

# The complex reality of mobility aids and ISO Standards in Transport

## Abstract

We all in a sense are unique in our capacities to care for each other while managing the complex reality of daily life. A fundamental concept is equal human rights.

More awareness is needed of the complexity of transport situations. The variety of passengers, the multiple actors involved and the tendency to blame workers or passengers when accidents happen needs attention. What happened? How, in a restorative culture, can we address the needs from first and second victims of an accident? Offer support, instead of immediately start searching the rules that are broken and who is to blame and to be fired.

And how as a society do we take wheelchair passengers serious? How to take the burden of their back, to be always alert that their personal situation is the basis of product prescription and safety requirements? It should be a joint effort to learn and improve instead of an individual burden! As a society, trying to improve the transport situation of people with a handicap, we stand before a fundamental choice: Do we keep blaming accidents on drivers and passengers for not fitting the abstract top-down rules? Or do we accept that real improvement relies on the common knowledge of complex practical transport situations, and passenger variability? Thus requiring communication, of the solutions found and learned, to improve resilience to pro-active handle the situation once risks appear.

## Introduction

After working a large part of my life in Research on the safety of the transport of people with a disability<sup>i</sup>, more and more I became aware of the limits of my knowledge concerning the daily reality of several aspects of transport. Although I have researched accidents, talked to passengers and drivers, written reports with recommendations for the Dutch Ministry of Transport, performed safety checks on taxi-buses, had real life experience on personally driving my complex disabled (foster) son, being driven by a taxi-bus together with my son and having experience in guiding the design of the 5-point safety belt in his last wheelchair<sup>ii</sup>. There is still a lot that I and other people in the field are missing. The Medical Device Regulation as such is clear. Standards are drawn up in a clear way. Complicated maybe, but not complex!

It is the interpretation of the MDR, the Standards, the difference between work as prescribed and work as done, the interaction of humans and all parties involved, that, in the daily practice under sometimes difficult circumstances, create a complex reality. A reality of which nobody alone can have a complete picture, although we sometimes think otherwise.

These insights came to me discovering a video from the late Richard Cook, "Resilience In Complex Adaptive Systems"<sup>iii</sup>.

- You cannot manage human error. People make mistakes.
- You cannot manage Risk to a zero level.
- You can learn from experience.
- You can learn even better and get more valuable insights on real life daily events when there is trust to communicate daily complex and real-world experiences between parties.
- Together we can limit the consequences of accidents and failures that occur.
- Resilience can only be improved if, in common trust and responsibility, proper communication exists beyond the borders of companies, government and people on the daily workplace.

In preparation of this opinion article three things struck me while reading material on the application in the transport of people with a handicap sector.

1. The response of the wheelchair and transport work field to the introduction of the Medical Device Regulation in the Netherlands, against the background of ISO standards and UN Convention on the Rights of Persons with Disabilities.
2. Limitation of the scope of Research projects is leading to exceptions not researched or insufficiently seen from a UN Convention perspective.
3. On X (twitter) a passenger complained about the use of a tie down system with broken front tiedowns. The first response in case of an accident is often to blame the driver for not following safety rules! But is that the whole story?

After an overview of part of the Background (citations) I will discuss these examples in more detail. And conclude with a recommendation how to improve Resilience and Safety.

## Background

### Convention on the rights of Persons with Disabilities

*The Convention on the Rights of Persons with Disabilities<sup>iv</sup> is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities. Parties to the convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that persons with disabilities enjoy full equality under the law. The Convention serves as a major catalyst in the global disability rights movement. Enabling a shift from viewing persons with disabilities as objects of charity, medical treatment and social protection. Towards viewing them as full and equal members of society, with human rights.*

### Disability Politics and Theory<sup>v</sup>

#### Chapter 5 The Rights and Social Models.

A.J. Withers et.al. distinguish negative rights and positive rights: *"Today, rights are understood as being a part of one of two broad categories: negative rights and positive rights. According to Young and Quibell (2000: 749), negative rights are those involving "equality of treatment," while positive rights involve "equality that requires special treatment." That is, positive rights are associated with accessibility and accommodations."*

#### Chapter 6 Radical Disability Politics

Loree Erickson: *"When we recognise disability outside dominant frameworks not as a deficit, but as a necessary and generative part of our lives, movements and social organisation – vital alternative ways of living and being are opened. Radical disability politics and practices allow us to interrupt violent and damaging ideologies about bodies, difference, vulnerability and power. Interdependence, as an example, a way of being and caring with and for each other that operates from the belief that we all have needs, we all need each other and we can all provide care, centres and celebrates difference and needs in a way that interrupts the individualism, isolation, and normalisation so key to the operation of oppressive logics. Individualism, isolation and normalisation join together to ensure that we remain disconnected from ourselves and each other. One of the most insidious ways movements are undermined is through the propagation of cultures of undesirability which create policies, environments, structures and ideologies that tell marginalised people that we are disposable unless we are consumable (e.g. rehabilitative and prison labour, medical and social work professions)."*

### Do Safety Differently<sup>vi</sup>

In the book "Do Safety Differently", Sidney Dekker and Todd Conklin define **safety clutter** as: "... *safety clutter is the accumulation of rules, policies, safety procedures, documents, roles, and activities that are implemented and performed in the name of safety but do not contribute to the safety of operational work. Safety clutter may well distract from those things that could help improve the safety of work.*" a little further Dekker and Conklin state: "*But clutter can take many other forms. Perhaps the most ridiculous clutter is also the most irritating for those who prefer to use common sense, who want to be taken seriously, and want to get work done. This sort of clutter comes from role and rule creep: the gradual spreading of safety rules or symbols that were never intended for the place they end up. But once there, they lose relevance and credibility—even if they can still get enforced. ... People who feel newly empowered can impose rules on others, which at the same time gives them more to do, more authority to do it, and surrounded by an aura of inevitability. They can even claim that, what they are doing is both ethical and necessary and that those who disagree are not taking safety seriously.*"

## Medical Device Regulation<sup>vii</sup>

In Europe the Medical Device Regulation (MDR) "*is part of the EU harmonisation legislation on health, safety and performance of products in the internal market.*" ... "*In this kind of legislation, the role of the harmonised European standards (hENs) is key: actually, for product characteristics, the content of legislation is limited to establishing essential requirements that products intended to be placed on the EU market must meet.*" ... *Products designed and manufactured according to applicable harmonised European standards the references to which are published in the Official Journal of the European Union (OJEU) benefit from a presumption of conformity with the relevant legal requirements.*"... "**However, in general the use of harmonized standards is voluntary.**" (**bold** added by the author) These quotes from the Medical Device Coordination Group (in document MDCG 2021-5) in a nutshell explain the relation between harmonised standards and legal requirements. *The concept of essential requirements is based on the assumption that the harmonised standards reflect generally acknowledgeable state of the art.*

## Synesis

In his book Synesis Erik Hollnagel emphasises that in a complex organisational environment we should not look at Productivity, Quality, Safety and Reliability in fragmented ways:

*"Final words We should be concerned about any issue that is essential for the existence and long-term sustainability of an organisation – but not in isolation and not in a fragmented way. On the contrary, it is absolutely necessary to overcome the consequences of fragmentation, whether it has historical or psychological reasons. To do so requires changing the ways that common problems and issues are addressed, first and foremost by being realistic about the scope and time window of changes. We should be concerned about productivity and do whatever we can to ensure both short- and long-term productivity goals – but not in isolation and not in a fragmented way. We should be concerned about quality and do our best to ensure that we achieve the quality we need – but not in isolation and not in a fragmented way. We should be concerned about safety when things go well and when they fail – but not in isolation and not in a fragmented way. And, finally, we should be concerned about reliability and try to ensure the necessary reliability of functions in every aspect of system performance – but not in isolation and not in a fragmented way."*

I suggest to add the positive rights to Accessibility as a fifth principle.

## Discussion

1. In Europe products like wheelchairs and seating systems have to comply to the essential legal requirements from the Medical Device Regulation, and manufacturers are held to follow up their products after market.

The idea behind the ISO 7176/19<sup>viii</sup> and ISO 16840-4<sup>ix</sup> Standards is that once a wheelchair base has been tested to ISO 7176-19 and a seating system passes ISO 16840-4 that different compliant wheelchair-bases and seating systems could be combined, of course with proper attention for the connecting interface. These combinations should not have to be tested once again.

In the Netherlands however, a lot of different combinations have been tested again, a requirement to appear on the branch organisation's list of preferred products, which excludes companies without the means to fund a large amount of crash tests. This has been a very costly and market disturbing exercise. From a liability point of view, manufacturers limit, in user manuals, the intended use to those combinations. They state that they are not liable for combinations or adaptations of products outside their intended use scope.

**Unfortunately for them, wheelchair users are highly unstandardised in their needs and exceptional by nature.**

This poses a problem for adaptation companies to fit the right wheelchair seating combination to the user, especially if traveling is essential in combination with wheelchair needed add on devices like Oxygen systems, robot arms etc.

Fortunately, accidents happen seldom. If everything goes well, the adaptation companies are praised for their skills. However, in case of a major accident the blame lands with the same worker, who was praised before. Blaming the last in line who added a back view mirror to the wheelchair seating combination... or even the user, who signed a claim waver for the use an exceptional wheelchair in transport. Well, was signing the waver a voluntary decision? Could the user decide otherwise? Could the user decide to not use a properly fitted wheelchair in transport, without the oxygen support? Has the adaptation company a choice to not adapt? Leaving users with complicated wheelchairs stuck and out in the blue? The ISO 7176/19 standard states very clear at the end of the introduction: *Transportation is only one of many daily activities that introduce unique circumstances and requirements that wheelchairs and people who use wheelchairs can experience. Wheelchair products that conform with this document will have additional features that provide increased level of occupant security and safety whilst their occupants riding in motor vehicles. However, a failure to conform with this document cannot be used to limit access to, and availability of, motor vehicle transportation for people who use wheelchairs.*

The UN Convention on the Rights of Persons with Disabilities has been ratified by many countries. Is acting against it, not against the law as well?

2. The paragraph in a master thesis on the restraint path of custom seating, about the scope of the research:

#### *"2.3.1 Out of scope*

*Only adults with normal anatomy will be considered throughout this study. The range of abnormality that custom seating accommodates for and the differences in children's anatomy could be, subjects of study in the future but are too diverse to be considered in the scope of this project. Equipment misuse is also not in the scope of this project."*<sup>ix</sup>

It is rather common in research to limit the scope, to keep research projects workable. But we do need to be aware of the consequences: The exceptions that are not taken into account, especially if regulations and common transport rules heavily rely on standards and research results. Exceptions concern people, people with an equal right to fulfilment of their needs, with an equal right on transport. In daily practice we face the consequences.

People cannot always sit straight up, sometimes they can only travel nearly lying down. An active low backrest wheelchair can be highly required by a person with a high spinal cord lesion, for manoeuvrability. The safe alternative a transfer to a seat costs a lot of energy from

the passenger. The lack of a high backrest does pose a risk in transport. Solutions are developed occasionally, but mostly not implemented at a large scale. (see <sup>xi</sup>) Another returning problem in wheelchair taxi transport is fixation of luggage and especially O<sup>2</sup> cylinders. Most taxi vehicles are lean equipped with standardised in-floor restraints on fixed distances. The driver is always on a tight time schedule and often puzzled how to handle exceptional wheelchairs and luggage.

The Code VVR rule: *"If the wheelchair passenger cannot be transported safely, then transport, if necessary, in the interest of all parties involved has to be refused."*<sup>xii</sup> The transport company, the driver decides what is safe, lacking knowledge on wheelchairs. What's next for the refused passenger? What does *"if necessary"* mean? There is a high need for information on good practice examples. Examples and solutions in situations where standard rules cannot be followed. Examples we can learn from. We do not learn from this currently set rule in the Netherlands. Again, if the driver transports and all goes well, the driver is great. If there is a major accident the driver is the victim, of the 'wrong' decision he took. The rule is not clear and discriminatory. Parties higher in the system have a role in the accident as well. Work field communication between transport companies and wheelchair manufacturers is, apart from a few positive exceptions, lacking. Safety in this area is a complex problem. Stop blaming each other and start working on common developed solutions.

3. On X (twitter) a complaint from a wheelchair passenger: A public transport train breaks down and passengers need to be transported further by buses. Wheelchair users need a wheelchair taxi-bus for transport. In this mentioned case apparently the front tiedowns in the taxi-bus were damaged and couldn't be used to restrain the electric wheelchair of the passenger.

The driver uncomfortably stating: "Well, they are broken, aren't they?" And started driving. Fortunately, it didn't go wrong.

Now how did this arise? Was the taxi-bus company suddenly hired? Were all other vehicles already in use? Loading electricity? Was it an old bus held in reserve, a spare vehicle lacking maintenance? If the driver refuses transport, because he discovers the broken restraints in the last moment, what happens to the passenger? How is replacement transport by the train company organised, concerning the current lack of drivers? Ad hoc, during already extremely busy pupils transport hours? A lot of questions I cannot oversee or answer. What I do know that this is not a driver's problem alone. This is not a driver's issue but a system problem of which we need to be aware. Yet, if it went wrong who is probably blamed and punished? Is that Just Culture?

These examples give an insight into the difference between theory, work as foreseen (in tender rules and ISO standards) and the complexity of daily practice. I can't blame individual workers taking decisions to get work done in an imperfect world. Especially if communication and cooperation between all involved parties are hindered by liability and distrust issues between higher end parties involved waving liability by a breach of "intended use".

## Safety Clutter

Safety Clutter plays an important role if differences between **Work as Intended** and **Work as Done** are not taken seriously enough. It can pose a risk that in daily life people with a handicap are denied transport on false grounds. Meanwhile drivers and passengers are unable to get attention for the real world risks they encounter and try to handle each day. Not learning from daily practise, the hard way by recurring accidents, for which drivers and passengers are held accountable. While they lack the influence to do something about it.

This dilemma is illustrated perfectly in a (Dutch) article in *Personenvervoer* (March 2019)<sup>xiii</sup> discussing the Code VVR and its implications in daily life. In the workplace a WMO advisor Sandra Jacobs (dewmoadviseur.nl) states: *"I have already received the first request for individual transport*



*since the client's wheelchair can no longer be transported together with other travellers because it does not meet the ISO standard. Can someone arrange that those involved know what is expected of them? It cannot be that we WMO advisors have work to do because transport requirements for wheelchairs are being tightened? Or have I missed an addition to my duties somewhere?*

(Translation from Dutch by the author)

Meanwhile daily life risks in transport do not receive proper attention. Sitting on a scooter while using the wheelchair lift is prohibited in the Code VVR, due to the risk of driving over the roll-stops and falling off the lift. The passenger has to step down from the scooter, manage three steps to enter the bus, or is wheeled in, in a separate hand driven wheelchair by the driver (at least if that wheelchair is available on the taxi-bus!) or the passenger has to stand on the lift holding the railing, supported by the driver to get in the vehicle. If these solutions pose a problem: transport is refused. New risks are taken to avoid a risk. The ergonomic false design of using a (handbrake type) handle for acceleration is probably the main reason for driving over the roll-stops maybe in combination with a high-speed setting (Hare instead of Turtle). This problem already exists for decades. Solutions do not receive proper priority. Guess who is held accountable if an accident happens? The scoot driver for the human error, and the taxi driver for not imposing a safety rule? And ... electric wheelchairs also have the power to drive over the lift's roll-stops and fall off a lift.

## Conclusion

If we want to improve ISO standards even further in a complex transport situation with passengers who are all different and need different support, we will have to place more emphasis on **Work as Done**. Currently there are too many top-down rules that, in the event of an accident, place responsibility on the driver or the passenger. In non-accidental daily practice, when drivers and passengers raise unsafe situations or make suggestions for improvement, they are hardly heard. There is a field of tension between:

- The work has to be done,
- it has to be safe,
- everyone has the right to good quality transport,
- not everything is financially possible.

This tension field must also be clear to the drafters of standards and rules. Not to wave responsibility to another party, but in a “can do” mentality. Situations are not wrong, but they can always be improved. You cannot say there is no money and then leave everything the same. That...is against the principle of the MDR. Especially if the same types of accidents repeat themselves over and over again. Or if people with the most severe disabilities have a much higher risk of being denied transport.

It is nearly impossible to always create an equally safe situation as described in the motor vehicle safety approval regulations. By strictly using these rules and applying them out of context in the situation of transport of people with a handicap.

For example: Handling a three-point safety belt, in case of an emergency, becomes a challenge if you are born with no arms.

There are many more examples like this.

Instead, we need an evidence-based learning cycle from practical experiences, as a source for standardisation.

Andrea Walraven-Thissen is trained in psychiatry and specialized in the prevention of trauma after disasters and (terrorist) attacks, in [a plea to go back to an evidence-based approach<sup>xiv</sup>](#) (Dutch), she states:

### **“Evidence Based First Response**

*In a changing world in which a lot is made a political issue, it is increasingly important that we work evidence-based. That process always consists of three parts, which you continuously evaluate;*

- *you conduct, analyse and implement scientific research*
- *you test your work process in case studies, based on field competence*
- *you test your work process against the experience of your target group.”* (translated from Dutch, RV)

## Information from work as done

- By providing drivers trust and confidence when they report unsafe situations, to avoid pre-accident situations.
  - What do they consider unsafe situations, how do they deal with it?
  - What have they learned from near accidents?
  - When did they refuse transportation and what did that mean for the passenger? Was there a follow up and how was it followed up? Where there contacts and cooperation with the restraint and wheelchair manufacturers? Which solution was found?
  - What is it like, to start as a new driver? What do you experience on a daily bases, and how do you feel about what happens? Why do so many drivers leave their job?
- By creating safe transport situations for drivers in consultation with passengers.
  - What do passengers need to be transported safely?
  - What is their perspective on safety, given their disability?

This also requires cooperation from the government in tendering for transport and providing the right resources. It requires cooperation from aid suppliers, adaptation companies and vehicle builders. This goes beyond the interests of companies and their liability policies. This requires sensible choices that are made jointly with passengers and the professional field and recorded for Government inspection. This involves a learning process to continuously improve the quality and safety of transport, building resilience to be jointly alert to opportunities and act pro-active on emergence of pre-accident situations.

As a society, trying to improve the transport situation of people with a handicap, we stand before a fundamental choice:

Do we keep blaming accidents on drivers and passengers for not fitting the abstract top-down rules.

or

Do we accept that real improvement relies on the common knowledge of complex practical transport situations, and passenger variability. Thus requiring communication, between all parties, of solutions found and learned, to improve resilience to pro-active handle the situation once risks appear.

You cannot be blamed to don't know what you don't know, but people have great 6<sup>th</sup> senses to feel that something is not quite right, ask questions to learn. Blame sucks anyway<sup>xv</sup>.

May I end wishing the reader, safe hours in transport, a fruitful discussion on proper accessibility, experienced drivers, a restorative just culture and, most and before all, let's improve safety together.

The Hague, April 21, 2024

Roelof Veenbaas

## Literature

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