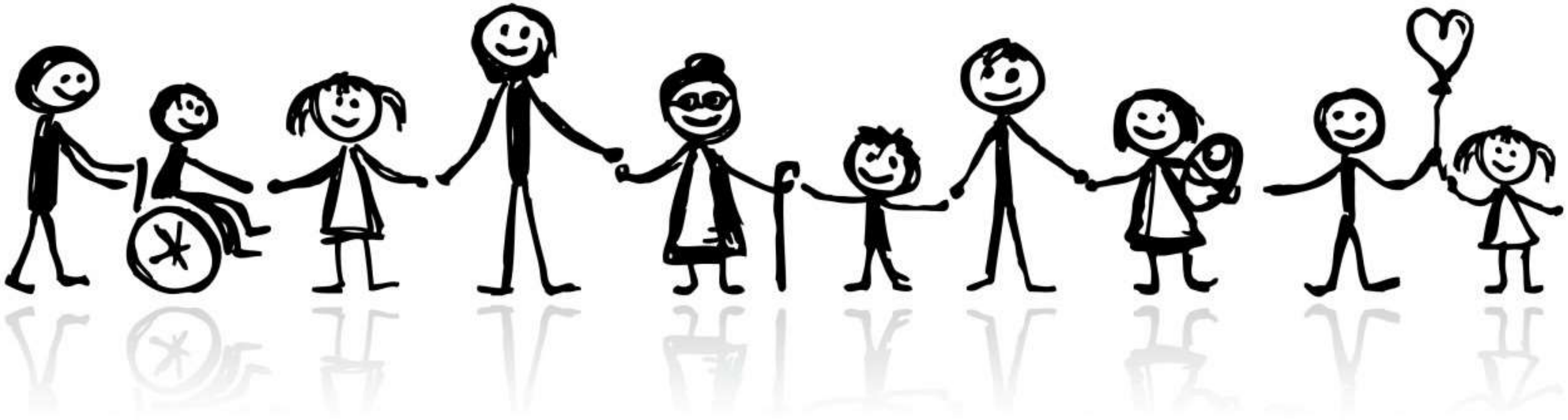


Parents as co-researchers: Participatory research in a project on family experiences with children with congenital deafblindness

Rosemarie van den Breemer, 3 June 2021,VID Specialized University, Oslo

Presentation today

I. Co-research: what, why and how?
II. Application in my project

I. Participatory research: What is it?

- “Co-production (Samproduksjon) in research entails the production of knowledge in which academically educated researchers cooperate with other actors in the research process for whom the research is relevant and/or has consequences” (Askheim et al. 2019, 24, my translation).

- Inclusion of ‘first-hand’ lived experiences in research process.
- Different research relationship: research *with*, instead of research *on* people (Borg et al. 2012), subject – subject relation (Skjervheim 2001; Wyller 2005).

Why? Historical roots

1) Ideological and political arguments:
    a) User-movements: political voice and emancipations of users (Rose 2017; Beresford 2013)
    b) Liberation theology: more democratic research praxis (Freire 1970)

2) Quality and pragmatic arguments:
    a) Heightens research validity and relevance (Boote et al. 2002)
    b) In Norway patient involvement becomes mainstream in 2000 (Malterud & Elvebakken, 2020)
        - Since 2014 mandatory in medical research when funded by regional health trusts.
        - Since 2016 mandatory for health projects applying to research Council of Norway (rCN).

How? Several levels (Beresford 2013, 142; Sweeney et al. 2009)

- User-involvement
  - User group advises in the project led by the researcher
    User/consumer involvement, patient/client engagement, public and patient involvement, expert-by-experience

- Co-production
  - Researchers and the group involved cooperate in the planning and excecution
    Collaborative research, participatory research, co-operative inquiry, community engagement in research, emancipatory research, co-production

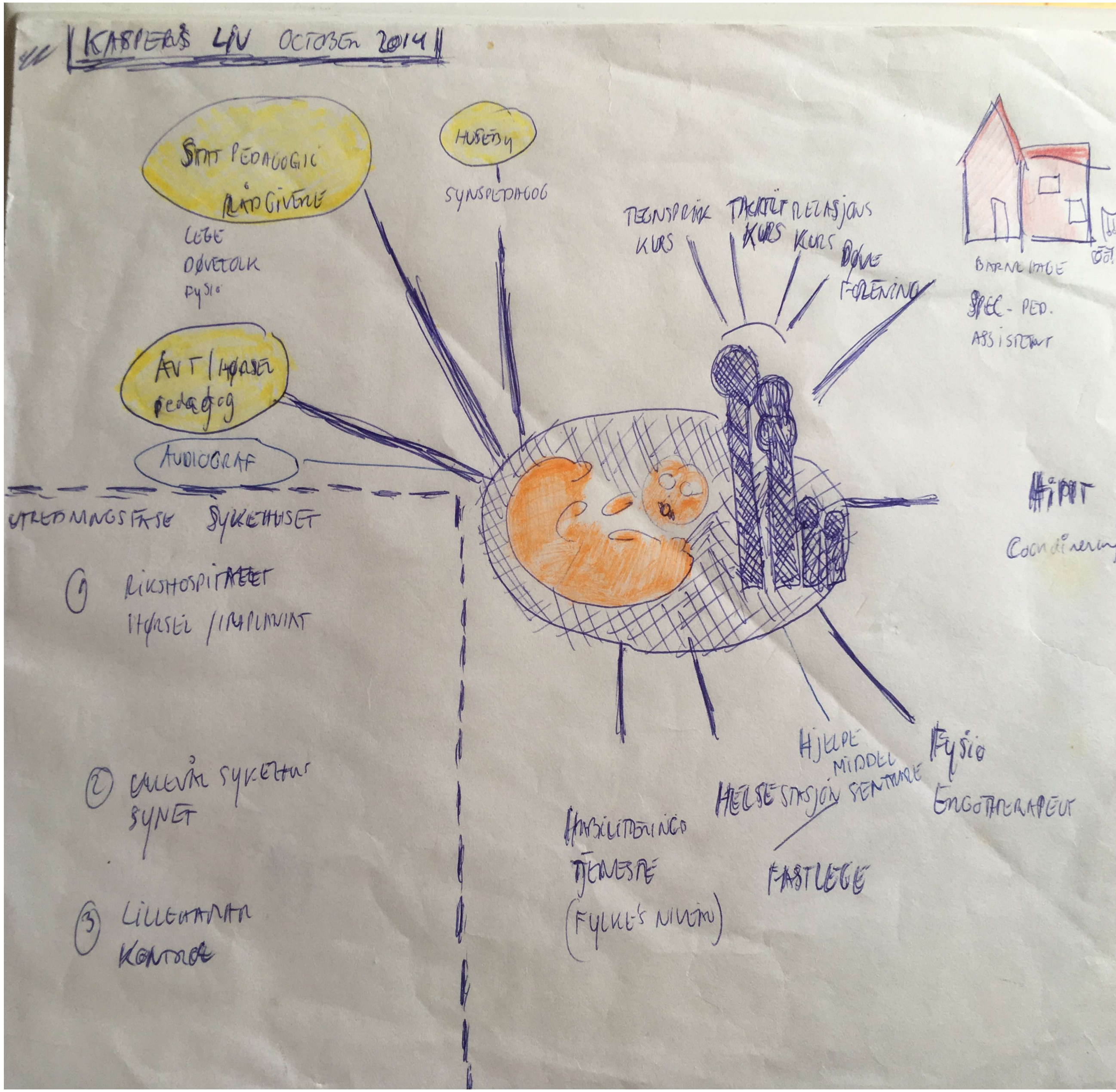
- User-led
  - Affected parties direct the entire research process
    Survivor research, MAD studies, user-led research, peer-research

II. The Disability Family

Case studies of the care and governance of families with children with congenital deafblindness in Norway and The Netherlands 1850-2021

My Disability Family

- Complexity of institutions facing the family
- Role of the one to be helped, yet increased knowledge and rights of the family
- Role of the 'sad and bereaved', yet pride and joy.



Project characteristics

- Comparative case study method
- Historical and institutional focus
- Experience and agency orientated:

1) In what way has the families realm of action (‘handlingsrom’) changed because of the contemporary care situation?
2) Epistemic agency: Do families feel they are being heard or recognized as knowledgeable? How do they make sense of their social position?

Why participatory research in my project?

- Enhance parents collective self-understanding (hermeneutic justice, Fricker 2007)
- Contribute with a vocabulary that can describe those experiences
- Increased validity and relevance
- Strengthen (parental) research networks on deafblindness across countries

Concretely:

- Auto-ethnography
- Cooperation with parent organisations in Norway and The Netherlands
- Parent co-researchers:

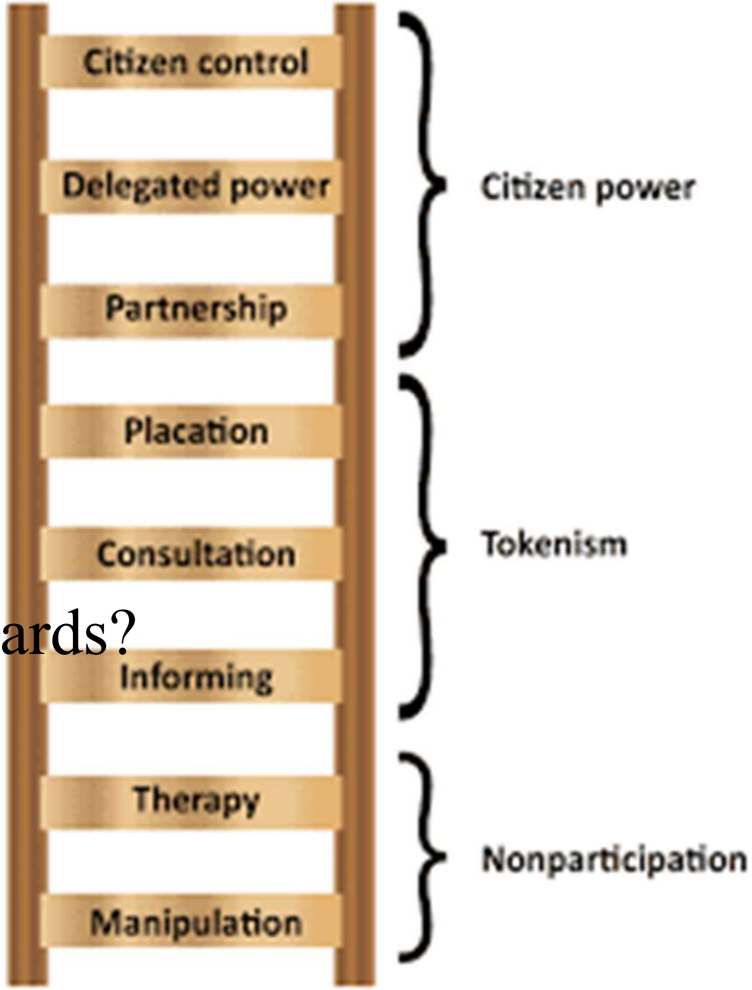
A. Start phase: (1) provide input for thematic focus; (2) help formulate interview questions (individual and for focus groups).

B. Excecution: (3) cooperate in planning and leading focusgroups and/or individual interviews; (4) have an advisory role in the interpretation of the material.

C. «Output»: (5) publish together, (6) present material together, (7) build networks that last after the projects ending.

Reported challenges with co-research in health studies in general

- Tokenisme (Beresford, 2013)
- Increased quality, or at the cost of academic standards? (Malterud & Elvebakken, 2020)



Ladder of participation (Arnstein, 1969)

Reported Pro's and Con's

Studies with parents as co-researchers (Shen et al. 2016)

- Parent empowerment (Woodgate et al. 2008)
- Better access to participants (Uding et al. 2007, 2009)
- Parents bring motivation & drive (Walmsely 2009)
- Enhance research relevance (Domecq et al. 2014; Stoep et al. 1999)
- Better dissemination (Uding et al. 2007, 2009)

- Disappointment for parents (Rowe 2006)
- Disengagement, lack of clear roles (Uding et al. 2007; Jurkowski et al. 2013)
- Lack of consensus because of wide range in experiences (Rowe 2006; Foster 2015)
- Time and resource demanding (Whiting 2012; Corcoran 2015)

Recommendations from the literature (Shen et al. 2017, 552)

- Early engagement to build relationships
- Provide support, encouragement and recognition to parents
- Be clear on roles
- Provide relevant training, rewards
- Have a trusting and positive work environment
- Plan for unpredictability

‘Objective/distanced’- versus ‘first-hand’ knowledge

- The greater the distance there is between direct experience and its interpretation, the more reliable it is.

- “(T)he shorter the distance there is between direct experience and its interpretation (as for example can be offered by user involvement in research and particularly user controlled research), then the less distorted, inaccurate and damaging resulting knowledge is likely to be” (Beresford 2003, quoted in Beresford 2013, 147).

Bibliography

- Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224. Retrieved from https://doi.org/10.1080/01944366908977225.
- Askheim, O. P. & Høiseth, J. R. (2019). Medforskerrollen- i spenningsfeltet mellom anerkjennelse, kooptering «tokenism» i Askheim & Lid & Østensjø (eds.) *Samproduksjon i forskning Forskning med nye aktører*, Universitetsforlaget, 214-227. https://www.idunn.no/samproduksjon_i_forskning
- Beresford, P. (2003). It's Our Lives: A Short Theory of Knowledge, Distance and Experience. London: Citizen Press in association with Shaping Our Lives.
- Beresford, P. (2013). From 'other' to involved: User involvement in research: an emerging paradigm*. Nordic Social Work Research,* 3(2), 139-148.
- Borg, M., Karlsson, B., Kim, H. S., McCormack, B. (2012). Opening up for many voices in knowledge construction. *Qual Soc Res*, 13.
- Boote, J., Telford, R., Cooper, C. (2002). Consumer involvement in health research: a review and research agenda. *Health Policy,* 61, 213–236.
- Corcoran J, Berry A, Hill S. (2015). The lived experience of US parents of children with autism spectrum disorders: a systematic review and meta- synthesis. *J Intellect Disabil*.19:356–366.
- Domecq J., Prutsky G., Elraiyah T. (2014). Patient engagement in research: a systematic review. *BMC Health Serv Res*.14:1–9.
- Foster V. & Young A. (2015). Reflecting on participatory methodologies: research with parents of babies requiring neonatal care. *Int J Social Res Methodology Theory Pract*.18:91–104.
- Freire, P. (1970). *Pedagogy of the Oppressed*. Penguin Books: London.
- Fricker, M. (2007). *Epistemic Injustice. Power and the Ethics of Knowing.* Oxford University Press: Oxford.
- Jurkowski JM., Greenmills LL., Lawson HA., Bovenski MC., Quartimon R., Davison KK. (2013). Engaging low-income parents in childhood obesity prevention from start to finish: a case study. *J Community Health*. 38:1–11.
- Malterud, K., & Elvbakken, K. T. (2020). Patients participating as co-researchers in health research: A systematic review of outcomes and experiences. Scand J Public Health, 1403494819863514. doi:10.1177/1403494819863514
- Moltu, C., Stefansen, J., Svisdahl, M., Veseth, M. (2012). Negotiating the coresearcher mandate - service users' experiences of doing collaborative research on mental health. Disability and Rehabilitation, 34(19), 1608-1616. doi:10.3109/09638288.2012.656792
- Nomaguchi KM. & Milkie MA. (2003). Costs and rewards of children: the effects of becoming a parent on adults' lives. *J Marriage Fam*. 65:356– 374.

- Rose, D. (2017). Service user/survivor-led research in mental health: Epistemological possibilities. Disability & Society, 32(6), 773-789. Retrieved from https://doi.org/10.1080/09687599.2017.1320270
- Rowe A. (2006). The effect of involvement in participatory research on parent researchers in a Sure Start programme. Health Soc Care Community. 14:465–473.
- Skjervheim, H. (2001). Deltakar og tilskodar 1940–2000 (473–481).
- Shen, S., Doyle-Thomas, K. A. R., Beesley, L., Karmali, A.,Williams, L., Tanel, N., McPherson, A.C. (2017) How and why should we engage parents as coresearchers in health research? A scoping review of current practices. Health Expect, 20(4), 543-554. https://doi.org/10.1111/hex.12490
- Stoep A., Williams M., Jones R., Green L., Trupin E. (1999). Families as full research partners: what's in it for us? *J Behav Health Serv Res*. 26:329–344.
- Sweeney, A., P. Beresford, A. Faulkner, M. Nettle, D. Rose, D. (eds.) (2009). *This is Survivor Research*. Ross-on-Wye: PCSS Books.
- Uding N., Sety M., Kieckhefer GM. (2007). Family involvement in health care research: the "Building on Family Strengths" case study. *Fam Syst Health*. 25:307–322.
- Uding N, Kieckhefer GM, Trahms CM. (2009). Parent and community partici- pation in program design. *Clin Nurs Res*. 25:307–322.
- Walmsley J, & Mannan H. (2009). Parents as co-researchers: a participatory action research initiative involving parents of people with intellectual disabilities in Ireland. *Br J Learn Disabil*. 37:271–276.
- Whiting M. (2012). Impact, meaning and need for help and support: the experience of parents caring for children with disabilities, life-limiting/ life-threatening illness or technology dependence. *J Child Health Care*. 17:92–108.
- Woodgate R, Ateah C, Secco L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qual Health Res*. 18:1075–1083.
- Wyller, T. (2005). Dydsetikk, medborgerskap og sosial praksis. I S. A. Christoffersen (ed.), *Profesjonsetikk*. Oslo: Universitetsforlaget