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)
• 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)
• 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