



Stakeholders in Disability Studies

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Preliminary remarks

- The field of Disability Studies has benefitted greatly from the work of Ingrid Baart
- The further development of Disability Studies requires attention for both strong and weak points
- Strong and weak points are not opposed to one another, but are connected/intertwined
- Dilemma's cannot be solved theoretically, but require reflection and practical action

Strong points related to stakeholders

- Success of Disability Studies increases the number of stakeholders
- Cooperation with scientists, policy makers, professional organizations, etc.
- People with a disability are major stakeholders in agenda-setting for scientific research, in policy-making, in improving quality of care

Weak points related to stakeholders

- Diverging interests between stakeholders
- Role of people with a disability often limited through regulations (i.e. in funding for scientific research)
- Lay knowledge not always valued/acknowledged
- It is sometimes difficult and counterproductive to try and understand people with (intellectual) disability (we have to 'accept that we cannot know')

Reflection on weak points

- Complex coordination is not a problem (simple coordination does not exist/work)
- Role of people with a disability is not one-dimensional, there are various ways in which people can contribute
- Lay knowledge -> experiential knowledge (not less, but different and complementary) (dissertation Karen Schipper)
- There are various ways of understanding (Hans-Georg Gadamer)
- Nothing is ever totally known (Socrates)

Dialogical understanding in DS (I)

- Dialogue between people with a disability and professionals
 - Developing agendas together (Tineke Abma, Christi Nierse, Tamara Visser, Linda Dauwerse, Wieke van de Borg)
 - Combining experiential expertise and professional expertise (Karen Schipper)
 - Take time and be open (Merel Visse)

Dialogical understanding in DS (II)

- Understanding people with a serious disability
 - Patient perspective (Minne Bakker, Jenny Boumans, Toine Pieters)
 - Reduction of coercion (Yolande Voskes, Elleke Landeweer)
 - Complex care (Arnold van Elteren, Marloes Moraal)

Conclusion

- Stakeholders always have diverging interests
- Disability Studies aim to give more stakeholders a voice (especially people with a disability)
- Voices are necessarily different and cannot be fully understood
- Weak points can be addressed through reflection and dialogue, within disability studies and with other partners