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All is not well: value codestruction and consumer illbeing in service systems

Johanna Katariina Gummerus
Department of Marketing, CERS, Hanken School of Economics, Helsinki, Finland

Deirdre Mary O'Loughlin
Department of Management and Marketing, University of Limerick, Limerick, Ireland

Carol Kelleher
Department of Management and Marketing, University College Cork, Cork, Ireland, and

Catharina von Koskull
Department of Marketing, University of Vaasa, Vaasa, Finland

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Abstract

Purpose – Following an interpretivist approach, the authors draw on semi-structured interviews with parents of children with autism spectrum disorder (ASD).

Design/methodology/approach – Responding to limited academic advancement, particularly in the context of consumers experiencing vulnerability, the aim is to deepen marketing scholars' understanding of value co-destruction (VCD) and its under-explored relationship with consumer ill-being.

Findings – Three forms of systemic VCD mechanisms emerged: obscuring, gaslighting and siloing. Ill-being comprised material, physical, psychological and social harms, which consumers experienced individually, relationally and collectively due to VCD. Family members' experiences of ill-being and vulnerability were deepened by service systems' inability to recognise the individuality of their needs and provide appropriate support.

Research limitations/implications – In line with the interpretivist paradigm, the focus on families of children with ASD, while illuminating, delimits the generalisability of the findings. The authors call for further research on consumer ill-being, VCD and vulnerability in other service and marketing contexts.

Practical implications – The findings highlight the need for service system adaptability to recognise and address unstandardised needs.

Social implications – Several systemic failures of (public) service systems which manifested as VCD mechanisms are identified.

Originality/value – The overall contribution is the development of a contextually driven characterisation of both VCD and ill-being and a deeper understanding of how these are interrelated. First, VCD revealed itself as

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a systemic failure to access, provide or integrate resources to meet actors' needs as manifested by the three mechanisms. Second, the authors characterise ill-being as comprising material, physical, psychological and social harms due to VCD, which are experienced individually, relationally and collectively. Finally, the authors illuminate the nature of vulnerability and delineate the entanglements between vulnerability and ill-being in a collective (e.g. family) context.

Keywords Value co-destruction, Consumer ill-being, Service systems, Vulnerability, Experience

Paper type Research paper

Introduction

Value co-destruction (VCD) has gained increasing academic and empirical attention (e.g. Echeverri and Skålén, 2011, 2021; Goto *et al.*, 2022) as it reveals how firms and other actors on their own or as service systems fail to help consumers. Even with the best of intentions, organisational and market attempts to increase consumer well-being may backfire, or spillover effects may harm consumers or other individuals (Blocker *et al.*, 2022), thereby leading to VCD. VCD is often treated as opposite to value creation: "similarly to how value creation denotes an increase in value, value destruction denotes a decrease in value" (Echeverri and Skålén, 2021 p. 228). Plé and Chumpitaz Cáceres (2010), who originally introduced the concept of VCD to the marketing literature, define it as "an interactional process between service systems that results in a decline in at least one of the systems' well-being (which […] can be individual or organizational)" (p. 431). Based on their recent systematic review of the VCD literature, Lumivalo *et al.* (2023) conclude that "value co-destruction is an alternative and parallel phenomenon to value co-creation occurring within a service encounter" that is subjectively defined (p. 168). However, VCD research lacks depth in comparison to the more developed value co-creation research (Alexander and Vallström, 2023). Moreover, although there is preliminary evidence of the negative consequences of VCD such as consumer defection (Goto *et al.*, 2022), complaining (Smith, 2013) and reduced well-being (Smith, 2013; Winston *et al.*, 2022), research on the topic remains scarce. Hence, further exploration of the nature of VCD and its negative outcomes is warranted (Alexander and Vallström, 2023).

Our aim in this paper is to deepen marketing scholars' understanding of VCD and its under-explored relationship with consumer ill-being. Despite theoretical and empirical advancements of well-being as a concept, there has been limited academic focus on ill-being and its relationship to other marketing phenomena, such as VCD. Within the marketing domain, well-being is traditionally characterised as an individual level psychological phenomenon defined as a consumer's cognitive and affective evaluations of her/his life including life satisfaction and positive emotions, e.g. happiness (Diener *et al.*, 1985; Iyer and Muncy, 2016). By comparison, ill-being, in discourses outside of the marketing domain, is usually associated with negative emotions and may be perceived as inversely proportional to well-being (Ryff and Singer, 2006). Furthermore, there is long-standing debate as to whether ill-being and well-being are inter-related or separate concepts (Headey *et al.*, 1984) and how they should be appropriately conceptualised and empirically investigated (Nunes *et al.*, 2023). As a result, potential linkages between ill-being and VCD remain unexplored, particularly within the marketing discipline. This represents a key motivation for this study.

Informed by Transformative Consumer and Service Research (TCR/TSR) perspectives (e.g. Anderson and Ostrom, 2015; Anderson *et al.*, 2013; Mick, 2006), our study is empirically contextualised in a setting where consumers are likely to experience vulnerability (Baker *et al.*, 2005; Hamilton *et al.*, 2015) due to their inability to identify and access resources in the systems in which they are embedded, which impact wellbeing. Acknowledging recent research underlining the importance of appropriate language in the field of consumer vulnerability

(Russell-Bennett *et al.*, 2024), we recognise the circumstances or situation of the person reflected by our use of the concept of *experiencing vulnerability* as opposed to employing the potentially harmful label of *vulnerable consumers*. Reflecting its complexity, consumer vulnerability is a multidimensional state, linked to a physical, cognitive or behavioural impairment (Pavia and Mason, 2014). Whereas vulnerability originally stems from "the interaction of personal states, personal characteristics, and external conditions" (Baker *et al.*, 2005, p. 134), one's status in a (service) system may alleviate or exacerbate the experienced vulnerability that is deeply rooted in the "powerlessness that arises from an imbalance in marketplace interactions" (Baker *et al.*, 2005, p. 134). Consumers' limited access to and control over resources "in ways that significantly inhibit their ability to function in the marketplace" (Hill and Sharma, 2020, p. 551) may have implications for their well-being (Visconti, 2016). While recent research has spotlighted the negative implications of resource misintegration for consumers experiencing vulnerability (e.g. O'Loughlin *et al.*, 2024; Kelleher *et al.*, 2020), a specific focus on consumer ill-being remains absent, and further research on the collective impacts of transformative service have been called for (Boenigk *et al.*, 2021).

Responding to this lack of academic scrutiny, our empirical study explores VCD as experienced by families with children who have autism spectrum disorder (ASD) and who may experience vulnerability (O'Loughlin *et al.*, 2024). ASD is a neurodevelopmental disorder that entails atypical social communication, repetitive behaviour and restricted interests (Hus and Segal, 2021). We explore family experiences by interviewing parents who interact with multiple health and public services, including education and social care systems. These services represent complex people-centred service systems (Breidbach *et al.*, 2016), where multiple actors with ongoing complex resource requirements interact over extended periods of time. For families with children who have ASD requiring ongoing resource and services, our findings reveal that consumer vulnerability is experienced both through the challenges of ASD as a lifelong condition and the experiences of lacking support from service systems.

Our study makes three important contributions to marketing scholarship. First, we identify and delineate a typology of three VCD mechanisms (*obscuring, gaslighting and siloing)*, which negatively impact multiple actors in service systems. Second, we characterise ill-being as comprising material, physical, psychological and social harms due to VCD, which are experienced individually, relationally and collectively. Third, we illuminate the nature of vulnerability and delineate the entanglements between experiences of vulnerability and ill-being in a collective (family) context.

Our paper is structured as follows: First, we discuss VCD as a systemic phenomenon, after which we consider its interconnections with ill-being. Next, we outline our interpretivist empirical study and present the findings. We conclude with a discussion of our theoretical contributions and the implications for service systems.

Value co-destruction: towards a systemic phenomenon

VCD as a concept was developed by Plé and Chumpitaz Cáceres (2010) to reflect consumers' negative co-creation experiences of interactions between firms and customers that was attributed to (service) systems "acting in an inappropriate or unexpected manner" (p. 430). The concept has its roots in Prahalad and Ramaswamy (2004) notions of markets as "value co-creation space" (p. 11), which portrayed consumers as active co-creators of value and their experiences as subjectively constructed. Because value co-creation requires resource integration (Peters, 2016), logically, then, failures in resource integration may lead to co-destruction. Smith (2013) proposes that VCD represents "a failure of the resource integration process to co-create expected value" (p. 1889).

Several other studies on VCD highlight the role of resource misintegration and resource non-availability (Echeverri and Skålén, 2021; Farquhar and Robson, 2017; Winston *et al.*, 2022). Studies identify resource absence, blocked access, resource deficiency, misuse (Vafeas *et al.*, 2016; Cui and Osborne, 2022) or obscurity (O'Loughlin *et al.*, 2024) as leading to resource integration failure. In a family context, Bruce *et al.* (2019) define VCD as diminished well-being/feeling worse off and acknowledge the detrimental effects when consumers must share resources, act on their own or collectively or lack agency. The authors further demonstrate that the "integrable quality" of resources, i.e. "the extent to which resources possess the characteristics necessary to support the (consumers') resource integration activity" (p. 180), may, when low, lead to VCD.

Beyond resource access or use-related causes of VCD, additional studies highlight how and where actors do not understand, are incapable of or disagree on how best to integrate resources (Laud *et al.*, 2019). Prior and Marcos-Cuevas (2016) propose that VCD entails general goal prevention and/or net deficits that derive from the lack of complementarity between actors' goals. Others highlight power asymmetries between service providers and consumers in public service systems coupled with failing to learn and engage in dialogue (Keeling *et al.*, 2021), as well as misaligned behaviours/practices between actors (Cui and Osborne, 2022). In addition, Engen *et al.* (2021) identify bureaucratic incompetence, mistakes and lack of transparency, leading to co-destruction in public service settings. Acknowledging the collective side of VCD, Quach and Thaichon (2017) link VCD to consumer interactions and conversations with multiple parties, extending beyond the brand to staff, other customers and the wider network of users and communities.

Recent research increasingly addresses the systemic nature of VCD and its wider impact. In their study investigating payday loan service interactions, Apostolidis *et al.* (2023) identify the negative well-being impacts of stigma on users. Their research not only highlights the direct impact on service users but also the indirect effects on others, such as family and friends, within wider social systems. Similarly, research on business relationships (Cabbidu *et al.*, 2019) has revealed that VCD diminishes social and relational value. Within a family context however, while there is acknowledgement that individual members influence each other, the perspective of the family "as extended customer entity" (Sandberg *et al.*, 2022) has been insufficiently studied. Some recent research has revealed how family members experience and accommodate negative outcomes for themselves in favour of other family members (Kelleher *et al.*, 2020). Against this backdrop, exploring VCD and its outcomes in a collective (e.g. family) setting is of interest and particularly within the context of families caring for children with additional needs such as ASD, where VCD may impact more severely on their experiences of vulnerability and ill-being. We discuss next well-being and ill-being as consumer outcomes.

Value co-destruction outcomes: well-being and ill-being

The seminal study by Plé and Chumpitaz Cáceres (2010) clearly links VCD with a decline in well-being, where well-being is restricted to a "*firm's* competitive well-being […][which] limits its capacity to adapt to its competitive environment" (p. 433). However, the potential impact of VCD on the well-being of individual and/or multiple actors, including consumers, was neither considered nor addressed. Due to VCD, consumers often experience adverse outcomes, which include negative emotions (e.g. anger, anxiety), negative behaviour (e.g. negative word of mouth, complaining) (Pera *et al.*, 2021; Sthapit *et al.*, 2023), resource loss (Smith, 2013) and an overall decline in well-being (Järvi *et al.*, 2018). Much of this research has centred on individual level impacts and negative outcomes (Diener *et al.*, 1985; Iyer and Muncy, 2016; Sweeney *et al.*, 2018) and there is limited understanding of collective or

relational impacts beyond individual levels. Acknowledging the consequences of VCD in terms of its outcomes, we next discuss perspectives on well-being and ill-being respectively.

Well-being

Conceptual and empirical understandings of well-being have emerged across multiple disciplines, including psychology (e.g. Dodge *et al.*, 2012; Diener *et al.*, 1985), sociology (e.g. Nomaguchi and Milkei, 2020), healthcare (e.g. Keating *et al.*, 2021), consumer behaviour and marketing (e.g. Iyer and Muncy, 2016; Abboud *et al.*, 2023; Apostolidis *et al.*, 2023) and human resource management (e.g. Nunes *et al.*, 2023). Psychologically, well-being has been related to eudaimonic well-being (purposeful life engagement) and hedonic well-being (positive affective states) (Ryff *et al.*, 2006). More recently, Abboud *et al.* (2023) identified direct links between power asymmetry and well-being, where low customer power directly affects customer engagement and negatively impacts customer well-being.

Other scholars consider that well-being: Arises from what a person has (the material), what they can do through their relationships with others (the relational) and how they feel and evaluate what they have and can do (the subjective) (Keating *et al.*, 2021, p. 613).

This underscores the link between resources and well-being. From a resource-based perspective, a sufficient supply of resources and an absence of exhaustion are key determinants of human well-being (Abbas *et al.*, 2022). Indeed, Dodge *et al.* (2012) define well-being as "the balance point between an individual's resource pool and the challenges faced" (p. 230). Thus, well-being involves a dynamic process where the individual seeks an equilibrium in relation to resource availability and supply in terms of their needs or desired value in use.

Ill-being

While wellbeing has been the subject of deep academic attention, particularly in sociological and psychological spheres, relatively scant attention has been given to the study of ill-being. Nunes *et al.* (2023) recent systematic review of well-being and ill-being highlights the importance of focusing on ill-being, as a counterpoint to well-being, across different disciplines. Their review of ill-being highlights the long-standing debate within psychological (e.g. Bradburn and Caplovitz, 1965) and sociological fields (e.g. Headey *et al.*, 1984) as to whether well-being and ill-being are separate concepts. While specific distinctions are highlighted between well-being (which some claim is influenced by psychological strengths-based perspectives) and ill-being (which is associated with vulnerabilities), both are interrelated (Huta and Hawley, 2008). Moreover, psychology scholars, such as Ryff *et al.* (2006), propose that ill-being not only refers to the absence of well-being, but also includes negative emotional impacts such as depression, anxiety and anger. While some approaches and theoretical frameworks have been developed to deepen the understanding about the determinants of and differentiators between well-being and ill-being, empirical investigation remains limited (Nunes *et al.*, 2023).

Focusing on service research and marketing scholarship more generally, negative well-being has been tacitly proposed to characterise adverse outcomes akin to ill-being (e.g. Apostolidis *et al.*, 2023). Within consumer behaviour, while ill-being is rarely explicitly defined, Ekici *et al.* (2018) explore shopping behaviours and identify ill-being as "perceptions that one spends too much time, effort, and money in shopping activities as reflected by complaints from family members, friends, and co-workers" (p. 337). They propose that one type of excessive behaviour (i.e. investing too much time, money or energy in excessive shopping) takes place at the expense of other areas of life, such as family, work,

social, leisure or finances (Ekici *et al.*, 2018). Thus, they see ill-being as holistic and socially embedded, directly impacting life balance and goal attainment. Such perspectives seem to align with those of Kelleher *et al.* (2020), who viewed value creation as relational, and showed how it may lead to negative outcomes (emotional loss, physical deterioration, financial impoverishment and social isolation) for an individual who engages in resource integration for the benefit of another person. Similarly, Sweeney *et al.* (2018) suggest that, while financial planning may lead to positive outcomes, customers may become worse off in terms of monetary resources, time and effort, lifestyle or emotional costs. However, an explicit discussion of ill-being was absent in both studies.

There has also been scant focus on the experiences of ill-being within families with children with additional needs. Based on their review, Nomaguchi and Milkei (2020) identified stressors relating to parenting of children with complex needs and emotional or behavioural challenges including time burdens, financial costs, social stigma and discrimination, leading to self-blame and isolation. While their study explored the impact on parents' psychological well-being, a specific focus on ill-being was absent. A focus on autism-related research reveals the burden of parenting, where the parents are at a higher risk of depression (Karra *et al.*, 2023) and hopelessness due to children's maladaptive behaviours such as aggression and withdrawal (Enav *et al.*, 2023). While this highlights the links between parents' ill-being and the children's condition (Enav *et al.*, 2023), there is a lack of understanding of the service systems' impact on ill-being.

In summary, ill-being and its relationship with other marketing phenomena such as VCD have received scant attention in previous marketing scholarship. Informed by TSR/TCR perspectives our study aims to address this research lacuna. We next describe our empirical study.

Methodology

Our empirical study aimed to deepen insight into the nature of VCD and explore its relationship with consumer ill-being. The focus of our study was parents who are also carers of their children with special needs, specifically ASD. ASD is part of neurodevelopmental disorders, with estimations of 1–2% of the population being affected (www.cdc.gov/ncbddd/autism/data.html). Children with ASD often face challenges in social relationships at school and home. Due to a combination of developmental, genetic and environmental risk factors, children with ASD vary significantly in their neural, socio-emotional and cognitive capabilities and symptoms (Wozniak *et al.*, 2017). These concurrent conditions associated with ASD are case specific and affect how early ASD is diagnosed (Hus and Segal, 2021). This may also make identifying appropriate treatment challenging. Parents were chosen because they are responsible for the child's well-being and, acknowledging ethical considerations, are appropriate representatives of their child with ASD.

This study focused on exploring parents' experiences of and reflections on their family's interactions with health, social care and educational actors and institutions who were tasked with supporting the specific complex care and developmental needs of the child and their families. These systems are highly human-centred as they depend on human actors to co-ordinate value cocreation (Breidbach *et al.*, 2016). The empirical research was undertaken in two European countries, Finland and Ireland, which were chosen purposefully: both countries have relatively small populations and strong national NGOs supporting families with ASD. In both countries, families face similar challenges in accessing and securing resources to meet their needs, which are related to both the complexity of the children's conditions and the complexity of the service systems with multiple actors, interactions and

interdependencies (Pinho *et al.*, 2014). Additionally, both research sites afforded the team deep access to ASD representative organisations and their members.

Sample selection and data collection

Following ethical approval, the qualitative study involved 15 in-depth interviews in Ireland and Finland which were conducted between September 2019 and May 2020. Two ASD representative organisations (one in each country) were approached and supported the recruitment of volunteer participants. Additional respondents were identified through snowballing which helped to build trust among participants (Sadler *et al.*, 2010). To reflect the purpose of the study which was to explore experiences of VCD and ill-being, questions were posed relating to participants' experiences of interacting with health service providers and related bodies and agencies as well as the extent to which they felt their child(ren)'s needs were appropriately met. They were also asked to share their perceptions of how they were treated in their interactions with health and other service providers and the impact of these experiences on them individually, on their child with ASD as well as on the other members of the family. A flexible interviewing approach was adopted to enable a natural conversational style, allowing new insights and directions to emerge (Denzin and Lincoln, 2017). All interviews were recorded upon consent, and assurances were given around confidentiality and anonymity. The interviews lasted between 1 h 15 min and 3 h 45 min and the data collection continued until saturation was reached (Saunders *et al.*, 2018). The sample of participants (Appendix) presents a rich variety of research settings, involving a range of conditions, length of care and family care contexts. The families in our study included children, adolescents and young adults (i.e. 18+). For simplicity, we use the term "children" to reflect all three age categories.

Data analysis

Each of the interview recordings was transcribed and the Finnish interviews were translated into English to enable individual and group coding by all authors. Following a hermeneutic approach (e.g. Thompson *et al.*, 1994) analysis and interpretation involved a back-and-forth approach between data and theory (Spiggle, 1994). The analysis firstly focused on participant experiences and challenges in dealing with service providers and service system in respect to their child with ASD and, secondly, how these experiences and challenges impacted the respondents and their families. While the VCD and ill-being literature guided the analytical process, themes emerged primarily from the data in relation to characterising both VCD and ill-being. Initially, the data was categorised in terms of perceptions and challenges of the system including restricted access to resources, poor treatment and various negative outcomes. Next, higher-order codes were abstracted leading to the development of the characteristics of both VCD and ill-being. In the case of VCD, for example, *parental blaming* was identified. Subsequent dimensionalisation (Spiggle, 1994) entailed further analysis of the nature of VCD where *parental blaming* became *Gaslighting*. Original observations regarding *Abandoning*, which related to pushing the consumer away, led through further analysis to it merging with *Siloing*, to reflect families being pushed towards certain (and often inappropriate) service silos. These iterations resulted in the development of a typology of VCD mechanisms comprising *Obscuring, Gaslighting and Siloing.* Following the same data-driven analytical process, ill-being was categorised as individual, relational and collective, with several outcomes which upon further abstraction, developed into *material*, *physical*, *psychological* and *social harms*. The final phase of data analysis, integration (Spiggle, 1994), involved the research team discussing and relating the findings to extant theory. These discussions enhanced collective understanding of parents' experiences, challenges and impacts and facilitated the identification of implications and recommendations. The research team also conducted member checks to

ensure trustworthiness and congruence of the interpretation with participants' experiences. To further facilitate sensemaking, the findings were also shared with the ASD representative organisations. The next section presents the findings.

Findings

To foreground the interrelationships between VCD and ill-being experienced by families with children with ASD, we first outline the ongoing challenges of caring for children with complex needs and the implications for parents and families. Following this, we identify and elaborate a typology of VCD mechanisms, which led to ill-being. We then characterise the multi-faceted nature of ill-being, as well as discuss how it is intertwined with experiences of systemic VCD.

Describing their intertwined roles of parents/carers, participants reflected on their lives within the family, wherein family members were interdependent. Parents highlighted their difficulties in balancing and supporting the needs and well-being of their children with ASD with their own and with those of other family members (e.g. siblings and partner). This was reflected by Siobhan (Irish, son, 10): "Everything we do in our family revolves around, 'Can he cope with this? Can he do this?' And I hate that".

Parents also felt an urge to support their children to achieve some level of independence and to "find his way in the world", as expressed by Essi, in relation to her son who has severe ASD. Until some form of independence is achievable, the extent of care and support required is significant, as reflected through Essi's claim that living with a child with special needs requires being "more of a parent":

> I suppose it's the same for all parents, being a parent does not end, even when the child comes of age, but I think that one must be more of a parent all the time for a child with special needs, so it would be important that he finds his place. And I feel that when he moves out, I will get some time for myself […] It will be a relief if we find a good place [supported living] where he can live. (Essi, Finnish, son 9)

The interdependence between family members was evident from how the eventual change in the child's living arrangements would allow Essi "some time for myself". This example similarly foregrounds the families' critical dependence on service systems to provide care.

The complex ongoing challenges that families highlighted for children with ASD included challenges relating to health, education, social relationships and family, reflecting the many service systems that they interacted with. They also underscore the different forms of VCD that emerge which we focus on next.

Systemic value co-destruction typology

Based on our analysis, we characterise VCD as the systemic failure within service systems to access, provide and/or integrate resources to meet actor needs manifested by VCD mechanisms, namely:

- Obscuring;
- Gaslighting; and
- Siloing.

Parents shared their experiences of VCD primarily through sharing their interactions with various service systems linked to their child's condition and needs. The VCD manifested in expressions such as "it's the system that's putting carers down" (Miriam, Irish, son 10). Parents reported that they failed to receive support from the complex, impenetrable and at

times hostile service systems that regarded them with suspicion. We next outline the systemic VCD mechanisms identified.

Obscuring

Obscuring refers to multiple specialist and professional service system actors failing to recognise and meet the complex resource configuration needs of consumers with ongoing and complex needs in a responsive and coordinated way. In many instances, service providers failed to recognise and accurately diagnose ASD in a timely manner, which hindered service and resource access. This left families isolated and struggling to make sense of children's challenges. This was critical, as without a diagnosis or formal acknowledgement of resource needs, and the related obligations to meet those needs within service systems, such needs remained unaccounted for, unaddressed and unmet.

Several participants recounted an initial minimisation of the children's symptoms by health professionals which, in some instances, led to misdiagnosis. For example, Lucy referred to the "struggle to get him [younger son] into the process" (Lucy, Irish, sons 8 and 5) and the battle with professionals for recognition of her child's condition. Aili lamented that her son's ASD was not diagnosed before he started school, despite his previous challenges in daycare:

> […] all kinds of specializing kindergarten teachers wanted to meet us and we kind of circled around the topic [son's behavioural challenges] […] but they never raised the issue that this child might have a neuropsychiatric disorder […] it does make me a bit angry. (Aili, Finnish, son 10)

Fintan recounted how his son's behavioural issues were initially attributed to his and his partner's parenting approach, although his son finally received the diagnoses of ASD and ADHD several years later:

> It began to show in school, in preschool that was the first signs, he went to throw a chair at his teacher, he was three years old, and we were advised to go see a psychologist […] her diagnosis was, 'the child – nothing wrong with the child, don't give him Coke and get him off the PlayStation'. (Fintan, Irish, son 19)

Similarly, Tess's case reflects a repeated lack of acknowledgment of the parent's concerns and resulting in a missed diagnosis of ASD by numerous health professionals:

> The GP wasn't taking a whole lot of notice. And we went to the public health nurse […] 'Oh we'll call the doctor in, come back in another couple of months' so then more waiting for an appointment with the doctor. We went back in and the doctor sent me away with the kind of thinking: 'oh do you know they're boys, they're fine healthy lads you know'. (Tess, Irish, sons 6)

Such examples of obscuring, in the form of delayed diagnosis or misdiagnosis and failure to provide appropriate resources, critically delayed the child's development and care plan and were lost opportunities to meet important milestones.

Gaslighting

In contrast to Obscuring, which relates to resource need identification and provision, *Gaslighting* refers to the systematic blaming and belittling of consumers with ongoing and complex needs and the disassociation by specialist service system actors from their resource integration responsibilities. In this way, powerful actors implicitly and tacitly sought not to be held accountable for resource access and integration failures experienced by actors in vulnerable positions.

Several parents recounted the constant belittling and blaming that they had to endure as they struggled to access necessary resources to support the well-being of their children. Some parents were perceived and treated as troublemakers, villains or fantasists as opposed to being engaged with as equal and critically important actors who were integral to co-creating well-being for their children.

Siobhan described the "massive culture of parental blame" in the service systems within which she was embedded and shared how she was made the scapegoat for her son's problems:

> There is a massive, massive culture of parental blame attached to special needs[…]. I've had it myself […] My son was in a very, very dark place, very like suicidal. I was sitting up all night every night […] And I went "please help my child. I don't know what to do. Is it the medication? Is it, like what's going on here?" and I was basically ushered out of her [the doctor's] office, that she was refusing to help him. And I rang my GP in tears going:
>
> What do I do? I can't, we can't keep going. He's not going to school […] we can't leave him for five seconds in case he does something, you know I'm up all night because I have nobody else to stay up with him cause it's only me at home.
>
> And he told me, and he showed me a copy of this letter that the doctor had sent to them saying that my reluctance to engage in parenting skills training was the root of all of his issues. (Siobhan, Irish, sons 13 and 10)

Similarly, Barbara describes her experience of attending a parenting course, where stories of other parents were shared and mocked by the psychologist running the course:

> […] the amount of time that I did go to those parenting courses and felt embarrassed […] the psychologist at the top of the room was talking about the mother whose son was following her with a knife and said, 'why didn't she just take the knife off him?'. Like this is, you know it was like this mother needed to discipline her child and she laughed, she laughed about it. This was a psychologist; this is my story. I'm not going to say a word about what's going on in my house in case my story is retold and laughed about. (Barbara, Irish, son 10)

Such gaslighting by professionals left parents like Barbara unable to seek advice for fear of her story being "retold and laughed about". This represented a severe form of VCD by service professionals who blame and belittle actors experiencing vulnerability and disassociate themselves from their responsibilities.

While there was ample evidence of a blame culture by powerful actors within the service systems, this was further accentuated by actors in the wider system including teachers, other parents and even family members who attributed the behaviour of the child with ASD to being a "bad parent" (Barbara, Irish, son 10).

Hence, gaslighting entailing parental blame, belittlement and stigmatisation was systematic and was exacerbated and perpetuated by multiple actors in the service systems.

Siloing

Siloing refers to specialist professional service system actors who control resource access, intentionally and unintentionally withholding resources from consumers with complex and on-going needs or forcing them to accept certain types of services. This resulted from fragmented and siloed service systems, whose actors were unwilling or unable to interact and coordinate with each other in terms of meeting the resource needs of consumers already experiencing vulnerability due to a family member's condition. As reflected by the following example, children with an autism diagnosis do not "belong" to the mental health system in Ireland:

> There is unfortunately a situation where children who have autism are being turned away from CAMHS, the child and adolescent mental health services, because they have autism. (Siobhan, Irish, sons 13 and 10)

For families, this meant that parents found it hard to access and navigate the several fragmented service systems that controlled access to the resources that they needed to secure for their children's needs and well-being.

Similarly, Patricia requested in vain for specialised training that she desperately needed to help her learn how to handle her child's violent outbursts:

> And you know it's the big white elephant in the room – violence between autistic children and their parents […] nobody talks about it […] nobody knows how to handle it […] they [special needs teachers] are meant to have the training to handle a violent child and some of them don't want to know […] His dad and I asked to have that training and they refused to give it to us. (Patricia, Irish, son 14)

Patricia's answer reflected how parents' felt abandoned and shut out from the service system. Such siloing was also evident in other service systems such as education as reflected by Aili who felt that the school that her son was attending was forcing him out of mainstream school and into a special needs class. While acknowledging his learning challenges, she and her husband felt "pushed" into a separate stream, despite their efforts to resist:

> It is difficult for him in an ordinary class and me and my husband, we have not wanted to give up although they have tried to push us elsewhere. (Aili, Finnish, son 10)

Similarly, Anneli pointed out that siloing became cumulative when one failure led to another solution being forced on the families:

> When we pointed out that the therapy did not work [because it was not suitable for ASD children], they [health care professionals] told us that she should go to hospital school, where she should spend weeks and stay at home only during weekends. Had we agreed to that, who knows what would have happened, considering all changes are hard for a child with ASD. (Anneli, Finnish, daughter 13)

Siloing therefore involved children and their families being excluded from the services they were entitled to and/or forced into inappropriate alternatives, resulting in significant and irreversible delays to the diagnosis, care-planning and ultimately the development of the child.

In summary, our analysis reveals a typology of VCD mechanisms linked to resource-related challenges and unmet needs experienced by families with children with ASD in their interactions with service systems. This typology of VCD comprising *obscuring*, *gaslighting* and *siloing* reflects critical failures by service systems resulting in families, in many cases, being inadequately or inappropriately supported to deal with their child's needs and compelled to seek help through personal networks and/or pay for private services.

In the following section, we illuminate the link between VCD and ill-being within our participant families.

Characterising consumer ill-being

We characterise ill-being as comprising material, physical, psychological and social harms resulting from VCD, which were experienced individually, relationally and collectively. The imbalance between the children's complex and ongoing resource and care needs and the inability to access and secure resources to satisfy them was a key trigger of ill-being.

In our findings, ill-being emerged as an individual, collective and relational phenomenon where the individual ill-being of one family member reverberated throughout the family and collectively impacted several family members. This spillover impact highlights the *relational* nature of ill-being especially evident in our family context. Thus, while the negative experiences among two or more family members suggested collective ill-being, the link (and potential direction) between the individual and the collective revealed ill-being's relational nature. Parents lamented that caring for their child with ASD cannibalised other areas of their and their families' lives, depleting time and resources for themselves and others in the family. The constant worry and concern about their children's well/ill-being and futures, as well as the extensive work that was required to navigate the service system took its toll on parents' ability to prioritise other goals, as starkly reflected in the following case. The inadequate and ad-hoc provision of services and supports resulted in Patricia's child being unable to cope or function on any level with his "whole life falling apart" and leaving him and their family "in crisis":

> His whole life is falling apart, not just school, his social life, his ability to be a member of society. He can't even function to do that. That to me is a crisis. (Patricia, Irish, son 14)

Furthermore, parents as primary carers experienced ill-being in relation to their child. Instead of being able to live a balanced family life, parents felt that their lives were put on hold to care for their children, and, as a result, they struggled to manage their everyday lives. In addition, ill-being caused by VCD also impacted other family members. This collective aspect of ill-being was reflected in the use of "we" and "the whole family". Anneli reflected on this as follows:

> […] it's a battle, and when she behaves in a challenging manner both towards us parents and at times towards her little brother, it is stressful […] It's hard for the whole family. (Anneli, Finnish, daughter 13)

While ill-being was experienced individually, relationally and collectively within families, it manifested as harms, as discussed next.

Experiencing ill-being as material, physical, psychological and social harms

Ill-being comprised material, physical, psychological and social harms which emerged from actors' inability to satisfy their needs because of co-destruction in service systems. Specifically, the challenges of caring for their child with ASD, alongside other family responsibilities, exacerbated by parents' limited agency to secure resources from the service systems and restricted them from engaging fully in life across several domains.

Material harm entailed an inability to realise work/career plans, opportunities and material goals due to VCD. This required parents to reconfigure their lives around caring responsibilities, to the detriment of their own personal and professional goals and ambitions. In essence, the care needs of the child came with significant financial penalties, impacting families' earning potential, standard of living and their ability to thrive financially.

Material harm was particularly evident amongst parents who felt compelled to stay at home, work shorter days or take on less demanding jobs to care for their children, which inevitably had financial consequences. Reduced financial incomes and lowered standard of living impacted all family members and was experienced collectively in terms of earning capacity, reduced spending power and a limiting of life opportunities:

> I mean we can't set our own standard of living anymore. We're capped, our income is now capped, whether we like it or not. And we must just accept that we can't have things, that given a different

> opportunity in life, we would be out there working and having what everyone else dreams of having within their capability to earn. We can't do that anymore. (Patricia, Irish, son 14)

Similar reflections were shared by Tess who was forced to give up her job to become a full-time carer and Aili who had to take sick leave from work due to the stress of caring for her child.

Physical and psychological harms were closely interrelated and manifested as the negative physical and mental health on consumers, coupled with an inability to cope with and overcome everyday struggles and challenges, realise opportunities and achieve goals related to life satisfaction and happiness. The physical and mental health of parents and family members was severely impacted, causing anxiety, depression and feelings of powerlessness and hopelessness and resulting in a failure to flourish.

For example, physical and psychological harms were reflected by Barbara who spoke about the lack of support from mental health services (CAMHS) for her son with ASD and ODD during his violent outbursts stating that her "family is not safe". As a result, experiences of physical and psychological harms were evident in her family:

> I was ringing CAMHS [mental health services] over and over again. They are not the service for me – they are not the service because it's anxiety and ASD, they're not the service, end of story. Like 4 or 5 phone calls with me going "my family is not safe, like my daughter has just got kicked in the head, somebody must do something". I don't know what that is, but somebody must help us, support us. […]Mary [younger daughter] was my huge worry because she had started to go in under the table (crying). And she had started to rock and put her hands on her ears (crying)[…] (Barbara, Irish, son 10)

Barbara's case not only reflected VCD in the form of lack of support by the system experienced by the family, but also the resultant physical and psychological harms for her daughter and her family. It further reflects the individual, relational and collective nature of ill-being. This is evident in how members of the family were individually affected by these harms (e.g. the daughter). Relationally, ill-being is evidenced through its inter-subjective impact i.e. how harms are experienced by family members in relation to the child with ASD (who suffers violent attacks) and in relation to each other (the mother worries about protecting herself and her family from physical and psychological harms while also seeking support for her son who is violent). Also, the family collectively suffers from such harms as it is under threat.

Physical and psychological harms were similarly reflected by Patricia and her husband, who experienced constant fear and physical danger in the face of their son's violent outbursts. This was coupled with the "heart-breaking" knowledge that no supports were available to them. The collective nature of the harms endured is further revealed in the use of "we", "our", "ourselves":

> And we are the ones living with autism 24 hours a day trying to handle our son who can suddenly turn violent and trying to defend ourselves and handle him properly without hurting him – it's heart-breaking […] no one wants to know. (Patricia, Irish, son 14)

In Hanna's case, her efforts and struggles to help her daughter, who faced multiple challenges in relation to mental and physical health, school and social relations, contributed to her own health problems and physical and psychological harms. The constant pressure to "police" her daughter who is unable to make any decisions for herself further amplified Hanna's feelings of not being able to cope and of being let down by a system that did not or could not help:

> They (public health system) should do it, but they don't. I called them (disability service) that I really need help, I cannot cope because I am not well myself because I feel like I have to be

> policing her all the time - dealing with her [lacking] executive functioning, really stop (her) like 'now you need to stop playing', 'now you need to eat', 'now you need to shower so that you have time to sleep'[…] (Hanna, Finnish, daughter 19)

Lumi, who had a traumatic experience with child welfare services after her oldest daughter got into trouble, shares her fear about having to face them again in relation to her two younger daughters who also have ASD. As a result, she feels compelled to modify her own responses to the daughters' behaviour and "will give in" to them to reduce the risk of a violent meltdown and trigger further intervention by the "child welfare circus":

> I do give in more and more, I won't escalate it, I just count days, they will be 18 one day, then they will leave and have their own homes. I won't be strict about something such as, 'now you must eat'[…] I don't know if it's a good or a bad thing, the most important thing is that the person who can, will give in. When the child cannot, I must. I have no choice; I don't want to end up in the child welfare circus again. [if the child's outburst become uncontrollable] (Lumi, Finnish, daughters 18, 16, 14).

Lumi's case shows how one actor's inability (in our case children with ASD) to be flexible, learn and follow the societal and familial norms forces other actors (parents and siblings) to adjust their behaviour even against their will, leading to psychological harm.

Social harm entailed an inability to participate in everyday social activities, to maintain social relations, to avail of social opportunities and to achieve social goals. Examples of social harm because of VCD included social isolation, feelings of exclusion and stigma and a failure to thrive socially.

Reflecting the link between psychological and social harms, Gerry recounted how caring for this son who has ASD, coupled with loss of his wife precipitated feelings and experiences of isolation and exclusion which in turn led to anxiety, and depression:

> […] last year especially when I was depressed, I isolated myself too much. But unfortunately, that's what it does to you. There were days I couldn't leave the house. I only left the house to drop [son with ASD] to school and pick him up. I'd make one trip into town a week to do my shopping and that was it, I used to dread meeting people. Because I wasn't willing to face them and talk to them because I didn't know how I felt. That's the way it affected me. I hibernated quite a lot […] I went down over a couple of months, and it took me a long time to come back up, that's the worst I've been. (Gerry, Irish, son 14)

Gerry shared his experiences of social harm and how he struggled to leave the house to collect his son who had ASD from school. He continued to experience psychological and social symptoms, albeit to a lesser degree, which reflected the depth of social harm that he suffered related to the pressures of caring alone for his child and the associated challenges of his condition.

Social harm in turn impacted parents and other members of the family who were unable to enjoy the normal activities of life such as work and interacting with colleagues, visiting friends, attending gatherings, events and parties without fear or anxiety about how their child would behave or what others would think of or how they would treat them. As an illustration of social harm, Lumi shared how her friends reacted when child welfare services became involved with their family. She and her husband felt judged, stigmatised and painfully excluded by those in a position to offer support, including the child's godparents:

> You tell your friends that yeah, we have this child welfare case ongoing, then there has been this icy distancing. […]suddenly it feels like the invitations to the kids' godparents decrease, or they don't come to our parties, there is this stigma […] But hello, this is my life, give me a guide on how to hide your child welfare status from your kids' godparents? Or how do you tell them about it? Like this basic, how do you keep your self-respect as a child welfare client - can you be a good parent? (Lumi, Finnish, daughters 18, 16, 14).

Social harm was further exacerbated by experiences of isolation and discrimination. Parents experienced on-going feelings of helplessness and powerlessness as they witnessed their children's social exclusion or suffered from it themselves. Anneli recounted how her daughter experienced exclusion and discrimination at school due to her condition and behaviour, and how the school failed to resolve the situation. She described how other parents responded with threats of child protection notifications and police involvement:

> When you have these external challenges, when they [other parents] attack and want to isolate your daughter from the other girls in the classroom, that hurts the most, because you can do nothing about it, and this other girl's mother threatened us with police and child protection notification. These situations have been the toughest ones. (Anneli, Finnish, daughter 13)

In summary, our findings reveal material, physical, psychological and social harms that underpin the ill-being, which emanates from VCD. It also highlights the challenges faced by actors with ongoing and complex resource requirements to have their needs appropriately met, to realise life opportunities and to ultimately thrive. The characterisations of VCD and ill-being are summarised in Table 1.

Discussion

Our aim in this paper was to build on marketing and TSR/TCR perspectives to deepen understanding of VCD and to explore its relationship to consumer ill-being. Our research offers three main contributions.

First, building on our empirical insights and adapting Plé and Chumpitaz Cáceres (2010), we characterise VCD as a systemic failure within service systems to access, provide or integrate resources to meet actors' needs manifested by VCD mechanisms, namely: obscuring, gaslighting and siloing. This characterisation sheds light on the nature of VCD and its consequences for families. Our participant families faced challenges in accessing service, as well as inadequacies relating to the level and nature of the services that were offered. Hence, family and service resources diminished. The three VCD mechanisms *obscuring, gaslighting and siloing* reveal how service systems fail to meet consumer resource needs, extending the previous research that has identified resource absence, deficiency, blocked access as reasons for resource integration failure (Cui and Osborne, 2022; Smith, 2013; Vafeas *et al.*, 2016). Our definition also distinguishes VCD from other concepts such as reduced well-being that some equate with VCD (e.g. Bruce *et al.*, 2019; Echeverri and Skålén, 2011, for a detailed review of VCD and related concepts see Echeverri and Skålén, 2021).

Obscuring underscored service systems' inabilities to proactively recognise consumers' individual and collective resource needs, which was key to securing appropriate and timely service access. This importantly sheds light on the reasons behind the observation that families experience resource scoping challenging when trying to resolve children's complex care needs, which may even result in feelings of entrapment and an inability to lead a meaningful life (O'Loughlin *et al.*, 2024). *Gaslighting* revealed how families were essentially (mis)treated, blamed and responsibilised as scapegoats for the inadequacies and failures within service systems, as they strove to secure resources. This is a significant systemic failure, considering Smith's (2013) observation that consumers experience loss of self-esteem as costly and co-destructive when interacting with firms. Such negative treatment may be partially due to socio-cultural expectations regarding the parents' role in and responsibility for their children's upbringing, but also for children not behaving according to social norms. Regrettably, professionals (and other actors) inaccurately attributed blame to parenting failures rather than to neurodevelopmental disorders. *Siloing*,

Table 1. Characterisation of value co-destruction and ill-being

Characterisation of value co-destruction	Value co-destruction as a systemic failure within service systems to access, provide or integrate resources to meet actors' needs manifested by value co-destruction mechanisms	*Characterisation of ill-being*	Ill-being as comprising material, physical, psychological and social harms resulting from value co-destruction, which were experienced individually, relationally and collectively
Value co-destruction mechanisms ill-being experienced as harms			
Obscuring	Obscuring refers to multiple specialist and professional service system actors failing to recognise and meet the complex resource configuration needs of consumers with ongoing and complex needs in a responsive and coordinated way	Material harm	Material harm entails an inability to realise work/career plans, opportunities and material goals due to value co-destruction
Gaslighting	Gaslighting refers to the systematic blaming and belittling of consumers with ongoing and complex needs and the disassociation by specialist service system actors from their resource integration responsibilities	Physical harm	Physical harm manifests as negative physical health, coupled with an inability to physically cope with and overcome everyday struggles and challenges, realise opportunities and achieve life satisfaction due to value co-destruction
Siloing	Siloing refers to specialist professional service system actors who control resource access, intentionally and unintentionally withholding resources from consumers with complex and ongoing needs or forcing them to accept certain types of services	Psychological harm	Psychological harm relates to negative mental health, coupled with an inability to psychologically cope with and overcome everyday struggles and challenges, realise opportunities and achieve life satisfaction, due to value co-destruction
		Social harm	Social harm entails an inability to participate in everyday social activities, to maintain social relations, to avail of social opportunities and to achieve social goals due to value co-destruction

Source: Authors' own work

which reflects how service systems either refuse to provide the required resources to actors or push certain types of undesired or inappropriate resources on families, extends earlier findings in collective contexts, where poor resource integrability for the family led to co-destruction (Bruce *et al.*, 2019) by showing how service systems may force consumers to use services that are incompatible with consumer resources. It also reveals how rigid and myopic institutional policies and practices make families pawns in a game of efficiency with intransigent and inflexible service providers. Further studies should therefore include a cross section of service system representatives to deepen multistakeholder understanding of VCD mechanisms and how they can be appropriately mitigated.

Second, we respond to the limited attention paid to ill-being within the marketing discipline by integrating work within broader sociological domains including research on families of children with complex needs (e.g. Nomaguchi and Milkei, 2020; Karra *et al.*, 2023; Enav *et al.*, 2023) to expand the conceptual and empirical understanding of ill-being within the marketing domain. While extant research has studied the impact and outcomes of various stressors on well-being, there has been an absence of focus on ill-being. Responding to this research lacuna, we characterise ill-being as a multidimensional outcome of systemic VCD comprising *material*, *physical*, *psychological* and *social harms*. Our study also reveals the individual, collective and relational nature of ill-being. Collective ill-being refers to negative experiences of VCD among two or more family members, whereas relational ill-being refers to the link between the individual and collective, i.e. its inter-subjective nature including its spill-over effects and its potential direction vis a vis other family members. This was especially evident in the context of our families where ill-being improved or disimproved in the case of individual family members, the family as a whole or for some in relation to others, with parents focusing on prioritising the needs of the child and, thus, accentuating their own ill-being and sometimes that of other family members. In many cases, the family collectively felt the effects of VCD, sharing the feelings of being neglected by service systems, left alone and unsupported. This collective ill-being extends earlier research that revealed how carers make trade-offs for the benefit of loved ones (Kelleher *et al.*, 2020) but did not account for the (collective) implications for the family as a whole.

The constant negotiation between balancing the welfare of the child with complex needs and other family members and responsibilities, while also navigating complex and shifting service system boundaries, burdened the parents significantly. This on-going, acute and challenging balancing act further exacerbated their experiences of physical, psychological, social and material harms. While recent studies have highlighted the link between parents' ill-being and children' behavioural challenges (Enav *et al.*, 2023), our research addresses the significant lack of understanding and interrogation of the systemic failures to support families, which result in multiple harms. Moreover, such harms were often experienced holistically; when one area became affected, it often had a domino effect on other areas of life.

Our study also indicates how certain VCD mechanisms and consumer ill-being may be related, although caution is required due to limited number of participants and specific study context. According to our findings, where actors experienced obscuring and gaslighting within service systems, psychological and social harm was reported. Similarly, *siloing* left actors alone to cope with resources integration challenges, which caused psychological, physical and material harms. It also seems plausible that *obscuring* not only caused families multiple harms which led to ill-being but also had detrimental effects on the service system, causing resources to be wastefully tied up in complaint handling and failure demand through an increase in re-referrals (Seddon, 2008) where families repeatedly interact with different actors in the service system to seek help. While our study reveals important insights

regarding the nature of VCD and its interrelationship with ill-being, our empirical data is based largely on parents' experiences of specialist/professional services. Further research is therefore needed to explore perspectives of broader range of actors including other family members, ASD representative bodies, health, education and social service providers and government agencies and policymakers. Furthermore, recognising the exploratory if critical nature of these preliminary observations, further larger scale research is warranted.

Third, our study responds to calls from TCR/TSR scholars to prioritise the research of consumers experiencing vulnerability who are embedded in service systems (Anderson *et al.*, 2013; Anderson and Ostrom, 2015), particularly the collective effects of transformative service (Boenigk *et al.*, 2021), and the experiences of the "extended customer entity" (Sandberg *et al.*, 2022, p. 10), in our case the family. As extant research acknowledges that vulnerability may be linked to physical, cognitive or behavioural impairment (Pavia and Mason, 2014), consumers need resources from service systems to live with or sometimes even overcome experienced impairments. However, the parents felt powerless as non-expert actors in the face of expert actors (service professionals) when negotiating resource access to meet the medical, education and developmental needs of the children. We show that in the context of public service systems, consumers face an acute form of powerlessness due to the criticality of their needs and through their acute dependency on resources, akin to powerless in the face of monopolies as discussed by Abboud *et al.* (2023).

Our findings also advance understanding of the nature of vulnerability as experienced by families and how it is intertwined with ill-being. We specifically advance the understanding of how the harms exacerbated experiences of vulnerability and were interrelated so that alleviating one type of harm could lead to deepening of another type. For example, material harm increased the burden of families as they had to reduce work hours to care for the children (or pay for services not provided for them). Thus, the financial status of the whole family was negatively impacted in the hope of improving the psychological and physical wellbeing of one family member (the child). Similarly, social harm accentuated vulnerability as families felt they were being looked down upon, scorned and questioned by service systems. As evidenced, some service systems (particularly child welfare) may be stigmatising as such, and this stigma spills over to other social relations. This social harm may be particularly powerful in deepening experiences of vulnerability, since it implies that families become alienated from others that could support them. Further research is needed to explore the interrelations between VCD, ill-being and vulnerability, e.g. how VCD and subsequent ill-being experiences directly impact immediate members of the family and others beyond.

Through these findings, our study exposes the crucial role of service systems in directly exacerbating or alleviating vulnerability which goes to the heart of TCR/TSR principles. In addition, while recent TSR/TCR research has begun to spotlight the implications of resource misintegration particularly for consumers who experience vulnerability due to limited agency or skills within complex service systems (e.g. Boenigk *et al.*, 2021; O'Loughlin *et al.*, 2024), our study begins to delineate the entanglement and relations between consumers' resource needs and ill-being in service systems. It also starts to unpack how they are impacted by the VCD mechanisms identified, highlighting the need for further investigation in other contexts.

Recommendations

Our study has exposed the deep-rooted and pervasive nature of VCD in service systems, and the significant and enduring ill-being experienced in the families caring for children with

ASD. Given the wicked and systemic nature of this problem, we argue for transformative change within these public health, social care, education and other service systems, which can only be achieved through revolutionary solutions. We therefore advocate for three revolutionary implications to mitigate systemic VCD and to reduce potential material, psychological, physical and social harms that constitute consumer ill-being.

Firstly, marketing and service systems should create shared key performance indicators (KPIs) instead of organisation specific ones to ensure system-wide service level and resource optimisation for children with complex needs and their families. In the case of public service systems, this would include identifying family- and child-specific KPIs that could be crafted in the form of service guarantees at or before the formal diagnosis stage. At the same time, this requires resourcing and supplementing services to redress current resource availability and suitability concerns. Secondly, acknowledging the importance of orchestration of resource allocation across integrated services (c.f. Kelleher *et al.*, 2020), health care systems should prioritise the patient/family centred design and reconfiguration of omnichannel solutions that involve single and central touchpoints across interconnected systems to ensure dedicated care and support pathways for families and children over the life course. Thirdly, the threat of engagement with child welfare systems currently raises the spectre of fear for parents as their remit is unclear, supports are restrictive and the quality of responses and interventions are variable. We strongly recommend that these highly divisive power and knowledge asymmetries should be addressed, and service transparency issues resolved.

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Appendix

Table A1. Profile of respondents and caring contexts

Participant	Gender	Family caregiving context
Aili, Finland	Female	Lives with son (10 years old) who has been diagnosed with ASD. Partner has two children from previous marriage. She has been on sick leave for several months
Anneli, Finland	Female	Married with two children, daughter 13 and son 10 years old. Daughter has been diagnosed with ASD. Works full time
Barbara, Ireland	Female	Married with four children (13- and 8-year-old girls and 13- and 10-year-old boys). The younger son has ASD, oppositional defiant disorder (ODD) and has been recently diagnosed with pathological demand avoidance (PDA). She gave up job as nurse to care for son
Essi, Finland	Female	Separated. Has a 9-year-old son who has been diagnosed with ASD: She is currently a student while caring for son
Fintan, Ireland	Male	Separated with three children (19- and 17-year-old boys and 14-year-old girl). He cares for the eldest son who has ASD and ADHD. The two other children live with their mother and the younger has been recently diagnosed with Asperger's syndrome
Gerry, Ireland	Male	Widowed for four years with three children 23, 19 and 14 years old. The youngest son has mild ASD. Gave up full time professional role to care for his youngest son
Hanna, Finland	Female	Separated. Lives with her only child, daughter (19 years old) who has been diagnosed with ASD. Works full time
James, Ireland	Male	Married to Lorna (participant). Three sons 10, 8 and 5 years old. The two younger boys have ASD. Works full time in a professional role
Lucy, Ireland	Female	Married to James (participant). Three sons 10, 8 and 5 years old. The two younger boys have ASD. Gave up full-time professional role to care for sons
Lumi, Finland	Female	Married with four children (adult son, three daughters 18, 16, 14 years old). Each of the three daughters have been diagnosed with ASD. Works full time
Miriam, Ireland	Female	Married with two sons (18 and 12 years old) and a daughter (15 years old). The younger son has ASD. She gave up part-time work to care for son
Patricia, Ireland	Female	Married with two sons (22 and 14 years old). The eldest son has mild ASD, Asperger's syndrome and OCD and anxiety. The youngest son has severe ASD, ADHD and oppositional defiant disorder (ODD). Both parents have given up work to care for sons
Siobhan, Ireland	Female	Separated. Has two boys 13 and 10 years old. The older son has severe ASD, ADHD and mental health issues and the younger son has ASD. Working part-time as a teacher while also caring for sons
Tess, Ireland	Female	Married with three children (a daughter who is 10 years old and twin boys who are 6 years old and who have ASD). Gave up a part-time position to care full time for sons
Veera, Finland	Female	Married with two adult children (son 26 and daughter 18). The daughter has been diagnosed with ASD, and mother suspects that the son also has ASD. Retired early as is financially independent

Source: Authors' own work

Corresponding author
Johanna Katariina Gummerus can be contacted at: johanna.gummerus@hanken.fi