parents see for the implementation of a systematic, early autism detection programme in our region (Flanders, Belgium). With this study, we aim to contribute empirically to the ethical debate on good and just early autism care in the age of neurodiversity. Data were analysed according to the QUAGOL methodology.

Three main themes emerged from our analysis. In their evaluation of early autism detection, parents discussed how a diagnosis helps gain a different perspective fostering understanding and recognition for both child and parent. Second, a diagnosis supports parents in adjusting their parenting practices, to justify this deviation from 'normal' parenting and to strive for such adjusted environments beyond the nuclear family. Third, an autism diagnosis induces ambiguities parents need to navigate, involving questions on whether and when to mobilise the diagnostic label and which language to use to talk about autism. We discuss the complex position of parents of a (potentially) autistic child in terms of moving back and forth across the ab/normal binary and describe implications for the ethical debate on early autism detection.

Introduction

In past decades, parents of a potentially autistic[23] child have been encouraged to engage in the earliest possible diagnostic assessment and intervention for autism (Zwaigenbaum et al., 2015). Yet nowadays, autism is increasingly viewed as an expression of neurodiversity deserving accommodation, rather than merely as a disorder in need of remediation or even prevention (Pellicano & den Houting, 2022). This changing conceptualization brings new questions to the fore on what is best to do for parents of (potentially) autistic children in these early life stages. Also, clinical practitioners, researchers and public health services might need to reconsider the goals and methods of early autism support. Put differently, it is a pressing and valuable task for the autism field to rethink wat *good and just* early autism care looks like in the age of neurodiversity. In what follows, we will briefly introduce the current academic debate on early autism detection, specify which new questions have come to the surface recently in this regard, and argue how this in-depth interview study with parents of potentially autistic children can help answering these questions.

Up to now, there has been a fairly broad consensus among autism scientists that early detection, diagnosis and intervention for autism are the way forward in optimizing care for autistic children and their relatives (French & Kennedy, 2018; Green & Garg, 2018; Magán-Maganto et al., 2017). Early detection and diagnosis of autism indeed provide an entry ticket to various services, such as early psychosocial intervention programmes. Compared to interventions in childhood and adolescence, programmes offered in the first

[23] We will use identity-first language in this manuscript in line with preferences of a majority of English-speaking autistic people (Keating et al., 2022). We have retained person-first language in quotes as they occurred in the interviews. This way we want to do justice to our participants' own words (in Dutch) and also to illustrate diverging opinions in Dutch-speaking regions, where person-first language is preferred by most people on the autism spectrum (Buijsman et al., 2022). We opted to use 'autism' instead of 'autism spectrum disorder' or 'ASD' since the latter two options imply an inherent coupling of autistic features to distress or pathology. To the contrary, the term 'autism' provides more space to capture the wide set of autistic, lived experiences that participants shared with us, whereas the clinical term 'ASD' is more strictly delineated by its diagnostic criteria.

years of life are expected to be more effective in supporting the child's development. The rationale here is that such early interventions would 'capitalise on experience-dependent neuroplasticity' and would enrich the 'diminished, unelaborated, and truncated social and communication learning opportunities' (sic.) of autistic infants (Landa, 2018, pp. 25–26). Therefore, the chief questions for the field have revolved around matters of accuracy and effectiveness of these early autism programmes (Hickey et al., 2021). For example, which detection instruments predict an autism diagnosis most accurately at an early age? How can an overly amount of false positive and, perhaps specifically, false negative screenings be avoided (Guthrie et al., 2019)? Which early interventions provide robust and large enough effect sizes to justify the effort and cost of their implementation as a public health programme (Sandbank et al., 2020)?

When looking at other public health ethics discussions, we see, however, that deciding on the rights and wrongs of early detection and intervention programmes has often involved more than weighing operational risks and benefits. For example, discussions on prenatal screening for Down syndrome and screenings and early treatments for breast cancer have spotlighted fundamental questions on drawing lines between health and disease, on *living well* beyond the boundaries of a 'normal' body and mind, and on reproducing structural discrimination of disabled people despite practitioners' good intentions (Parens & Asch, 2003; W. A. Rogers, 2019).

Autistic scholars and neurodiversity proponents have raised similar conceptual questions in autism research over the past years. These questions include whether we can conceive of autism beyond a clinical diagnosis or neurodevelopmental disorder in need of treatment, and what legitimate goals and targets are for clinical support (Ne'eman & Pellicano, 2022). For autistic adults, interventions are already increasingly modelled on neurodiversity claims of acceptance of difference and accommodation of the environment, such as generating adapted workplaces and sensitizing colleagues about autism (M. C. Lai et al., 2020). With some notable exceptions (Fletcher-Watson, 2018;

Leadbitter et al., 2021; Schuck et al., 2022), applications of the neurodiversity paradigm are, however, still largely unexplored terrain when it comes to young children and the sphere of early detection and intervention.

Recently, some scholars have called for a broader reflection on such conceptual issues when developing early autism detection and intervention programmes (M. C. Lai et al., 2020 (Annex 1); Manzini et al., 2021). In their agenda-setting review 'The Ethics of Autism', Hens, Schaubroeck and Robeyns (2019) identified key clusters of autism-related ethical questions. One of those clusters concerns questions on parental rights and duties about obtaining an early autism diagnosis and pursuing interventions for their child. For example, can parents decline a diagnostic assessment? Is it the parents' duty to aim for optimal (or 'normal'?) functioning of their child through interventions? Or should parents instead accept and accommodate their child's autism as a neutral, neurological difference?

Apart from such calls to broaden the ethical debate, much of the actual work still needs to be done to reshape clinical practices oriented towards young autistic children and their relatives. Recently, some valuable theoretical contributions to this ethical debate have emerged (Brown et al., 2021; Chapman & Botha, 2022; Leadbitter et al., 2021; MacDuffie et al., 2021; Schuck et al., 2022). One of the authors of this manuscript (GJV) contributed as well to this debate by analysing early autism interventions with a disability-sensitive interpretation of the concept of vulnerability. Vanaken (2022c) theorised that early autism interventions do not need to be set aside as mere reproductions of the pathology paradigm of autism. Yet, he argued that these care practices could be remodelled around obligations of solidarity and empowerment and therefore be reclaimed as spaces for political contestation contributing to the social change that neurodiversity proponents call for.

Empirical work on the ethics of early autism care is, however, still scarce. Therefore, we are convinced it is essential to explore the viewpoints and experiences of autistic people and their relatives regarding these topics. They are indeed directly involved actors bringing valuable knowledge and lived experiences to the discussion table (Newell, 2006). The interview study we present here explicitly aims to contribute empirically to the debate by understanding how parents of (potentially) autistic infants think about early autism care[24]. Our research questions were twofold: (1) Which advantages and risks do parents of a child at an increased likelihood for autism see for clinical implementation of an early detection programme in Belgium? (2) How do they experience their role as a parent of a young infant being tracked for autism characteristics?

Methods

The description of our methodology is based on the 32-item, 'Consolidated criteria for reporting qualitative studies' (COREQ) (Tong et al., 2007) and the 'Key criteria for successful submissions of qualitative manuscripts to JADD' (van Schalkwyk & Dewinter, 2020).

Participants

We conducted 14 semi-structured, in-depth duo interviews with 26 parents of 14 children taking part in the *Tracking Infants At Risk for Autism* (TIARA) study[25]. TIARA is a prospective, longitudinal cohort study on the development of children at an increased likelihood for autism between the age of 5 and 36

[24] In our wider research project on the ethics of early detection and intervention, we are currently conducting a separate qualitative study on the topic with autistic adolescents.

[25] The phrasing 'at-risk for autism' is widely used in research settings. We support the move away from such terminology as this frames autism as a threat or as a condition to be prevented. Although this phrasing is part of the TIARA-acronym, the consortium now prefers more neutral language such as 'increased likelihood' for autism (Bottema-Beutel et al., 2021; Fletcher-Watson et al., 2017).

months. The study includes siblings of children with an established autism diagnosis, infants born prematurely under 30 weeks of gestation and infants with persistent, medically insufficiently explained feeding problems[26]. In our interview study, these three groups are represented as follows by the 14 parent couples: prematurely born children (n = 3), children with medically unexplained feeding problems (n = 4) and children with an older autistic sibling (n = 7). The gender, age, educational attainment and reported ethnicity of interviewed parents are presented in Table 1. Children were between 11 and 16 months old when the interviews occurred (corrected age for preterms). Parents were asked to participate in the interview study during their visit to the TIARA baby lab. In case of interest, their contact details were passed to the first author. Twenty parent couples were contacted of which two did not respond and four declined mainly due to time constraints.

Our interest in these parents' opinions and experiences stems from their unique position as TIARA-participants. First, these parents' children have been labelled 'at-risk' for autism without being necessarily concerned themselves about their child being on the autism spectrum, which is an exceptional experience. Second, as they chose to take part in an early detection study, these parents might resemble well future early adopters of early detection programmes.

The interviewees differed in terms of their experiences with autism. Answers and stories shared by parents of the sibling group were primarily based on their lived experiences in parenting an older, autistic child. Parents from the feeding difficulties and preterm groups, however, were not entirely naive in their responses either. Many of them also had some relevant experiences with autism, be it in professional settings, extended family contexts or in their circle of

[26] When designing the TIARA-study, we hypothesised that such feeding difficulties could be associated with increased odds of being autistic. Yet, it still has to be shown that such feeding difficulties actually represent an increased likelihood for autism (Field et al., 2003), as this has been done before for the preterms and siblings groups (McDonald & Jeste, 2021). In contrast to prematurity or presence of autism in the family, we do not conceptualise medically unexplained feeding difficulties as etiological factors, but rather as potential early manifestations of autistic features such as atypical sensory perception.

friends. Two parent couples explicitly stated not to have any experiences with autism beyond some general ideas circulating in the public sphere (Interviews (IV) 3, 12). None of the interviewees self-identified as autistic. For these reasons, we indicated parents' relevant autism experiences as well in Table 1 and, when relevant, these experiences are spelt out too in the Results section, indicating when parents shared a personal experience versus an expectation which did not directly rely on first-hand experience with autism.

Despite being aware of the increased theoretical likelihood for their child to be on the autism spectrum, none of the parents was especially worried about their child at the time of interviewing. For two parent couples in the feeding difficulties (IV 11) and preterm group (IV 12), the initial recruitment into the early detection protocol took them by surprise and caused some stress. These two couples reported that the experience of the child's development being followed up during the study visits and their own perception of seeing their child developing as expected, made them feel more comfortable over time. Other parents in the preterm group referred to increased likelihoods for a variety of medical and developmental conditions as a factor which did not make them worry particularly about autism. In the sibling group though, parents did elaborate on their heightened awareness about potential autistic features in their youngest child, as they often compared to the sibling with autism.

Data collection and analysis

All fourteen interviews were conducted in Dutch by the first author in a face-to-face home setting with both parents, where possible (see Table 1). Two students (Master of Medicine) participated in the first five interviews as part of their master's thesis. We obtained written informed consent from each participating parent (Ethics Committee Research UZ/KU Leuven, S61507) and provided a brief oral introduction stating that we were interested in parents' opinions on the benefits and risks of clinically implementing early autism detection in Flanders. JS and KH developed a semi-structured interview guide based on their respective

experiences as senior clinical practitioner and autism researcher (JS) and as philosopher and (bio)ethicist (KH)[27]. This guide remained unchanged after a mock interview. The duration of the interviews ranged between 50 and 105 minutes with an average of 75 minutes per interview. Interviews with parents from the sibling group tended to last longer than those with parents from the preterm and feeding difficulties groups, probably because they had more autism-related experiences to draw from. Interviews were audio recorded and fully transcribed verbatim using *f4* software (Audiotranskription, 2023). All names (people, schools, etc.) were pseudonymised in the transcripts. Transcripts were not sent back to participants. Data collection and the first steps of data analysis were done in parallel to define when new interviews did not add up anymore to the existing data, this is when we noted that no significantly new themes were discussed in additional interviews.

We employed the Qualitative Analysis Guide of Leuven (QUAGOL) to analyse our data (Dierckx de Casterlé et al., 2012). The QUAGOL guide is a comprehensive and systematic approach to qualitative data analysis mainly embedded within Grounded Theory and consisting of two parts: a preparatory, inductive phase leading up to a list of codes and a more deductive phase including actual coding and analysis of the emerging concepts. In this first part of the analysis following QUAGOL, the first author (GJV) made a narrative, one-page summary of each interview, staying close to the participants' words and phrasings. Next, each *narrative report* was developed into a *conceptual report* by rephrasing and restructuring them more abstractly and schematically. The other team members listened to or read the original interviews to verify whether these conceptual reports captured the essential elements of each interview concerning the research questions. Adjustments to these reports were made during regular team meetings. A cross-case analysis of the 14 conceptual reports led to a list of 20 codes which we briefly described in two or three sentences based on our understanding at that point. In the second part of the

[27] The topic list has been included as an annexe at the end of this chapter.

analysis, we used NVivo12 to code the transcripts with our inductively derived code list while making memos throughout this process. Based on the fragments assigned to each code, we fleshed out our understanding of codes, becoming 'concepts' described each in 200-500 words. Lastly, we integrated these well-described concepts in an overarching storyline, checking back with the conceptual reports to verify this reflected the most relevant parts of the data, including both majority and minority views and opinions.

Researchers' background and community involvement

Following guidelines on reporting on qualitative studies in the field of autism research, we also want to provide some background information on us as researchers. At the time of the study, Gert-Jan Vanaken (GJV) is a medical doctor and PhD candidate working on the ethics of early autism care. He combines empirical, qualitative work with theoretical reflections at the crossroads of disability studies and bioethics. GJV has a particular interest in contributing to the development of neurodiversity-affirmative autism care practices. Ilse Noens is a professor in educational sciences and chair of the Leuven Autism Research (LAuRes) network. She conducts participatory research on parenting and effective psychosocial support for autistic people. Jean Steyaert (JS) is a professor in child & adolescent psychiatry and head of clinic at the Expertise Centre for Autism at the University Hospitals Leuven. His research focuses on early autism detection and biomedical autism interventions. Petra Warreyn is an assistant professor in clinical psychology. Her work mainly focusses on the early development of and care for children with or at elevated likelihood for autism or learning disabilities, taking into account contextual factors. Lotte Van Esch is a postdoctoral researcher at the Parenting and Special Education research unit (KUL) Leuven. She is involved in coordinating the TIARA-study and she has previously conducted both quantitative and qualitative research on parenting autistic children. Kristien Hens (KH) is a research professor in bioethics and co-founder of the Autism Ethics Network. She focuses

among other things on ethical and conceptual questions about developmental diversity and psychiatric diagnoses.

Results

We structured the concepts arising from our analysis into an overarching storyline entailing three themes which are presented below: (1) gaining a different perspective after a diagnosis, (2) parenting differently, and (3) navigating the ambiguous aspects of an autism diagnosis.

Theme 1: Gaining a different perspective

When reflecting on the potential *value* of an autism diagnosis, nearly all parents extensively talked about aspects of improved understanding and recognition as two direct, beneficial consequences of such a diagnosis.

Parents across three groups expected or experienced that the knowledge and information that comes with an autism diagnosis (would) help them understand better how their child feels, thinks and reacts. Some parents described it as putting up a different pair of glasses to look at the child and be more empathizing and comprehending regarding behaviours they would have otherwise not understood. A parent couple from the sibling group (IV 2) said the following about their oldest autistic son:

> Mother*: If we had already looked at him from that perspective as a baby, it would have spared him quite some trouble. If we had noticed back then that there was a link between him being irritable and going to that busy fair the day before, well… But that is not how you view things then. You only see your child is unwell and you wonder why. If we could have viewed him through a different pair of glasses back then...*
>
> Father: *…then we would have understood him a whole lot better.*

Such improved understanding is not only expected to be helpful for the child, but also for parents themselves in order to feel less frustrated, powerless or uncertain about their parenting skills. A mother (IV 1) who has an autistic son with a co-occurring intellectual disability shares the following about a potential diagnosis for her younger daughter:

> *Of course, it will still be a quest (…), but at least you won't be frustrated, or so frustrated, because you have a frame of reference. Whereas, if you don't know anything, my experience is that you are simply hitting the wall.*

Next to improved understanding of their child's functioning, parents expected or experienced that a formal autism diagnosis could also provide a sense of recognition, both for the child and for themselves. Parents reported or feared that when their child presented atypical development features or behaviour, third parties such as friends, family and other caregivers did or would fail to appreciate this in a pre-diagnostic phase. Atypicalities were sometimes brushed away to reassure parents, but more often parents discussed how third parties attributed blame to the child itself or to parents. Blaming the child for its atypicalities manifests itself mostly via pejoratives, such as 'naughty', 'annoying', 'feisty' or 'spoiled'. Parents perceived or anticipated blame towards themselves in terms of having insufficient pedagogical skills and in unsolicited or inappropriate parenting advice.

According to parents, a formal diagnosis could or did provide recognition to the fact that their child indeed functions and develops differently compared to most children, without immediately attributing blame. Across the three groups of interviewees, parents indicated such recognition would or did help them to counter pejoratives or (implicit) accusations of poor parenting expressed by other family members, friends or caretakers. A mother from the feeding difficulties group (IV 11) who had a late-diagnosed autistic sister herself, shared the following:

> *I do think it eases things if you can explain why your child is so upset, or why they act out in certain ways. So, people understand oh, that's why, it's not just an 'annoying' child. Because that was the stamp given to my sister. You know… I do think it is easier for people to understand when there is a 'label' -to say it that way, even though it's maybe not the right word to use.*

A father (IV 2) of four children, of whom two have an autism diagnosis said that

> *as a parent of a child with autism, you sometimes seem to be the parent that didn't educate his child. While at home, you are endlessly spending time moving things in a good direction. When you get the autism label, a sense of recognition comes along. Okay, you are doing your best and it is autism that is in play, and it is not, or not entirely, about the quality of your parenting. For me that is important.*

Theme 2: Parenting differently

> Father*: At this very young age, between one and two years old, I think the main thing is to educate parents on how to engage with their child (…) rather than focusing on the child itself* (IV 10, preterms group).

Beyond the more cognitive aspects of improved understanding and recognition, the vast majority of parents across groups discussed the relation between obtaining an autism diagnosis for their young child and being facilitated to *do* things differently as a parent. This change involves attuning their parenting behaviours towards their child and striving for other caregivers to adjust their interactions to generate autism-friendly environments for their child to develop and grow up in.

Parenting adjustments, competence and deculpabilisation

In all fourteen interviews, parents shared how they expected or experienced that an autism diagnosis would help them reshape their pedagogical practices to

accommodate their child's needs. Among other examples, this included practices such as introducing more predictability and structure in their daily lives, using strategies to prevent and deal with meltdowns, generating less sensorially overwhelming environments and communicating in a more concrete and visually supported way. A father from the feeding difficulties group (IV 6) without much personal autism experience hypothesised the following:

> *Within the autism field, there are probably methodologies to improve parenting, instead of always being angry, having to ignore it, or not being aware of what is happening. (…) I can imagine when your child receives too many stimuli, when she is always overwhelmed in the supermarket, you can either be angry or not taking her there anymore, but maybe- and I am just thinking out loud, you can bring a thick pair of sunglasses. Those might be silly things that can avoid turning a futility into a drama, if you are aware of this at least.*

Post-diagnostically, parents evidently kept experiencing day-to-day parenting challenges. However, parents from the sibling group described some beneficial, emotional aspects after adjusting their parenting behaviours. Compared to the pre-diagnostic phase characterised by uncertainty over their child's development and their own parenting skills, parents mainly reported decreasing feelings of guilt and increasing perceptions of parenting competency.

> Mother*: We became very uncertain about ourselves, but thanks to this diagnosis and the support, he found himself again, he found rest, and we did so too at a record pace. It explained so much, in the sense that things were not our fault.' (…)*
>
> Father: *'It was just like, wow, we are doing just fine as parents, but our son is just different* (IV 7, siblings group).

Parents in the preterms and feeding difficulties groups did not elaborate much on this last topic, except for one mother from the preterm group, who did not have any particular experience with autism (IV 12).

> *I would feel guilty, if he could have benefited from additional support, such as early interventions. If you know about this in time, you can opt for it. But if you only know at a later point that he could have learned things earlier, then it would feel like we could have helped him better [than we did] actually.*

Justifying difference

Although these relatively straightforward adaptations in parenting behaviours do not strictly require a formal autism diagnosis, parents in the sibling group often emphasised that obtaining the diagnosis served as a turning point after which they felt more *legitimised* to try out such new things while stopping certain practices that did not work well for them.

A father from the sibling group (IV 8) for whom the diagnosis of his oldest son made a big impact on his parenting behaviour reflected on this legitimation as follows:

> *And once you get the diagnosis, it clicks, and things suddenly fall in place. It makes you deal much better with this story, which is definitely a psychological thing. Nothing actually changes, but because someone else defines what is going on, I was like: okay, yes! And then, it became much easier to determine how I reacted to him in our interactions.*

Parents described how the diagnosis would or did support them to differentiate their approach between autistic and non-autistic children, to resist the idea they would need to be '*the tough parent that does not give in to their child*' (IV 13, preterms group) and to deviate from typical and oft-advised parenting strategies. Two parent couples from the sibling group said the following about this:

> Mother*: Without any prior knowledge about autism, who would think ah, you need to put some silly illustrations or pictures in the right order… No one thinks about that! You think about those stupid episodes*

of the Supernanny: "if you do this, you get that, and you may put a little sticker on your card." But that does not help at all (laughs)! (IV 2).

Father: *We relied much on standard educational practices: putting him in the corner, giving time-outs. We already followed a Triple-P training, about positive parenting, which did not work at all for him. (…)* Mother*: Yes, you stick to the parenting patterns that you've been raised with yourself, and with that Triple P training and so. (…)* Father*: 'For years, we've been putting him in a corner [as a disciplinary measure], until that corner looked all brown from his dirty hands* [pauses] *until they* [i.e. autism practitioners] *told us that was pedagogically useless for children with autism. So, if you can detect autism earlier, that would be a lot easier* (IV 14).

Fathers from the preterms and feeding problems group with a limited experience with autism sometimes specified the need for justification in more detail. For them, making '*all kinds of exceptions*' in their parenting practices could only by justified when the autism diagnosis was formalised. In case there would only be an increased likelihood or a suspicion of autism, efforts to adjust parenting practices could be superfluous and thus more difficult to justify.

As said, parents in the sibling group mentioned that an autism diagnosis for their oldest child functioned as a justification for adjusting their parenting practices. However, when it comes to a possible diagnosis for their youngest child, there were two strands of opinions within the sibling group. Some of these parents stated that they would want to let their child have a diagnostic assessment in any case, expressing the need for confirmation whether their child is autistic to parent adequately. For some other parents within the sibling group though, this need for an early diagnosis seemed to have dissipated to some extent as they already gathered experience in parenting an autistic child and diversified their view of 'normal' parenting.

A mother from the sibling group (IV 14) reflected on the potential need for a diagnosis for her youngest child:

> *If our daughter would have been the first-born, we would already have done the tests probably. But now our boundaries have shifted because of our older son [with autism]. (…) Also, some adaptations we made for him, simply became common practice in our family, so maybe it [autism-related difficulties] will be less noticeable for her.*

Striving for adjusted environments beyond the nuclear family

In addition to changes in parent-child interactions, many parents discussed the value of an autism diagnosis as a tool to strive for adjusted environments for their child beyond the nuclear family. The diagnostic label could provide parents with language and legitimation to communicate with family, friends, day-care workers, kindergarten teachers etc., to take steps towards an autism-friendly environment for their child.

> Father (IV 12, preterms group): *Also, towards family… prejudices do exist, you know. People easily point the finger at others, saying something is wrong. But then [i.e., with a diagnosis], you can actually name what it is, so people can also learn to engage with him correctly, for example in child day care.*

Most parents, in particular those from the sibling group with a practical experience in these matters, emphasised however that such efforts are often not self-evident. A lack of sufficient and relevant knowledge or stereotypical views about autism often stand in the way. This generates tensions and doubts among parents on whether and when it is favourable to disclose their child's diagnosis. These kinds of ambiguities that are raised by an autism diagnosis are discussed in the next section.

Theme 3:
Navigating the ambiguities of an autism diagnosis

Parents discussed how a formal autism diagnosis might help to foster increased understanding, can provide recognition for experienced difficulties and efforts, and can be a tool to strive for a more autism-friendly environment for the child. Various parents did, however, also discuss some more ambiguous aspects of obtaining an early autism diagnosis. Here, there are two subthemes: (1) mobilizing the diagnostic label: blessing or curse? and (2) doubts about 'correct' terminology to speak about autism.

Mobilising the diagnostic label: blessing or curse?

In order to benefit from the understanding and recognition a diagnosis might provide, this diagnosis generally needs to be disclosed. Parents discussed several points of doubt on whether to mobilise the diagnostic label in certain situations. First, they described or anticipated that appropriate knowledge about autism in child day-care and at schools is often lacking. By consequence, even after obtaining an autism diagnosis and sharing this with other caretakers, parents reported or expected that this would not necessarily result in the expected accommodations. Many parents did express their hope that teachers in regular educational settings would learn more in their training about autism and other developmental conditions.

In addition, one father from the preterms group (IV 13), who has a limited personal experience with autism and who works as a teacher himself, shared his worries about teachers adapting their practices merely based on the child's diagnostic label:

> *This (sharing of the diagnosis) is also a risk towards others. Very quickly, you get a stamp like 'this one has autism and everything which goes wrong will have to do with that.' They will already look different at our child. I would find it regrettable when a teacher immediately sees*

the document that mentions the autism diagnosis and therefore changes his practices without truly knowing the child.

This links to a second issue with disclosing their child's autism diagnosis to others. Parents reported or feared that autism is too often interpreted in a stereotypical, negatively connotated and all-encompassing way. While the diagnosis might give indeed a new perspective on the child's functioning, which may help understanding certain behaviour, several parents critically positioned themselves towards such one-size-fits-all interpretations of autism as these can become overly dominant and overshadow their child's unique characteristics and strengths.

> Mother (IV 7, siblings group): *His diagnosis [referring to older sibling] is known at school. But during parent-teacher moments and care coordination meetings, they often start talking about his weaknesses and difficulties, and only at the end some positive points are highlighted. (…) Father: While this is not even always necessary. As parents, it also really nice to hear that your child is simply doing well; rather than: 'we do not notice so much that autism affects him that badly?*

Based on his intuitions and on the experience with the autistic daughter of a close friend, one father from the feeding difficulties group (IV 6) phrased the discussion on the benefits and risks of labelling a child as follows:

> *The biggest disadvantage (of obtaining an autism diagnosis) is the pigeonholing (…). As parents we could start looking for solutions within that category of autism. But outsiders, they never think broadly within categories. People always think they know what it's like to be autistic, while it is such a broad spectrum. (…) But then, hey, in case our daughter would be autistic, whatever people think of that, it would not interest me, if we can turn that (diagnosis) into something positive.*

Some parents did indeed share their intentions or experiences to break negative connotation and stereotypical interpretation of autism, for example by talking openly about autism to people around them. A father from the preterm group (IV 10), trained as a nurse, said that

> *if you are overly protective of your child, then everyone will look at your son like: oh, he has autism and this and that. Some people in our environment will definitely panic. And then it is our job to say, act normally, these are the things that you need to take into account. So, I think that the stigmatization is something you have control over yourself (as parent).*

Some other parents, mainly from the sibling group, also addressed this same topic of trying to resist stereotypical understandings of autism by talking openly about autism to their family. A mother of three (IV 2), of whom the oldest two already had an autism diagnosis said that *'autism is simply present (within our family conversations). Very normal, very ordinary. So, let's not be silly, no taboos. And maybe that is the biggest advantage of having an early diagnosis.'*

The 'right' words

Throughout the interviews, parents across groups and across levels of experience with autism were very regularly reconsidering the words they used as they wanted to refer to autism as a condition.

> Mother (IV 12, preterms group): *It is often not easy for parents, because there is something wrong. Although that is maybe not correct to say so, but it isn't a normal child either (…). Actually, it is not okay to say that 'something is wrong', according to me. Because everyone is unique. But on the other hand, there is the standard, and then you have children or people who fall outside of that standard. So, that does not mean that something is wrong, but yeah.*

Mother (IV 2, sibling group): *Our home guidance practitioner once said, some researchers work on the idea that autism is not a diagnosis but rather that there are two kinds of brains in the world. So, I would find it really cool that one day, it would turn out that there is nothing abnormal about our children, but that it is... Uhm… No disease…* Father: *Like you are either a boy, or a girl, you are either autistic or you're not.*

Discussion

We initiated this interview study with questions on how parents would weigh potential benefits and risks of early autism detection programmes. Would parents indeed think that earlier is always better? However, when we analysed parents' responses, it turned out that, rather than clear lists of benefits and risks, we had collected stories, experiences and expectations which represented complex, nuanced positions towards early detection and diagnosis.

First of all, the expectations and experiences shared by the parents in this study reaffirmed that being a parent to a child who differs from the developmental norm is often a challenging task in many respects. In accordance to the existing qualitative literature on prediagnostic experiences (e.g. Jacobs et al., 2020), parents discussed aspects of misunderstanding their child, feelings of guilt, frustration, lack of self-perceived parenting competency, and not being recognised as 'good parents' by others. One way to summarise these challenges experienced or expected in a pre-diagnostic phase, is that they could not be the parents they wanted to be for their child. Against this backdrop, nearly all participating parents held a positive overall position towards diagnosing autism at a young age, as they expected or experienced this diagnosis would support them in their challenges.

Moreover, the value of such an autism diagnosis at a young age seemed most of all *relational* in nature. Following an autism diagnosis, parents described how it provoked a '*click*', changing how they thought about and engaged with

their child, how they perceived themselves as parents, and how they related to third parties such as extended family and other caregivers. Importantly, parents described that an official diagnosis could serve as a justification to think, feel and behave differently as a parent, compared to what they initially thought of as 'normal' parenting. On the other hand, parents reported that deviating from the norm and explicitly mobilizing the diagnostic label generated new tensions as well, flowing from narrow or stereotypical views on autism held by relevant people in their child's life.

Navigating the ab/normal binary

Overall, our findings underscore parents' complicated position of navigating between either of two spheres that are available in their societal context: the realms of 'the normal' and 'the abnormal'. However, both sides of this binary divide seem to come with a fairly rigid set of norms and expectations, not only in respect to the child's development and behaviour, but also regarding the conception of what it means to be a good parent. When these parents no longer feel comfortable in their role, the diagnostic label offers a way out of the expectations of 'normal development' and 'normal parenting'. Yet, even when the diagnosis is welcomed in this sense, parents tend not to settle down in the sphere of the abnormal either.

Some parents shared indeed how they did or intended to work through the tensions generated when mobilizing the diagnostic label of autism. This involves a careful reflection on when and to whom to disclose their child's diagnosis to obtain certain accommodations, and when not to speak about it to avoid negative or unhelpful reactions. In accordance with McLaughlin & Goodley (2008), we could describe such goal-oriented choosing between various discourses without being fixed to one or the other, as 'strategic agency' on the part of parents. Moreover, when the time is right, some parents explicitly choose to talk openly and positively about autism at an early age within their household and with relevant others. This finding confirms Russell & Norwich's (2012) earlier

observations of parents taking a pro-active position in a post-diagnostic phase to destigmatise or normalise autism. Lastly, some parents explained how a 'new normal' came about within their family as their adapted, more autism-friendly parenting practices and choice of family activities simply became part of their routines. Be it at micro-scale, we can interpret this as parents engaging in a sort of 'politics of practice' (Hart, 2014), redefining the dominant norms on development and parenting that reign outside of the family by means of everyday practices. To some extent, this kind of politics of practice was also reflected by parents struggling to find the right words and correcting themselves in the terms they used to refer to autism. By referring to autism in terms of deficits and disease, they echoed the dominant discourse in society, but by trying to reformulate they also showed motivation to resist and change this discourse into a more neutrally phrased one.

We believe the latter observation sheds a new light on the position of parents in autism and autistic communities. In our study, we have seen that parents are simultaneously *subjected to* the challenges raised by a binary normal/abnormal ideology centred around neurotypicality as the norm, while they are also *subjects* themselves who take an active role in undermining this divide. This contrasts the oft-cited histories of pro-cure parental advocacy groups which have been often perceived by autistic self-advocates and the neurodiversity movement as their political adversaries (Pripas-Kapit, 2020; Silberman, 2015; Sinclair, 1993; Waltz, 2013). Rather, our findings suggest that parents as well do experience a position of 'otherness' and the perception of not fitting into society's expectations (Ryan & Runswick-Cole, 2008). So, next to autistic people themselves, parents of autistic children do seem to endure certain negative effects of a neurotypical-dominated society in their struggle to be a good parent. Based on this experiential overlap, we expect that ideas and discourse of the neurodiversity movement might be valuable for parents as well.

Implications for the ethical debate on early autism care

The goal of this study was to enrich the ethical debate on early autism detection and diagnosis with the perspectives of parents of a potentially autistic child. Based on our findings, there are at least three insights and implications for this debate.

From early to timely

First, the value of an autism diagnosis for parents seems to be context dependent. Rather than considering a diagnosis as an inherently good or bad thing, parents rather discussed how the diagnosis might be valuable within a given societal context and at a specific moment in their lives. Especially when parents experienced or anticipated they could not be 'good parents' to their child, a diagnosis appears welcome to them. The timing at which parents reach this point does differ though. In line with our analysis, we suggest that a main determinant of this timing is whether parents and relevant others need a justification to accept the child's developmental difference, and to engage in an adjusted pedagogical approach. As we have seen in the siblings group for example, while some parents wanted to have their child assessed as soon as possible, other parents indicated that the need to obtain an early diagnosis for their youngest child was lower compared to their older child with autism, as the norms within their family shifted over time on what counts as 'normal' development and parenting.

This might imply that it could be more valuable to think in terms of a 'timely' autism diagnosis, at least from parents' perspectives, rather than thinking in terms of an early diagnosis at a fixed age as is often proposed in the context of universal or targeted screening programmes. A timely diagnosis, rather than merely an early one, would do more justice to the experiences and expectations shared by parents in this study. Indeed, a diagnosis was not merely valued as the outcome of an abstract process of objectively determining individual autism characteristics of their child. Parents rather described the important relational functions of an autism diagnosis taking place in a specific

context. place in a certain context. In current clinical practice, providing such a timely diagnosis is not self-evident though. In our Flemish context for example, prioritization schemes help to speed up diagnostic assessments for autism under the age of two-and-a-half to three years, yet, waiting lists go up to two years for (pre)school-aged children and adolescents. This obviously undermines the idea of a timely diagnosis.

Also, these findings suggest that a 'pre-symptomatic' detection of autism (from parents' viewpoint) might not be welcomed by all parents. In such cases, prediagnostic experiences will differ markedly from the ones described in this study, potentially lessening the need for a diagnostic label to foster understanding, recognition, justification for altered parenting practices etc. As we discussed before, some parents wanted to know whether their child was autistic irrespective of experienced problems or needs. Other parents from the sibling group indicated that the function of a diagnosis was not the same anymore for a second or third child, as they already changed many of their parenting practices and expectations. Parents without much autism experience also indicated they wanted to be offered support at a time that they experienced issues, rather than before.

From ab/normal to neurodiversity

Second, our analysis shows that parents of (potentially) autistic children are being negatively impacted by the conceptual ab/normal divide. On the one hand, a formal diagnosis seems necessary to justify a different parenting approach and to ask other caregivers to adapt their practices as well. On the other hand, mobilizing the diagnostic label often leads to stereotypical, narrow and negative interpretations of autism. Parents' language use illustrated their ambivalent position, as they changed between and regularly corrected themselves, visibly struggling to use the 'correct' terminology.

Moving away from this binary conceptualisation towards a neurodiversity approach to autism might help tackle these experienced difficulties.

Neurodiversity proponents understand autism as one form of variation within a wide diversity of minds, functionings and ways of developing, be it a minority one associated with strengths and vulnerabilities that are partly dependent on the accommodations society offers (Dwyer, 2022). When parents would be more familiar with neurodiversity approaches, we hypothesise that they would feel less pressured to stick to what they perceive to be the normal parenting practices. Accepting that there is a diversity of ways in which children develop could help parents to embrace as well that diverging parenting practices are needed and justified for their child, without necessarily needing an official diagnosis at that point. In post-diagnostic settings, parents might benefit from neurodiversity-discourse to discuss their child's needs and accommodations in a more neutral way, rather than reinforcing a negative perception of autism as pathological condition by default, in need of treatment and remediation per se.

In a recent editorial in the journal *Autism*, Brown et al. launched a call to support a neurodiversity approach from the early start of clinical autism trajectories: '*it is critical that diagnosticians, who are often one of the first to frame autism for families, consider moving away from the medical model's deficit-based story to a more balanced, neurodiversity-framed view of autism'* (Brown et al., 2021, p. 1171). Indeed, clinical practitioners seem well placed to acquaint parents with neurodiversity-thinking. This would obviously require adequate training for these practitioners, which could be extended as well to practitioners at well-baby visits, caregivers in child day care, and teachers. All these professionals play some role (formal or informal) in noticing (and communicating) a child differs from the developmental norm and/or are involved in implementing an autism-friendly environment once a diagnosis is established.

From descriptive to productive

Lastly, our findings suggest that important aspects of why parents value an autism diagnosis for a young child are related to the actions they undertake as parents themselves. Of course, we have found that a diagnosis changes the personal state of affairs for parents, such as deflecting blame and providing a better understanding of their child. Yet, we have seen as well that parents mobilise the diagnosis to change the societal state of affairs as well, via what we have referred to as politics of practice. This way, an autism diagnosis does clearly not only function as a descriptive or a prescriptive term, which sets in stone how things are or should be; an autism diagnosis seems to be a *productive* label too, which opens space for parents to start doing things differently and work towards autism-friendly environments. Parents are, thus, not simply subjected to the diagnosis and the professional advice which follows, but clearly also subjects themselves playing an active role in putting the diagnosis to work and turning it into something of value in their lives.

This finding might inspire researchers and practitioners to reshape the kind of support offered to parents. Now, post-diagnostic services for parents are either rather descriptive, such as psychoeducational sessions, or largely prescriptive in nature, such as parent-mediated early intervention programmes. Based on our findings, it seems valuable to reflect on how such services can also gain a 'productive' edge and support parents to think critically about raising an autistic child within a neurotypical society.

Strengths and Limitations

With this study we aimed to contribute empirically to the urgent debate on the ethics of early autism detection, diagnosis and intervention. In contrast to earlier qualitative studies embedded in prospective infant sibling studies, our inquiry differs in terms of methodology, positionality and goals (Achermann, Bölte, & Falck-Ytter, 2020; MacDuffie et al., 2020). We opted for full-fledged in-depth interviews with both parents (when possible) conducted at their home, using

open-ended questions rather than for a tightly structured interview administered during the study visit. Also, our aim was not to evaluate parents' satisfaction of and suggestions for early detection research practices, but rather to engage with them in a critical reflection on early detection from their proper perspective. Lastly, the first and last author of this manuscript were only engaged in the ethical work package of the TIARA study, and not in other parts of data collection and analysis. This way, there was more space to reflect on the goals and methods of such early detection research, compared to earlier work. Despite being time-intensive, the QUAGOL methodology for data analysis proved to be apt to handle the data generated with this diverse group of parents. Due to its case-oriented approach, constant comparison within and between cases, and its data-generated codes, we managed to tap well into common threads of the fourteen interviews, while also managing to make comparisons between the subgroups (Dierckx de Casterlé et al., 2021).

Some of our findings, such as those described in Theme 1 are not entirely specific for 'early' autism detection and diagnosis and confirm findings of earlier qualitative work reporting on the experiences of parents of school-aged children and adolescents on the autism spectrum (Jacobs et al., 2018; van Esch et al., 2018). As we mentioned before, we could interview a very interestingly situated group of people as they represent potential early adopters of targeted, early autism detection, be it in a research setting. Obviously, this group does not represent all possible parents who might be approached in future in a universal autism screening programme. For example, many of our participants had some relevant experience with autism, all interviewees were white and relatively highly educated. Also, as they were TIARA participants and agreed to be interviewed for this study as well, our interviewees might have had a positive baseline attitude towards detecting autism early in life. At the same time, we have learned that this group of parents held nuanced and even critical opinions regarding the value of early autism detection as described in Theme 2 and 3.

Acknowledgments

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5. Getting the timing right

an in-depth interview study with autistic adolescents on the value of a timely diagnosis

This chapter is in preparation for submission to a peer-reviewed academic journal.

Abstract

In Western countries, autism diagnoses are ever more assigned in the first years of life. But is earlier, necessarily *better*? An early diagnosis might offer potential benefits both to parents and children, but when autistic people are assessed as infants or toddlers, they have no say in the diagnostic process. Ethically, there is a potential tension here between parental duties and rights, and the child's developing autonomy. Overall, our study aims to contribute to the ethical debate on early autism diagnostics, specifically against the backdrop of the ongoing shift towards neurodiversity approaches to autism.

We engaged with 18 autistic adolescents to understand better how they experience autism and their autism diagnosis, and more specifically, how they think about the right timing of such a diagnosis if such an ideal timing exists at all. Data were analysed according to the QUAGOL guidelines.

Four themes emerged from our analysis: [1] Describing autism by what it is not, [2] Feeling (in)different, [3] Drawing up the balance of the label's value, [4] Getting the timing right. In our interpretation of these findings, we discuss adolescents' critical consciousness of autism in a neurotypically-dominated world, the benefits of a timely, rather than a strictly early diagnosis, and the role of supportive and well-supported parents in turning an early diagnosis into something of value for autistic people.

Is it always better to obtain an autism diagnosis in infancy or early childhood? Or, should a diagnosis be postponed until adolescence or adulthood to involve the autistic person in the decision-making? Which conditions do such preferences depend upon? The in-depth interview study presented here investigates how autistic[28] adolescents experience autism and their autism diagnosis, and more specifically, how they think about the right timing of such a diagnosis if such an ideal timing exists at all. In the introductory section, we will first contextualise these questions. Then, we will briefly review previous qualitative studies with autistic adolescents on this topic. Lastly, we will situate this particular interview study against the backdrop of our wider research project on the ethics of early clinical autism care, and formulate the concrete research questions for this interview study.

Introduction

Clinically, an autism diagnosis frames autistic characteristics and experiences as expressions of a set of deficits which cause a negative impact on multiple domains of functioning. Also, autism is generally operationalised in clinical practice as a lifelong condition (Botha & Cage, 2022; World Health Organization, 2019). Therefore the diagnostic label tends to stick to a person for an entire lifetime. Moreover, beyond its strict clinical definition, the autism label comprises many meanings that can impact various spheres of life for the diagnosed person (Hens, 2019). For example, an autism diagnosis may influence how people view themselves, how relevant others perceive and interact with

[28] We will deploy identity-first language in this manuscript as preferred by a majority of English-speaking autistic people in Western countries (Keating et al., 2022). We have retained person-first language in quotes as they occurred in the interviews. This way we want to do justice to our participants' own words (in Dutch) and also to illustrate diverging opinions in Dutch-speaking regions, where person-first language is preferred by most people on the autism spectrum (Buijsman et al., 2022). Where possible, we opted to use 'autism' instead of 'autism spectrum disorder' or 'ASD' since the latter two options imply an inherent coupling of autistic features to distress or pathology. To the contrary, the term "autism" provides more space to capture the wide set of autistic, lived experiences that participants shared with us, whereas the clinical term 'ASD' is more strictly delineated by its diagnostic criteria.

them, and how they navigate public life. Potential beneficial impacts of a diagnosis for the autistic person can be increased access to adequate support, exculpation of atypical behaviour (Jacobs et al., 2020), positive identification with being different from the norm (Huws & Jones, 2008) and finding a sense of community under the banner of autism and neurodiversity (Dekker, 2020). Yet, undesirable impacts do take place as well upon disclosing an autism diagnosis, such as being confronted with negative stereotypes (Treweek et al., 2019), (self-)stigmatisation (Berkovits et al., 2019) and discrimination (Romualdez et al., 2021). In other words, being assigned an autism diagnosis can be a life-changing event.

Despite the significance of this label, an autism diagnosis is currently most often assigned to toddlers and children (van 't Hof et al., 2021) who cannot (easily) voice their opinion on the relevance of obtaining this diagnosis. Of course, there can be justifiable reasons for diagnosticians and caregivers to agree on assigning this label when this is relevant for a given child in a given context. Yet, at the same time, there are certain ethical tensions here as well. One such tension arises between the aim to do good for the child (by assigning a timely diagnosis and giving access to appropriate care) and respecting the child's developing autonomy abilities (to co-decide on receiving a diagnosis) (Hens et al., 2019). Also, as touched upon, assigning an autism diagnosis might lead to disadvantageous outcomes associated with autism's conventional, medical conceptualisation as an undesirable set of deficits. On the other hand, some of the beneficial impacts of being labelled autistic flow exactly from autism's reclamation as a positive or at least a neutral aspect of one's identity, which can give rise to a sense of recognition and community (to some people) on the autism spectrum (Jones et al., 2015). These tensions are important talking points in debates on the ethics of early autism detection and diagnosis programmes (MacDuffie et al., 2021; Manzini et al., 2021).

Some previous in-depth interview studies have tapped into related questions, even though these studies were not (always) explicitly situated in the

debate on the ethics of early autism care. In the next section, we provide a narrative, non-systematic review of qualitative research with autistic adolescents relevant to our research interests here.

In one of the first publications of its kind, Huws and Jones (2008) described how the diagnostic label enabled autistic adolescents to review and understand previous life experiences. The authors termed this 'biographical disruption': receiving and knowing about their diagnosis was a turning point in these adolescents' life as it changed how they viewed themselves, how others perceived them and how their educational and professional opportunities developed. In another interview study with autistic adolescents, Mogensen and Mason (2015) reported on the effects of an autism diagnostic label on adolescents' self-identity, which ranged from feeling oppressed to feeling proud about being autistic. Based on their interviews, these authors suggested that such labelling effects are not random. Adolescents tended to experience their diagnosis as advantageous when it helped them understand themselves and gain control over their lives. For example, after disclosure of the diagnosis adolescents reported that learning and self-managing to structure their days made them fare better. The opposite tended to be true when the autism diagnosis led to reduced control over their lives, for example when their diagnosis was used as an argument to change schools against their will.

Another theme emerging from earlier work touches upon autism-related identity formation in adolescents. In a systematic review and meta-synthesis of qualitative research with youth with a psychiatric or developmental diagnosis, O'Connor and colleagues (2018) found that autistic adolescents differ in such identity-related aspects from adolescents with chronic mental health conditions as a primary diagnosis. According to this analysis, autistic adolescents, compared to other clinical groups, would appreciate their diagnostic label more positively, and express a preference for obtaining their diagnosis earlier in life. Yet, autism is not simply understood as a positive thing either. Jones et al. (2015) described a 'state of incongruence' among their interviewees 'wanting to reject the part of

their diagnosis that they disliked or perceived as socially unacceptable while simultaneously maintaining the parts of their diagnosis that made them unique or talented' (Jones et al., 2015, p. 1493).

As signalled above, our interview study is embedded within a larger research project investigating the ethics of early autism detection and intervention programmes. This research is situated in Flanders, Belgium. In our region, early clinical autism care is currently offered on indication (based on child characteristics) as of the second year of life. This approach of initiating diagnostic assessments on indication implies indeed that a significant part of autism diagnoses are still established later in childhood or adolescence, as was the case for our participants, or even in adulthood. Anno 2023, there are no systematic early autism screening or intervention programmes in place in Flanders. Targeted early detection and socio-communicative parent-mediated interventions are, however, under investigation and considered for clinical implementation (see for example www.tiara-studie.be, Vanaken et al., 2020, Limburgse Stichting Autisme, 2022, and Van der Paelt, Warreyn, & Roeyers, 2013).

In our overall research project, we study the ethics of these current evolutions against the backdrop of the ongoing shift towards neurodiversity approaches to autism (Dwyer, 2022; Pellicano & den Houting, 2022). Therefore, our overarching research question is how good and just early autism care could look like in the age of neurodiversity. In line with calls from neurodiversity proponents and autistic self-advocates (Fletcher-Watson et al., 2017; Pukki et al., 2022), we are convinced that engaging directly with autistic people is key to inform this ethical debate on early autism detection and diagnosis. In this respect, we have previously studied views from autistic adults and those of parents of very young children (Hens & Langenberg, 2018; Vanaken et al., 2023). Adolescents' views on the appropriate timing of an autism diagnosis have not yet been studied in depth, particularly not from an explicit neurodiversity perspective. Nevertheless, adolescence is a key developmental period in terms

of identity formation and autonomy development and therefore we opted to conduct in-depth interviews with autistic adolescents between the age of 16 and 18 years old. Our research questions for this particular interview study were the following. How do the interviewed autistic adolescents experience autism and their autism diagnosis? What do they consider a good timing for diagnosis, if at all? Does the timing of diagnosis impact whether and how these adolescents embrace autism as part of who they are?

Methods

Our study design choices and methodological reporting are based on the 32-item, "Consolidated criteria for reporting qualitative studies" (COREQ) (Tong et al., 2007), on the key criteria for reporting qualitative autism research as defined by Schalkwyk and Dewinter (2020), and on the methodological suggestions in Williams et al.'s meta-synthesis of qualitative research with autistic pupils (Williams et al., 2019).

This way, we aim to overcome some of the issues the qualitative autism literature has faced before. As is the case for autism research in general (Russell 2019), there is a dearth of qualitative research with female and intellectually disabled autistic participants (for a notable exception, see Berkovits et al., 2019; Fayette & Bond, 2018; Williams et al., 2019). Also, autistic youth's contextual variables, such as educational settings, are often not sufficiently described and diverging experiences and opinions are sometimes underreported in favour of a single, coherent storyline. McLaughlin and Rafferty (2014) reported that authors tend to interpret autistic adolescents' stories through a clinical lens confirming their autism diagnosis, rather than interpreting these stories as proper experiences carrying non-clinical value as well. Also, in studies that simultaneously interviewed adolescents and parents or clinical practitioners, the experiences of adolescents tend to be overshadowed by those of the other participant groups (Williams et al., 2019). The study presented here is also vulnerable to such

critiques, yet, as detailed in the methodological section below, we have taken these issues to heart when designing and conducting this study.

Recruitment and participants

We conducted 18 semi-structured in-depth interviews with autistic adolescents between the age of 16 and 18 years. These adolescents were recruited via the database of the Expertise Centre for Autism embedded within the University Psychiatric Centre KU Leuven, Belgium[29]. The Ethics Committee of the University Hospitals of Leuven provided ethical permission for this study under study number S62947. We collected informed assent from the participating adolescents and informed consent from their parents before the interview[30].

For feasibility reasons, we started by including 12 adolescents with a documented total IQ above 80. We purposively sampled participants in a 1:3 female:male ratio, and in a 1:1 ratio relating to the timing of diagnosis (under the age of 10, or above the age of 12). In a second round of interviewing, we included 6 additional adolescents with borderline total IQ scores, i.e. between 60-80. Here we kept the same gender distribution, yet 4 out of 6 obtained their autism diagnosis under the age of 10. Table 2 provides an overview of the participants' characteristics.

[29] This patient database comprises all persons that have obtained a diagnosis of an autism spectrum disorder (ASD) at the centre, following the DSM-5 diagnostic criteria, or a DSM IV equivalent when diagnosed before 2013. The centre is situated in an academic hospital but it has a wide appeal in the region. The centre mainly focuses on diagnostic assessments for autism and low-frequency follow-up for care coordination. Listing in the database therefore does not imply that the person in case is currently in clinical follow-up.

[30] We sought adolescents' assent by firstly sending them the adolescent version of our study information brochure by either email or post. We invited them to read and discuss possible questions already with their parents. When meeting for the face-to-face interview or at the start of the video call, we took time to go over this information orally, step-by-step, and adolescents could ask questions at this point. Participants were offered two cinema ticket vouchers as compensation for their efforts.

Table 2: Participant characteristics

Interview	Age	Age at diagnosis	Gender	Total IQ	Educational setting*	Duration	Modality
1	16	9	female	80-120	regular	34	F2F
2	16	8	female	80-120	regular	39	F2F
3	17	4	male	80-120	regular (currently)	36	F2F
4	17	3	male	80-120	special	50	F2F
5	18	7	male	80-120	regular	68	F2F
6	17	9	male	80-120	special	52	F2F
7	17	14	male	>120	regular	43	videocall
8	17	14	male	80-120	regular	45	videocall
9	18	15	female	>120	regular higher education	82	videocall
10	16	12	male	>120	special	67	videocall
11	16	14	male	>120	regular	68	videocall
12	17	14	male	80-120	regular	54	videocall
13	16	4	female	<80	special	63	F2F
14	16	3	male	<80	special	39	F2F
15	16	15	female	<80	special	66	videocall
16	16	5	male	<80	regular (currently)	58	F2F
17	17	13	female	<80	regular	57	F2F
18	17	6	male	<80	special	39	F2F

F2F: face-to-face, Interviews 11 and 12 are still to be analysed

For various reasons, we chose to present IQ ranges rather than IQ scores. First, these scores are several years old for most adolescents, as IQ testing dates back to the time of their autism diagnostic assessment. Also, total IQ is an imperfect summarising outcome as it pulls together various, and potentially heterogeneous cognitive abilities. The main reason that we included IQ ranges, instead of leaving out IQ as a descriptor entirely, is to indicate the diversity of the interviewees in this respect. We find this important as below-average IQ scores are often an exclusion criterium in autism research. The downside of reporting IQ is that readers might consciously or unconsciously attribute different levels of credibility to the experiences and opinions of our interviewees. To buffer this potential effect in part, we only report the IQ ranges in Table 2, yet, we do not repeat those when citing individual adolescents, in contrast to choices made by other authors (Berkovits et al., 2019).

For context, 'special education' comes in various shapes in Flanders. Relatively unique in our region is the 'type 9' special education which is autism-specific. Some of our adolescents also attended non-autism-specific special education designed for intellectually disabled students. Special education in Flanders exists both in a segregated and more integrated way. Integrated special education means that classes, for autistic students, for example, are organised within a regular school. Yet, in our study, we did not ask adolescents to clarify their educational context beyond the regular/special education categories.

Data collection

Participants were given the option to choose between three interview modalities: (1) a face-to-face conversation at a place of their preference, (2) a video call via Skype, and (3) a written chat via a secured messaging platform. Earlier research has demonstrated that offering digital modalities increases accessibility for autistic people to participate in in-depth interviews (Mattys, Noens, Evers, & Baeyens, 2018; Benford & Standen, 2011; Hens & Langenberg, 2018). Eleven adolescents chose a face-to-face conversation, all chose their home as their

preferred place. Seven opted for a Skype call, no one opted for written communication. All but one interview were conducted in Dutch, one was conducted in English (Interview 13).

We provided the topic list of the interviews a couple of days beforehand. During the face-to-face interviews this topic list was visible on the table, during Skype calls we asked participants to have the printed list nearby or at hand in another window on their computer. This way, the topic list functioned as a visual support providing structure to the conversation. This topic list has been developed by an interdisciplinary team (GV, JS, KH) with complementary experience in qualitative research, (bio)ethics and clinical practice with autistic people. The topic list and some additional methodological considerations are provided in the Annex. Interviews lasted between 34 and 82 minutes, averaging 55 minutes. The interviews were recorded and transcribed verbatim using *f4transkript* software (Audiotranskription, 2023). Names and other identifiers were pseudonymised during the transcription process.

Data analysis

We employed the Qualitative Analysis Guide of Leuven (QUAGOL) to analyse our data (Dierckx de Casterlé et al., 2012). The QUAGOL guide is a comprehensive and systematic approach to qualitative data analysis mainly embedded within Grounded Theory. It consists of two parts. First, there is a preparatory, inductive phase leading up to a list of codes. Second, there is a deductive phase of the actual coding of the transcripts based on the list of data-driven codes developed before. Based on the coded fragments, codes are developed in well-described concepts which are then structured in themes and subthemes. A more in-depth description of how our research team applies this guide in practice can be found in the methodology section of a previous article (just like a transparent insight into the background of the authors involved) (Vanaken et al., 2023). For this study in particular, we kept McLaughlin and Rafferty's call in mind (2014) not to view the interview data merely through the

medical lens of autism's diagnostic criteria. We avoided interpreting the adolescents' experiences merely as symptoms confirming the diagnosis. Rather, we intended to start with a blank sheet, to accept the views of the participants as those of experts of their own lives, and then to reflect critically on those views. The quotes cited below are a direct translation from the original transcripts in Dutch.

Results

As said, with this study, we aimed to investigate how autistic adolescents experience autism and their autism diagnosis, and how they think about the appropriate timing of such a diagnosis, if such an ideal timing exists at all. Four themes emerged from our analysis: [1] *Describing autism by what it is not,* [2] *Feeling (in)different,* [3] *Drawing up the balance of the label's value,* [4] *Getting the timing right.* At first sight, only the fourth theme deals directly with adolescents' views on diagnostic timing. Yet, as will become clear, the first three themes are key to fully understanding and appreciating adolescents' opinions on the value of a timely autism diagnosis.

Theme 1: Describing autism by what it is not

At the start of the interview, we asked participants if they could tell us something they knew about autism or how they explained it to others. Many participants started by pointing out that autism is notoriously hard to define. They indicated that autism manifests differently across the autism spectrum, that they lacked the knowledge to give an all-encompassing description. Autism is '*too big of a word to describe*' said one of them (Interview 5).

Yet, despite difficulties in formally describing autism, adolescents tended to agree that autism is not a single thing, and many of them referred to the diversity of characteristics of autistic people. '*It is a spectrum, and there are very different symptoms* [sic]. *And everyone who has it has part of it. No one has all*

of it' (Interview 10). For this adolescent, underscoring autism as a spectrum was key *'because often people read or hear something about autism, and then they think that everyone who has autism, is like that.'* In their efforts at describing autism, several adolescents found it important to elaborate on this line of thought. Without prompts in this direction, they went on to clarify what autism is *not*, or at least *not for them*. One 17-year-old who studies youth and disability care pointed this out in a clear way.

> *In school, we now have to read a book about a boy who has autism (…) and the book mentions that the boy loves patterns, that he loves mathematical stuff, and at the end of the book there is this appendix with mathematical formulae. But for me, all of this does not apply. I do not like math, although that autistic boy from the book does. I am attracted to the social sector, youth and disability care in particular, that is where I am better at* (Interview 4*).*

Another 16-year-old girl highlighted that

> *many people think they know what autism is, but they assume then that autism means, for example, that you always require things to be the same, that you prefer standing on your same spot, but I don't. People think they get me, but often they don't* (Interview 2).

For seven interviewees (Interviews 1, 2, 7, 8, 13, 16, 18), distancing themselves from these stereotypical or incorrect views on autism took an additional shape. They stressed that their autism was not 'that bad' or not 'so severe' as they thought it was for others. Some mentioned this in passing, like a 17-year-old boy who got his autism diagnosis around three years ago, who said he '*understood that ASD* [sic] *is extremely big. Some also think straightforwardly like me, but others can have something else',* which was important to mention for him, '*because if you say autism, then you think about that one person who can hardly go about, who acts weirdly'* (Interview 8). For others, such downward comparisons on the autism spectrum were not merely mentioned in passing but

were core to their narrative. Another boy (Interview 16) said: '*Yeah, for some people you really see they have that [i.e. autism], like really strongly, for others a bit less. With me, you don't actually see it, I just know it for myself. And that makes it difficult: do people see whether I have it or not?*'. This last quote comes from a 16-year-old who had been told only a year ago he was autistic, although his diagnosis had been established over ten years before. In elementary school, he went to special education, and now he actively tries to hide his diagnosis and his educational history from his peers in regular high school. During the interview, he went a long way to clarify that despite some oddities, he really was

> *a normal boy. (...) I don't have to go to the hospital, or I don't have anything going on in my body or whatever. No, I am just like anyone else, but yeah. (...) I have that [i.e. autism] a little bit, but apart from that I am perfectly normal. I engage with my friends normally, I don't make any weird movements. I just talk ordinarily about life and stuff, doing normal things* (Interview 16).

Here, we wrap up Theme 1 which illustrated how participants *described* autism, be it often in terms of what it is not. Theme 2 zooms in on how participating adolescents *experienced* autism and (potential) autism-related differences from the norm.

Theme 2: Feeling (in)different

A first group of adolescents (Interviews 1, 2, 8, 13, 15, 16, 18) shared experiences about not feeling particularly '*different'* compared to others, or even feeling plainly '*similar to other people*' (Interview 18). Whether someone feels different or not, obviously depends on who they are comparing themselves with. Generally, adolescents made these comparisons with people they engage with in their daily lives and not so much with an abstract idea of the typical 16- to 18-year-old. For example, when we asked a girl who attends special education whether using the quiet playground at school made her stand out compared to her classmates, she responded: *'Me and my friends, we all go there'* (Interview

15). In other words, certain autism-related behaviours and choices do not manifest as out-of-the-ordinary in this girl's school setting, but these features are rather shared with peers and relatively well accommodated in this case. As consequence, for this first group of adolescents, the experience of being autistic, largely operates in the background of their lives. In this respect, one boy said '*I don't think about it all the time, in fact, I hardly ever think about autism'* (Interview 8).

Despite such expressions of relative indifference towards autism, these adolescents did name certain experiences as autistic experiences.

> *Autism is part of who I am, but in daily life, it does not occupy me, because I simply don't feel bothered. Except for one thing: my planning. I really cannot stand it when things… I like to know beforehand what is going to happen, and I find it difficult when things change last minute (Interview 2).*

Another girl said: '*Sometimes I forget I have autism, but when I am in a situation where I get really angry, then I turn into another person. Then, sometimes, I think, oh this might be my autism coming to the surface*' (Interview 1).

Responding to the question of whether she experiences autism more explicitly in certain situations compared to others, a third girl responded the following:

> *Yes, when there are appointments I am not prepared for. For example, I had to go to an interview that I forgot about. And all of a sudden mom entered the classroom and we had to leave. I didn't know where we were going. (…) that felt overwhelming* (Interview 15).

This way, these adolescents seemingly understand autism as (negatively valued) manifestations of person-environment mismatch or emotional loss-of-control, and not so much as a given that also shapes neutral or more positively valued experiences. For example, this last girl also talked about how she could spend many hours in a row at her drawing desk enjoying being absorbed by the activity.

Autistic scholars have described such experiences in terms of 'flow states', which is (at least partly) appreciated as a desirable autistic feature (McDonnell & Milton, 2014). Yet, the interviewed girl explicitly stated this state of flow had nothing to do with autism for her.

For other adolescents, autism is something which is more woven into their daily lives and appears more systematically at the forefront of their thinking (Interviews 3, 4, 7, 9, 10, 17). *'Psychologically, it is a big part of who you are, because every day and every week, you have to deal with that and with how you behave'* (Interview 4). These adolescents reported feelings of autism-related difference more explicitly compared to peers. One boy said, *'I've been having this feeling all my life. (...) I have always known I was different, the label just confirms that I am different, it confirms something I already knew'* (Interview 7). For most interviewees here, this experience of feeling different is a long-standing one, which indeed predated their awareness of their autism diagnosis and which was expected to continue over time. *'Autism will always be part of who I am, and that influences all my choices. Not necessarily in a negative way. But it will always influence me, because my way of reasoning is just like that, because I have ASD. And I don't think that will change anytime soon'* (Interview 9). As a consequence, receiving their autism diagnosis, or being told about it, was something relatively unsurprising for this subgroup of adolescents.

Theme 3: Drawing up the balance on the label's value

Next to describing autism and to sharing experiences of autism-related (in)differences, adolescents spoke about how they perceived the value of their autism diagnostic label, if at all. Two categories of responses emerged from our analysis: (1) the label's direct value for the adolescent themselves, (2) the label's indirect value, mediated through other people.

The label's direct value for oneself

Considering the label's value for oneself in a more direct way, there were two positions: some adolescents experienced little additional value from the diagnosis for themselves, while others did. In terms of group composition, there is overlap between those experiencing little additional value (Interviews 1, 2, 8, 13, 14, 15, 18), and those feeling not very different compared to peers, as discussed before. One girl, growing up in a family with two autistic brothers and two autistic parents, phrased this position of little additional value as follows: *'I don't experience much difference as it [i.e. autism] does not bother me. Except for missing out on the extra support in elementary school, it would not have bothered me if I never got the diagnosis' (Interview 2).* Two boys clearly stated that they did not care at all about having received the diagnosis (Interviews 14, 18). Two girls (Interviews 13, 15) indicated here that for them it is '*good to know*' about their autism diagnosis, although explaining why that was the case seemed difficult. In one of those interviews (Interview 15), the mother of this girl, who was present in the room, made a clarifying addition: '*In fact, that [autism diagnosis] was not that important for us. But for school it was'.* The adolescent girl added: '*Oh yes, now I remember, it was for that internship,*' referring to the possibility to engage an additional mentor reserved for those interns with a formal autism diagnosis. For context, this girl received a diagnosis of intellectual disability earlier in life. This first diagnosis already guided her parents, other family members, teachers and the girl herself to a large extent in organising her life in an accommodating way. At the point of interviewing, the additional and more recent autism diagnosis only had little direct added value.

A second group of adolescents spoke about how they did experience value for themselves in having obtained an autism diagnosis (Interviews 3, 7, 9, 10, 17). Here, they mentioned how the label provided recognition for experienced differences, exculpated undesired behaviours, explained atypicalities, and helped to position themselves towards these differences, behaviours, and atypicalities.

Below, we elaborate on the latter two functions of the label: explaining atypicalities and positioning oneself.

According to several adolescents, knowing one is autistic helped to 'explain' why one thinks differently for example, finds joy in things others might not, and gets upset by situations deemed unremarkable by others. Here, adolescents understood 'explanation' more as an individual process, and not so much as in 'explaining something to others'[31]. An 18-year-old girl phrased it as follows:

> *I wasn't surprised to hear I had autism, it rather explained things to me, my behaviour and my thoughts. It explained why I react in certain ways in some situations. And why some people can handle these situations better than me* (Interview 9).

The diagnostic label gives these adolescents a frame of reference to think about their current and past selves. One girl said for example: '*I used to be very fixated on wearing the right gloves, and now I realise in such situations, alright that is because of autism*' (Interview 17). She explained afterwards that knowing such tendencies are associated with autism did not necessarily make her change those behaviours, but it helped her to experience behaviours in a more accepting, welcoming way.

Next to explaining difference, the diagnostic label also helped some adolescents in positioning themselves concerning their experiences of difference from the norm. This positioning can mean being more accepting of oneself, but also deliberately choosing moments to blend into a (neurotypical-dominated) group, or hiding autistic features more systematically. One boy, who appeared fairly at peace with his autism diagnosis, put it as follows:

[31] Also, 'explaining' should not be interpreted here necessarily as causally explaining something, in its scientific sense. Such causal claims would obviously run into the conceptual fallacy of 'reification', mixing up the construct of the diagnostic label with the 'actual' and 'underlying' pathways that shape autistic behaviour (as far as these exist in any knowable way). When autistic behaviours are first considered as criteria to assign the autism diagnostic label, and then this label is considered as explanation for these very behaviours, one is running around in circles.

> *If I would have known earlier which things are different for me, then I could have paid more attention maybe to those aspects, without changing myself into someone else entirely different of course, which is not possible. In that sense, the label could help, because you know better in what respect you are different (…) But you cannot focus on being different too much, because if you think that something is wrong with you and you don't accept yourself, friends won't do so either. That's a big step, realising there isn't something wrong with you, but that you are just different. And that there are small things you can do about that, but that you should not try to change yourself fundamentally, because that doesn't work at all (Interview 7).*

For another adolescent, this 'positioning oneself' translated into attempts to blend in among non-autistic peers and to hide autistic features actively (Interview 16).

> *On the one hand, I would rather just not have autism. But on the other hand, I am happy to know I have it, so I can be aware of how I behave and how I talk. I try to laugh less exaggeratedly, just trying to laugh normally. Making sure I don't say any stupid stuff.*

The label's indirect value mediated via others

When zooming in on the diagnostic label's indirect value, mediated via the actions of others, there is a range of aspects adolescents brought up. According to our participants, an autism diagnosis provided them with an official justification to access specific care services and accommodations. Also, when parents, teachers, and friends are aware a child is autistic, our interviewees thought it would be easier for these people to take into account particular autistic features and needs during interactions which could reduce misunderstandings, frustrations or conflicts. Yet, making others interact in such more autism-accepting ways, generally requires adolescents to disclose their diagnosis explicitly to these other parties. In the case of our interviewees, parents were

always aware of the diagnosis, as all participants received their autism diagnosis as minors with their parents taking a leading role in initiating the assessment. Almost all adolescents indicated they found it understandable that their parents initiated a diagnostic assessment at a certain point in time, even though obtaining such a diagnosis potentially has long-lasting impacts on their life. The following quotes illustrate this position. '*I can imagine, that as a parent, you want to know what your child has. That's normal'* (Interview 18). '*If parents think that something is wrong, then they have to know what is going on, so they don't always worry'* (Interview 8). '*This way they can change how they behave and raise their child, and maybe look out for the right school'* (Interview 5).

When it comes to other people than parents, adolescents spoke about the balancing act of disclosing their diagnosis. According to the interviewees, the main aim of disclosing one's diagnosis is that the other party takes autistic features and needs into account, although this accounting does not always takes place. One boy put it as follows:

> *Okay, you can say this to people and hope they take it into account, but at the same time you don't always want to send this message to the world, as in reality, people don't always do take it into account* (Interview 7)

Without prompts in this direction, many adolescents relied here on a distinction between 'taking into account' autistic features and needs, and 'being treated differently' because of their autistic features or diagnosis. Here, 'being treated differently' clearly had a more negative connotation. One girl shared a telling anecdote which took place during her internship as a caregiver in a hospital (Interview 17).

> *The people really saw me as "the intern with autism", not just an intern. (…) The head nurse told me, "I come specifically for you to the ward to help you". But, for me, a regular nurse would have been just fine. (…) I don't need a head nurse to teach me, just because I have autism. I just*

wanted to be treated as an equal. Sometimes I will face some difficulties, but then I will just ask for help, head nurse or not.

This episode illustrates how 'being treated differently' connects to paternalistic interaction patterns and stereotypical, negatively charged or simply incorrect views of autism, on behalf of the other party. Moreover, as this girl indicated, diagnostic disclosure can lead to autism becoming one's 'primary identity' ('the intern with autism') in the eyes of the other, even when this does not match with the adolescent's perception (Thompson-Hodgetts et al., 2020).

Given such potential pitfalls, most adolescents therefore only share their diagnosis when they feel it is needed to resolve a certain tension, for example when they feel they are being misunderstood or considered rude when sharing their thoughts in a straightforward way (Interview 3, 9, 17). In situations and contexts where they can blend in or pass as non-autistic (Interviews 1, 2, 9, 16, 17), or when their environment is already well aware of their autism diagnosis (Interviews 4, 6, 13, 14, 15, 18), disclosure is considered less urgent. Some adolescents shared experiences of unwanted disclosure of their diagnosis, for example when having to show a justificatory document in the classroom to obtain accommodations. Finally, and this was rather an exception, one girl shared a story of sharing her diagnosis with her boyfriend, not so much out of an urgent need to resolve tension, but because she trusted this information would be in good hands (Interview 9).

Theme 4: Getting the timing right

When asked about an adequate timing of an autism diagnosis, overall the interviewees expressed themselves in favour of a relatively early autism diagnosis. For the interviewees, a 'relatively early' diagnosis meant that the diagnosis would be assigned at a moment when they cannot be fully aware of what this means, roughly speaking under the age of six to eight years, depending on the child.

According to many interviewees, a first potential advantage of a relatively early diagnosis is to help create more fitting and supportive environments in early life to grow up in, both at school and at home, even when they cannot be aware of their diagnosis themselves at that point. Several interviewees explained this as follows. One adolescent diagnosed at age 12 argued this was *'way too late because it can be found much earlier'. (…) And if they would have known it in elementary school, they maybe could have taken this a bit into account and things would have been a whole lot easier'* (Interview 10*)*. Another boy, diagnosed at age 14, said: '*the earlier you get your diagnosis, the bigger part of your life people can take this into account*' (Interview 7). A girl, diagnosed at age 8, suspected that not having a diagnosis in elementary school would lead to '*missing out on opportunities to get additional support'*, which was something she appreciated when being in elementary school (Interview 2). A girl, diagnosed at age 15, explained that '*certain things have gone particularly wrong, at school and at home, because I have autism. But if I had reacted differently at that time because I knew I had autism, we could have avoided some trouble'* (Interview 9).

Also, most adolescents were convinced that a relatively early diagnosis is not only helpful and needed for themselves but also for their family members, particularly their parents. Here, similar arguments were echoed from the previous subtheme on the 'indirect value of the autism label'. One participant said the following.

> *If autism is diagnosed early, the advantage for parents is that they know better what to do. If they wait until adolescence for example, then things will get complicated. So, I am not sure if there is an ideal age for diagnosis, but at least before adolescence* (Interview 6).

Next to acknowledging their parents' need to 'know what is going on with their child' and 'how to deal with that', some adolescents also recognised the potential difficulties for parents in such situations. '*I think for every parent, it is useful to*

know whether your child has autism, but this is also just difficult because later on, you will have to tell your son or daughter' (Interview 16).

Another boy considered

> *it could be emotionally rough for parents [when they hear about the diagnosis] because they realise they will need to care more for their child than expected. So that is maybe a disadvantage of an early diagnosis, but even though it can be rough, earlier is better, at least you know what to do with your child then* (Interview 6).

One girl also acknowledged parents' balancing act of considering an autism diagnostic assessment, knowing that mainstream views of autism are fairly negative.

> *I get that parents do not want their child to have an autism diagnosis, because people sometimes have a wrong image of what it is, while for some who have autism, it does not stand out at all, or they only have some small things that make you notice. But people sometimes think it is something severe and I think that scares parents. They do not want their child to have it because other people think badly about it* (Interview 2).

In addition to indirect advantages mediated via external support or their parents, several adolescents also pointed to more *direct* advantages of a relatively early diagnosis for themselves. Knowing they are autistic themselves as soon as reasonably possible could help self-exculpating and explain atypical characteristics and help position themselves towards these characteristics (Interviews 3, 4, 7, 9, 10, 16).

> *I think it is best to know as early as possible, because, yeah, you have to grow up with it, you have to learn to live with autism. And growing up, that is what you do when you are young, not when you are fifty. (…) Earlier is better because otherwise, you might suffer for years not knowing what is going on, making bad choices in your life. With an early*

> *diagnosis, you can grow up with that, learn what it is, and deal with it* (Interview 3).

However, to engage consciously with one's autistic features, one needs of course to be informed about the diagnosis. Here, it is important to disambiguate the timing of *assigning* the diagnosis in clinical practice and *communicating* it to the child.

> *Once the diagnosis can be established properly when the characteristics can be noticed, then I would just go for it. The child doesn't need to know straight away, but at least the school and parents can know it this way'* (Interview 10).

Another boy added here, '*as soon as the child can understand it, then they should be told (…), I really believe that is the best thing to do'* (Interview 4).

Adolescents differed in opinion on what the right age is to communicate the diagnosis explicitly. For some, this is around seven or eight years, for others around the start of secondary education, i.e. around twelve years of age, depending on the abilities and needs of the child to appreciate this knowledge. More explicitly, several adolescents pointed out, though, that waiting too long, or keeping the diagnosis a secret, are undesirable and may potentially lead to disturbing experiences at the time of delayed disclosure. Two adolescents experienced such a delayed disclosure themselves (Interviews 6 and 16), and one 16-year-old, diagnosed at age 5, said the following: '*I only learned about it last year. (…) Then they said it, and of course, it throws you off completely. (…) I was appalled, I did not expect this at all'* (Interview 16).

Apart from these positions that stressed the advantages of a relatively early diagnosis, we also documented some opposite views. Two participants raised doubts about receiving their diagnosis earlier than they did right now, as they *'did not feel different from others'* (Interview 14), or feared to be *'treated differently in elementary school'* (Interview 8). Also, two adolescents took a position of indifference (Interviews 13, 15) stating they did not really care about

the timing of their diagnosis, as they did not care much about their diagnosis at all.

Considering very early diagnosis

For the interviewees, a 'relatively early' diagnosis thus meant the diagnosis would be assigned at a moment at which they are not yet fully aware of it. Yet, in the research literature and clinical practice, the term 'early' detection and diagnosis of autism tends to be reserved for practices within the first three years of life (Øien et al., 2021). When we prompted our interviewees to reflect on assigning an autism diagnosis to infants and toddlers in particular, they voiced some advantages, a few doubts and a range of conditions to take into account. The advantages mentioned were mainly iterations of arguments mentioned before, i.e. generating a more accommodating environment to grow up in, and on helping parents to find their way in raising an atypically developing child. In terms of doubts, one adolescent questioned whether such a very early diagnosis could be technically possible and reliable, and another one wondered what the label's impact on a child would be in early life (Interviews 4 and 7).

We zoom in now on the conditions for valuable, early diagnostics which adolescents mentioned, as these bring some new elements to the fore that were not yet part of this analysis. Two conditions stood out. The first one was that adolescents indicated a diagnostic assessment should only be considered when the child displays some (potentially) autistic features. A second condition was that post-diagnostic support should be possible and relevant before considering a diagnosis. Assigning an autism diagnosis at a point in time when it is still unclear for parents and other caregivers how to engage with this knowledge adequately, was not supported by the adolescents who talked about this. Post-diagnostic support should be concrete and adapted to the specific case at hand.

> *They need to be able to say what is going on exactly, what autism does for this child in particular. Because if they say, he has autism and just*

> *leave it at that, parents might start thinking: my child will act weirdly later. And parents might start spoiling their child and so* (Interview 8).

Also, according to another adolescent, information about autism should be well-balanced and not only focusing on deficits. He said that '*an important aspect when assigning a diagnosis is to show there are not only downsides (to autism), but that the child also has been lucky in other respects*' (Interview 7). A third condition concerned the role of parents in the post-diagnostic period. Having supportive parents was not taken for granted by adolescents.

> *I think the value of an early diagnosis depends a lot on the parents. Personally, I know some people who will surely end a pregnancy when they would know their child would be autistic because they want a normal child per se. (...) But if you have supportive parents, who are eager to learn about autism, then I think such an early diagnosis could definitely help* (Interview 9).

Therefore, parents should also be well-supported themselves to engage appropriately with their autistic child. *'I think it would be a good step when there is a lot of guidance (for parents). Because you cannot just tell parents: your child has ASD, and then move to the next child'* (Interview 9). We will return to this last condition in the discussion below.

Discussion

We initiated this interview study to improve our understanding of how autistic adolescents experience autism and their autism diagnosis, and more specifically how they think about the 'right' timing of such a diagnosis. Because of our choice for in-depth interviews, we want to be careful not to generalise our findings beyond the actual group of participants. To accommodate this limitation, we will position our findings first within the body of existing qualitative autism literature and neurodiversity and disability theory. Second, we

will turn our gaze beyond the particularities of the 18 adolescents we interviewed and discuss the implications of this study for the ethical debate on early autism diagnostics.

Critical consciousness

Our analysis firstly showed that the interviewed autistic adolescents tended to describe autism in terms of what it is not, or at least not to them. For some, this meant clarifying which autistic characteristics applied to them, and which ones did not. Some adolescents also engaged in downward social comparisons on the autism spectrum to establish their own position. This echoes earlier findings reported by Huws and Jones (2015). In our interpretation, these cautious formulations of what autism is and is not, indicate that interviewees were often aware that their interlocutors already have specific ideas in mind about autism. Explaining their understanding of autism, therefore, implied taking a position in relation to existing, mainstream views and discourses of autism, which are often stereotypical, pejorative or simply incorrect ones. Among the interviewed adolescents, no one explicitly claimed autism as a political identity in the way some autistic self-advocates do (Kapp, 2020b). However, by discussing autism in these careful, cautious ways, taking into account pre-existing, mainstream views, these adolescents do seem to hold a form of critical, political consciousness about autism. Moreover, this awareness of mainstream interpretations of autism also played out in adolescents' considerations on when and why to disclose their diagnostic label, for example in their distinction between 'taking into account' autistic features and 'being treated differently' because they are autistic. Our interpretation here is that these autistic adolescents are not opposed to being accommodated by others or to being on the receiving end of care relations. But they do seem to view diagnostic disclosure and accommodations as a double-edged sword: it can be helpful, but it can also reproduce harmful stereotypes and unjust power relations, even despite good intentions on the side of the other.

This critical perspective ties in with the conclusions of a review of 37 qualitative studies on disclosure perception by autistic and non-autistic people (Thompson-Hodgetts et al., 2020). Here, the authors concluded that autistic adolescents (and adults) were rather reluctant to share their diagnosis due to perceived negative outcomes and stigma, although they did feel pressured to do so sometimes. This conclusion contrasted the position of non-autistics who mostly anticipated positive disclosure effects such as increased understanding and social acceptability regarding atypical behaviours (Thompson-Hodgetts et al., 2020). Our interpretation of accommodation as a double-edged sword also feeds in with existing literature on the ethics of care in the context of disability and neurodivergence. Care practices directed at disabled people can be much needed and welcomed, at the same time, the unequal power relations inherent in caring relations also risk aggravating the marginalised position of the cared-for (Kittay, 2011; Scully, 2013; Vanaken, 2022c).

In this same vein, our findings indicate that adolescents' value judgements on their autism diagnosis are acts of balancing potential benefits and harms. In this balancing act, adolescents reach different points of equilibrium. None of the interviewees actively resisted or disputed their diagnosis, but for some, the diagnosis operated rather in the background of their lives, while for others it functioned more at the forefront. Our data do not offer grounds to make strong statements on how to understand this difference. But we hypothesise that the diagnostic label functions more on the background, and therefore adds less direct value, in life stages and situations where adolescents feel they are either well-accommodated (Interviews 15 and 18), or when they can 'pass as normal' without too many negative implications (Interviews 1 and 2). Another element that could help explain this attitude, is the presence of other autistic people in the adolescents' daily lives but this requires further investigation. The presence of other autistic family members or peers could help 'normalise' autistic features and offer pockets of connection and understanding (Milton et al., 2022).

To be clear, the distinction we discuss here between more passive versus more active engagements with the autism diagnostic label does not serve any normative purposes. Based on our findings, we cannot (and do not want to) call a value judgement on these matters. Rather, both ways are probably best understood as relevant reactions to the concrete contexts these adolescents live in.

Timely, rather than early diagnostics

When asked about their views of diagnostic timing, nearly all interviewees proved to be in favour of a relatively early diagnosis, i.e. a diagnosis which is assigned before a child can be (fully) aware of its differences compared to peers. A few adolescents, though, indicated they were indifferent to their diagnosis, including its timing. Adolescents' arguments in favour of such a relatively early diagnosis expanded on two aspects mentioned before concerning the value of an autism diagnosis in general. First, a relatively early diagnosis might help generate better-accommodated environments to grow up in. Second, it might help them relate to and live with autism as soon as they are old enough to be informed about the diagnosis. This favourable position regarding early diagnosis is in line with the findings of a recent mixed-method study (Oredipe et al., 2023). This study investigated the relationship between autistic college students' age at which they learned about being autistic, and their current levels of well-being and views of autism. The authors reported a beneficial quantitative association between learning about autism earlier in life and quality of life scores at the time of the study. Qualitative findings of this same study pointed to 'access to support' and increased 'self-awareness' as potential explanatory factors for the association between diagnostic disclosure and quality of life (ibid, p. 7), much in line with our findings.

In our own study, adolescents thus largely supported a relatively early diagnosis. But this position did not imply a *carte blanche*. As presented in Theme 4, it matters a lot what happens post-diagnostically. Establishing a diagnosis

should first and foremost help address or prevent experienced problems of autistic children and their relatives. Assigning a diagnosis at a point where such concrete action cannot be implemented yet has less value, according to several adolescents. In this sense, speaking of a 'timely' rather than an early diagnosis might be more helpful.

Supportive and well-supported parents

Next to the appropriate timing, the actions and attitudes of parents and clinicians are important to turn an early autism diagnosis into something valuable: supportive and well-supported parents are key. Two aspects matter here. First, clinicians should provide parents with sufficient, personalised information and support which do not only focus on autism's downsides. This feeds in with a recent call directed at diagnosticians to engage in neurodiversity-affirmative discourses from the very start of the diagnostic process (Brown et al., 2021).

Second, adolescents hope their (non-autistic) parents are eager to learn more about autism, even though parents might start from a pathologised, negatively connotated view of autism. Such efforts on the part of parents are much-needed indeed. Some recent evidence points to an association between more negative, self-stigmatising views of autism and learning about autism early in life (Oredipe et al., 2023). Also, when parents and clinicians are the main sources of knowledge about autism, as compared to online information sources, autistic people tend to hold more negative views of autism (Bury et al., 2022). According to Riccio and colleagues (2021), parents can also counteract this. Sharing information about the autism diagnosis to one's child openly, voluntarily and without excessive delay would foster a more affirmative view of autism. Waiting for a situation that forces diagnostic disclosure[32], and concealing the diagnosis for too long were associated with self-stigmatising views of autism in

[32] In our study, we came across at least one clear example of such forced disclosure. At the age of 12, one boy learned he was autistic as he saw his mother handing over a document mentioning the diagnosis while registering for high school. The adolescent described this as an unsettling experience.

adolescence (ibid). Moreover, it seems that parents who are autistic themselves are better positioned and more confident to inform their child in such affirmative ways, as they can build on their own experiences (Crane et al., 2021).

Implications for the ethical debate on early autism care

As touched upon in the introduction, this interview study started from an acknowledgement that the voices of autistic people often go unheard in the decision to start a diagnostic assessment at an early age. In addition, we indicated that this study is part of a more comprehensive research project on the ethics of early autism care which also involved an interview study with parents of a child at an increased likelihood for autism (Vanaken et al., 2023). Indeed, in autism's political history, autistic people and parents of autistic people were often not on the same page when it came to judgements on good autism care (Pripas-Kapit, 2020; Silberman, 2015). Therefore, we aimed to make space for diverging takes on early autism diagnosis by interviewing both (mostly non-autistic) parents as well as autistic youth. Despite our initial assumptions though, it seems that the experiences and stories shared by participating parents on the one hand, and adolescents on the other, have more in common than we anticipated.

Finding common ground

Throughout the interviews, we observed that adolescents occupied fairly generous positions towards their parents. Many of them acknowledged the difficulties of raising a child developing atypically and showed an understanding of parents' choices to initiate a diagnostic assessment to get more grip on the situation. Compared with the fierce online and offline discussions between autistic self-advocates and non-autistic parents of autistic children in the English-speaking Western world, we see two potential explanations for this relatively generous position of our interviewees. First, among our participants (and arguably also in the Flemish region at large), strong autism identity politics are

not very prevalent, and neurodiversity approaches to autism are still in their early days. Second, our interviewees were all diagnosed as a minor which probably gives rise to different experiences and positions towards their parents compared to the majority of the current generation of autistic self-advocates who received their diagnosis as adults, having lived decades without (formal) recognition of their differences from the norm.

Adolescents' remarks on how their diagnostic label functions as a service entry ticket, as a broker of understanding, and as justification for autism-adapted parenting styles converge with established findings from the qualitative literature on parenting autistic children (DePape & Lindsay, 2015; Jacobs et al., 2020). Also, in our previous parent interview study (Vanaken et al., 2023), we described the complexity parents experience in 'navigating the ab/normal binary'. Just like the adolescents in this current study, parents had to undertake a balancing act, weighing potential benefits against risks, for example, in choosing when and to whom to disclose their child's diagnosis with the risk of invoking stereotypical, negative or incorrect views on the part of their interlocutors.

Moreover, in this parent interview study, we described the context-dependency of valuing a timely autism diagnosis. For example, some parents indicated that an autism diagnosis for a second or third autistic child in their family was less urgent than for the first one, as they already had relevant knowledge and accommodations put in place to serve certain autistic needs. This finding echoes the lesser added value some of the interviewed adolescents attributed to their diagnosis as they already spent much of their lives in well-accommodated settings.

Obviously, the experiences of autistic people and their (non-autistic) relatives are not identical and our aim is not at all to overshadow the experiences of autistic youth by those of their parents - as has been done too often in qualitative autism research (Williams et al., 2019). Yet, we believe it is noteworthy that 'experiences of neurodivergency' seem to expand beyond the bodies and minds of neurodivergent people themselves, as close relatives such

as parents also live through (part of) the social and societal pressures of *neuronormativity*. This way, our findings empirically illustrate theoretical descriptions of disability -and by extension, neurodivergency- as fundamentally *relational* phenomena. Disability theorist Alison Kafer for example has put this as follows:

> *Friends and family members of disabled people are often affected by ableist attitudes and barriers, even if they are not themselves disabled. (…) not only does disability exist in relation to able-bodiedness/abled-mindedness, such that disabled and abled form a constitutive binary, but also, to move to a different register of analysis, disability is experienced in and through relationships; it does not occur in isolation. My choice of a relational model of disability is intended to speak to this reality* (Kafer, 2013, p. 8).

Relations, rather than rights

When we introduced the ethical debate on early autism diagnostics at the start of this paper, we mainly zoomed in on the potential tension between parents duties and rights and children's autonomy. On the one hand, parents should be able to seek appropriate clinical care for their child as they see fit, including a diagnostic assessment for autism. On the other hand, children should be protected against having important life choices determined by others before they can make those decisions themselves, which is sometimes referred to as children's 'right to an open future' (Feinberg, 1980; Manzini et al., 2021). Yet, based on our findings, it seems less interesting to take an ethical approach that aims for such rights-based and universally applicable answers. Instead, a relational and contextualised approach might be more fruitful here (Hens, 2021). As it appeared from our analysis, obtaining and mobilising an autism diagnosis is not considered either *good* or *bad*. The value of a timely diagnosis depends on the functions the diagnosis can fulfil for a given individual, in a given context. During the first years of life, children cannot play an active role here themselves.

Therefore, it is up to practitioners and parents to undertake appropriate action to turn an early diagnosis, into a timely and valuable one, be it inspired by the experiences and opinions of autistic people, such as we documented in this study (Kourti, 2021).

Strengths and Limitations

With this study, we aimed to contribute to topical debates in autism research and practice on how to integrate new ideas emerging from neurodiversity theory into clinical autism research and practice, and the ethical debate on early autism care in particular. Importantly, our choice for in-depth interviews implies that our findings are not easily generalisable beyond the specific group of participants. Yet, throughout our discussion section, we have pointed out where our findings corroborate the ones from previous qualitative studies with autistic adolescents. Despite this disclaimer on generalisability, we believe it is a methodological strength and ethical amelioration to have included participants with below-average intellectual abilities, as this subgroup on the autism spectrum is too often excluded from research (Fayette & Bond, 2018).

According to the adolescents who opted for the video call option, this facilitated their participation as it felt less socially intrusive than a home visit, and using a headset while video calling avoided distraction from other stimuli in the room. Providing the topic list beforehand and visualising this during the interview were also appreciated by participants. Despite our efforts at increasing accessibility, we have also noticed the limitations of the classical in-depth interview methodology in capturing the experiences and opinions of those adolescents with below-average intellectual abilities. This also has to do with the nature of our research and interview questions requiring a certain metacognitive reflection on something abstract as an (early) autism diagnosis. In future research that we, an others, will have to continue reflecting on the inclusivity of our research questions and methodologies. Participatory, arts-based approaches and insights from post-qualitative inquiry might aid here to engage with the

experiences of people across the entire autism spectrum, including those with below-average intellectual and verbal communication abilities (St. Pierre, 2021; Van Goidsenhoven & De Schauwer, 2020).

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Annexe: Topic List

Before the first actual interview question, we asked which terminology the participant was used to and comfortable with to refer to autism. During the interview, we stuck then to the preferred terminology of the adolescent, instead of using 'autism' as indicated in the topic list below *('We know that you have been assigned a diagnosis of autism spectrum disorder. Some people rather speak about autism, ASD, Asperger's or PDD-NOS. Which words do you prefer?').* All adolescents indicated they used either 'autism' or 'ASD', some added 'Asperger's' as an additional option.

- If someone wants to learn more about autism via you, how would you explain autism?
- Do you sometimes feel different compared to the people around you? How do you notice?
- When did you learn you have an autism diagnosis?

- To what extent is autism part of who you are?
- Do you think you were born with autism? What does that mean to you?
- Do you experience autism differently in various contexts?
- How do you see your future?

When designing the topic list, we took into account potential pitfalls when engaging with autistic people in qualitative research. Fayette and Bond (2018) signalled that the power imbalance between researcher and participant might generate pressure to provide an exact, right answer to the questions asked. Moreover, abstract or future-oriented questions can be confusing. Therefore we started the interview by stating explicitly that the questions are not like a test or an exam, that there are no right or wrong answers and that it is no problem if they could not answer the question. For each question in the topic list, we prepared alternative phrasings that were more concretely formulated in case needed.

6. Cripping vulnerability

a disability bioethics approach to the case of early autism interventions

This chapter has been published elsewhere before.
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Abstract

The relationships between neurodivergent and disabled communities, and healthcare practices are marked by ambivalence. While there is a history of harmful and discriminatory practices, the clinical encounter also holds beneficial and empowering potential for neurodivergent and disabled people. To address this ambivalence, this paper's central question is whether and how bioethical decision-making in healthcare settings can become more informed by critical insights from neurodiversity and disability studies. The bioethical debate in Western countries on early interventions for young autistic children will be the case animating my theoretical propositions. I provide a working definition of such a 'disability approach to bioethics' and review the obstacles in both mainstream bioethics and disability studies this approach has to overcome. Then, the ethical concept of vulnerability, its feminist reinterpretation and its potential for disability bioethics are introduced. Instead of using the concept in its traditional, problematic sense, I propose that vulnerability can be reclaimed, or cripped, by neurodiversity and disability movements to do the exact opposite: to trouble the demarcation between the vulnerable and the invulnerable, to stress structural injustices over individual deficits, and to justify solidaristic, empowering interventions over paternalist ones. Finally, this 'cripped account of vulnerability' will be applied to the case of early autism intervention.

Introduction

The relationships between neurodivergent and disabled communities, and healthcare practices are marked by ambivalence. On the one hand, there is a well-documented history of discriminatory and harmful healthcare interventions regarding neurodivergent and disabled people, which will be illustrated below (Chapman & Bovell, 2020; Ouellette, 2011). On the other hand, healthcare practices also hold beneficial potential and provide necessary services. Neurodivergent and disabled people continue to seek and value clinical help, for example, to receive a diagnosis and thus formal recognition, to find support in navigating various social services or to obtain a remedy for impairing aspects of disability, such as mental health problems (Roche et al., 2021).

To address this ambivalence, this paper's central question is whether and how bioethical decision-making in healthcare settings can become more informed by critical insights from neurodiversity and disability studies. To this extent, I will build on the parallel with feminist approaches to bioethics and propose a 'disability approach to bioethics'. Expanding on the work by feminist and crip scholars, I will argue that a universalised and politicised concept of 'vulnerability' offers much potential for such a disability-informed ethical approach. The ethical debate on early intervention for young autistic children will be the case animating the theoretical propositions[33].

This paper is composed of four sections. First, the case of early autism interventions will be introduced as it is taking place in many high-income countries. Second, I will formulate a working definition of a 'disability approach to bioethics' and the issues in Western bioethics and disability studies this approach will have to overcome. Third, the merits and pitfalls of the ethical concept of 'vulnerability' will be discussed in the context of such a 'disability

[33] I'll mainly use identity-first language ('e.g. autistic person), in line with preferences of English-speaking autistic communities. Sporadically, I'll employ person-first language (e.g. children with autism) to underscore diversity of opinions on this topic, for ex. in Dutch speaking regions (Bottema-Beutel et al., 2021; Wevers, 2020).

bioethics'. Finally, I will arrive at a 'cripped account of vulnerability' by applying the concept to matters of disability in general and the case of early autism interventions in particular.

Ethics of early detection and intervention for autism

In recent years, developing early, psychosocial interventions for autistic infants and their families has been among the top priorities of autism researchers in high-income countries. The aim of such interventions is to improve key social and communicative skills during critical, developmental phases in the first years of life. These improvements are expected to benefit autistic children's functioning and quality of life over time (Landa, 2018).

Opposing cure, affirming neurodiversity

Although a variety of autism interventions has always existed, particular autism interventions are marked by a history of controversy, e.g. Applied Behavioural Analysis (ABA). ABA-interventions for autistic children have been common practice in English-speaking, Western countries. Initially, ABA consisted mainly of 'discrete trial training' rewarding children when displaying 'normal' behaviour such as looking the therapist in the eye, while punishing them for displaying typical but often harmless autistic acts such as hand flapping. Autistic adults in North-America and Europe have strongly criticised ABA's means and ends as it would attempt to normalise or even cure autistic behaviour, and undermine autistics' autonomy and authenticity (Chapman & Bovell, 2020; M. Dawson, 2004).

In opposition to the pathological view of autism which underpins such normalising interventions, autistic researchers and self-advocates have gathered around the idea of neurodiversity. The term neurodiversity was coined in the late 1990s by autistic sociologist Judy Singer (1998) and journalist Harvey Blume.

Singer initially described the 'neurologically different' as a new political category along with gender, race and class, building on existing ideas such as the social model of disability. At this point in time, two central claims can be distilled from neurodiversity theorising[34].

First, the neurodiversity paradigm underscores the existence of natural and valuable diversity in human types of cognitive, emotional and behavioural functioning without immediately assuming a hierarchy among these 'neurotypes'. Neurotypical people might be in the majority, but under this paradigm, they are not conceived as inherently superior to neurodivergent minorities such as autistics, ADHDers, Tourettics and others. This claim for acceptance of diversity drives the resistance against ableist research, clinical practices, and language use, focusing on prevention, treatment and cure (Bottema-Beutel et al., 2021; Chapman & Bovell, 2020).

Second, neurodiversity proponents recognise distress and disablement experienced by neurodivergent people. Instead of attributing these disadvantages to individual deficits, though, they primarily point to structural processes of marginalisation and oppression. In reaction to these structural injustices, the neurodiversity movement manifests itself as an emancipatory, social justice movement. Proponents strive for a more just society in which discrimination against neurodivergent people in educational, healthcare, labour settings etc. is tackled, and privileges for neurotypical people are reformed into rights for all, irrespective of neurotype (Chapman, 2019).

[34] There is no such thing as *the* ultimate neurodiversity paradigm or theory. As in all academic fields and social movements, a variety of views floats around. One such point of contention is whether neurodivergency is mainly to be seen as an *identity* category one can either adhere to or not, or if neurodiversity paradigm(s) should rather be seen as a critical *perspective* instead, as a way of 'looking and talking back to power – of 'queering' the cognitive normative gaze' (Rosqvist, Stenning, & Chown, 2020, p. 228). In this latter sense, there is indeed a clear parallel with concepts of 'queer' and 'crip', in the sense that these do represent fluid, non-essentialist identity categories whose common denominators are the critical positions towards power manifested in gender, sexuality and bodily norms (Vanaken & Van Goidsenhoven, 2021).

Current debates on early autism programs

Moving back to this paper's exemplary case, one can see that most interventions currently under development for young children with autism, move beyond contested 'discrete trial trainings'. Behavioural techniques such as reinforcement are evidently still part of such programs, however, more recent interventions depart from the abstract, clinical setting where the child and therapist are sitting face-to-face. So-called 'Naturalistic Developmental Behaviour Interventions', or NDBIs, use daily, naturalistic settings instead to foster children's development of socio-communicative skills. Often, parents are trained to conduct certain techniques, such as eliciting joint attention through eye contact in playful settings, while interacting with their child at home to increase practice time and generalise skills to daily situations (Sandbank et al., 2021).

Despite these evolutions, the controversy over these early interventions has not settled at all. In the fall of 2021 for example, autistic scholars and advocates raised concerns over a recent publication in *JAMA Pediatrics* reporting 'a significant reduction in the severity of ASD behaviours' through a parent-mediated, developmental intervention (Whitehouse, Varcin, et al., 2021, p. 8). Children involved were between 12 and 36 months and were at an elevated likelihood for autism. At the age of 3 years, 18 months after the intervention, significantly fewer children in the intervention group ticked off the necessary boxes to fulfil the diagnostic criteria of autism than the control group. In other words, the intervention diminished features of autism and, for some, led to a kind of 'prevention' of an autism diagnosis.

This publication led to an outcry on social media by autistic self-advocates (Neurodiversity Advocates, 2021). They felt harmed, collectively, by the ongoing conceptualisation of autism as an inherently pathological condition that needs to be prevented, or at least treated. Self-advocates would have rather seen an intervention in line with autistic priorities, such as improving mental health issues or quality of life in general. They also feared harm in a more individual sense. Children might lose access to services if they fail to obtain a formal autism

diagnosis. Also, training children in normal behaviours might lead them to 'camouflage', or hide atypical features in order to fit in. Reportedly, it is mainly autistic girls and women engaging in such camouflaging behaviours and bearing the associated costs on their mental health, such as anxiety, depression and suicidality (Cook et al., 2021). Lastly, power imbalances in the study design were questioned; i.e. were autistic people involved?

In their counterreaction, the study's authors made a valuable argument regarding the risk of missed diagnoses, in favour of needs-based services over category-based ones (Green & Whitehouse, 2021; Whitehouse, Green, et al., 2021). In reply to the other points, though, the counterreactions were more oppositional. First, they claimed to adopt neurodiversity and participatory schools of thought, although their publication did not mention this. Also, they claimed this bottom-up reaction from the autistic community might 'discourage young scientists from wading into autism research' and 'thwart ongoing treatment studies and future investment'. Last, some[35] argued that therapies for 'desperate families' of 'low-functioning' children would be paused as a result (Askham & Dattaro, 2021, pp. 2–3). This latter attempt to break up the autistic community into so-called 'low-functioning' autistics in desperate need of professional help and 'high-functioning' self-advocates ignoring these needs, is seen by many as anti-neurodiversity rhetoric (Van Goidsenhoven & Vanaken, 2021).

The ethical stakes of early autism programs

Clearly, bottom-up resistance evokes tensions in autism research, with two apparent camps in the ethical debate. On the one side, much of mainstream academic literature assumes that developing these early autism programs is the right way forward. Consequently, current discussions in the field mainly involve questions of operationalisation and implementation, i.e. which intervention

[35] This last comment was not made by any of the authors of the Whitehouse et al. 2021 study, but by another autism researcher interviewed on the topic who was not involved in the study.

methodologies are most effective, at what age should they start, what is an optimal cost-benefit ratio etc. Neurodiversity critiques, on the other side, may make us infer that clinical interventions for autism should always be considered a no-go, as the focus should be on removing societal barriers outside of these clinical settings.

However, the ethical discussion on early autism interventions deserves better than a debate on whether these interventions are *inherently* right or wrong. More valuable ethical questions would inquire whether and how such early interventions can avoid or lessen existing harms for the heterogenous group of infants on the spectrum and their families, without causing additional harm; how early autism interventions can be an opportunity to redress structural injustices without reproducing current, unjust power asymmetries.

A proper bioethical analysis of this case holds the potential to answer these questions and contribute to the debate in two ways. First, a robust ethical underpinning may strengthen the political claims of the neurodiversity movement and anticipate co-optation or authority-based counterreactions like the ones illustrated above. Second, a bioethical analysis might help build alliances with autism researchers and clinicians. Autism professionals intend to lessen or avoid harms for autistic people, which is a strong, ethical commitment which they share with neurodiversity advocates. In a similar vein, principles of doing well, promoting justice and respecting autonomy are both critical principles for healthcare professionals *and* for neurodiversity proponents (Chapman, 2019). Bioethical arguments and terminology might thus help bridging both camps.

Up to now though, bioethicists nor neurodiversity scholars haven't engaged much with each other's fields (Hens et al., 2019). The fairly recent entry of neurodiversity studies into academia might explain this lack of crossover. However, when we look at the more established interactions between bioethics and *disability studies*, it seems that time in itself does not suffice to arrive at a

fruitful crossover. The next section will analyse which current tensions need to be overcome to arrive at a proper disability approach to bioethics.

Disability bioethics

Neurodiversity theorising shares some critical aspects with the academic and activistic disability movement. Both aim to reconceptualise disorder into difference, as discussed above, and take up the struggle for social justice for those who differ from able-minded and able-bodied norms. Neurodiversity proponents have highlighted the experiential and theoretical links between being autistic and being physically, sensory or intellectually disabled. Although daily realities might differ, some claim a shared affinity between disabled and neurodivergent people as both live their lives in a minority body-mind in a society where able bodies and typical minds are still the norm (Bertilsdotter Rosqvist, Chown, et al., 2020; Chapman, 2019; J. Singer, 1998). Below, I build on this shared affinity by drawing parallels between bioethics' interaction with disability, and a neurodiversity-informed, ethical analysis of early autism interventions.

Defining disability bioethics

The field of bioethics and the disability movement have clashed several times over the past decades, particularly on life-or-death issues such as prenatal selection or assisted suicide for disabled people. Despite these tensions, some feminist ethicists have explicitly integrated a disability perspective in their work and vice versa (e.g. Kafer, 2013; Kittay, 2019). However, most attempts at cross-pollination between bioethical and disability thinking are still taking place in the margins of the respective fields. Consequently, a more systematic 'disability approach to bioethics' is still far from being established as an acknowledged line of academic inquiry, particulary when compared to the now well-established 'feminist approaches to bioethics'.

Interestingly, a handful of interdisciplinary scholars have started to define the contours of such a disability approach to bioethics, or 'disability bioethics' in short (e.g. Ouellette 2011; Scully 2008; Garland-Thomson 2017; Stramondo 2016). My working definition is the following: disability bioethics are approaches to bioethics conscious of the empirical and theoretical insights offered by disabled (and neurodivergent) ways of living. These approaches conscientiously apply those insights in their questioning, methodology, theory and ultimately in their recommendations to ameliorate the state of affairs for disabled people.

My proposition is that the ethical concept of 'vulnerability' offers an interesting, theoretical framework for disability bioethics. Before discussing this in depth, I look at the challenges in both bioethics and disability studies, which the proposition needs to overcome to make a valuable contribution to a disability bioethics approach.

Issues with bioethical thinking on disability

Bioethics is often defined as a strand of applied ethics studying ethical problems emerging from advances in biology, medicine and technology. A relatively frequent critique of mainstream, Western bioethics though, is that it has turned into a docile facilitator of business-as-usual biomedical research and practice, rather than being its critical watchdog, as in the early days of bioethics (Brody, 2009). As such, bioethics has been reproducing some of the same structural injustices pervading the rest of society. This critique already inspired the development of feminist and queer approaches to bioethics and applies to matters of disability as well.

American legal scholar Alicia Ouellette examines this latter critique in her book *Bioethics and Disability* (2011). She discusses an extensive set of controversial, bioethical cases involving disability. Ouellette concludes that heavy-handed claims of a new eugenic logic in Western bioethics promoting the

eradication of disabled people are overstated. She does find convincing evidence, though, for an ableist bias in bioethical thought:

> *Babies are left to die because they are born with disabling or potentially disabling conditions. Healthy growth is stopped and functioning organs are removed from children with disabilities when such interventions would never be allowed for nondisabled children. Parents are charged with child neglect for failure to cede to social and medical pressure to use medical technologies to cure traits in their children deemed defects by medicine but a valuable human variant by their parents. (...) Fertility specialists deny services based on assumptions about the ability of persons with disabilities to parent. Doctors unquestionably accept as reasonable decisions by adults with disability to die regardless of the surmountable social problems faced by the patient (2011, p. 319).*

Issues with disability thinking on bioethics

In disability studies and activism then, there are some problematic aspects as well hindering a fruitful, interdisciplinary crossover with bioethics. The issues I identify are threefold

First, ethical arguments are often not made sufficiently explicit in disability scholarship (Scully, 2008). Much of the disability literature aims to complexify disability as a phenomenon and to read disabled lives through multiple viewpoints (e.g. Goodley & Runswick-Cole, 2012) as a critique to unidimensional views of disability as mere tragedies in need of a cure. However, by focusing on complexity over reductionism, the style and language of disability scholarship differs markedly from the analytical approach in much bioethical research. Much bioethical literature aims to disentangle dilemmas into bite-sized elements to ease the application of ethical theories and principles, before arriving at concrete normative recommendations. Such explicitly formulated, normative positions are rather scarce in disability studies. Disability scholars seem to be somewhat wary of defending norms whatsoever, possibly

because the deconstruction of norms in society is core to the field, albeit oppressive, ableist ones. Nevertheless, main objectives in disability studies such as challenging ableism or empowering disabled people are without any doubt normative activities themselves. Viewed this way, the lack of bioethical terminology and traditional, ethical theory in disability scholarship is remarkable (Garden, 2015).

Second, the oft-cited 'models of disability' leave little room to criticise clinical research and practice constructively. Social, minority politics and cultural models of disability provide theoretical tools to argue for the removal of social barriers to equal participation, for disability rights legislation and for diversified cultural representations. Of course, these models served to dismiss normalising clinical practices, but next to that, they have often left bioethicists and clinical practitioners wondering how disability studies relate to their daily work. Meanwhile, disabled people continue to seek clinical advice, be it for diagnostic and thus formal recognition purposes, to find help navigating services or to obtain a remedy for impairing aspects of disability (Roche et al., 2021). These models of disability do not seem to engage much with these practices that are important for disabled people and happen to be at the core of bioethics' interest.

A third issue with disability thinking arises on the central role of 'independency', one of the few concepts with an ethical connotation in the disability movement. Western disability rights groups, such as the Independent Living movement, protested the lack of self-determination under institutionalisation and claimed their position as full-fledged citizens who should have decision-making power on how to organize their lives. In an early critique of the medical model of disability, the Independent Living-analysis pointed to the child-like and disempowering dependence on institutions, professionals and relatives as a key problem for disabled people. 'The concept of care,' as some have put it, 'seems to many disabled people a tool through which others are able to dominate and manage our lives' (Wood, cited in McCrary, 2017, p. 378).

Instead of being reliant on these forms of governmental, medical and familial care, reducing social barriers, consumer control over personal budgets and the hiring of personal attendants became key steps in the struggle for 'independence'.

Organising around the ethical ideal of independence comes at a cost, though. Among others, feminist philosopher of disability Eva Kittay (2019) points out how the ideal of independence is an excluding one, as some disabled people will never be independent as they are in continuous need of support. Independence as the central claim to rally behind, thus, risks drawing new binaries within the disability movement. For example, in the earlier discussion of early interventions for autism, we have seen these binaries popping up when researchers argue that the claims of 'high-functioning' autistic people hamper 'low functioning' autistics to access interventions. On the contrary, Kittay favours embracing *dependence* rather than chasing behind the neoliberal agenda of individual responsibility and productivity, modelled on able-bodyminded views of personhood. '*Bringing this understanding into the lifeblood of society can be a precious contribution bestowed upon us from the community of disabled people'* (2019, p. 163)[36].

To wrap up this section, one can say that a disability approach to bioethics clearly has several issues to overcome. It must deal with ableist biases in bioethics, and it has to translate disability insights into normative and ethically underpinned arguments departing from the flawed ideal of independency and addressing the essential ethical domain of clinical research and practice. The following section will introduce the ethical concept of vulnerability as a promising theoretical contribution to a disability approach to bioethics.

[36] Recently, queer disabled people of colour have started to organise around *disability justice* principles, departing from the individual-focused, single-issue *disability rights* groups. These disability justice principles highlight interdependency, cross-disability solidarity and intersectional struggle (Berne et al., 2018). Also within the neurodiversity movement, solidarity across neurotypes and across levels of needed support have become a key topic (Bertilsdotter Rosqvist, Chown, et al., 2020). This paper's scope does not allow to point out more similarities, although the proposed 'cripped account of vulnerability' probably fits well with these ideas.

Vulnerability revisited

Vulnerability is often understood as a state of being in which one is at risk to be wronged. At the same time, one is limited in capacity to overcome this risk. Since it concerns a conditional, forward-looking state, i.e. the potential harm or injustice has yet to arrive, vulnerability implies a call to action to prevent harm from happening. This way, 'vulnerability' differs from 'dependency' as it is not merely a descriptive but also a normative term.

Traditionally, 'vulnerability' featured in Western research ethics to indicate one's inability to give a valid informed consent. To avoid coercion or hard paternalism, special precautions were formulated to protect vulnerable groups, such as children or intellectually disabled people, in the form of more favourable benefit-risk ratios or even outright exclusion from research. Over the years, lists of vulnerable groups continued to grow though, to include a vast amount of people such as people living in poverty, ethnic minorities, chronically ill people, elderly persons, pregnant women, the institutionalised etc. (W. Rogers, 2013).

This labelling approach to vulnerability led to two strands of criticism. First, some say 'vulnerability' became too *broad* in the sense that, according to the expanding lists, almost anyone can be labelled 'vulnerable' simply by being part of a certain identity category (Luna, 2009), fixing people in a political position of powerlessness and lack of agency (Butler et al., 2016). Second, the overly *narrow* interpretation of vulnerability in bioethics has been criticised as well, as it would only refer to autonomy-deficits such as the inability to give informed consent. Beyond autonomy-deficits, unjust background conditions and structural injustices can be a source of vulnerability as well. Indeed, informed consent procedures do not protect against 'dangerous protocols, researchers with conflicts of interest, or dysfunctional institutions, all of which make participants vulnerable by increasing their risk of harm' (Rogers, 2013, p.67).

To address these critiques, various theorists have formulated alternatives. Florencia Luna for example, suggests the idea of vulnerability as *layers* instead of *labels* (2009), avoiding the application of the term vulnerability to large groups at the same time. Another influential account is Martha Fineman's *universal* approach to vulnerability (2013). She contrasts a (neo)liberal conception of personhood and citizenship with a physically embodied and socially embedded, vulnerable view. Judith Butler (2016), then, remarks that reclaiming vulnerability in social justice struggles doesn't imply accepting paternalistic forms of remediation, nor settling for victimhood. Rather, she proposes that vulnerability, 'understood as a deliberate exposure to power, is part of the of the very meaning of political resistance as an embodied enactment' (p.22). This way, mobilising 'vulnerability' changes from being an avoidable term which doubles down on marginalisation, to a productive term which might help formulating ethical arguments that support the social change neurodiversity and disability movements are working towards.

Interestingly, feminist ethicists Wendy Rogers, Catriona Mackenzie and Susan Dodds (2012)**,** and bioethicist Henk ten Have (2016) both came up with comparable frameworks of vulnerability, integrating the aforementioned critiques and alternatives. Rogers et al. define a framework consisting of two primary sources of vulnerability: 'inherent and situational vulnerability'. This latter source also implies a subcategory named 'pathogenic vulnerability'. Ten Have retains two overarching categories as well: a philosophical view of 'anthropogenic vulnerability' and a political view of 'special vulnerability'.

According to Rogers et al., inherent sources of vulnerability arise from our human embodiment, dependence on others, and neediness as human beings. When thinking about our basic needs and wants for food and water, housing, energy, mobility, social interaction and support etc., it is hard to claim that anyone of us is entirely invulnerable in these respects. To be vulnerable is a descriptor of human life. Therefore, vulnerability is not something negative per se that needs to be overcome entirely. On the contrary, this common-sense idea

of being vulnerable gives rise to claims of care, accommodation and solidarity towards one another. As socially embedded and embodied beings, inherent vulnerability reminds us that meeting our needs and wants can be challenged at any time in life. Ten Have adds here that vulnerability caused by our relational nature is 'anthropogenic' in the sense that this is what makes us human.

Ten Have posits that, as human beings, we cannot claim some invulnerable position from which we can reflect on the vulnerable other. In a more applied sense, as clinicians or ethicists, one cannot reflect on vulnerable disabled or autistic people without recognizing one's own vulnerability. On this view, there is no simple 'us' and 'them', no simple invulnerable and vulnerable groups. We are all inextricably part of a web of dependencies. This web can give rise to practices of care and mutual aid, solidarity and cooperation. Nevertheless, at the same time, these dependency relations may also involve domination, oppression and exploitation. This feature links the universal understanding of vulnerability to the second one, i.e. situational or political vulnerability.

We might indeed all be vulnerable, but for some, the risk to have essential needs go unmet is exacerbated due to asymmetries in dependency relationships. 'Personal, social, political, economic, or environmental situations of individuals or groups' play an important role here (W. Rogers et al., 2012, p. 24). The positions we occupy in this web of dependencies make it more or less likely to benefit from advantageous relationships or to be harmed by maleficent ones, as touched upon above. One example is that all autistic children and their families are dependent on a formal diagnosis to gain access to specific clinical services. Yet, girls, children of colour, and those raised in low-income families are less likely to receive this diagnosis in a timely manner (Hosozawa et al., 2020). The negative association between mothers working full time and their possibility to engage in early intervention programs for their autistic child is another telling example how not all parents are situated equally in this web of dependencies (Bradshaw et al., 2020). Overall, this second understanding of vulnerability as situational, or political as ten Have puts it, can thus help to translate relevant

concepts of structural injustice, power asymmetries and intersectionality into disability bioethics. Within this description of situational vulnerability, Rogers, Mackenzie and Dodds also highlight a particularly troubling subcategory, i.e. pathogenic vulnerability:

> *These may be generated by a variety of sources, including morally dysfunctional or abusive interpersonal and social relationships and socio-political oppression or injustice. Pathogenic vulnerabilities may also arise when a response intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones. A key feature of pathogenic vulnerability is the way that it undermines autonomy or exacerbates the sense of powerlessness engendered by vulnerability in general* (W. Rogers et al., 2012, p. 25).

As discussed before, certain aspects of the early intervention study by Whitehouse and colleagues (2021) could be understood in this framework as inducing pathogenic vulnerability. The intervention intends to ameliorate autistic lives but doubles down on the harmful presentation of autism as a set of deficits and on the asymmetrical power relation between autism professionals and autistic communities.

Overall, this reconceptualisation of vulnerability provides some valuable insights. On this view, vulnerability is not purely a negative condition, but it refers to a universal aspect of being human in relation to others and to the physical environment. Vulnerability is no longer just an indicator of a lack of autonomous decision-making, yet it becomes a critical tool to analyse background conditions and power asymmetries as specific (groups of) people experience them. Also, the ethical obligations stemming from this revised view of vulnerability differ. Negative obligations such as protection or exclusion of vulnerable groups make space for the avoidance of paternalism, as the pathogenic understanding of vulnerability posits. Beyond avoiding harm, this new view also gives rise to positive obligations of fostering autonomy and

justice, which I will discuss directly in the context of disability in the following section.

Cripping vulnerability for a disability bioethics

At first sight, proposing a disability bioethics centred on vulnerability may seem somewhat alienating to disabled people. In Western bioethics, healthcare and public discourse, vulnerability is, indeed, dominantly interpreted as a weakness or an autonomy deficit. In this form, vulnerability-discourses are often mobilised to justify unsolicited interventions on marginalised groups, including disabled people. Or, as we have seen in our case as well, people in power may present themselves as vulnerable in order to turn down bottom-up resistance. This way, traditional interpretations of vulnerability precisely represent the unjust power dynamics of ableism that disability and neurodiversity scholars and activists aim to dismantle (Spaan & Schippers, 2020).

However, the feminist reinterpretation of vulnerability challenges this concept's hegemonic understanding. What is more, it turns things upside down. Instead of using vulnerability in its traditional, problematic sense, disabled and neurodivergent communities can reclaim it to do the exact opposite. It can trouble the demarcation between the vulnerable and the invulnerable, stress structural injustices over individual deficits and justify solidaristic, empowering interventions over paternalistic ones. Building on this reinterpretation, the formerly problematic term vulnerability gets turned into a productive one. Or, to use a different lexicon: vulnerability can be 'cripped' in the sense that the traditional interpretation of vulnerability is read against the grain, given a twist and put to work in favour of disabled people's interests. This reclamation of 'vulnerability' parallels the way the term 'crip' has been reappropriated by ill and disabled folks from being a derogatory term ('cripple'), to a critical tool and ironic self-reference breaking up ordinary binaries between undesirable, disabled

bodies and desirable, able ones (Kafer, 2013; Vanaken & Van Goidsenhoven, 2021).

Disability and universal vulnerability

Universal aspects of vulnerability shed new light on the needs of disabled and neurodivergent people and how to respond to those. Needs for accessible healthcare, education, decent work, mobility, housing, leisure, social support etc., are shared needs, although their manifestation may vary given the diversity of body-minds we inhabit.

Regarding our case for example, every parent needs support in raising their young child, seeks information about their developing child, and asks for help when they feel insecure. Young children, in turn, need sensitive and responsive caretakers who stimulate their development. The need to develop social and communicative skills through engagement with others is not categorically different in autistic children, even though it may be expressed differently.

In this respect, inhabiting a 'normal' body-mind gives a certain comfort because many parts of society are organised to accommodate those 'normal' needs structurally. This way, the omnipresence of dependency relations is largely obscured for able-bodyminded people, and they might experience a kind of independence. For disabled and neurodivergent people however, these same dependencies are often much more visible and explicit (Lid, 2015; Scully, 2013). Inspired by the universal take on vulnerability, 'ableism' can be described then as the set of practices which structurally privilege the needs of able body-minds over those of disabled and neurodivergent ones. In this sense, recognising universal aspects of vulnerability underpins reasonably well the first claim of the neurodiversity movement as discussed above, i.e. to acknowledge that humanity entails a natural and non-hierarchical diversity of minds.

Besides differences in whose needs are met, there are also discrepancies in how this catering of universal needs is justified. Meeting disability claims for

accessibility and reasonable accommodations are now often perceived as a form of charity or as burdensome, costly efforts to meet so-called 'special needs'. Under the universal view of vulnerability, these claims can be rephrased as a call for taking up shared responsibility in the spirit of solidarity. Solidarity, indeed, is often defined as a sense of unity within a group based on the community of interests and objectives. Focusing on universal aspects of vulnerability may extend this sense of unity beyond the able/disabled, typical/neurodivergent, 'high/low', us/them binaries (Heikkilä et al., 2020). Solidarity is thus not based on a pre-existing identity category, nor does it entail forcing others to act in according to one's self-interest. Here, the ethical ground for solidarity is the realisation that meeting our needs is fundamentally an interdependent affair that entails vulnerability of unmet needs for all of us (Magnani, 2020).

Disability and situational vulnerability

Focusing on universal aspects of vulnerability helps to break some of the dis/abled boundaries. Nevertheless, the second, i.e. situational or political source of vulnerability is equally vital in a cripped account of vulnerability. We might all have needs to be met, but we are not all disabled, we are not all a bit autistic, as is regularly claimed. Nor do we all live in societies that define (in)dependence alike. Such claims would indeed 'conflate all experiences of physical, mental, or sensory limitation without regard to structural inequality or patterns of exclusion and discrimination,' as crip theorist Alison Kafer points out. 'Deconstructing the binary between disabled and able-bodied/able-minded requires more attention to how different bodies/minds are treated differently, not less' (2013, p. 14).

Indeed, autistic children and their families often find themselves in positions of increased vulnerability compared to non-autistic families, even if autism is not considered a vulnerability per se. Children with autism do experience more mental, behavioural and physical health problems, drop out of day-care and school more frequently and become victims of bullying more often. At the same time, parents of young autistic children experience a lack of

recognition and support, report increased stress levels and deliver above-average care labour in the private sphere. Moreover, autistic children and their families are also at risk of being wronged as subjects of healthcare interventions. Despite good intentions, professionals still largely decide on the objectives, methods and discourse of such programs, including early interventions. As mentioned, this can be described as inducing pathogenic vulnerability. Finally, autistic self-advocates can also put themselves deliberatively in a vulnerable position by speaking out publicly against harmful practices and risking a backlash from conservative powers-that-be, as shown before.

Situational and pathogenic understandings of vulnerability imply thus ethical obligations to address these particular wrongs without causing additional ones. Or, as described before, it requires to 'avoid harm without harming' and 'tackling injustice without reproducing injustice'. This does not mean clinical care for disabled and neurodivergent people is always problematic, but it does turn clinical practices into political spaces where status quo gets contested. Concretely, when designing early autism interventions, professionals should be aware not to double down on the issues autistic people highlighted as harmful or unjust. Instead, early interventions should tackle prioritised difficulties of autistic children and their families in ways that redress pathological understandings of autism and rebalance unjust power relations between professionals and receivers of care. This obligation might be summarised well as an obligation to *empower* people who experience situational vulnerability.

I understand empowerment here in line with its original, more radical conception in Paulo Freire's liberatory pedagogy where it refers to 'producing social change through mutual deliberation and critical thinking about the shared situationality [i.e. the sociopolitical conditions] of individuals' (Chiapperino & Tengland, 2015, p.211). More specifically, in a healthcare context, I see empowerment both as an outcome and a process. Empowerment as an outcome refers to having (more) control over the determinants of one's quality of life. As a process, empowerment implies creating professional relations where both

individual healthcare users and disabled and neurodivergent communities take (more) control over the change process, determining both the goals of this process and the means to use (ibid). This way, demanding to be empowered based on an acknowledgement of heightened vulnerability doesn't imply being passive, but rather becoming an active agent in the change process.

Although implicit, this obligation of empowerment seems to be at the heart of two recent efforts to formulate neurodiversity-informed early autism interventions. According to Leadbitter et al. (2021) and Schuck et al. (2022), a first, key change would be to engage systematically in meaningful partnerships with autistic people and communities when developing, testing and implementing such interventions. Instead of aiming to reduce autism symptomatology for example, autistics-endorsed priorities such as overcoming anxiety, improving quality of life and fostering autism acceptance by others, should guide outcome-setting and measurements of success of early interventions. Departing from therapist-led, more rigid interventions, researchers should continue working on child-led and parent-mediated programs taking place in naturalistic settings. Starting developmental interventions from autistic strengths and fostering healthy, autistic ways of reaching relevant functional outcomes can be ways of embracing developmental diversity without taking a non-interference position. Also, rather than focusing on the individual child, more attention should go to changing its environment, both in private as in public spheres. Such improvements in person-environment fit could be obtained through neurodiversity-informed psychoeducation on autism for key people in the child's world, including experiences from autistic people themselves.

Undoubtedly, striking the right balances will remain an ongoing challenge for all parties involved. For example, fostering communicative skills in order to promote children's autonomy could be in line with autistics-endorsed outcomes. At the same time, overly intensive socio-communicative exercising may cause overburden for children, just like camouflaging does for adolescents and adults.

Evidently, the cripped account of vulnerability is no silver bullet, but it does propose an ethical framework to have these complicated discussions.

Overall, I do see Leadbitter & Schuck's suggestions as applications of the obligation to empowerment, both as outcome and process. What the cripped account of vulnerability adds here, is an ethical groundwork for these suggested reforms in early autism interventions in particular, and for the emancipatory goals of the neurodiversity movement in general. Clearly, a neurodiversity-informed approach to early autism interventions, does not require the elimination of clinical interference. I rather propose that clinical practices become spaces of constructive, political contestation where social change happens as neurodiversity and disability movements advocate for.

Conclusion

In summary, this paper outlined the contours of a disability approach to bioethics. Beyond pointing to ableist biases in mainstream bioethics, I analysed which issues in disability studies need to be overcome to contribute to such a disability bioethics. Then, building on previous work of feminist scholars, I proposed a cripped account of vulnerability as a valuable ethical tool for the case of early autism interventions in particular, and for this emerging disability bioethics in general. This proposition holds two key strengths. First, it provides an ethical underpinning for claims of neurodiversity and disability movements in a way that might appeal to clinical practitioners and researchers as well. Second, this cripped account of vulnerability offers alternatives for ableist narratives on clinical care. It supports a move away from treating, curing or preventing disability, from narratives of 'costly accommodations' and 'special needs', and from idealising independency and individual autonomy. Instead, it introduces ethical narratives of interdependency, a shared responsibility to care and solidarity to meet each other's needs. Also, the cripped account of

vulnerability highlights empowerment in its radical sense as means and ends of care for disabled and neurodivergent people.

Looking ahead, I believe more scholarly work is needed to clarify how vulnerability relates to different aspects of ethical theory, in the context of disability. The relationship between vulnerability and other ethical concepts such as justice and responsibility could be strengthened. Also, vulnerability's position regarding more systematic ethical frameworks, such as principlism, the capabilities approach and care ethics could be clarified. Lastly, the relation between disability bioethics and other bioethical approaches 'from-the-margins' such as feminist, queer and critical race bioethics could be formulated more explicitly. Evidently, now it will be up to disability and neurodiversity communities, and to autism professionals to decide whether or not this cripped account of vulnerability sufficiently appeals to benefit their work. As Judith Butler remarks however, it might not be 'sufficient politics to embrace vulnerability [as ethical argument] as if that might inaugurate a new order of moral values', without continuing to resist ableist practices (2016, p. 25). In any case, I hope it did become clear that embracing and mobilising vulnerability can support such resistance very much.

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Part Three:

Discussion and conclusions

7. Towards neurodiversity-affirmative early autism care

Some 200 pages before this one, I started this dissertation by stating that the fields of autism research and practice find themselves amidst a series of structural changes. Ever more, autism is considered an expression of neurodiversity, instead of a set of deficits contained within the boundaries of an individual's body and mind. Social and societal contexts are pointed to as potentially enabling or disabling factors for a flourishing life, and autistic people, as a neurominority, are claiming their role as experts on how to live good autistic lives in neurotypical-dominated societies (Gillespie-Lynch et al., 2017; Pellicano & den Houting, 2022). It is against the backdrop of these changes that I investigated the question of whether and how early, clinical autism care for young autistic children and their parents could be shaped in an ethically justifiable way: what could *good and just* early, clinical autism care look like in the era of neurodiversity?

In *Part Two: Main*, I presented four studies that engaged with this overarching question in various ways. Despite the different approaches these separate studies took, I see at least one thread running through all four: each chapter started from, identified or analysed a specific conflict between the actors involved in the ethical debate on early, clinical autism care. These explorations of tensions were inspired by, but also echoed, pre-existing political fault lines in the autism field, as introduced in *Part One*. Chapter 3 dealt with tensions between the interests of children participating in early autism research, their parents and researchers making decisions on which research findings should be returned, and under what conditions. Chapter 4 empirically explored parents' views on detecting autism in early life and documented their experienced and anticipated struggles to be good, 'divergent' parents in a society constructed around a dualism of ab/normality. The interview study with autistic adolescents described in Chapter 5 was inspired by the anticipated autonomy conflict generated by assigning an autism diagnosis to a child who has no direct say in this process. Finally, Chapter 6 dived into the frictions between mainstream

bioethics and disability studies and between neurodiversity proponents and biomedically-oriented autism researchers.

Over these past years, I have struggled with the distinction between critically *describing* what is at stake in this debate, versus taking up the more complex and fragile work of *prescribing* or suggesting how things could be different. Also, I have often wondered whether my research was not rather a *political* analysis of the early autism care debate, whereas I was supposed to be working on an *ethical* one.

In this final Chapter, I will share some reflections on how a *reparative* and *entangled* take on ethics has helped me to see things more clearly in these respects. In the very last section, I will apply this reparative and entangled stance to spell out some guiding elements on how *neurodiversity-affirmative early autism care* can get us closer to the *good and just* care for young autistic children and their parents I have been searching for; or to put it with Alison Kafer once more, to the good and just early autism care I *desire*.

Reparative and Entangled Ethics

Many applied ethical debates, including the one I engaged with in this dissertation, require a deep dive into the diverging interests, positions and ideas of the actors involved. Borrowing from Eve Kosofsky Sedgwick, we could call this approach a *paranoid style* of reading an ethical debate. Indeed, my starting point for these preceding chapters was chiefly a critical, suspicious one. I was actively looking out for contrasting opinions, covert power differentials, and implicit ableist assumptions. Yet here, in this final chapter, I want to open the door to a different style and engage with these diverging interests, opinions, and ideas with a more *reparative attitude*.

From a paranoid to a reparative ethical attitude

Paranoid and reparative reading styles are conceptual tools coined by queer literary scholar Eve Kosofsky Sedgwick (2003). Around the turn of the previous century, Sedgwick remarked that feminist and queer thinkers largely relied on a single strategy to deliver cultural and political critique. They took a suspicious stance towards a text or practice, anticipating bad intentions on the part of the writer or practitioner and did not take the risk of being surprised. To Sedgwick, it seemed as if there was hardly any space left for more constructive, empathetic ways of delivering criticism, of trying to look for the positive in a text or practice despite clear shortcomings, or as Sedgwick put it: '*in a world where no one needs to be delusional to find evidence of systemic oppression, to theorize out of anything but a paranoid critical stance has come to seem naive, pious, or complaisant*' (Sedgwick, 2003, pp. 125–126).

I came across these terms of paranoid and reparative reading in Des Fitzgerald's book Tracing Autism (2017). Here, Fitzgerald analysed his interviews with autism neuroscientists not in an overly critical paranoid way as he initially intended, being a science and technology studies (STS) scholar. Instead, he aimed for a reparative style of analysis. This way, he looked for the nuances and constructive openings these scientists made rather than trying to point out solely where they made potentially reductive, stereotypical, or harmful assumptions about autism. Commenting on Sedgwick's initial essay, Heather Love (2010) characterises reparative reading as attending to 'multiplicity, surprise, consolation, rich divergence, creativity and love' (ibid, p. 237). Or put in a more mundane way, the distinction between paranoid and reparative reading styles parallels the oft-cited quote about engaging in a discussion by 'listening to comprehend' versus 'listening to reply'. For me, the point of reading a text, or an ethical debate, reparatively, thus boils down to being open to what is valuable and constructive in the different positions of the actors involved, and to be open to positive surprises, even when there are motives to doubt whether there are good intentions in play (Ellis, 2021). At this point in my dissertation, I feel

attracted to this reparative ethical attitude at the end of my dissertation for two reasons.

First, there are the actual findings and conclusions of our studies that draw me towards this reparative attitude. This work described in the previous chapters made me understand better the relational and interdependent dimensions of living autistic lives in a neuronormative society. The two interview studies, described in Chapters 4 and 5, highlighted an overlap in the negative impacts of neuronormativity on both autistic people and their (non-autistic) parents. Without reducing autistic experiences and interests to those of non-autistic parents, this finding provides a common starting point for those two groups of actors to work on neurodiversity-affirmative approaches to care. In Chapter 6, I argued that the concept of vulnerability can help generate a common ground as well, be it for neurodiversity proponents, (mainstream) bioethicists, and clinical practitioners to coalesce around obligations to solidaristic and empowering early autism interventions. These openings towards a relational and interdependent understanding of autistic experiences warrant a reparative, rather than a paranoid attitude to the ethics of early autism care.

Second, this reparative attitude is also inspired by recent developments in applied neurodiversity theory. As touched upon in the Introduction, various neurodiversity proponents recently published critical, but constructive proposals to *reform* clinical research and practice, rather than *abandon* it altogether (Chapman & Botha, 2022; Leadbitter et al., 2021; Schuck et al., 2022). By promoting reform rather than revolution, neurodiversity proponents implicitly rely on parents, researchers, clinical practitioners, ethicists, policy makers etc. to play a part in the social change process. In other words, neurodiversity proponents advocate a form of shared responsibility to address the structural disadvantages experienced by autistic people (Young, 2011). It is not just up to autistic activists, self-advocates, and scholars to wipe all existing practices off the table and start from scratch. Non-autistic parents, researchers, and

practitioners also have the ability and responsibility[37] to help ameliorate the state of affairs for autistic people by changing research and care practices from the inside out. If we think back about the speech by the autistic self-advocate pioneer Jim Sinclair (1993), cited in Chapter 2 ('*We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support.')*, this call towards non-autistic people to be active allies in the struggle for social change, might have always been part of the neurodiversity movement. If we believe, as I do, that these different actors can indeed coalesce around the shared effort to ameliorate our societies at large, and clinical autism practices in particular, a reparative rather than a paranoid ethical attitude seems the better fit.

To be clear, my goal is not to try and pacify the vibrant debate on good and just early autism care with some kind of middle-ground solution satisfying no one, or serving the status quo more than its contenders. Up to a certain point, disagreement, conflict, and polarisation can be productive dynamics to stir things up, and sometimes settling conflicts too quickly is counterproductive. So, in my attempt to take a reparative ethical attitude to early autism care, my goal is not to resolve the debate once and for all and then move on to the next ethical case. Instead, I hope to offer some constructive suggestions that might appeal to the various actors involved, be it with a specific focus on clinical practice. At the same time, I also hope these suggestions themselves can become the subject of contestation and criticism, fostering further discussion within autism and autistic communities. Thus, in line with several commentators on Sedgwick's work

[37] It was not my initial intention to go this way, but while writing I realised I came close to Donna Haraway's concept of response-ability, which deserves a reference here, mainly as a reminder for myself to explore this maybe in more detail in the future. 'Responsibility is not about right response, but rather a matter of inviting, welcoming, and enabling the response of the Other. That is, what is at issue is response-ability — the ability to respond. The range of possible responses that are invited, the kinds of responses that are disinvited or ruled out as fitting responses, are constrained and conditioned by the questions asked, where questions are not simply innocent queries, but particular practices of engagement. So the conditions of possibility of response-ability include accountability for the specific histories of particular practices of engagement. (…) 'Therefore, response-ability is a way of creating an hospitable or ethical culture by considering the heterogeneity of all possible pasts and futures' (Darananda, 2018).

(Ellis, 2021; Love, 2010), I agree that it is not a matter of making a definitive choice between paranoid and reparative styles but seeing them as separate tools which can be useful in different situations and at different times. Building on the paranoid fundaments of the previous chapters, I believe the time is ripe now to take a more reparative attitude.

Politics, Ethics, Entanglements

I am aware that much of my vocabulary in these past paragraphs has been somewhat political, speaking of struggles, coalitions, allies, and social change. As I said, I have often wondered throughout these past years whether my work is not more *political* than *ethical.* And if that is the case, does an explicitly political positioning undermine the credibility of an ethical analysis? Or is the opposite true? Also, how do ethics and politics actually relate to one another in this context?

Over time, I have become less worried about such possible contradictions between ethics and politics, as I have come to believe that thinking about ethics is not an isolated activity, but a fundamentally entangled affair[38]. When we want to reflect on good and just autism care, it is inevitable to engage with questions that are not ethical ones, strictly speaking. Clearly, the role of bioethicists in research should extend beyond ticking the boxes on research ethics checklists. Bioethicists should critically engage as well with the various underlying assumptions researchers make when designing and conducting their work. Thinking with Mary Midgely, my supervisor Kristien Hens positions the bioethicist '*as philosophical plumber par excellence*'. She explains:

[38] This observation about entanglements is of course not new. Via colleagues, I came across the work of feminist new materialists such as Karen Barad, who coined the composed term 'ethico-onto-epistemology' to underscore the intrinsic entanglements of these philosophical disciplines (Barad in Geerts & Carstens, 2019). I did not engage with primary work of new materialists, but I am adding this footnote again as a 'note to self' (and maybe to others as well) to explore this work in more detail in relation to applied ethical debates on neurodiversity.

> *Bioethicists are often engaged in scientific research projects. They are ideally situated to make the structures and stories explicit to guide a specific scientific practice. Sometimes these structures are weak and need to be fixed (…) Besides thinking about structures and dealing head-on with the messiness of the world, bioethicists and plumbers have in common that they connect things. Bioethicists are neither fish nor fowl, and as liminal creatures, they can bind and bring into dialogue disciplines that are usually worlds apart, such as the humanities, biology, and philosophy'* (Hens, 2022, p. 228).

On this view, the bioethicist's role in the debate on good and just early autism care is also to engage with the following *plumbers'* questions. How do we conceive of autism as a phenomenon: do we see autism as a neurobiological developmental disorder, or as an expression of neurodiversity (Bervoets & Hens, 2020)? What do relevant knowledge and expertise consist of? What do we need to know to make well-considered ethical judgements? For example, do we need more expert-led, randomised controlled trials to prove the efficacy of early autism interventions, or do we want to know more about how such early care practices are experienced by autistic people and their relatives (Gillespie-Lynch et al., 2017)? And, as researchers, practitioners, parents, and ethicists, what values do we commit to? Objectivity, neutrality, evidence-based practice, or more overtly political values such as fostering social justice for and emancipation of autistic people (Arnaud & Gagné-Julien, 2023; Vanaken, 2022c)?

Of course, I am oversimplifying things here by presenting the options in a black-and-white way. Yet, these exemplary questions underscore that investigating the conditions for good and just early autism care requires taking a position in debates which are not ethical ones in the strict sense of the word. Or, returning to some of the terminology discussed at the end of Chapter 2, we could say that *ethical* questions are fundamentally entangled with questions of *ontology* (i.e. beliefs about reality), *epistemology* (i.e. beliefs about knowledge production and transfer), and *axiology* (i.e. beliefs about the role of values in

research and practice); and as the examples suggest: these questions certainly have political dimensions as well.

This entangled view does not only apply to neurodiversity approaches, but also to approaches reliant on a medical model of autism. The difference here is that neurodiversity proponents, including myself, take positions in more explicit ways, whereas such positioning often remains more implicit or less articulated in mainstream approaches to autism. By consequence, it is not so much a matter of trying to separate ethics from politics. Rather, it boils down to making conscious and well-considered choices about the political positions one defends while conducting an ethical analysis (Arnaud & Gagné-Julien, 2023).

In the next and last section of this dissertation, I will provide a set of constructive, reparative suggestions towards good and just autism care, explicitly engaging with the entangled assumptions of the neurodiversity paradigm.

Affirming neurodiversity in early, clinical autism care

If we[39] commit to an understanding of autism as an expression of neurodiversity, not a disorder per se, what is then the role of clinical autism research and practice? Do these fields even have a role at all?

To answer these questions, we need to step away (at least temporarily) from viewing clinical autism research and practice merely as targets for paranoid critique. Instead, we could see those fields as potentially *reparative spaces*: spaces where current dominant understandings of autism and problematic power relations are not just uncritically reproduced, but consciously and collectively

[39] I deliberately use a mixed meaning of 'we' in this final section. At once it will refer to clinicians, to autistic people or to all at the same time. My aim here is to reflect the blurry borders and interconnections between carers and cared for, experts and laypeople. Also, this shifting and broad 'we' is also a tribute to the mixed affiliations I hold myself, being an autism researcher, a neurodiversity proponent, a clinician, a relative, a friend and an ally of autistic folks.

reconfigured by the involved actors[40]. Autistic and non-autistic carers and cared-for could engage in clinical research and practice as if it were coalitional struggles: struggles that still require putting up a fight, yet, not so much against each other, but against problematic conceptions of autism and autistic people. With this reparative, but inherently political attitude in mind, we could start reading early autism diagnosis and intervention against the grain and put those practices to work in favour of the people who need this ameliorative work most. In other words, clinical autism research and care could be *cripped*.

Claiming to adopt a neurodiversity-affirmative approach to early autism research and care is one thing. However, to do justice to the neurodiversity paradigm, one must take the responsibility for thinking through the entangled ethical, conceptual, epistemological, and political questions that arise (Kafer, 2013). How can autistic people and their relatives be *supported* in the difficulties they experience *without pathologising* autism as such? How can expertise grounded in lived experiences effectively complement existing *professional expertise?* How can *socio-political* change be promoted via the predominantly *individual* interactions that characterise clinical practice?

In what follows, I will discuss these questions and propose three guiding elements for such neurodiversity-affirmative, early autism care[41]: (1) careful concepts, (2) careful expertise, and (3) careful politics. For reasons of clarity, I

[40]'*Rather than exploring the interface between research and autistic communities, we look to academic space as a site of emancipation in itself'* (Bertilsdotter Rosqvist et al., 2019). My aim is to extend calls like these to clinical spaces as well.

[41] In this context, I prefer 'neurodiversity-affirmative' over phrasings such as 'neurodivergence-informed' (Chapman & Botha, 2022) or 'autism-friendly'. 'Affirmative' stresses the neurodiversity paradigm's ethical imperative to emancipate and not just tolerate or be friendly towards neurodivergent people. The word 'affirmative' situates this approach alongside other emancipatory struggles that mobilise 'affirmative action' as tactic. I admit that some authors prefer 'neuro-affirmative', or use it alongside 'neurodiversity-affirmative' (Hartman et al., 2023). Yet for me, this phrasing remains unclear with respect to what needs to be affirmed. Instead, 'neurodiversity-affirmative' stresses the point that 'diversity-as-the-norm' is what we aim to affirm. Also, I write about 'care' to open the door for connections with rich philosophical and political debates on care and care ethics (in relation to disability) (Held, 2006; Kittay, 2019). To be more specific when needed, I add the adjective 'clinical', and write about support or interventions when this is more apt.

have chosen to discuss these three elements separately. But it will become clear that these are also connected to one another, in line with the entangled take on ethics I described.

Careful concepts

The way I see things, a neurodiversity-affirmative approach to early autism care is an approach that is not structurally opposed to early autism detection, diagnosis, or intervention. As we have seen before in the interview studies, a timely autism diagnosis has the potential to fulfil a range of valuable functions for both parents and autistic youth: to feel (perhaps just temporarily and partially) recognised, understood, and justified to act divergently in a neuronormative society. In Chapter 6, I then built on a universal and politicised understanding of vulnerability to think differently about good and just care for autistic needs. I speculated on the potential of solidaristic and empowering ways of organising early autism interventions with a lesser risk of reproducing pathologising conceptions of autism and of worsening unjust power relations between caregivers and care users. Based on these findings and arguments, my take is that recognition and support in early life may well be compatible with a neurodiversity-affirmative approach to autism care. The crux of the matter lies in how we understand and shape these practices, in how we conceptualise ‘early’, ‘diagnosis’, and ‘intervention’. Careful reconceptualisations of these terms are needed. In Chapter 4, I already argued to move away from ‘early’ autism detection, towards a notion of timely autism detection. I will not repeat that suggestion here in full, but to me, timely autism detection is a practice that is primarily grounded in parents’ and children’s lived experiences, rather than in technical measurements at fixed ages irrespective of the actual needs and wants of the child and its parents. Instead, timely autism detection carefully considers whether a diagnostic assessment could lead to a valuable outcome in the specific case at hand, rather than assuming that establishing a diagnosis is always a good thing, irrespective of the relationships and contexts it will interact with. Below,

I will take more space to reflect on the concepts of autism 'diagnosis' and 'intervention' in neurodiversity-affirmative ways.

Reconceptualising autism diagnosis

The current clinical operationalisation of autism as 'autism spectrum disorder' is fundamentally a pathologised one. Autism criteria are described in the DSM-5 as 'deficits', and significant 'impairments' in daily functioning are required to assign an autism diagnosis (American Psychiatric Association, 2013). This diagnostic manual does not make strong claims on how to understand autism conceptually, as this extends beyond its scope. However, the manual uses explicit deficit-language and positions 'autism spectrum disorder' in the chapter on neurobiological disorders. This way, it obviously hints at a medical model of autism. This current operationalisation makes it difficult for diagnosticians to adopt a depathologised understanding of autism during consultations and report writing. Also, as we have seen in the interview studies in this dissertation, the dominant and dualistic framing of autism as an undesirable disorder clearly set apart from desirable normality, complicates the lives of autistic people and parents of autistic children in many respects. My colleague Jo Bervoets phrased this aptly as a Catch-22 situation for autistic people who might think: '*I'd be disordered if I accept to be autistic, but if I'm in good mental health I have to accept I'm not autistic'* (Bervoets & Hens, 2020). We have seen similar dynamics at play in Chapters 4 and 5. Especially when it comes to disclosing their (child's) diagnosis to third parties, both parents and autistic adolescents shared how they often had to walk a tightrope: either they communicate the diagnosis risking pity, paternalisation or discrimination, either they keep the diagnosis undisclosed, risking missing out on much-needed understanding and accommodation. Of course, some autistic people and their relatives resist this dynamic by actively claiming a positive autistic identity (Hens & Langenberg, 2018). However, such positive, or at least more neutral identity claims could

become available to many more people on the spectrum, if autism would be clinically operationalised in depathologised ways in the first place.

In response to the negative side-effects of autism's current clinical operationalisation, some commentators have proposed eliminating categorical classifications of autism altogether (Timimi et al., 2010). Such eliminativist calls are not only targeted at autism but are generally part of a wider critique of psychiatric classification systems (Hoge Gezondheidsraad, 2019). This anti-classificatory stance is often accompanied by calls for an alternative diagnostic practice: psychological, or clinical case formulation. In case formulation, a practitioner provides a '*narrative and thick description of the patient's experienced problems in relation to the individual context and with the aim to foster increased understanding of the issues at hand and to provide guidance for next clinical steps*' (ibid, own translation, p. 2). The acclaimed advantages of formulating a case, rather than assigning a classificatory label, are that it would do more justice to the dimensional distribution of mental health problems and relies less strongly on essentialised and biomedical conceptualisations of mental health conditions (Rose, 2018).

I agree that case formulation offers certain advantages -which is why also in Flanders quality guidelines advise to combine categorical and formulated diagnostic approaches in autism assessment (Hellemans et al., 2018). But at this point in history, I do not believe it is desirable to eliminate categorical classifications entirely, at least not for conditions such as autism. As we have seen in both interview studies, our participants hardly experienced diagnostic labels as restrictive or oppressive, rather the contrary. I agree here with neurodiversity theorist Robert Chapman (2021) who argued against clinical case formulation as a replacement for categorical classificatory approaches to autism diagnostics. According to Chapman, the autism label is valuable because it is '*epistemically helpful'*. Despite internal diversity on the spectrum, the categorical diagnostic label helps autistic people to make sense of their experiences together, which can serve emancipatory goals. For some, this sense-

making process involves interacting with other autistic people directly (Crompton et al., 2020); for others, it involves learning about autism via books, blogs, videos, games, psychoeducation, podcasts, etc., options that give access to this collective knowledge on autism, without having to disclose one's own diagnosis (Bury et al., 2022)[42]. This aspect of sharing experiences and improving knowledge about one's own (or one's child's, for that matter[43]) way of being in the world, would definitely be more complicated, or even impossible if autism would not exist as a category one could relate to.

Moreover, Chapman (2021) fears that case formulation approaches would give an excessive amount of power to small diagnostic teams that can do their own thing. This way, it would be hard to track how autism diagnostics actually take place and critiquing such practices gets even more complex. Criticising categorical classificatory approaches to autism is of course not self-evident either. Yet, public discussions leading up to new editions or revisions of psychiatric manuals such as DSM offer some opportunities for debate and participatory co-creation (see for example the lobbying work of the Autism Self-Advocacy Network in the development of DSM-5, Kapp & Ne'eman, 2020).

In my opinion, the way forward, at least in the medium term, is to clinically reconceptualise autism in a depathologised way, while remaining open to categorical and formulated operationalisations of experienced problems related to and coloured by autistic features (Bervoets & Hens, 2020). Concerning a depathologised operationalisation of autism, I think there already is a breadth of research to build on. There is, for example, insightful qualitative research

[42] This survey of 198 autistic adults suggests that learning about autism from professionals and (non-autistic) parents is related to a more negatively charged, stigmatised understanding of autism. Those participants who learned about autism through online blogs and social media showed both a more positive and a more accurate understanding of autism (Bury et al., 2022). Of course, the direction of such associations can also be the other way around, i.e. those people already having a more positive attitude towards autism might prefer to find their information online, and vice versa.

[43] One father put this succinctly in one of the interviews described in Chapter 4: *'Labelling can be quite stigmatising indeed as it is a form of pigeonholing. And outsiders all believe they know what can be found in that pigeonhole: they think they know what autism is about, which they often don't. But for you as parent, the label functions as a demarcation line: it helps you to start searching within that demarcated space of autism to find tips and trick that work for you and for your child'* (Interview 6).

describing autistic characteristics from the inside out, such as the work on autistic experiences of stimming behaviours (Kapp et al., 2019). Efforts such as those made by Murrah, Milton, Green, and Bervoets (2022) seem valuable as well here. In their recent paper, *The Human Spectrum: A Phenomenological Enquiry within Neurodiversity,* this *neuro-mixed* group of authors describes key aspects of autistic phenomenology from the inside out, rather than as a set of behavioural features observed from the outside. Concerning the operationalisation of autism-related experienced problems, recent work on autistic burnout, autistic inertia, autistic meltdowns, and autistic suicidal behaviour can provide inspiration (Buckle et al., 2021; Mitchell et al., 2021; Raymaker et al., 2020).

Legitimate questions here are whether such a depathologised, more neutral description of autism should still be part of diagnostic manuals such as the DSM and whether formal, categorical operationalisations of autism-related difficulties will not simply perpetuate the same dynamics of pathologising autism as such. In this respect, it might be valuable to compare this proposal to the removal of homosexuality as a classification at the introduction of DSM III-R, and of reconceptualising 'gender identity disorder' in DSM IV as 'gender dysphoria' in DSM 5 (American Psychiatric Association, 2013; Psychiatry.org, 2022). A point of difference I see already, at least compared to homosexuality, is the lesser potential of self-identifying as autistic, versus self-identifying as gay. As we have seen, for autistic people, being recognised as autistic might already be valuable at a young age, well before one can self-identify.

Also, our empirical findings have underscored that the relational dimension of an autism diagnosis is key to its perceived value. Even though it can remain a struggle to get all involved caregivers on the same page even after an official diagnosis has been assigned, we learned from parents and adolescents that the diagnostic label has the potential to communicate and justify needs and expected accommodations more clearly. To fulfil these functions, I think autistic people, relatives and professional caregivers benefit from a (minimal and perhaps temporal) shared understanding of what autism is. Therefore, relying

solely on self-identification and a manifold of autism definitions would probably undermine the communicative and justificatory functions of the label in our current society (this might obviously change in the future). The importance of such a shared understanding becomes even more pressing when we would reflect on matters such as disability allowances and other governmental support systems, which currently rely heavily on categorical classifications of disease as gatekeeping mechanisms.

Although I like speculating about how autism diagnostics might evolve in the future, as clinicians we cannot simply sit and wait around for this to happen[44]. As long as the official operationalisation of autism in manuals such as DSM is not changed, (neurodiversity-affirmative) clinicians will have to find ways to relate to this pathologised and deficit-based conceptualisation of autism. It is not my intention to solve this issue here, but merely to reflect on it and formulate some suggestions that emerged in conversation with my clinician-researcher colleagues at the Parenting and Special Education Research Unit at KU Leuven.

One way to deal with the situation would be for clinicians to openly acknowledge the difficulty they face and admit they take a dual stance here. Clinicians could be transparent in their conversations with care users and in their report writing that the current DSM operationalisation of autism still plays a significant role in diagnostic assessment and in providing access to certain services, accommodations and allowances. They could point out that diagnostic criteria for autism spectrum disorder are nowadays still the only frame of reference to assign an official autism diagnostic label, which means the diagnostic assessment will look into whether these deficit- and impairment-based criteria apply. However, working with this operationalisation does not have to mean that clinicians endorse the underlying pathologised view of autism. Clinicians could stress, for example, that this deficit-based view is *a* perspective

[44] And admittedly, neurodivergent clinicians are already taking the lead here, see for example the recently published work by Hartman et al. (2023)

on autism which is contested and that other views are gaining strength. In diagnostic report writing, we could imagine a more neurodiversity-affirmative 'main report' which describes whether or not the autism diagnostic label applies, which mobilises difference- rather than deficit-based terminology, but which also acknowledges experienced difficulties in relation to the relevant contextual factors at hand, and which describes the services that can be offered based on the particular needs of the care user. This main report could be accompanied by a 'technical annexe' that discusses whether and how the different diagnostic criteria apply in a more traditional way, and which categorical classifications can be assigned (Ilse Noens, personal communication, February 17, 2023). Also in verbal conversations with care users, autistic features could already be discussed as differences instead of deficits. Social and societal factors can already be referred to as potential enablers or disablers for flourishing and materials based on lived autistic experiences, such as drawings, video fragments, writings, etc. could already be used during consultations to make space for insider perspectives on autism. Ideally, all of this is initiated, or at least announced, from the very start and not merely in a post-diagnostic setting (Brown et al., 2021). Of course, people consulting an autism diagnostic centre differ in their pre-existing ideas and expectations, and introducing neurodiversity-affirmative ways to talk about autism will need to be paced accordingly.

I certainly admit that I am quite demanding: I ask clinicians to work both *with* and *against* current, pathologised operationalisations of autism. But as we have seen in our interviews with adolescents and parents, autistic people and their relatives are walking this tightrope all the time as they struggle to position themselves to mainstream, deficit-based views on autism. Moreover, for autistic people in particular, such identity management dynamics are deeply personal and often require much emotional labour. Having this in mind, I believe that clinicians are able and responsible as well to make a comparable effort in their role as professionals, be it supported by future research that helps them make this change.

Reconceptualising early intervention

This next section deals with early autism *interventions.* I agree, thinking together clinical autism interventions with a depathologised, neurodiversity-affirmative understanding of autism might seem a *contradictio in terminis*. After all, the clinic primarily serves to deal with pathology. If autism is not a pathological condition as such, but a mere expression of neurodiversity, then what do autism interventionists still have to offer to autistic people, one could ask. If we would adhere to a strict social model of disability, there would be little room for clinical practitioners to ameliorate the lives of autistic people. The focal point of this model, indeed, lies in the material, disabling structures of society and not so much in individual, clinical encounters. However, the political-interactional account of neurodivergent experiences I discussed in Chapter 2, can help bypass this (presumed) stalemate. Viewing autistic people's experienced problems as emergent from interactional mismatches between individual and contestable social and societal factors (Dwyer, 2022) opens up the possibility to intervene in these mismatches. On this account, it is possible to conceptualise autism in a non-pathologised way *and* remain open for clinical care for the actual problems and difficulties autistic people and their relatives experience[45].

In a pioneering blog post, Sue Fletcher-Watson (2018) already pointed out that neurodiversity approaches are not incompatible with autism intervention programmes per se. In the past two years, a handful of academic publications came out where authors took up the task of thinking through in more detail what such a neurodiversity-affirmative take on (early) autism interventions could look like (Chapman & Botha, 2022; G. Dawson, Franz, et al., 2022; Leadbitter et al., 2021; Schuck et al., 2022).

Kathy Leadbitter and colleagues (2021), for example, propose three principles to take into account when developing early autism interventions.

[45] This political-interactional account of neurodiversity also counters oft-cited critiques that neurodiversity approaches would merely sugar-coat actual problems and therefore only apply to intelligent, verbally fluent autistic people with little support needs.

Neurodiversity-affirmative interventions should (1) never aim to 'cure' or 'normalise' autistic children, as this is both unattainable and undesirable; (2) address external factors to improve the 'goodness-of-fit' between a child and their environment; (3) remain open to targeted interventions for autistic behaviours that are '*disadvantageous in and of themselves (…) either because they cause harm or discomfort to the autistic individual, or violate other's rights*' (ibid, p. 3). These three overall principles require interpretation of course. To this extent, Leadbitter et al.(2021) make some additional recommendations.

First, they underscore the importance of considering autistic children's *'internal drives and experiences',* before identifying certain autistic behaviours as undesirable and, therefore, as targets for intervention. Examples include stimming behaviours and echolalia. In many cases, stimming is a way to process and communicate intense experiences, and it can be a source of genuine pleasure as well (Kapp et al., 2019). This kind of knowledge provides a solid argument for avoiding labelling atypical behaviours as stimming systematically as undesirable, just because the outsider's eye fails to see the desirable aspects of such behaviours. Also, some evidence is emerging of the role of echolalia in reaching functional verbal communication skills, be it via atypical developmental routes (Mottron, 2017). If confirmed, this would be an argument to steer away from modelling early socio-communicative interventions on neurotypical developmental pathways, such as fostering joint attention and imitation skills as the main pathway to functional communication (Schreibman et al., 2015)[46]. Similarly, it would be valuable to study the developmental dynamics of depathologised and autistics-led cognitive theories of autism, such as HIPPEA, an autism-specific application of predictive coding theory (Van de Cruys et al., 2014), and monotropism (D. Murray et al., 2005). Monotropy theory, for example, states that autistic minds tend to have 'attention pulled more strongly towards a smaller (or even single) number of interests at any given time,

[46] Some of my colleagues have recently started a promising nation-wide study (BeLAS) to investigate such atypical language development pathways in autistic children (Roeyers et al., 2022).

leaving fewer resources for other process' (F. Murray et al., n.d.). Being pulled in does not merely entail a *cognitive* process of paying attention. It also implies aspects of emotional and sensory arousal related to the topic of interest. This can result in a state of flow. Such flow states can be desirable, but the inertia involved can also complicate switching attention quickly from one activity to the other. Autistic theorists have recently started to apply monotropy theory to autistic play and development, suggesting that the autistic child's strong interests and ways of paying attention are not merely an indicator of divergence from the developmental norm, but they can be productive starting points to engage with actively as to develop new skills, building on the child's internal drives (Donzelli, 2021; Lawson, 2020; NannyAut, 2021). These hypotheses open up interesting new research routes to study how flourishing, early autistic development can be fostered starting from the position that there is not a single right developmental route that all children have to take to reach desirable outcomes.

Overall, my point here is that a neurodiversity-affirmative approach to early intervention should embrace diversity in developmental pathways to reach desirable outcomes (Hens & Van Goidsenhoven, 2023). As consequence, the ambition should be to develop timely interventions that inform and teach parents and other caregivers how to engage *with* rather than *against* autistic developmental dynamics (Fletcher-Watson, 2018; Leadbitter et al., 2021).

This point on rolling with, rather than resisting diversity in development, brings us to a second specification by Leadbitter et al. (2021). Here, they echo Fletcher-Watson (2018), and others made similar suggestions too (G. Dawson, Franz, et al., 2022; Schuck et al., 2022): targets and outcome measures for early autism interventions should prioritise the needs autistic people indicate themselves. This step would reconceptualise our understanding of what an 'effective' early intervention entails. In Chapter 1, we have seen that effectiveness in early autism intervention is generally defined by its potential to

influence IQ scores or core autism characteristics. Taking into account autistics-endorsed priorities will shift the definition of intervention success.

In the past years, some empirical studies have looked into these intervention priorities of autistic people. Oft-cited priorities include improving quality of life, tackling mental health problems such as anxiety and depression, and fostering positive understandings of autism among autistic people themselves and among relatives (Pukki et al., 2022; Roche et al., 2021). These priorities provide a clear call to action towards clinical researchers and practitioners. Again, neurodiversity perspectives on autism do not demand a non-interventionist stance. Still, the focus and methods of interventions should be brought in line with the actual difficulties autistic people and their relatives experience.

What is still underdeveloped in this respect are insights into the intervention targets that autistic children, adolescents and adults find appropriate for very young children on the autism spectrum (Gillespie-Lynch et al., 2017; Manzini et al., 2021). Another challenge is to match abstract priorities of 'improving quality of life' for example, with the concrete realities of intervention science. Because of the way the concept and questionnaires are constructed, quality of life measurements are not very sensitive to short-term changes tracking the effectiveness of interventions (Evers et al., 2022). Multi-year follow-up is probably to scope effects on such distal outcomes (Manzini et al., 2021; Pickles et al., 2016). Also, as I will point out below, there is no such thing as *the* autistic community which can be consulted to obtain a single, representative advice on intervention priorities (Voronka, 2016). Nevertheless, consulting a variety of people on the spectrum and allowing for a diversity of priorities to emerge from such consultations, would definitely help improve early autism interventions' social and ecological validity (Schuck et al., 2022). Choices for specific interventions in a clinical setting should thus be guided by the preferences of autistic communities, but these choices should obviously also consider the particular needs and characteristics of the person or family in case.

Up to now, I discussed suggestions to ground early interventions in autistic developmental pathways to meet autistics-endorsed intervention priorities. However, even when taking these two suggestions to heart, certain difficulties and conflicting interests will probably remain. For example, improving functional communication is a potential common ground between the priorities of autistic people and pre-existing priorities in the clinic, but Schuck et al. (2022) ask the following question in this respect: '*Non-neurotypical gesturing can be a part of the Autistic way of being. However, teaching a child to gesture in order to communicate their needs will likely improve their quality of life. Should teaching gestures therefore be an intervention goal?'* (ibid, p. 4636). They respond that the intention matters here: merely increasing social desirability does not justify such an intervention, but if there are indications at hand that teaching neurotypical gestures helps improve overall well-being, then it might be justified. While I agree with this line of thought in principle, I think it is difficult to consider intentions only. Mainstream, biomedical autism researchers already use quality of life discourse to justify their research, often without evidence that the conducted research actually improves the quality of life of autistic people (Lord et al., 2022).

I do not have an easy solution to this kind of dilemma, where there seems to be a contradiction between pursuing autistics-endorsed priorities and preserving autistic authenticity. The only thing I want to add to the debate here is that it is not very helpful to continue thinking in terms of a static set of autistic behaviours that would constitute autistic authenticity as such. I do not claim there is no such thing as autistic authenticity, but as said before, I do not think this authenticity can be reduced to the level of behaviours only[47]. What we *do*, might differ from who we *are*. Behaviours are very much a result of dynamic

[47] There is some evidence though, that underscores the importance for autistic people of 'being true to oneself' on a behavioural level. Some authors hypothesised that this finding is linked to preference for honesty over conformity ascribed to autistic people (Cage et al., 2016). This kind of generalisation will obviously not apply to all autistic people, but I am adding this note as an additional layer of nuance for the dilemma at hand.

interactions between cognitive and emotional dynamics, and environmental influences (Hens, 2022). In other words, one cannot easily claim that a child has become less autistic merely because it has been taught to wave to say hi in a neurotypical-dominated social situation. This can just be a deliberate (and therefore desirable) strategy that helps to get through such situations and move on, being as autistic as before. Obviously, dilemmas like this require further exploration, but this modest addition might help find ways around it.

What this example also shows is that a neurodiversity-affirmative approach to early autism care is not necessarily a conflict-free affair. Tensions will probably remain because of the quantitative minority/majority dynamic playing its role, putting pressure on autistic people to blend into neurotypical contexts. Also, parent-child relations are inherently challenged by tensions and divergent interests, irrespective of the neurotypes involved. In that sense, it is perhaps not problematic per se that there are ongoing tensions that need to be worked through, or accepted, as those are inherent to parenting and growing up.

To move forward on reconceptualising early autism interventions in neurodiversity-affirmative ways, future research is needed to address questions such as the following ones. What are autistics-endorsed intervention priorities for infants and toddlers? What are practically useful outcome measures that capture such priorities well? How can interventions pay attention to addressing existing, experienced problems associated with autism, *and* be affirmative as well in the literal sense of the word? Emerging evidence points to the beneficial impact of affirmative autism attitudes on mental health among autistic people. Therefore, we should investigate, for example, how interventions can promote personal and collective self-esteem, and autistic pride (Chapman & Botha, 2022; Cooper et al., 2017).

Here, I conclude the first guiding element ‘careful concepts’. As I have underscored several times, reconceptualising autism diagnosis and intervention in neurodiversity-affirmative ways will require including first-hand experiences

of autistic people as genuine sources of knowledge. The next section on 'careful expertise' explores this in more detail.

Careful expertise

The second main element I see for neurodiversity-affirmative early autism care is 'careful expertise'. Traditionally, mostly non-autistic professionals have been the experts *par excellence* in the autism field, both in research and clinical practice. Expertise here is grounded in academic training and clinical or research experience. Despite possible personal experiences with autism, the expertise held by these professionals is mainly grounded in outsiders' knowledge: non-autistic people studying the characteristics of autistic people to determine what is best for them (Pellicano & den Houting, 2022). In such positivist approaches to knowledge production, people with first-hand experiences of the phenomenon under study have long been considered 'too close' and 'too personally involved' in the phenomena under study (Rehman & Alharthi, 2016). Acclaimed deficits in central coherence, mindblindness and reading one's own emotions would make autistic people particularly uncredible sources of information about their own lives (Botha, 2021b). Meanwhile, it has been pointed out forcefully that such exclusions from academic knowledge production not only constitute an epistemic injustice but also thwart opportunities to generate better quality knowledge[48] (Fricker, 2007; Friesen et al., 2021; Hens et al., 2019).

[48] There are different lines of argumentation to support this claim, such as feminist social epistemology ones (Harding, 2015). I was helped by critical realists' take on judging the quality of objective knowledge (Botha, 2021b; Kourti, 2021). For critical realists, 'objectivity' refers to how well knowledge approximates reality. Striving for objectivity is understood as a process-related attitude which is reflected in the scientific endeavour to bring our perception of an object under study as close to that object as possible. Lived experiences are one such layer of knowing reality, which is why these are indispensable to reach good quality knowledge. Also, for critical realists, objectivity does not have to do with neutrality, as is the case for positivists. Certain knowledge can be at the same time more objective and less (politically and ethically) neutral. For example, when autistic people report on the desirable dimensions of stimming behaviours, then this would be a piece of knowledge that helps reaching a more objective understanding of autistic features, but it clearly also holds ethical and political value, in the sense that it might reorient the focus of autism interventions.

In response, participatory research practices have found their way into the autism field over the past few years, both internationally and in the Flemish context (Academic Collaborative Centre for Autism, 2022; Fletcher-Watson et al., 2019). Participatory research comes in various colours and shapes, but the shared ambition is to meaningfully involve autistic people in autism research. This involvement can range from participation in determining research priorities and research questions, over designing and conducting studies, to interpreting and disseminating findings (Nicolaidis et al., 2019). Importantly, the assumed distinction between non-autistic researchers and autistic participants is ever more fading, as autistic scholars, autistic consultants and autistic self-advocates are claiming their space in the academic context (Bertilsdotter Rosqvist et al., 2019). This ongoing evolution to complement outsiders' with insiders' knowledge is definitely something that is supported by autistic self-advocacy groups (Pukki et al., 2022). Specifically for early autism care, more participatory research work is needed to improve insights on healthy autistic developmental pathways, on the phenomenology of autism as a fundament for a depathologised conceptualisation of autism, and on the preferences and priorities for clinical support in early life.

However, as this evolution towards participatory research involves a redistribution of power, additional questions and risks arise concerning these new 'politics of lived experiences' (Voronka, 2016). People may live through similar experiences, but make sense of them differently, and form different opinions based on this sense-making. Jijian Voronka points this out as follows: '*Some of us as "experts by experience" want more of the same; some of us want to transform systems; some of us want to tear them down. Lived experience in and of itself does not dictate our approach to the topic at hand'* (ibid, p. 198). 'Having lived experiences' does not generate a homogeneous bloc of people that can easily be represented. Therefore, future participatory autism research has to reflect on whose experiences will be taken into account and on how to engage meaningfully with the internal diversity of contrasting experiences, sense-making and opinions on the spectrum. Particular attention is needed here

regarding autistic people facing multiple systems of oppression at once, such as queer autistics, autistic people of colour, but also non-verbal and intellectually disabled autistic people (Botha & Gillespie-Lynch, 2022). Neurodiversity criticists often point to the movement's flawed inclusion of and relevance for multiply disabled autistics. This line of criticism gave rise to (contested) new terminology such as 'profound autism' (Lord et al., 2022) and to calls to revive the dominance of parents and parental organisations in care and research priority-setting (A. Singer, 2022). Among others, Sue Fletcher-Watson replied forcefully to these critiques by underscoring the importance of embracing autistic expertise *'there is so much to be learned from autistic people who can describe their inner experiences, and thereby help the rest of us better understand those who are less eloquent'* (Fletcher-Watson, 2023). But also, rather than trying to split the autism spectrum in those who can and those who cannot easily express their opinions and preferences, researchers and clinicians should increase their efforts to come up with creative methodologies to engage with all autistic experiences[49].

Experience-based expertise

For the Flemish context, we hope to see findings from participatory autism research incorporated into clinical practice, as this is hardly the case yet. Yet, we could also imagine that knowledge based on lived autistic experiences finds a more direct place in clinical practice. Instead of only being viewed as 'the cared for', the time is ripe to consider autistic people also as carers themselves as well. First of all, it is important to acknowledge here that autistic clinicians, autistic community organisers and autistic parents are already doing care work (Moore et al., 2020). Inspiring examples from abroad are advocacy and peer-support groups for neurodivergent clinicians such as Autistic Doctors International (2019) and the Association of Neurodivergent Therapists (2021). My suggestion is, however, to think about how autistic people and the knowledge their

[49] For an inspiring example of effective post-qualitative research with a minimally verbal, intellectually disabled young woman, see (Van Goidsenhoven & De Schauwer, 2020)

experiences contribute to, can be implemented more structurally in Flemish clinical practice as expertise-by-experience.

Expertise-by-experience in healthcare contexts refers to knowledge and expertise that flows from individual experiences of illness, disability, and receiving care, and that is mobilised for emancipatory purposes for other ill or disabled people and their relatives. Under most definitions in this context, experiences can only lead to knowledge and expertise when they have been processed and reflected upon in conversation with others in comparable but unidentical positions, and after some amount of skills training, e.g., learning to listen, reflect, and communicate, in clinical contexts (Draeck et al., 2018). As such, there is a continuum between having lived through certain experiences and holding expertise to mobilise experience-based knowledge in clinical contexts for emancipatory purposes.

In various domains of healthcare in general and mental healthcare in particular, experts-by-experience already play a role. In clinical autism practice, at least in Flanders, this is still rare. Arguably, the same dynamics are at play here as in autism research: for a long time, autistic people have been conceived in terms of deficits, for example in theory of mind abilities. Most notably here, autistic people have been claimed to lack (sufficient) empathy, a skill generally considered key to clinical practitioners. This might explain why the clinical autism field, at least in our region, is still dominantly occupied by non-autistic practitioners and why autistic clinicians face difficulties to disclose their own diagnosis and identity. Yet, if we think along the lines of *the double empathy problem*, we reach a conclusion that contrasts this current state of affairs.

> *The initial conceptualising of the double empathy problem was critical of theory of mind accounts of autism and suggested that the success of an interaction partly depended on two people sharing similar experiences of ways of being in the world. (…) In simple terms, the 'double empathy problem' refers to a breakdown in mutual understanding (that can happen between any two people) and hence a*

> *problem for both parties to contend with, yet more likely to occur when people of very differing dispositions attempt to interact. (…) This is not to say that autistic people will automatically be able to connect and feel empathy with other autistic people they meet any more than two random non-autistic people would; however, there is greater potential for such, at least in how being autistic (or not) shapes experiences of the social world.* (Milton et al., 2022, p. 1901)

On this account, engaging autistic experts-by-experience in clinical care holds the potential to increase understanding between caregivers and autistic care users. Of course, it is an empirical question whether autistic care users would indeed appreciate consulting autistic caregivers. Yet, previous social psychology research inspired by the double empathy problem has provided some evidence that within-neurotype communication offers benefits over cross-neurotype communication (Milton et al., 2022). Beyond mere communicative aspects, this innovation could also help provide the recognition for experienced difficulties and differences that many autistic people and their relatives seek in clinical encounters. Moreover, representation also matters here. Positive or neutral autistic representation is still scarce in the public domain. Seeing autistic people occupying a function as a clinical caregiver might inspire parents and autistic children, adolescents, and adults to reconsider their views on autism. Clinical practitioners as well might change their perspective once autistic people are no longer only clients or patients, but also colleagues and fellow experts[50].

In direct interaction with care users, I imagine autistic experts-by-experience running their consultations within a clinical centre, (co-) facilitating group-based psychoeducation sessions, and participating in care coordination meetings where parents, practitioners, teachers and other caregivers discuss and decide on the care trajectory of an autistic child. More behind the scenes, autistic

[50] Following the structural participation of autistic self-advocates in our Leuven Autism Research consortium, we have witnessed a positive change in how fellow researchers think, talk and write about autism and autistic people. A similar dynamic could, arguably, take place in clinical teams.

experts-by-experience could also be full members of clinical team discussions where clinical cases and the centre's policies are discussed.

Successfully embedding experts-by-experience in clinical autism practices will inevitably require some experimentation before arriving at fruitful constellations. Yet, now already, we can reflect on a few potential pitfalls. I think of issues of representation and accessibility.

As touched upon above, 'having lived experiences' does not generate a homogeneous bloc of autistic people (Voronka, 2016) and this generates a first pitfall. Hence, just as in autism research, reflection is needed on how to translate the diversity of experiences and opinions among autistic people into concrete clinical practices. It might already be helpful if a sufficiently large and diverse group of autistic people could take up roles as experience-experts. But even then, transcending one's own experiences and opinions will still be required. This is where (ongoing) education is useful. Of course, increasing the numbers of (outed) autistic psychiatrists, psychologists, and therapists would be valuable (Moore et al., 2020), yet much potential also lies in shorter, lower-threshold training, followed up by intervision sessions, for autistic people without a professional background in mental health care. Beyond teaching practical skills, such training and intervision sessions can be places for exchange of candidates' personal experiences, and places where other, external experience stories can be read, listened to, and reflected upon. As mentioned, such training and intervision might help to make the shift from individual, anecdotical stories to actual expertise, recognising the internal diversity on the autism spectrum[51].

A second potential pitfall to be mitigated is the accessibility of clinical spaces for autistic caregivers. Here, I think of accessibility in material ways, but also in terms of organisational culture and interpersonal attitudes (Draeck et al., 2018). I focus on the latter here. As said, complementing professional knowledge

[51] Vigilance will be required to make sure such training programmes do not turn into gatekeeping structures that exclude certain sets of experiences because of atypical learning and interaction styles of the candidate. Designing such programmes will thus already require a neurodiversity-affirmative approach.

with knowledge based on lived experiences involves an aspect of redistributing power and admitting that current knowledge has its value, but also its limitations. Therefore, an attitude of *epistemic humility* on the part of current non-autistic practitioners might help greatly in making clinical spaces accessible and comfortable for autistic experience-experts (Van Goidsenhoven & Vanaken, 2021). As described by Anita Ho, epistemic humility is

> *a disposition as well as a commitment. It arises out of professionals' acknowledgment of the boundary of their expert domain as well as their fallibility. It means a commitment to make realistic assessment of what one knows and does not know, and to restrict one's confidence and claims to knowledge only to what one actually knows about his/her specialized domain. In particular, it is a recognition that knowledge creation is an interdependent and collaborative activity'* (Ho, 2011, p. 117).

Clearly, this guiding element of careful expertise does not demand throwing existing professional expertise out the window. Instead, it is a call to consider the value and limitations of professional expertise carefully and humbly and to make space for complementary expertise grounded in lived experiences.

Careful politics

Here we arrive at the third and last guiding element I propose for neurodiversity-affirmative autism care: engaging in careful political work throughout our caring practices. As discussed extensively before, adopting a neurodiversity perspective on autism implies adopting a political position. However, as clinical practitioners, researchers, parents, and care users we do not see ourselves easily as political actors. Nevertheless, there is extensive literature on the political dimensions of the activities we carry out in these roles: caring and parenting are political all the way down (Piepzna-Samarasinha, 2018; Ramaekers & Suissa, 2012; Tronto, 1993). Therefore it might seem I am introducing a false distinction between the neurodiversity's call for *socio-political* change, versus the

predominantly *individual* interactions that characterise clinical care. Yet, stressing the political dimensions of care in this specific context matters to me for two reasons. First, this specification will help to buffer against a potential depoliticisation of the neurodiversity-affirmative approach I argue for. As we have seen before, some authors are eager to write about neurodiversity without actually committing to the paradigm's political nature (e.g. Baron-Cohen, 2017; M. C. Lai et al., 2020; Lord et al., 2022). This is something I want to avoid. Second, this specification offers yet another opportunity to underscore that being explicit about values in research and practice does not undermine the quality of our work, but rather the contrary (Arnaud & Gagné-Julien, 2023).

The neurodiversity movement works towards social justice for and emancipation of autistic people. In Chapter 6, I tried to concretise these overarching aims and apply them to clinical settings. Based on an understanding of autistic needs as both universal and situational vulnerabilities, I argued that clinical researchers and practitioners have obligations to act in *solidaristic* and *empowering* ways vis-à-vis autistic care users and their relatives. In my view, this is how clinical actors can also take up part of the shared responsibility to be political actors in the struggle for social change.

Two examples might clarify this. First, we can think back on the suggestion to design parenting support interventions that engage with rather than work against autistic developmental pathways. To me, offering this kind of service to parents of autistic children is not a *special* service or an exceptional *accommodation*. In our current Western societies, parents are flooded with formal and informal advice on how to raise their (neurotypical) children (Ramaekers & Suissa, 2012). Therefore, providing neurodiversity-affirmative parenting support is a matter of solidarity. It acknowledges and affirms that all parents can use a helping hand when raising children, irrespective of the developmental routes they take.

Second, the suggestion to make space for autistic experts-by-experience as clinical caregivers exemplifies how responding to the obligation to empower

could take shape. Empowerment in healthcare settings is best seen as both an outcome and a process (Chiapperino & Tengland, 2015). Empowerment as an outcome refers to having (more) control over the determinants of one's quality of life. As a process, empowerment implies creating professional relations where both individual care users and autistic communities take (more) control over the change process, determining both the goals and means of this process. This second, processual aspect of empowerment is put into practice, for example, when autistic experts-by-experience would become part of clinical teams, co-deciding on and participating in delivering appropriate care to autistic people and their relatives.

Being explicit about the political values we commit to and the ethical obligations we respond to, probably means going out of our comfort zones as clinical researchers and practitioners. However, I think the pressure from neurodiversity proponents to be explicit about such values should be welcomed. No matter what we do, clinical research and practice are value-laden, even when we consider them to be neutral. Making such 'invisible politics' visible is therefore one of the key contributions of the neurodiversity movement so far (Arnaud & Gagné-Julien, 2023). Moreover, being open about the values and aims of research and practice also provides transparency towards research participants and care users. Such transparency is important, to give those who want, the opportunity to disagree in turn.

Also here, for this last suggestion on political positioning, I believe carefulness is key. Caring practices can be political spaces where concepts and power relations are contested. At the same time, caring spaces should always be inclusive practices where people can ask for help and support, irrespective of their ideological convictions. When reforming early clinical autism care, we should be vigilant not to exclude care users who think in non-neurodiversity-affirmative ways or who might be initially opposed to or in doubt about such approaches. At the same time, if we are serious about changing practices from the inside out, we cannot simply set aside our conceptual, epistemic, and political

commitments because those asking for clinical help do not agree. What is needed instead, is a careful approach that differentiates between care users' readiness to think differently about autism and to adapt the pacing of neurodiversity-affirmative support practices accordingly.

Conclusion

Oftentimes, ethical analyses examine what *is.* This is something I could have done as well on the topic of early autism detection and intervention. I could have looked into specific early autism care practices, pointed out specific ethical issues, and formulated advice for amelioration (MacDuffie et al., 2021; Schuck et al., 2022). Rather than taking such a backwards-looking approach in this final chapter, I opted to turn the gaze forward. Instead of normatively analysing *what is*, I built on the findings of my previous studies to engage in a 'speculative ethics', imagining *what could be* (Puig de la Bellacasa, 2017). Or to return to Alison Kafer's vocabulary, I tried contributing to crip futures, futures where autistic people are no longer marginalised, normalised or even deliberately brushed away, but actually welcomed and desired (Kafer, 2013).

In the spirit of reparative reading, I used this final chapter, to explore where autistic people, their relatives, researchers, and practitioners can find common ground and work together, without assuming this will happen in an entirely conflict-free way.

My overall take is that early autism care should not be abandoned, but reformed. I positioned early autism care practices as productive spaces for social change. By actively engaging in such care practices, I see the potential for the different actors involved to coalesce around the aim of ameliorating early autism research and practice from the inside out.

Also, I pointed out that whenever we talk about ameliorating the state of affairs, whenever we think about how to get closer to good and just early autism care, we have to engage, inevitably, with questions that extend beyond ethics in

its strict sense. Ethical questions, analyses and recommendations are fundamentally entangled with questions of how we understand the phenomena under study, how knowledge about these phenomena is produced, and which (political) values we commit to. Based on this 'entangled ethics', I proposed three guiding elements for a neurodiversity-affirmative approach to (early) autism care: careful concepts, careful expertise and careful politics. As will have become clear by now, the choice for 'careful' as an adjective was not a coincidental one. Reconceptualising autism diagnosis and intervention, diversifying expertise, and politically committing to the emancipation of autistic people are part of our caring practices. This is one way to refer to them as 'careful': these actions are full of care, and they contribute to good and just care. But 'careful' also refers to prudence. And despite my determination to move forward in the suggested direction, I am also convinced that we should move in gentle, careful ways as pointed out in the previous sections.

Reforming current early autism care practices into neurodiversity-affirmative ones will be a large amount of work. It requires the commitment of many people and thinking and writing about changing care practices are only the first steps of the struggle. Actually putting the suggestions that emerged from this piece of research to practice, and working through remaining and new obstacles: that is where the actual change happens; and my colleagues and I are eager to be part of it. In the Epilogue hereafter, I will give some insights into our future research plans which aim to contribute to neurodiversity-affirmative early autism care.

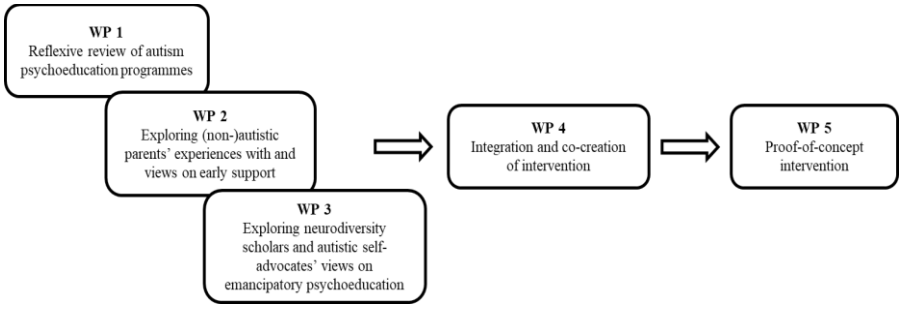
Epilogue

the EPANEMA project

This dissertation has arrived at its final pages, but the work to imagine and shape good and just early autism care is obviously not over yet. For my colleagues and me, this future work to contribute to neurodiversity-affirmative ways of designing care practices has already started under the banner of the EPANEMA project. This project aims to Empower Parents of Autistic children through Neurodiversity-affirmative psychoEducation[52]. PhD candidate Lies Van Den Plas, my current supervisory team and myself, will co-create and test a group-based, multi-session psychoeducation programme for parents of recently diagnosed, young autistic children. Both in developing and delivering this programme, we will collaborate closely with autism and autistic communities in Flanders, and neurodiversity proponents from across the globe. As indicated in Figure 1, the project will consist of five work packages (WP). The qualitative work of WP 1-3 will provide input to design the workshop series collaboratively with different involved actors in WP 4 before running a proof-of-concept intervention study in WP 5.

[52] Readers might wonder what the 'M' and 'A' refer to in the EPANEMA-acronym. The only role of these last two letters is turning the acronym into a well sounding on. The benevolent reader might recognise the hint at Rio De Janeiro's Ipanema beach, paying a little tribute to Paolo Freire's Brazilian origins.

Figure 1: Work packages EPANEMA project



I am sharing the outline of this new project here as I see it as an attempt at putting the three guiding elements of a neurodiversity-affirmative approach to early autism care into practice.

First, we aim to develop a 'carefully conceptualised' intervention. Instead of targeting the child's individual characteristics directly, we hope to contribute to pedagogical climates where a more nuanced understanding of autism reigns, in line with neurodiversity perspectives on autism and in line with the reported priority of autistic people to focus interventions on making their direct environments more understanding and accessible[53].

Second, we will put the suggestion of 'careful expertise' into practice. Research-wise, we will pursue this ambition by exploring lived experiences of both autistic and non-autistic parents (WP 2), by documenting the standpoints of neurodiversity proponents and autistic self-advocates (WP 3), and by organising co-creation groups designing the actual psychoeducation programme (WP 4). More innovatively, our project will also contribute to rebalancing power injustices in clinical autism knowledge production and distribution. In the first months of her doctoral research, my colleague Lies Van Den Plas already

[53] The abovementioned paper by Schuck et al. (2022) only sorted after we wrote the EPANEMA project proposal, but one of their suggested innovations ties in neatly with our plans. *'Provide psychoeducation related to neurodiversity to parents (in collaboration with Autistic consultants/employees) as early as the first diagnostic feedback session'.* This suggestion strengthens our conviction that our work will fit well into a neurodiversity-affirmative approach to early autism care.

documented how the most commonly used psychoeducation programmes in Flanders are largely written from non-autistic, outsider perspectives. In the EPANEMA programme, we aim to do things differently. Content-wise, sessions will be inspired by lived autistic experiences and (applied) theoretical work by autistic scholars. This will involve applied and accessible discussions of 'neurodiversity' and 'the neurodiversity paradigm'. Introductions to 'the double empathy problem' (Milton, 2012), 'neuronormativity' (Radulski, 2022), 'minority stress theory' (Botha & Gillespie-Lynch, 2022), and 'camouflaging' (Cook et al., 2021) could find their place as well. Structure-wise, the psychoeducation workshops will be co-delivered by autistic people. So here as well, we aim to contribute to rebalancing power relations by making space for autistic people not just as care users and as objects of expertise, but also as carers and experts themselves.

Finally, also the third guiding element for neurodiversity-affirmative care can be found in EPANEMA: careful political engagements. Clearly, one of the goals of this group-based, emancipatory programme is to raise critical consciousness on autism in parents of newly diagnosed young children. This way of looking at education as a tool for emancipation is inspired by critical pedagogy approaches. Here, education is not just seen as transferring knowledge in one direction, from the teacher to the student, or from the expert to the layperson. Critical pedagogists see empowering education as 'producing social change through mutual deliberation and critical thinking about the shared situationality of individuals' (Chiapperino & Tengland, 2015). This aspect of mutuality and shared situationality explains why we believe it is important to do this type of psychoeducation in a group, rather than individually.

The project and the final programme have political dimensions, yet, we aim to act politically in a careful way. For me, this means we avoid *imposing* new ideas on parents. Rather, we will offer new frames of reference within back-and-forth conversations with parents, adjusted to their pace. Here, will have to take into account that some parents will be more open to neurodiversity-

affirmative views than others. For some parents, some time will also need to pass before they can engage in this kind of programme. To me, good and just early autism care is determined to take parents on board in these neurodiversity-affirmative views on autism, but good care is also respectful towards the difficult positions parents occupy here.

I admit this project will not be a panacea. Obviously, it will not resolve all tensions in the debate on early autism care. We hope the EPANEMA project might serve as one step among many in extending the neurodiversity paradigm to the clinic and bringing us closer to *good and just* early autism care. Affirming neurodiversity in clinical practices will not be an easy task and much work is still to be done to translate the many entangled layers of the neurodiversity paradigm to clinical practice. Yet, with this project, my colleagues and I are ready to roll up our sleeves and contribute to *cripping* early clinical autism practices, read them against the grain, and turn them, step-by-step, into neurodiversity-affirming ones.

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Obtaining a PhD degree is often seen as a milestone on the trajectory to becoming an *independent* researcher. At the very same time, this dissertation has been packed with references to the unavoidable *dependencies* that characterise human life. If there is one thing I learned, it is that academics clearly do not escape this web of dependencies. We are dependent on funders, on collaborators, on students, on consultants and participants, and on colleagues in cleaning, logistics and administration. Moreover, we rely on a cultural and political climate that allows academia to be both a safe and brave space where socially relevant research questions can be explored freely. I am immensely grateful that I have been privileged to be part of this web of dependencies, which allowed me to do my work in the first place and that supported me to grow as an academic.

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