

Psychological effects of speech impairment.

ISAAC International Conference
Lisbon, July 21-24, 2014

Bom dia! I apologize for the horrible English pronunciation of the Portuguese phrase.

In my abstract, I promised a substantially extended version of the 30 minute talk I gave in Oslo last year, including some practical exercises. I counted on having an hour at my disposal, but as I have only half an hour, I cannot possibly keep all my promises.

Therefore, I have prepared two versions of this session.

One is a traditional talk, more or less the same I gave in Oslo, hopefully with 5 minutes or so for discussion at the end.

The other version consists of a very brief introduction, without the promised suggestions for future research, then a kind of experiential exercise, where the main point is observing your own emotional reactions during the exercise, and then hopefully 5 minutes for discussion of the experience.

So, which version do you choose?

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First, a disclaimer: I am a mathematician and a philosopher, not a psychologist. As philosopher, I may be a jack of all trades, but I have no academic background for what I am talking about today. However, I will present some general thoughts on the matter, hoping that some mutual learning and teaching may occur.

I invite you to consider the following questions: How will various degrees of speech impairments affect the sensitive interplay between how other people see you and your own self-image? What strategies are available to cope with the unavoidable communication imbalance? How do various kinds of AAC aids influence the communicative process?

This is a mainly theoretical presentation, partly utilizing the framework provided by Goffman (*Presentation of Self in Everyday Life* and *Stigma*). It will be restricted to persons with approximately normal sensory, cognitive, and language skills, mainly due to my limited knowledge of other relevant groups, and the unfeasibility of covering more in a brief presentation. Suggestions for possible empirical investigations will be offered. I will also draw upon my personal experience, and the experiences of people I know (of course with due regard to their anonymity).

There is not much to be learned from earlier research. Indeed, when I tried to “google” the issue, I came up with almost nothing. Eventually, Stephen von Tetzschner sent me five papers, some of which I may refer to later in this talk. However, there seems to be no comprehensive study of these issues in the group I intend to talk about, from the current century! In my view, this very fact just accentuates the need for further research.

I assume most of you are somewhat familiar with Goffman’s work, so for the sake of brevity, I shall just say that in *Presentation of Self*, Goffman analyzes the social interactions of everyday life, using the metaphor of a theatre performance. As actors on “the social stage”, we try to convey certain “roles” to our “audience”. We have a front stage, where we present our role, and a back stage, where we may withdraw mentally to change masks and props. At the same time, we are the audience of the other actors, and there is a very complex interaction constantly going on. Of course, we may try to fool our audience, but most of the time we try to perform as who we think we really are, or at least wish we were. Still, our role changes all the time, with the circumstances and the audience, it is impossible to perform our total self image, even to ourselves (we are also part of our own audience).

In *Stigma*, with the subtitle *Notes on the Management of Spoiled Identity*, Goffman investigates further the special characteristics of this interplay if a person is in some way deviating from the “norm” in the relevant setting. Then, try as we may, we can never fully play the role of a “normal person”, our “identity is spoiled”. If possible, we may try to fool our audience by hiding our deviation. If not, we may develop different strategies to protect our identity or self image. We may withdraw, by limiting our participation in the society of “normal people”, we may internalize the majority’s image of us, thus minimizing the tension in the interaction, we may come together with other similar “deviators” and fight for recognition by the “normal” majority. In the last case, there is always a question of what kind and degree of recognition we can realistically aim for, and how to go about negotiating with the majority.

Now, let us look more specifically at the situation for the group I consider myself as belonging to: speech-impaired people with approximately normal sensory, cognitive, and language skills. Our group is assumed to have no problem understanding normal speech, and

internally forming what we want to say. We just can't "get it out" properly. (I will try to consistently use "we" instead of "they", as I don't want to dis-identify with my group, even in this somewhat "scholarly" setting.)

In communicating with normal speaking persons (whatever that is), this makes for an imbalance of exchange, even with technical aids (which I will shortly return to). If we are lucky, we might get in a word or two edgewise, while our partner, at normal speed, may contribute the equivalent of a written page or two. Even with a considerate and patient partner, we are, or at any rate feel, forced to compress our verbal messages. (This is confirmed in *Focus group interactions*, Helmsley et al, 2008.) In most informal conversations, "small talk" is a very important social glue, helping to negotiate a common definition of the over-all situation (vide Goffman). We are more or less excluded from this situation-defining activity, as we cannot afford much, if any, small talk. Many of us may partly compensate using non-verbal communication, which is anyway the major part of building and maintaining a consensus on what the given setting is all about. Still the imbalance is very conspicuous.

In the more subject oriented parts of the conversation (talking about a movie or a book, discussing the distribution of household chores or what to do about the garden, participating in a political debate or a seminar), the same imbalance is present. Also, although non-verbal communication still plays an important role, the verbal part is more indispensable here. Without words, you may be able to indicate whether you agree or disagree with the preceding speaker, but not why, and not what your own opinion is, or, if you agree, what more subtle differences might still be present. ("I agree with your over-all conclusion, but I would like to add...") Also, words are not the whole story. Speech is a wonderfully flexible means of communication, and consists of much more than the words themselves. A large part of the communication content is actually carried by prosody, emphasis, pitch, etc. Thus, even if we manage to get the words across, much of the content we intended to convey may be lost.

Now, how does this affect us, and you? That is actually hard to tell, both for you (meaning the group of "normal speaking" persons) and for us. You may never have been in a similar situation, and for us it is the "normal" situation. Yet, by putting our "mirror neurons" to good use, both groups may gain some tentative insight into the other group's reactions, making comparison possible. Despite huge individual variations, there are some recognizable common themes: First, and most obvious, in a "normal speaking" society, we are the deviators, the ones with a stigma, in Goffman's terminology. In my experience, in the case of disability in general, and even more in the specific case of speech impairment, this stigma tends to take the form of what I call the "eternal child syndrome". We are simply seen as children, regardless of our age. Of course, this is better than being seen as villains, crooks, or monsters, or as God's visitations upon our parents' sins, as may still be the case in some parts of the world. Still, it is hardly conducive to our equal participation in mainstream adult society. We may not feel like deviators from the outset, but the "normal speaking" society at large more or less unconsciously force this identity on us. Generally, we will very clearly observe the difference between "normal speaking" persons' general attitude towards their "peers" and towards us. Of course, we rebel against it, sometimes very vigorously, as this attitude difference is experienced as far more challenging than the speech impairment in itself. However, no one can uphold a state of total rebellion for long (as shown very clearly by the famous Stanford prison experiment, Zimbardo et al), so sooner or later they/we will to some degree internalize our deviator status. Typically, there will be a kind of oscillation between internalizing and rebellion, as none of these two available states are comfortable in the long

run. Of course, if we rebel, we are not normally met with such harsh sanctions as in the Zimbardo experiment. However, we may be met with incredulity or bafflement, which in fact can be a very effective sanction. They may understand that we are angry or upset, but they simply don't get why. This initial reaction may later transform into more or less well-concealed pity as (parts of) the reason may finally dawn on them, or exasperation (why can't you be reasonable, we are doing the best we can?). And we will subside, of course, until the next rebellion. The main point is that **any** reaction from us will only cement our deviator status, our stigma. Catch 22, damned if you do, and damned if you don't.

The solution? Maybe, on our part, a final once and for all internalizing or accepting the objective fact that we are speech impaired, without in any way accepting any kind of "inferiority" that may be perceived as flowing from that fact. That is, of course, much easier said than done, and may not even be entirely possible. The inferiority aspect is so ingrained in the total picture of our speech impairment that it may not be fully separable. The very word "impairment" is a clear indication of this: We are "impaired", we "lack" something, we are "sub-normal" in some way. And I am part and parcel of the system, too: Blind people "lack" the sense of sight. Of course, I regard them as "equals", but oh, how wonderful it feels to be "normal" in that respect. When I remember, I am grateful for being able to see "normally", as you may be grateful for being able to talk "normally". But if we are honest, we must admit that there is more to it than mere gratefulness. To call it "gloating" may be an exaggeration, but I do sense a kind of Pharisaic self-contentment deep down in myself, accompanied by that tiny uneasiness flowing from the knowledge that I may also become blind.

Therefore, I cannot really blame you (again meaning not necessarily you who are present here, but the average "normal speaking" person). We all share that same human weakness, and we all have to struggle with our attitudes. Still, despite all the difficulties, I do believe it is a struggle worth taking.

On your part, (again meaning the average "normal speaking person), I may suggest a recognition that the oscillation between internalization (or resigning) and rebellion I mentioned earlier, is a normal part of any grief process. And we are grieving, even those of us who never had the experience of "speaking normally". After all, we hear the "lost possibilities" around us all the time. Grieving may be harder and take longer time for some individuals than others. Some of us may need help, maybe even professional help, to get through it. For some, there may be a point where "normal grieving" turns into psychic disorder. I think we need to be much more aware of this fact. Of course, speech impairment poses extra challenges for any therapy process. This may require inventive variants of the methods involved, or even development of new methods.

Time to move on to the impact of diverse AAC devices on the communication experience. Generally speaking, such devices are a great support, as is confirmed by the participants in the study reported in *Perceptions of Leisure by Adults who use AAC* (Datillo et al, 2007). You might almost say that any device is better than none at all. However, the participants also reported some problems. It seems most of them were using what I call "open vocabulary devices" based on some kind of typing (conventional finger typing, eye control, stick attached to the forehead, switches, scanning, etc.). As mentioned earlier, speed is important for participating in normal conversations, and here all devices are too slow (even if you are very fast at typing), thus requiring "normal speaking" participants to wait for your response. Otherwise, you would need to be a psychic to know what will be the topic when you finish typing your contribution. Other problems include decreased visibility of LCD's when

outdoors, difficulty hearing the synthetic voice in noisy environments, inability to bring the device in certain situations, and, of course, the device may be accidentally unplugged or out of order.

The other main kind of AAC devices is “limited vocabulary devices”, with a fixed collection of words and phrases to choose from. Although new words and phrases may be continually added, such devices don’t meet the communication needs of the group I consider here. The best option may be an open vocabulary device with word prediction (enhancing the speed somewhat), and some readymade often used phrases.

An additional advantage many users report (and I can confirm from my own experience), is that people tend to get curious about the device. This curiosity may be a social icebreaker, and lead to further interactions. However, in some cases it doesn’t work out that way. I remember a young receptionist at a hotel, staring at my Lightwriter as if it was ET himself, obviously not at all comprehending what this thing might be. I half expected her to call the police.

Also, even the best AAC devices are no use if they are not available (for financial or other reasons), or are withdrawn as the person leaves school, as is documented in *Why is the potential of AAC not being realized?* (Hodge 2008). This is really a political issue, which I hope is getting some momentum from the paragraphs on communication in the UN convention on the rights of persons with disabilities.

In conclusion, AAC devices may considerably alleviate communication difficulties, but do not in any way abolish them. Nonetheless, any positive contribution to a person’s quality of communication is invaluable. The positive correlation between quality of life and quality of communication found in *Post-School Quality of Life for Individuals with Developmental Disabilities Who Use AAC* (Hamm and Mirenda, 2006) is not very surprising.

Time is running out, and I promised to offer some proposals for future research. I don’t know if I am really qualified to do so, but anyway, here goes:

Many, probably most, AAC users have other disabilities in addition to their speech impairment. Even in the more restricted group I am considering, it may therefore be difficult to single out what psychological effects are due to the speech impairment per se. However, in my view this doesn’t need to be a serious obstacle to obtaining valid results, if you either use relatively “disability-homogeneous” groups in your studies, or distinguish different disability categories in the analysis of the results. For us, what matters is the total picture, and what interventions or changes in our daily life situation may be needed.

Focus group studies, as Datillo et al and Helmsley et al, are a great way of doing qualitative research. I am, however, tempted to quote from the conclusion of Helmsley et al: “The results of this study indicate that a focus group of adults with complex communication needs can proceed with features of interaction evident in focus groups of natural speakers (e.g., consensus, disagreement, dominant and non-dominant views, persuasion, and story-telling).” In other words, the results indicate that we are normal human beings. What a surprise! WE knew that all along, but evidently the research community and society at large didn’t. Therefore, THEY need research to tell them that, given half a chance, lo and behold, we perform and react like any other group of people. (This rather obvious fact is also confirmed by *Talking to Teenagers* (Wickenden 2011), showing that the teenagers interviewed

identified themselves more as teenagers than as disabled.) Alas, as we are dependent on the society surrounding us, we too need that research...

Nonetheless, we do need more knowledge about the exact nature and extent of the psychological stress and risk factors involved in being speech impaired. The big picture may be rather obvious, but the details aren't, and they are also important.

Generally, we need both quantitative and qualitative studies of all kinds. To my knowledge, most studies have been "snap shot" studies, gauging the situation for a limited group of people "here and now". We also need longitudinal studies, following some of us for many years, if possible "from cradle to grave", to discern trends of development. With our disrupting family structures, at least in Western societies, aging is an increasingly lonely business for most people, and I wouldn't be surprised to find it even worse for our group.

Also, we know that disabled people in general are over-exposed to physical abuse, including sexual abuse. I would assume that having a speech impairment would make you even more vulnerable, but hard empirical evidence is probably needed to get protective measures in place. I know a girl, without any natural speech, who was sexually abused in kindergarten. She used signs to communicate, but only her parents were able to understand her, and when they told the police, they were not believed. The girl was not even interviewed. Admittedly, to interview her was a challenge, but a challenge they had no right to refuse.

In addition, I would like to see studies specifically addressing our psychic health, and how to facilitate the all-important communication in therapy situations (including how to educate psychology and psychiatry professionals on both AAC and physical accessibility). It might seem that most of us are surprisingly strong and robust people, but it stands to reason that you won't see those who aren't strong out on the street. They are more likely to literally "suffer in silence".

Speaking of streets, I'd like to do some actual "street research", observing naturally occurring interactions between AAC users and others on the street, in the church, at political meetings, at cultural events, etc. This may require some adaptations of standard research methods, or even development of brand new ones.

That's all. Hopefully, we still have a handful of minutes for questions and comments.

I will end my talk with a well-known song by Simon and Garfunkel, for this is what it is all about, isn't it: "daring to disturb the sound of silence".

Thank you for your attention!

Sound of silence

Hello darkness, my old friend
I've come to talk with you again
Because a vision softly creeping
Left its seeds while I was sleeping
And the vision that was planted in my brain
Still remains
Within the sound of silence

In restless dreams I walked alone
Narrow streets of cobblestone
'Neath the halo of a street lamp
I turned my collar to the cold and damp
When my eyes were stabbed by the flash of a neon light
That split the night
And touched the sound of silence

And in the naked light I saw
Ten thousand people, maybe more
People talking without speaking
People hearing without listening
People writing songs that voices never share
And no one dared
Disturb the sound of silence

"Fools", said I, "You do not know
Silence like a cancer grows
Hear my words that I might teach you
Take my arms that I might reach you"
But my words, like silent raindrops fell
And echoed
In the wells of silence

And the people bowed and prayed
To the neon god they made
And the sign flashed out its warning
In the words that it was forming
And the sign said, "The words of the prophets are written on the subway
walls
And tenement halls"
And whispered in the sounds of silence

References:

Michael Rutter and Lynn Mawhood: *The long-term psychosocial sequelae of specific developmental disorders of speech and language*, in *Biological Risk Factors for Psychosocial Disorders*, ed. Michael Rutter and Paul Casaer, Cambridge University Press, 1991

Dattilo, John, Estrella, Gus, Estrella, Laura J., Light, Janice, McNaughton, David and Seabury, Meagan (2007): *"I have chosen to live life abundantly": Perceptions of leisure by adults who use Augmentative and Alternative Communication*, *Augmentative and Alternative Communication*, 23:1, 1 – 13

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First, a disclaimer: I am a mathematician and a philosopher, not a psychologist. As philosopher, I may be a jack of all trades, but I have no academic background for what I am talking about today. However, I will present a very general framework, before we do a simple exercise designed to put some experiential flesh on the bones. My hope is that some of us may continue mulling over our experience in the hours and days ahead. I will be available for you at any break or meal during the conference, and you may also e-mail me afterwards.

Now, my introduction:

I shall partly utilize the framework provided by Goffman (*Presentation of Self in Everyday Life* and *Stigma*), as a theoretical background for what I have learned, mainly from my personal experience, and the experiences of people I know. There is not much to be learned from earlier research. Indeed, when I tried to “google” the issue, I came up with almost nothing. Eventually, Stephen von Tetzschner sent me five papers, some of which I may refer to later in this talk. However, there seems to be no comprehensive study of these issues in the group I intend to talk about, from the current century! In my view, this very fact just accentuates the need for further research.

I assume most of you are somewhat familiar with Goffman’s work, so for the sake of brevity I shall just say that in *Presentation of Self*, Goffman analyzes the social interactions of everyday life, using the metaphor of a theatre performance. In *Stigma*, with the subtitle *Notes on the Management of Spoiled Identity*, Goffman investigates further the special characteristics of this interplay if a person is in some way deviating from the “norm” in the relevant setting.

Now, let us look more specifically at the situation for the group I consider myself as belonging to: speech-impaired people with approximately normal sensory, cognitive, and language skills. Our group is assumed to have no problem understanding normal speech, and internally forming what we want to say. We just can’t “get it out” properly. (I will try to consistently use “we” instead of “they”, as I don’t want to dis-identify with my group, even in this somewhat “scholarly” setting.)

In communicating with normal speaking persons (whatever that is), this makes for an imbalance of exchange, even with technical aids (which I shall have no time to talk about). If we are lucky, we might get in a word or two edgewise, while our partner, at normal speed, may contribute the equivalent of a written page or two. Even with a considerate and patient partner, we are, or at any rate feel, forced to compress our verbal messages. (This is confirmed in *Focus group interactions*, Helmsley et al, 2008.) In most informal conversations, “small talk” is a very important social glue, helping to negotiate a common definition of the over-all situation (vide Goffman). We are more or less excluded from this situation-defining activity, as we cannot afford much, if any, small talk. Many of us may partly compensate using non-verbal communication, which is anyway the major part of building and maintaining a consensus on what the given setting is all about. Still the imbalance is very conspicuous.

In the more subject oriented parts of the conversation (talking about a movie or a book, discussing the distribution of household chores or what to do about the garden, participating in a political debate or a seminar), the same imbalance is present. Also, although non-verbal communication still plays an important role, the verbal part is more indispensable here. Without words, you may be able to indicate whether you agree or disagree with the preceding

speaker, but not why, and not what your own opinion is, or, if you agree, what more subtle differences might still be present. (“I agree with your over-all conclusion, but I would like to add...”). Also, words are not the whole story. Speech is a wonderfully flexible means of communication, and consists of much more than the words themselves. A large part of the communication content is actually carried by prosody, emphasis, pitch, etc. Thus, even if we manage to get the words across, for instance by using some AAC device, much of the content we intended to convey may be lost.

Now, how does this affect us, and our “normal speaking” partners? Well, despite huge individual variations, there are some recognizable common themes: First, and most obvious, in a “normal speaking” society, we are the deviators, the ones with a stigma, in Goffman’s terminology. In my experience, in the case of disability in general, and even more in the specific case of speech impairment, this stigma tends to take the form of what I call the “eternal child syndrome”. We are simply seen as children, regardless of our age. Of course, this is better than being seen as villains, crooks, or monsters, or as God’s visitations upon our parents’ sins, as may still be the case in some parts of the world. Still, it is hardly conducive to our equal participation in mainstream adult society. We may not feel like deviators from the outset, but the “normal speaking” society at large more or less unconsciously force this identity on us. Generally, we will very clearly observe the difference between “normal speaking” persons’ general attitude towards their “peers” and towards us. Of course, we rebel against it, sometimes very vigorously, as this attitude difference is experienced as far more challenging than the speech impairment in itself. Typically, there will be a kind of oscillation between internalizing and rebellion, as none of these two available states are comfortable in the long run. Of course, if we rebel, we are not normally met with such harsh sanctions as in the famous Zimbardo prison experiment. However, we may be met with incredulity or bafflement, which in fact can be a very effective sanction. They may understand that we are angry or upset, but they simply don’t get why. This initial reaction may later transform into more or less well-concealed pity as (parts of) the reason may finally dawn on them, or exasperation (why can’t you be reasonable, we are doing the best we can?). And we will subside, of course, until the next rebellion. The main point is that **any** reaction from us will only cement our deviator status, our stigma. Catch 22, damned if you do, and damned if you don’t.

I promised to offer some proposals for future research, but due to lack of time, I cannot do so. In the “lecture version” I do, and of course you may have that version sent to you by e-mail if you wish.

It is time for the exercise. My assistant will let you draw pieces of paper at random, which decide whether you are in group A or B. Each group will be given a sheet of instructions to read. These instructions must not be communicated to the other group. Then we will form pairs of one from group A and one from group B, and the exercise may begin.

References:

Michael Rutter and Lynn Mawhood: The long-term psychosocial sequelae of specific developmental disorders of speech and language, in *Biological Risk Factors for Psychosocial Disorders*, ed. Michael Rutter and Paul Casaer.

Dattilo, John, Estrella, Gus, Estrella, Laura J., Light, Janice, McNaughton, David and Seabury, Meagan (2007) "I have chosen to live life abundantly": Perceptions of leisure by adults who use Augmentative and Alternative Communication', *Augmentative and Alternative Communication*, 1 – 13

Hemsley, Bronwyn, Balandin, Susan and Togher, Leanne (2008) 'I've Got Something to Say': Interaction in a Focus Group of Adults with Cerebral Palsy and Complex Communication Needs', *Augmentative and Alternative Communication*, 24:2, 110 — 122

Instructions for group A:

Bad news, I am afraid. For the next 5 minutes or so, you are very severely speech impaired, unable to utter a single word, by speech or by writing. But you have a message that you urgently need to convey to your partner in group B. You may use facial expressions, gestures, body language (but no indecent behavior, thank you!), but no words. And remember to monitor your own internal reactions as the exercise unfolds.

Instructions for group B:

Your partner in group A is severely speech impaired. (S)he is trying urgently to convey some message to you, without words. Even if you do understand the message, you should ignore it completely. Acknowledge the person, be kind in a condescending way, smile, try to soothe and calm your partner, but totally ignore the message, and even the very fact that (s)he is trying to communicate something to you. Then, after a couple of minutes, you may “understand” that your partner is trying to communicate: “Oh, you are trying to say something? What is it?” Make some guesses, totally off the mark, and as your partner becomes more frustrated, try again to soothe and calm him/her, as you would a child having hurt its knee. And all along, try to monitor your own inner reactions as the exercise unfolds.