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On the care of Locked-in Syndrome patients

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1 Introduction

On the morning of 12 July 1999, Jose C., then thirty-three years old, suddenly fainted when he was about to take a shower. After days of close monitoring in the hospital, during which he showed no sign of consciousness, the doctors concluded that he had suffered a stroke that had left him in a persistent vegetative state. The medical team informed Jose's wife and family that, given the extensive physiological and neurological damage the stroke had caused, it was highly unlikely he would survive longer than two months.

Over the weeks that followed this devastating diagnosis, Jose's wife, Maria, identified what seemed to be a barely noticeable pattern in the movement of his right-hand index finger. She alerted the medical team, but the doctors dismissed the idea that the movement could be a sign of conscious brain activity, attributing it instead to the sort of spasmodic muscle contraction typical of patients in vegetative states. Four months after the initial stroke, however, and as the result of Maria's dogged insistence, the medical team acceded to perform additional tests to discard the possibility of conscious action. To their surprise, the results showed that despite the damage the stroke had caused to Jose's nervous system he remained fully aware and conscious, capable of hearing, understanding, reasoning and commanding the movement of his right-hand index finger. The medical team reversed its initial assessment and diagnosed him with Locked-in Syndrome.

Locked-in Syndrome (hereafter LIS), also known as coma vigilante, is a rare neurological disorder normally caused by infarct, haemorrhage, or trauma leading to a brainstem lesion. It entails complete paralysis of nearly all the voluntary muscles of the body, except for vertical eye movement. Outwardly LIS patients resemble those in vegetative states, but there is a crucial difference: LIS patients remain fully aware and conscious, with their intellectual capabilities intact. Hence the name of the disorder: the individual is locked inside his body, unable to express his consciousness and translate his thoughts and intentions into words or actions.¹

1 In 2000, a local court declared Jose ‘totally incapable’. In Spanish law,
 2 the classification of an individual as totally incapacitated triggers the
 3 ‘replacement of his will’ by the appointment of a legal guardian that oper-
 4 ates under the regime of *tutela* (tutelage) (Código Civil [2008]: Title X).
 5 Having found the person unable to govern himself, the court, through a
 6 power of attorney, proceeds to transfer his legal *persona* to another person,
 7 who, with judicial supervision, then becomes his legal representative. The
 8 individual is stripped of some of his civil rights – such as the ability to
 9 enter into a contract or administer his property – as well as of most of his
 0 political rights, notably the right to vote. The declaration of total incapac-
 1 ity, in other words, effectively removes that individual from the political
 2 life of the community.

3 In 2004, Jose C. appealed this ruling. Despite his severe physical disabili-
 4 ty, he argued, his mental faculties remained intact. In a landmark
 5 decision, the regional Appeals Court ruled in his favour and restored his
 6 voting rights, as well as the rest of the lost legal powers. Jose left the state
 7 of tutelage and regained his status as a full-fledged member of the com-
 8 munity. A particularly noteworthy aspect of this ruling, and an issue we
 9 will discuss in detail below, is that the Court’s decision was not motivated
 0 by a sudden improvement in Jose’s physical condition – which, as is cus-
 1 tomarily the case in LIS patients, had remained essentially unaltered. The
 2 new legal judgment was grounded, rather, in the fact that over the four
 3 years that had passed since the initial decision, Jose had gained access to a
 4 series of augmentative communication devices, particularly voice repro-
 5 duction software and a specially adapted computer interface that allowed
 6 him to use the Internet. With the help of these adaptive technologies, Jose
 7 had become able to translate internal mental states into speech and, to a
 8 lesser degree, actions. As a result, he again became intelligible to the legal
 9 system as an actor ‘capable of governing himself’, and thus entitled to the
 0 recognition of his full legal *persona*.

1 In this chapter, we explore the interaction between adaptive technolo-
 2 gies, systems of care, and the intelligibility of LIS patients as full legal
 3 persons, subjects endowed with the standard range of civil and political
 4 rights. Dependent for the display of their self-governing ability on a
 5 heterogeneous assemblage of communicative devices, caregivers and,
 6 increasingly, computer interfaces, LIS patients and the socio-technical
 7 configurations in which they are immersed unsettle some of the biological
 8 presuppositions at the heart of Western legal and political systems
 9 (Pottage and Mundy 2004; Rose 2007; Strathern 1992). The canonical sep-
 0 aration of persons and things, as well as the traditional definition of the
 1 human body as the natural container of the person, become problematic
 2 assumptions when, as in the case of LIS patients, the production of intelli-
 3 gible *personae* is dependent on the imbrication of bodies, technological
 4 devices and extended systems of care. We will focus on the heuristics that
 5 characterize legal knowledge as it attempts to apprehend and classify these

new mixtures of biological, technical and social components. This will allow us to understand how key political categories, like that of citizenship, are being redefined by the intersection of legal techniques of personification and new assistive technologies.

Our argument will draw on a comparison between the case of Jose C. and that of Mauricio, a Spanish LIS patient who also appealed a ruling of total incapacity after regaining the ability to communicate with others. Unlike Jose, however, Mauricio saw his legal status confirmed by the Spanish Supreme Court, and never recovered his full legal *persona*. Both Jose and Mauricio engaged in arduous attempts to display before the courts the qualities – awareness, communication, self-governance – that the law demands for the attribution of legal personhood. The disparity of their fates draws our attention to the legal mechanisms and practices of care whereby the disabled and mute human body is made to coincide with, or, alternatively, is disentangled from, the category of ‘person’, that ‘still imprecise, delicate and fragile’ legal construct (Mauss 1985 [1938]: 1).

The contrasting legal fates of Jose C. and Mauricio will allow us to advance three claims. First, that novel techno-scientific knowledges and devices – whether in biotechnology, reproductive technologies, human-computer interaction or neurocognitive enhancement – blur the biological demarcations traditionally employed by Western legal systems to define the boundaries of the political subject. These knowledges enable the delegation and materialization of internal processes and capacities, such as speech, intentionality or agency, onto different devices and techno-scientific systems, thereby giving rise to *distributed forms of personhood*.

Second, we suggest that, confronted with bodies thoroughly dependent on distributed networks of people, objects and devices, the law becomes once again the fundamental machinery of personification. The notion of the citizen as an autonomous, self-contained, self-governing body is still the cornerstone of the legal machinery for the production of persons, but this notion must be deployed flexibly to contend with novel socio-biotechnological hybrids. It is up to the law to make anew the distinction between the socio-material configurations that give expression to forms of being entitled to civil and political rights, and those which fail to produce the kind of projection of personhood the law requires in order to recognize individuals as full-fledged legal subjects. As the discussion of our two cases will show, this process of legal demarcation depends on the kind of evidence that different socio-technical configurations are able to produce: the devices and technologies through which the person is presented can be seen by the courts as vehicles for the expression of a self-governing self, or as screens hiding an ineffable being. The former vision leads to the recognition of the LIS patient as a full legal *persona*; the latter triggers a moment of radical suspicion, as if the law refused to presume an autonomous self behind – or at the centre of – the assemblage of people, devices and technologies through which the patient is re-presented to the world.

Finally, we will explore the implications of these examples of legal (un) intelligibility to a reconsideration of the key juridico-political category at stake, that of citizenship. The jurisprudence on LIS patients offers a tantalizing opportunity to rethink citizenship as a fragile *position* embedded in socio-technical systems and compatible with intense forms of care, rather than as an abstract *condition* grounded in an isolated, self-governing body.

2 Silence, unknowability and communicative aids

LIS has a rather particular history. The first descriptions of the syndrome may be found in literature, rather than in medicine. The most famous example is Alexander Dumas' 1844 novel *Le Comte de Monte-Cristo*, where the writer introduces the character of Monsieur Noirtier de Villefort, an old Bonapartist who, after suffering an apoplectic stroke, was left as 'a corpse with living eyes' (Dumas [1844] 1996: 564). Two decades later, in 1867, Émile Zola provided a very similar description of the syndrome in his novel *Thérèse Raquin*, the story of an old widow who suffered a crisis that left her 'a walled-up brain, still alive, but buried in a lifeless frame' (2008: 146). In the term 'Locked-in Syndrome', as in some of its French or Spanish equivalents – 'maladie de l'emmuré vivant', 'síndrome de cautiverio' – one still hears the echoes of this literary genealogy. The condition remained medically unknown until 1941, when it was first discovered by a group of Oxford neurosurgeons (Cairns *et al.* 1941), but it remained without a name for two further decades, until the American neurologists Fred Plum and Jerome Posner coined the term 'Locked-in-Syndrome' in the 1966 edition of *The Diagnosis of Stupor and Coma*.

Plum and Posner described there the case of the 'de-efferented' individual, a person 'with no means of producing speech or movement', and defined his condition as a combination of quadriplegia, lower cranial nerve paralysis and mutism with preservation of consciousness, vertical gaze and upper eyelid movement (see also Smith and Delargy 2005). The reason for the late medical definition lies in the difficulty of diagnosis and the outward similitude between LIS patients and those in persistent vegetative states. Given the nearly total paralysis of the patient, there are hardly any behavioural cues from which doctors can infer the presence of a living conscience in the inert body. An individual suffering from classical LIS can only resort to the vertical movement of her eyes to convey alertness to others. This signal, however, can be easily misinterpreted as one of the involuntary muscular movements common in patients in comatose states. Furthermore, most LIS patients suffer on the onset of the syndrome forms of neurological impairment that can make eye movement inconsistent or easily exhausted. 'A high level of clinical suspicion' write Plum and Posner, 'is required on the part of the examiner to distinguish a locked-in patient from one who is comatose' (4th edition, 2007: 7). It is indeed often a relative, not a doctor, who first identifies signs of awareness in the patient: a

review of forty-four cases of LIS found that in just over half of the cases it was a family member who first realized that the patient was conscious (Leon-Carrion *et al.* 2002). The verification of the diagnosis depends then on the willingness of doctors to perform additional tests to measure brain activity, a task that is often further complicated by other effects of the brainstem injury, such as memory loss, deafness or severely distorted hearing. The cognitive and neurobehavioural assessment of the patient will thus typically evolve over weeks and months, as slight improvements in his state (such as the partial recovery of head movement) allows the medical team to slowly confirm his responsiveness (Smart *et al.* 2008).² Even today, when the condition is widely known in the scientific literature and technologies to identify cerebral metabolism are commonly available, LIS is detected on average seventy-eight days after the onset of the condition – and it is not difficult to find cases in which the patient remains misdiagnosed for several years (Leon-Carrion *et al.* 2002).

Right from the start, then, LIS patients are dependent on different technologies and expert knowledge systems for the proper identification of their predicament, and its differentiation from other conditions, such as vegetative or minimally conscious states. Once the patient is stabilized, the paramount task is to facilitate his capacity to translate mental states and thoughts into words and actions. Different communicative aids, joining the body to diverse constellations of people, artefacts and technologies, are routinely used to enable LIS patients to express their desires and thoughts. The most basic and widely used interface is an alphabet board with the letters of the alphabet written in different rows and columns (see Figure 3.1)

While the board is held in front of the patient, someone points to a letter, noting it down when the patient selects it (for instance, by producing two rapid upward eye movements). This operation is repeated again, letter by letter, until a full word emerges. This laborious form of communication often offers the patient his first opportunity to break out of the imprisoning silence brought on by the syndrome. It is, however, an excruciatingly slow method: the composition of a simple sentence can take several minutes. The process is extremely tiresome to the patient and prone to misunderstandings, repetitions and errors.

A	B	C	D	End of word	
E	F	G	H	End of sentence	
I	J	K	L	M	N
O	P	Q	R	S	T
U	V	W	X	Y	Z

Figure 3.1 Alphabet Board (source: Smith and Delargy (2005)).

1 Over the years, different patients and medical teams have essayed a
 2 variety of alternatives to improve the efficiency of the alphabet board.
 3 Jean-Dominique Bauby, a French LIS patient, rearranged the letters of the
 4 board by placing the most commonly used first, and was able thanks to
 5 this abbreviated method to increase the speed of communication and
 6 write his famous book *The Diving Bell and the Butterfly* (Bauby 1998). Other
 7 improvements to this communicative interface have included the
 8 separation of vowels and consonants in different columns, or the addition
 9 of common daily actions and commands to the board, such as 'open',
 10 'close', 'eat', 'give me', etc. Although the introduction of these variations
 11 can certainly improve the speed of communication, this type of interface
 12 only allows the patient's communication to emerge at a pace and in a form
 13 that barely affords the expression of very simple commands and orders.

14 The limitations and legal implications of this communicative interface
 15 were made evident during Mauricio's appeal against the declaration of
 16 total incapacity. As we noted earlier, in Spanish law the declaration of total
 17 incapability is applied to individuals who, due to inborn or acquired phys-
 18 ical impairment or mental illnesses, are unable to govern or care for them-
 19 selves. The relevant article of the Civil Code is commonly used to
 20 characterize individuals in vegetative states, or suffering from neurological
 21 or psychiatric conditions such as dementia, schizophrenia or Alzheimer's.
 22 Its extension to LIS patients is contentious. Although the syndrome dis-
 23 ables their bodies and breaks the connection between internal states and
 24 actions or words, patients suffering from LIS preserve their mental facul-
 25 ties unscathed. If they retain their capacity to think and will but lack the
 26 power to actualize these capacities, do LIS patients warrant a declaration
 27 of total incapacity?

28 In 1997 a local court in Betanzos, a city in the northwestern region of
 29 Galicia, had reached that conclusion in the case of Mauricio. He immedi-
 30 ately appealed the decision, on the basis that, despite his extreme physical
 31 disability and after living with LIS for several years, he was still in full pos-
 32 session and control of his mental capacities. He retained the ability to
 33 understand speech and text, and to reason autonomously; what he lacked
 34 was solely the physical capacity to autonomously display those capacities in
 35 the form of words or actions. By declaring him totally incapacitated, Mau-
 36 ricio alleged in his appeal, the court had 'silenced his undoubted mental,
 37 cognitive and volitional capacity, as well as his ability to communicate and
 38 express his will' (Tribunal Supremo Sala de lo Civil [2004], 584/2000).
 39 The claim was backed by medical analyses attesting to the fact that the syn-
 40 drome had left Mauricio's higher mental capacities intact, and therefore
 41 did not compromise his capacity to govern himself. The forensic report
 42 considered proven that 'Mr Mauricio is owner of his acts and has sufficient
 43 capacity to take decisions in all areas of his life, although he needs the aid
 44 of another person for their physical execution' (ibid.). When the Appeals
 45 Court, in spite of the medical evidence, turned down Mauricio's appeal,

his lawyer took the case to the Spanish Supreme Court, which in 2004 finally rejected his appeal and upheld the initial declaration of total incapacity. Mauricio was to remain under the guardianship of his mother.

One aspect of the Supreme Court's ruling is particularly striking. During the appeals trial Mauricio had tried to demonstrate his ability to communicate by means of an alphabet board. The Appeals Court's decision had included a detailed description of this attempt, a description that five years later the Supreme Court reproduced verbatim in the justification of its decision:

Showing him a laminated card, the nurse asks D. Mauricio whether he wants to say something, and she slowly points with a pen to each letter of the alphabet; D. Mauricio chooses the desired letter with an affirmative nod, slightly moving his head and eyes downward; next the nurse writes down the chosen letter, and continues pointing to the letters until D. Mauricio chooses the next one, she writes it down again, until D. Mauricio has completed what he wants to say: 'today is Thursday.'
(*ibid.*)

This description of Mauricio's communicative efforts provides a clue to the reason why the Supreme Court, despite the evidence presented in support of the claim that Mauricio's mental capacities were intact, decided to uphold the declaration of total incapacity. For the Supreme Court the decision on whether Mauricio ought to be classified as 'totally incapacitated' hinged solely on the *evidence* of his autonomy; on proving, in the Court's (and the law's) oft-repeated phrase, his 'ability to govern himself' (*ibid.*). It is not enough, the Court reasoned, to find signs of consciousness, proof of internal volitional or cognitive capacities. The focus ought to be, the Court argued, on the 'factual reality of the person' (*ibid.*); that is, on whether the person is legible to the law as a self-governing subject in and through the actualization of those internal capacities. In other words, whether Mauricio retained his mental abilities, even his ability to communicate, was a secondary consideration, since the key issue was his ability to evince the 'natural competence to rule himself and administer his property' (*ibid.*).

Rather than featuring as proof of Mauricio's ability to express an autonomous and intact mental capacity, the laborious production of 'today is Thursday' operated in the Court's ruling as evidence of his incapacity for self-government. His attempt at communication exposed, in the Court's eyes, the degree of mediation involved in eliciting his self, Mauricio's absolute reliance on the actions and interpretations of others to express thoughts, intentions and desires. Crucially for the Court, the board, the card and the pen remained powerless objects unless activated by the nurse, and the Court interpreted this reliance on the actions of 'third persons' as evidence of a lack of autonomy. Mauricio's communication, the Court declared,

1 'is not spontaneous, is not produced on his behalf, but on behalf of third
2 persons, he thus lacks the liberty to carry out the decisions he has previously
3 adopted, in relation to his own person as well as the administration of his
4 property' (ibid.). This dependency was further aggravated, in the opinion of
5 the Court, by the fact that the interface was only effective for people with
6 previous knowledge of Mauricio's state – that is, when used by people aware
7 of the fact that his winks were part of an effort to communicate, and not
8 mere unintentional (and thus meaningless) blinks. And even if the interloc-
9 ator were fully cognizant of Mauricio's conscious state, the communicative
0 interface is prone to misunderstandings, repetitions and errors – a wink can
1 easily be mistaken for a blink, and vice versa. The limited portability of the
2 interface is one of the key arguments the Court adduced to justify its
3 decision: this system, it argued, 'might be sufficient for his relationships with
4 the people in charge of his care, but is not enough for a normal communi-
5 cation with his external environment that would allow him to rule himself
6 and his property' (ibid.).

7 The Court exerted to the full the suspicion that this system of commu-
8 nication represented, or could eventually become, a form of ventrilo-
9 quism, in which Mauricio's self only emerged through the interpretations
0 of spokespersons. In these circumstances, it was impossible to verify if and
1 when the messages that emerged through the socio-technical system of
2 assistance were an accurate reflection of his actual thoughts and desires,
3 the projection of a veiled but intact and authentic self, or a fraudulent
4 impersonation of Mauricio's self. The social, technical and material
5 aspects of the system in which Mauricio was inserted and through which
6 he spoke – nurse, laminated card, pen – only offered a highly mediated
7 expression of his internal state; they were in fact further proof of a loss of
8 his powers of 'self-government'. The Court brought this point home by
9 repeatedly mentioning in its decision Mauricio's aphasia, and by empha-
0 sizing several of the activities of his daily life for which he was fully depend-
1 ent on highly intensive care systems. Permanently reliant on the help and
2 supervision of others to carry out routine physical tasks, it was 'impossible'
3 for Mauricio to perform 'normal behaviour' (ibid.).

4 Mauricio's case reveals some of the conditions under which a subject
5 becomes (un)intelligible as a full legal person. By disabling his body, LIS
6 had removed the element that sustained the architecture of relations
7 between self, thought and actions, and rendered his self knowable as a
8 self-governing individual. Medical and physiotherapeutic interventions
9 had attempted to reinstate the conditions of intelligibility by complement-
0 ing Mauricio's impaired body with a new socio-technical system of support
1 and care. If the combination of body, alphabet board and nurse enabled
2 Mauricio to communicate his thoughts and be intelligible to others as a
3 living mind, in the eyes of the Supreme Court it still did not allow him to
4 demonstrate the specific form of personhood legal knowledge requires to
5 apprehend an individual as a full legal subject.

We are reminded here of the oft-found etymology of the Latin *persona*: *per/sonare*, the mask through which the voice of the actor sounds (Mauss 1985 [1938]). Whether the mask is deemed to elicit a truthful personification of the self, or suspicion of its reality is, however, dependent on the modalities and forms of authentication legal knowledge chooses to deploy. The visible mediation of other agencies, most notably the nurse, meant for the Court that, regardless of his inner capacities, the display of Mauricio's self was ultimately dependent on the actions of a third party, and on that third party's ability to adequately interpret the signs produced. For the Court, this mediation triggered a moment of undecidability: Mauricio was so thoroughly embedded in systems of care and elicitation that the Court could not ascertain with full certainty a self-governing actor at the centre of the mesh of agencies, devices and processes of mediation with which it was presented. What was meant as a deed of personification – the production of 'today is Thursday' as evidence of Mauricio's intact will – was for the judges indistinguishable from an act of impersonation – of 'third persons' generating, controlling and interpreting his communications. The Court, in other words, chose to foreground the network and its connections at the expense of the hypothetical autonomous subject at its centre. It saw in the system of care and communication evidence of Mauricio's unknowability as a full-fledged legal person, rather than a machinery for rearticulating his intelligibility.

3 Technological enhancement, distributed personhood and the invisibility of mediation

Jose M.'s case offers an illuminating contrast. In the theatrical game of perspectives – between mask and person, foreground and background, role and impersonation – that defines the relationship between LIS patients and the law, Jose managed to appear in the eyes of the Court as a self-governing individual. In contrast to Mauricio's case, the socio-technical configuration through which he presented himself was, the Court concluded, a simple aid to the presentation of an intact self. Like Mauricio, Jose M. had begun using the movement of his eyes and an alphabet board to communicate with family and carers soon after the diagnosis of locked-in syndrome. Yet, after intense and prolonged physiotherapeutic care he was able to slowly regain full control over his right hand's index finger, and a degree of mobility in his neck. This brought about a radical change in the architecture of relations through which Jose could express himself and become intelligible to others as a conscious subject. With the help of an especially adapted trackball mouse, he was soon able to use an array of computer-based assistive technologies and, through them, regain some of his lost agential capacities. For example, voice reproduction software and a set of speakers attached to his wheelchair allowed him to produce speech through a digital voice. The Internet further

1 extended these new communicative capacities by enabling him to interact
 2 and communicate with people outside his immediate environment via
 3 e-mail, social networking sites, blogs or chats, and was also instrumental in
 4 transforming intentions into actual and consequential actions, such as
 5 managing his bank accounts or purchasing goods and services online.
 6 Thanks to these computer-based interfaces, Jose wrote the first book-long
 7 autobiographical account of life with Locked-in Syndrome in Spanish, *El*
 8 *síndrome de cautiverio en zapatillas* (Carballo 2005).

9 Jose's case is indicative of the sorts of aids and mediations that are
 0 slowly being made available to LIS patients – aids and mediations that
 1 unsettle the legal assumption of the (healthy and able) biological body as
 2 the natural container of the person. By connecting the body with different
 3 combinations of hardware and software, such as wireless head-pointing
 4 devices, keyboard-scanning devices (which replicate on screen the *modus*
 5 *operandi* of the alphabet board), eye and gaze movement recognition inter-
 6 faces, etc., the patient's agency is materially distributed along and enacted
 7 through novel socio-technical configurations. So-called 'environmental
 8 control units', for example, enable users to regain partial control over
 9 their home and work environments by operating different electronic
 0 appliances. Recent experimental developments in the field of neuro-
 1 science have taken the logic of these adaptive technologies a step forward
 2 by employing brain-computer interfaces and deep-brain stimulation to
 3 translate neural processes into outcomes without the use of muscles or
 4 further material connectors (Fenton and Alpert 2008; Schnakers *et al.*
 5 2009). Although still experimental, these technologies have already pro-
 6 duced some noteworthy breakthroughs. A group of researchers at the
 7 Wadsworth Center have employed EEG technology, in which the subject
 8 wears a cap fitted with a series of electrodes connected to a computer, to
 9 translate the user's brain activity into simulated keystrokes and commands
 0 (Fenton and Alpert 2008: 123). Through this system, the patient can
 1 potentially learn to perform word processing, write e-mails, or move a
 2 robotic arm via the computer. Another research team recently implanted
 3 an electrode into the brain of a LIS patient, allowing him (through the
 4 use of software that translates brain signals into sounds) 'to produce three
 5 vowel sounds with good accuracy' (Smith 2005).

6 With these adaptive technologies the traditional mind-body interface is
 7 replaced by a complex socio-technical system as the means to express the
 8 self and to connect it with its surrounding environment. Rather than
 9 merely 'extending' or 'enhancing' the impaired capacities of a pre-existing
 0 person, these technologies constitute a scaffolding through which the LIS
 1 patient gains a new capacity to act, speak and be known as a full-fledged
 2 person. They can be seen as a radical example of Clark and Chalmers'
 3 (1998) thesis of the 'extended mind'. Challenging 'internalist' approaches
 4 that see cognitive processes as operations taking place within the brain,
 5 Clark and Chalmers advocate a form of 'active externalism' according to

which certain cognitive processes can be seen as taking place in and through extended systems in which the brain is just one more element along other environmental and technological devices. One example of such ‘extended’ cognitive operation is the act of remembering, which rarely takes place ‘in the brain’ alone. We normally use all sorts of devices, from scribbled notes to PDAs, to inscribe, fix and retrieve our memories. According to this externalist view, these devices are not mere passive containers of our internal memories since they actively shape the form and extent of the cognitive processes and capacities through which we remember and, therefore, the very content of our memories – each technological configuration enables a particular form and structure of memory. Remembering, in other words, is not merely an operation that takes place through the neural operations of the brain: it requires the coupling of the brain and different environmental devices. ‘If we remove the external component the system’s behavioural competence will drop’ (Clark and Chalmers 1998: 8–9). The brain and these external devices constitute a *coupled system* that can be considered a cognitive system in its own right.

The assistive technologies employed by LIS patients implore the difference between internal and external processes – not only for conventional ‘cognitive’ operations, but also for some of the agential and communicative capacities that commonly define personhood. Hardware and software devices are as functionally important as the brain in the production of a singularized and distinct person. These technologies complicate any easy demarcation between inside and outside, between the ‘biological’ individual and the ‘technological’ devices and processes on which it relies. The trackball mouse, voice-reproduction software, the wheelchair or the electrode cap constitute the architecture through which the LIS patient regains his capacity to act and become intelligible as a person. As the contrasting cases of Mauricio and Jose illustrate, different technological configurations enable different distributions of these agential and communicative capacities and, consequently, different forms of personhood. It is not just the mind, therefore, but the person itself that emerges as a distributed system – that is, as a coupling of the body and extended technological devices.³

Jose C.’s litigation affords us an opportunity to observe, in a striking moment of juridical redescription, how legal knowledge might apprehend such a distributed system as a fully formed *persona*, and how, in so doing, the legal system may be upholding a notion of citizenship compatible with the requirement of continuous, intense and all-encompassing care. As Jose recounts in his book (Carballo 2005), he decided to appeal the declaration of ‘total incapacity’ when he realized that many of the elderly people living in his nursing care facility, individuals whose mental capabilities had visibly deteriorated, retained nevertheless their full legal rights, including the right to vote, whereas he had been deprived of full legal personhood despite the fact that his cognitive and volitional capacity remained intact following the onset of LIS. Against the opposition of the public prosecutor,

1 the Appeals Court ruled in Jose's favour and mandated the 'reintegration'
2 of his capacity. In all but a critical step the Court followed the reasoning
3 that the Supreme Court applied to Mauricio's unsuccessful appeal. As in
4 Mauricio's case, the medical assessments submitted to the Court con-
5 firmed Jose's 'full cognitive and volitional capacity', as well as the severe
6 impairment of his physical abilities (Jdo. De Primera Instancia de Val-
7 ladolid [2006], 00030/2006). What led the Court to reverse the declara-
8 tion of 'total incapacity' was Jose's demonstrated ability to 'materially carry
9 out his decisions through the assistance of a computer with Internet'
0 (ibid.). The Court noted in particular his capacity to manage his own bank
1 accounts over the Internet, drawing once again the long-standing connec-
2 tion between the ability to manage oneself and the capacity to administer
3 one's own property. 'The judicial examination', the Court noted,

4
5 confirms his physical suffering, the conservation of his cognitive and
6 volitional faculties, and his ability to use technical means to express
7 his will, even to the point of carrying out on his own some of these
8 decisions, all of it after being subject to a physiotherapeutic treatment
9 that has allowed him to recover the degree of mobility necessary to
0 make use of auxiliary means of communication.

1
2 The difference with respect to Mauricio's case rested on the availability
3 in this instance of different technological platforms, particularly those
4 facilitating access to the Internet. While Mauricio's display of personhood
5 – via alphabet board, pen and nurse – was seen as the presentation of a
6 fully intermediated subject, always at the mercy of the actors and devices
7 through which it projected himself, the Appeals Court saw in Jose's actions
8 on the Internet proof of his capacity of self-government, and of his relative
9 independence from the actions of third parties. 'Technical means to
0 express his will' and 'auxiliary means of communication' were also
1 available to Mauricio, yet in that case these enhancements of the patient's
2 powers of communication did not make him knowable to the law as a self-
3 governing self; they rather triggered the Court's suspicion.

4 The reason for the divergent outcomes in Mauricio's and Jose's cases is
5 to be found in what the Supreme Court called the 'factual reality of the
6 person'; that is, in the way each of the respective socio-technical systems of
7 care allowed each patient to evince his personhood. Although the alpha-
8 bet board enabled Mauricio to communicate, he was dependent on the
9 actions and mediations of a third person. This mediation triggered a
0 moment of undecidability in which the Court could not know whether the
1 *persona* that emerged from these mediations was a true representation of
2 Mauricio's self or a simple act of impersonation. Rather than the expres-
3 sion of a self-sufficient person, the Court chose to see a form of ventrilo-
4 quism that delegated to a third, unaccountable person the power to
5 materialize Mauricio's thoughts and intentions. The introduction of

assistive computer-based technologies in Jose's case radically altered the conditions of knowability of Jose's self. By adhering his body to different interfaces, Jose was able to bypass the mediation of any co-present third person, and to appear in the eyes of the Court as the indisputable source of the words and actions that emerged from this system. The redistribution and enhancement of his capacities did not result in a dispersal of his personhood, but rather in its intensification (see, in this context, Mialet 1999). That is, the redistribution enabled Jose to emerge as an actor demonstrably capable of thinking, communicating and acting autonomously. The severe physical and motor impairments became secondary, as the Court came to believe it could judge, and verify, his power of self-government by directly linking actions and words to mental states without the mediation of physical processes or the intervention of visible others.

The Courts were able to devolve to Jose full legal and political rights because the system composed of Jose's body and different assistive technologies produced the kind of evidence legal knowledge normally demands for the recognition of natural persons. The operations carried out on the Internet – the Court, as we noted, was especially taken by Jose's management of his bank accounts – were accepted as the indubitable expression of a self-governing actor. The discrepancy with the Supreme Court's ruling on Mauricio's case suggests that the nature of the components of the socio-technical system of care and mediation which LIS patients come to depend on makes a difference as far as their legal status *qua* political subjects is concerned. This raises an important concern over the equity of a system that grants – or in this case restores – full citizenship only to those patients who have access to expensive and technologically intensive forms of assistance, but that deploys the full scale of legal suspicion when those interfaces appear mundane or particularly laborious.

In the case of Jose C., the Court was able to balance the law's emphasis on 'self-government' as the fulcrum of full citizenship with the appreciation of the forms of intensive care and distributed action that characterize the form of life under Locked-in Syndrome. The restoration to Jose C. of his full civil *persona* offers an opportunity to rethink citizenship as a fragile *position* in need of constant care, rather than as an inalienable *condition* inscribed in our bodies. It is this notion of citizenship, a notion compatible with the reliance on intense and distributed forms of socio-technical support and knowledge, that we want to explore in the following section.

4 Citizenship as care

When it struck down the initial declaration of total incapacity, the Appeals Court suspended Jose's regime of *tutela* – tutelage by a legal guardian – and introduced in its place a different legal figure, that of *curatela*. *Curatela* harkens back to the *cura* of Roman law: 'a guardianship that protects the interest of youths ... or incapacitated persons' who, while being

1 recognized as *sui juris* (that is, possessing full legal and political rights),
 2 were in need of temporary or partial protection (Black's *Law Dictionary*,
 3 7th edn, 1999: 386). The term is generally translated into English as 'con-
 4 servatorship' or 'curatorship', but the Spanish word conveys etymological
 5 connections to 'care' and 'cure' that these English words barely express.⁴

6 With the change from *tutela* to *curatela*, the Appeals Court shifted the
 7 focus of the law's interest, from the transference and representation of
 8 Jose's will to the supervision of the forms of care to which he was entitled.
 9 The key distinction between the two conditions is that under *curatela* the
 0 actor retains – or, in Jose's case, recovers – full civil rights, including the
 1 right to vote and administer his property, whereas in a situation of *tutela*
 2 the subject is divested of his legal *persona*. The role of the court-appointed
 3 'curator' is limited to assisting the person in relation to the physical needs
 4 specified by the Court; the purpose of the legal intervention is to supervise
 5 the provision of the forms of care and help that would enable a partially
 6 incapacitated individual to carry out the actions necessary for his suste-
 7 nance (see Código Civil [2008], Title X, chs II, III). 'It is not necessary,'
 8 the Court ruled on Jose's appeal, 'to make up for⁵ the will of the claimant,
 9 which he conserves in full, but to assist him in the material execution of
 0 those acts he chooses to do but is unable to carry out on his own.' Rather
 1 than replacing or representing the subject's will, then, the curator's func-
 2 tion is 'to strengthen, control and channel' it (Jdo. De Primera Instancia
 3 de Valladolid [2006] 00030/2006).

4 The care received by a patient placed under the legal regime of *curatela*
 5 should in principle be no different from the care he would receive under
 6 the condition of *tutela*. The difference is that under *curatela* that care is all
 7 the law concerns itself with, whereas in a situation of *tutela* the law is prima-
 8 rily preoccupied with the handover of rights and the mechanics of legal
 9 mediation that follow a declaration of total incapacity. Thus *curatela*
 0 describes a legal complementing of the person that is squarely focused on
 1 the care of the body, its needs and the material execution of its desires,
 2 rather than on the legal representation of the will that the figure of the legal
 3 guardian implies. In this final section we would like to explore the implica-
 4 tions of such a figure, a legal *persona* that is deemed complete (from the
 5 point of view of rights and entitlements), but at the same time is defined in
 6 terms of the physical body's lacks and needs. For what the Appeals Court
 7 effectively construed in the case of Jose C. was a model of citizenship that
 8 rests on an assortment of devices, interfaces and communicative prostheses,
 9 a legal subject that displays his powers of self-government through bio-
 0 technological interfaces, a *persona* that is the result of socio-material media-
 1 tions but can be known by the law with the pristine clarity of the fully
 2 autonomous self. Unable to locate the source of personhood in the self-
 3 contained, healthy body, the Court nevertheless recognized Jose's distrib-
 4 uted personhood as a legally able subject, disentangling his disability and
 5 physical dependency from the issue of his citizenship.

The case of the LIS patient before the law resonates with Annemarie Mol's (2008) discussion of the forms of care that accompany life with diabetes. Mol argues that we should understand the ailing body, the body in need of care, as a fully formed, even the standard form of political life. Mol wants to challenge those philosophies of citizenship that, explicitly or implicitly, are premised on the possession of a body that can be 'controlled, tamed or transcended' by the individual's will (2008: 31), a notion of the political subject for which reliance on the care of others – persons or things – mars the ideal of the self-governing and autonomous citizen. Would Mol's argument still hold at its limit: a conscious human body completely reliant on and enmeshed in practices of care, the individual afflicted by LIS? The Appeals Court's ruling on Jose's case, and particularly the legal figure of *curatela*, shows that it does, by describing a status that reconciles all-encompassing care and full citizenship.

Care of the LIS patient is, needless to say, much more critical, forceful and encompassing than that received by individuals with diabetes. It involves supplying all the material and physical requirements of life: ensuring adequate oxygenation and preventing the complications caused by immobility and incontinence, in addition to providing assistance for all forms of physical activity – breathing, swallowing, positional changes, etc. The eyes, often the main instrument of communication, need to be protected against corneal ulceration; pathological crying, a condition common to LIS patients (Bauer *et al.* 1979), is sometimes treated with selective serotonin re-uptake inhibitors. The intensity of these activities demands a complex, and expensive, system of care that includes a full-time professional carer, the attention and effort of relatives, and a constellation of artefacts and technologies, such as feeding tubes, a multi-position bed, a wheelchair and other especially adapted vehicles to transport the patient.

And yet, despite the intensity of this care, the arguments put forward by Mol in her defence of *patientism* – the understanding that living with a disease can provide a new standard model of the citizen – can illuminate the legal and political position of LIS patients. First, because the body in care, even the body of a LIS patient, is an active body. 'In order to stay alive,' Mol writes, 'a body cannot just hang together casually. It has to act' (2008: 39). The relationship of the body to the practices of its care is not a passive one: 'We do not engage in care despite, but with, our bodies' (2008: 40). This is nowhere more evident than in patients with Locked-in Syndrome. The LIS-affected body must act, not only in the socio-technically mediated fashion we discussed earlier when describing the aids that enable communication, but in the very manner in which the body responds and adjusts to the practices of care and to its providers. The relationship of the LIS patient to his body cannot be described in terms of control – the traditional relationship between will, desires and physical actions has been thoroughly broken, and the body is fully reliant on a distributed system of life support – but the active participation of the patient

1 is nevertheless part and parcel of the regime of care. Care does not simply
 2 happen to the patient; he remains engaged in the nursing and nourishing
 3 activities that, now distributed along an ever more complex set of devices,
 4 technologies and people, sustain his ability to be an actor in the world.

5 An element of this engagement is captured in medical discussions of
 6 the LIS patient's involvement in decisions about his care, in oft-heard
 7 arguments about the need to consider him a party in the assessment of
 8 treatment options. 'At the bedside,' write Plum and Posner in *The Diagnosis*
 9 *of Stupor and Coma* (4th edn 2007: 7), 'discussion should be *with* the
 10 patient, not, as with an unconscious individual, *about* the patient.' Smith
 1 and Delargy (2005: 407), reporting on their own experience caring for LIS
 2 patients, write that: 'Although cognitive ability should not be overesti-
 3 mated, survivors' views regarding the focus of acute treatment, rehabilita-
 4 tion goals, and life choices should be formally sought'. In the guidelines
 5 for the 'care and management of profoundly and irreversibly paralyzed
 6 patients with retained consciousness cognition', produced by the Ameri-
 7 can Academy of Neurology in 1995 and which include, as 'the most
 8 extreme example', individuals afflicted by LIS, it is clearly stated that such
 9 patients should be in a position to make decisions about their treatment
 10 choices. The presence of consciousness is the critical factor: 'Clinical
 1 decision-making for these patients should proceed along the same line as
 2 clinical decision-making for non-paralyzed, competent patients, that is,
 3 physicians have the obligation to follow the health care decisions compe-
 4 tently made by their patients' (American Academy of Neurology 1995).

5 Yet the activity and engagement of the LIS patient in his care goes beyond
 6 the provision of information and his ability to make punctual decisions about
 7 his care. It extends to the patient's relationship to the different components
 8 of the assemblage of people, artefacts and devices that sustain his personal
 9 and social existence. In her analysis of how the body afflicted by neuromus-
 10 cular disease adjusts to the wheelchair, Winance noted the hard work on the
 1 material and emotional links between body and device necessary for the
 2 latter to become a personal prosthesis; it is only through 'hard and lengthy
 3 work' (2006: 66), on the part of the device, the patient, and those assisting
 4 their mutual adaptation, that the aid 'becomes part of the body (and the
 5 person) in the sense that it modifies the way the person perceives, moves,
 6 and relates to the world' (2006: 58–59). The 'common materiality' that
 7 Winance describes as the effect of this process of mutual adjustment is at the
 8 same time enabling and disabling – it defines the transitions between
 9 comfort and pain, it constitutes what is allowed and what is forbidden
 10 (Winance 2006: 66). What we want to suggest here is that the LIS patient
 1 carries out forms of work and engagement – cognitive, physical and emo-
 2 tional – that go well beyond the provision of 'informed consent' to treatment
 3 decisions. This work, whether we characterize it as 'adjustment' to the arte-
 4 factual environment or 'attuned attentiveness' to the care practices of others
 5 (Mol *et al.* 2010: 15), is essential to sustaining the collective forms of action

that characterize the LIS patient's involvement in the world. *Curatela*, 'curatorship', is a good legal articulation of this position, in its ability to recognize physical disabilities and emphasize the importance and intensity of care – for the provision of which it creates a system of judicial supervision – while recognizing the full legal and political personhood of the patient. In contrast to the exclusive preoccupation with *autonomy* that shapes the regime of tutelage, *curatela* directs the law towards the complementing of the patient's *agency* through different systems of care and support (see Willems (2002) for a discussion of the distinction between autonomy and agency).

The centrality of care to Jose's restored legal *persona* takes us away from the notion of citizenship as an inalienable condition deriving from inherent human capacities – such as the capacity to perform certain cognitive operations or to carry out actions autonomously – and moves us in the direction of citizenship as a precarious position in need of constant care. Yet, as we have argued, to care and to be cared for are not subjective dispositions but complex practices embedded in socio-technical systems of support and knowledge. The case of LIS provides a telling example of the ongoing, collective effort that is required to produce and, crucially, *sustain* the conditions of intelligibility required to become a full-blown citizen. When seen from the perspective of care, citizenship emerges, then, as a position that is carved out and made available collectively.

5 Conclusion: infrastructures of care and the production of citizenship

Hard cases make bad law, as the adage goes. Locked-in Syndrome is perhaps a condition too exceptional to draw far-reaching conclusions. It offers, however, a valuable test case to explore how the boundaries of personhood are negotiated in the face of new forms of techno-scientific enhancement. The development over the past decades of novel biotechnologies, neurocognitive and computational interfaces, and other, more mundane assistive devices, has given rise to hybrid and distributed forms of personhood that call into question the identification of the person with the biological individual. The application of some of these technologies to LIS patients reveals that the capacities and processes that have customarily defined the person – agency, intentionality, speech – need not be performed within the confines of the biological body, but may be enacted through extended systems of care and knowledge.

The disparity of outcomes in the two cases discussed in this chapter illuminates the difficulties of legal knowledge in recognizing and adjudicating legal personhood once the biological boundaries of the body can no longer be taken as the obvious marker of the autonomous self. The LIS patient projects a fragile, highly mediated, techno-socially distributed form of personhood, whose conversion into a legal *persona* raises a number of difficulties. It is as if the law were for a moment thrown back to a situation

1 of undecidability, and was forced to build the distinction between ‘person’
 2 (*persona*) and ‘thing’ (*res*) from scratch again. Yet, as Pottage (in Pottage
 3 and Mundy 2004: 5) reminds us, ‘the problem is that humans are *neither*
 4 person *nor* thing, or simultaneously person *and* thing, so that law quite literally
 5 makes the difference’.

6 We are here reminded of the Latin origin of the modern notion of the
 7 person. As Marcel Mauss famously wrote, in the Roman world ‘the person is
 8 more than an organisational fact, more than a name or a right to assume a
 9 role and a ritual mask. It is a basic fact of law’ (Mauss 1985 [1938]: 14). This
 0 basic fact – the constitution of the person in opposition to things and
 1 actions – needs to be reconstituted and upheld in the face of a multiplication
 2 of hybrids thrown up by modern techno-scientific knowledge. The law
 3 is called to adjudicate over these new mixtures to determine which socio-
 4 material combinations are entitled to the rights of ‘natural persons’. As we
 5 have seen in the cases of Mauricio and Jose, this process of adjudication is
 6 uncertain and contentious. It depends on producing, by novel means, evidence
 7 of the sorts of qualities the law has long associated with the recognition
 8 of natural persons. A specially adapted mouse, computer-based assistive
 9 technologies and Internet-based banking were used, in Jose’s case, to demonstrate
 0 to the Appeals Court an ability to govern oneself. The alphabet board, the pen,
 1 the assisting nurse and Mauricio’s persistence were not enough to display this
 2 same quality to the Supreme Court, for they left the judges with the lingering
 3 suspicion that what they had witnessed could in fact be an act of impersonation,
 4 rather than personification.

5 Mauricio thus remained in the limbo of *tutela* – his will represented, for
 6 key legal and administrative purposes, by his mother acting in her capacity
 7 of legal guardian. Jose, on the other hand, was reintegrated into the political
 8 community as a subject endowed with full civil and legal rights through the
 9 figure of *curatela* – a form of existence that reconciles full citizenship with
 0 an intense regime of care. With the imposition of *curatela* the Court de facto
 1 recognized that Jose’s intelligibility as a political subject, as a citizen, could
 2 not be simply found within his body, but was dependent on an extended system
 3 of care, on the continuous use of a distributed network of expert knowledges
 4 and technologies. In so doing it opened the door to a notion of citizenship
 5 in which the biological individual is not seen as the necessary correlate of the
 6 political subject.

7 LIS patients are not alone in pushing the boundaries of legal personification.
 8 Patients in vegetative states, human embryos or individuals with mental and
 9 physical disabilities or suffering from addictions are other examples of ‘boundary
 0 subjects’, whose status as persons – and the nature of their civil and political
 1 rights – is dependent on the varying configurations of different systems of
 2 knowledge and care. The apparent proliferation of these liminal forms of
 3 personhood is partly the result of new techno-scientific platforms, partly an
 4 effect of the law’s continuous interrogation of its own categories. In any case
 5 it challenges the viability of

a notion of citizenship that takes the self-contained, self-mastered biological body as the ultimate standard, in a world increasingly populated by thoroughly mediated forms of life.

In this chapter we have argued for the need to depart from the notion of citizenship as an inalienable condition of the bounded biological individual, and to treat it instead as a position defined by the intersection between legal forms of personification and infrastructures of support, knowledge and care. The LIS patient is not, in this respect, different from his fellow citizens, but the extraordinary laboriousness – physical, technical, emotional – involved in producing evidence of his personhood before the law lays bare the socio-technical conditions of citizenship. The cases of Jose C. and Mauricio P. illustrate how the intelligibility of the patient as a self-governing person is dependent on the kind of *evidence* produced by the different mediations and prostheses through which the individual presents himself. Yet as the diversity of fates of Jose C. and Mauricio attests, the scrutiny of the law falls unequally on the evidence produced by different technologies: some socio-material arrangements stand a better chance to be considered *mere* conduits or aids for the expression of the autonomous self. The implication is that citizenship is unevenly distributed; it is a function of the relation between the type of evidence produced by different techno-scientific systems of care and of the specific modalities and forms of authentication legal knowledge chooses to deploy in each case. If we consider citizenship as an abstract, immaterial quality, residing somewhere in the self – a self that can be found, moreover, within the boundaries of the body – we will tend to miss these differentials. A socio-material perspective on citizenship, one that regards citizenship as the result of distributed, collective efforts, as a position sustained by relationships of care, knowledge and assistance, is a first step towards confronting the inequity of its distribution in an era of proliferating techno-biological hybrids.

Notes

- 1 Three varieties of the syndrome are generally identified in the medical literature: classic, incomplete and total (Bauer *et al.* 1979). In its classic form, the patient has full consciousness and is only capable of vertical eye movement. Patients suffering from incomplete LIS preserve or manage to recover other types of voluntary movement, whereas in the case of total LIS the patient suffers ‘total immobility and inability to communicate, with full consciousness’ (Smith and Delargy 2005: 406). There are chronic and transient forms of the condition in each of these three categories.
- 2 Smart *et al.* (2008: 451–452) describe the slow and highly elaborate progression of the diagnosis for an initially comatose patient who recovered spontaneous eye movement.

Although it was possible to elicit reproducible eye movements to command, the patient’s fluctuations in arousal and persistent ocular bobbing notably compromised the consistency of the responses. It was not until the arousal disorder and ocular bobbing resolved that he was able to consistently follow eye-movement commands.

- 1 Alfred Gell (1998) used the notion ‘distributed person’ to refer to the different ways in which the self becomes ‘distributed’ through the persons and objects that bear the sign of its agency. The objects we produce are *literally* externalized parts of our selves, and act as ‘indexes’ of our agency. It is in this sense that it is possible to claim that an artist becomes ‘distributed’ in the artworks she produces, or that her works are indexes of a ‘distributed’ person. Our use of the phrase in this chapter is different from Gell’s. We employ it to describe the different modes in which extended techno-scientific systems of support and care enable the self to act and become intelligible as a distinct person.
- 4 The term ‘conservatorship’ is used in Anglo-American law to describe situations where an organization or individual is placed under the limited or temporary control of an external actor. For instance, in 2008 the US financial institutions Fannie Mae and Freddie Mac were placed into the ‘conservatorship’ of the Federal Housing Finance Agency. Mentally ill or severely disabled individuals are also commonly placed under ‘conservatorship’. This legal form has also been used in efforts to remove individuals, against their immediate will, from religious sects.
- 5 The Spanish verb *suplir* may be translated as both ‘replace’ and ‘make up for’.

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