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Fifteen years ago, my girlfriend Trudy and I fell in love with a house situated in a small village in the northeastern part of Friesland. And as most of you probably know, the Frisians have their own language. And, as it turned out, in the part we moved to they spoke a kind of Frisian that even the other Frisians couldn't understand well and to us it was complete gobbledegook.

Just after our first week over there we got invited to a birthday party and a bit nervous we showed up at the right time and at the right place, offered our congratulations and presents and were introduced to the rest of the guests and I got seated between two middle aged women.

After 20 minutes of sitting there in silence, not understanding a word from what was being said and feeling very uncomfortable I suddenly could make out a few words. And a bit later I was sure: They were talking about skin-problems; something I could relate to.

Gladly I jumped to the occasion and opened my mouth to say: "I can relate to that, as a kid I used to have a greasy skin, especially on my forehead, causing breakouts of pimples there"

And then everything went horribly wrong and I heard myself say: "I can relate to that! As a kid I used to have a greasy foreskin"

I now had the attention of the entire room that had fallen quiet at that confession and my face turned red while I was thinking I have to correct this and explain it that it just came out wrong.

So in complete panic I yelled: "Oh no no no! Oh God no! That came out wrong, I didn't mean that, I am circumcised".

Yeah....well....it wasn't considered that funny back there and then in that part of the Bible-belt....We now live in the middle of the Netherlands again in Wageningen.

The reason I am sharing this with you is to show you that being at the table is one thing, being able to contribute and to be a valued guest over and over again is an entirely different story. **Slide 2** For that you always have to be and stay part of the solution. Adding to problems, or becoming a problem by showing up or speaking out too often or at the wrong times will not get you at the table ever again. Another thing is that you have to have your facts right and you have to be transparent, coherent and realistic in your suggestions.

When I first joined Inspire2Live I was overwhelmed with the amount of knowledge and brilliant ideas that popped up on almost a weekly or even a daily basis. But it also confused the hell out of me. I had no idea who was doing what and with what purpose something was communicated just right there and then at that time. In a lot of cases it seemed to land nowhere which wasn't doing justice to the idea and the work put into it. I couldn't see any follow-up given to it and I also missed the coherence in it all. It felt a bit like all indians and no chiefs and I felt completely lost in the middle of all that. And if that goes for me, I can assure you that this is also the case for relative outsiders like civil servants, journalists and politicians.

So how do you get from there to coherence into everything we do and how do we get what we want without getting into a fight over it, spoiling our chances and those of our fellow PA's at the next table? How do we prevent to be or to become a problem at the table? When do we communicate what and with what purpose? How can we plan ahead and use or create momentum pro-active instead of having to react on what others do or say and in a way being late at the table?

Well if you want coherence, lucky for us, there is something we all have in common in whatever it is we do, Something everything we do relates to, and that is our right to health. **Slide 3** One of the human rights. And that right is not just about entitlements, but also about “underlying determinants of health”. These include for example safe drinking water and adequate sanitation and safe food.

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The right to health entitles people to a lot of things that we have on our agenda. Amongst others: The right to a system of health protection providing equality of opportunity for everyone to enjoy the highest attainable level of health; and the right to prevention, treatment and control of diseases and access to essential medicines. All to be provided to all without any discrimination.

There are some common misconceptions about the right to health **Slide 5**

- a. The right to health is NOT the same as the right to be healthy. So if you got the sniffles there is no use in blaming the government and in demanding compensation.
- b. The right to health is NOT only a programmatic goal to be attained in the long term. In fact, States must make every possible effort, within available resources, to realize the right to health and to take steps in that direction without delay.

c. A country's difficult financial situation does NOT absolve it from having to take action to realize the right to health. No State can justify a failure to respect its obligations because of a lack of resources. States must guarantee the right to health to the maximum of their available resources, even if these are tight. While steps may depend on the specific context, all States must move towards meeting their obligations to respect, protect and fulfill. **Slide 6**

And that last part says it all: STATES must MOVE towards meeting their OBLIGATIONS to respect, protect and fulfill. So all of a sudden WE are not the problem-owners at the table anymore. **Slide 7** WE are not the guys and the girls who are there to complicate things, but instead WE are there with answers to the GOVERNMENTS problems when it comes to health. Problems THEY have to address. If not in the way WE suggest, in any another way, as long as it gets addressed and solves the problem.

So in a way that makes things more easy for us. All we need now is a document I like to call a lobby agenda in which we describe all those problems we see in relation to respecting, protecting and fulfilling our right to health. In other words: the gap between the current situation and the situation we consider to be the best. And our answer on how to move towards that situation without making it our problem. With such a lobbyagenda we will be able to address every problem we encounter without the risk to be considered part of the problem instead of the solution. Without the risk of being accused of being incoherent. Everything we do will be placed in the same context: That of our Right to Health; the governments responsibility. And we will be able to pick our battles, choose or create momentum and act pro-active. And by giving the faces and quotes of our fellow Patient Advocates that are not longer among us a place in the lobby agenda, we will show everyone that it is not just a theoretical exercise, and that failing to solve the problems has a face.

And to create such a lobby agenda we need your help. You know best what problems you encounter in your efforts to reduce incidence, to provide the best diagnostics, to develop, register and have new treatments implemented. To provide the best psychosocial-care or after care. To reintegrate at work again. So as of today, every single problem you can think of when it comes to the right to health stops being your problem.

As of today it all becomes the problem of the government and as such part of our lobby agenda. And of course we are all willing to help and do suggestions in that lobby agenda on how we think the government can reduce incidence or get better results in diagnostics and treatment and how, where possible, we can reduce costs as well. But if the government decides to address the problem in a different way, fine by us. As long as the problem we face gets addressed and we get the same results.

What the government CAN'T do anymore from today onwards is telling us it is someone else's problem or simply ignore it.

So lets liberate ourselves during the working lunch from those long felt problems weighing on our shoulders.

I have made a handout for the four groups with some questions to help you find those problems that shouldn't be weighing on your shoulders and I would like to ask you to come up with as many as possible. We don't need an in-depth analysis because we only need the basis input now to draw up a lobby agenda. And we will start doing that right after this annual and we will make sure to keep you involved in that. While you are working and enjoying your lunch I will be joining each group for a while to answer questions if any and to make sure that the outcome will provide a proper basis for our lobby agenda.

I hope you will all have a pleasant and productive lunch and hope to see you back here at 1.45 We will then hear from each group in five minute pitches the highlights and the problems they like to see addressed and maybe, as a service to the government, they even already have suggestions when it comes to solving these problems or closing those gaps as you will.

Thank you very much for your attention and I'm looking forward to working with you on our very first lobbyagenda!