Dignity of dependence: welfare state reform and the struggle for respect
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Appendix 1  Main questionnaire

**Introduction**
- Getting acquainted
- Explain the structure of the interview
- Request permission to record the interview

**Publicly financed care, situation before AWBZ measure**
- Reason of the request for support with daily living (AWBZ) in kind and/or in cash
- Type of care received, type of care-giver
- Goal and use of this care
- Availability of other AWBZ-entitlements or other forms of publicly financed care

**Publicly financed care, situation after AWBZ measure**
- Re-assessment trajectory: written or by telephone, by representative or client,
- length of time, notification about outcome
- Experience of the re-assessment
- Outcome of re-assessment
- Meaning of outcome for (dis)continuation of previously publicly financed care
- Influence of re-assessment for support with daily living on use of other AWBZ-entitlements (e.g. personal care)

**Publicly financed care, knowledge about the measure**
- Way of being informed about the (upcoming) measure
- Idea of why the measure was enacted
- Consideration on making use of the right to appeal
- If made an appeal; how was it dealt with and what was the result
- Reasons for consent/denial in transferring information from CIZ to the local authorities

**Publicly financed care, persisting needs after measure**
- Meaning of the cuts to entitlements for the client
- Effects on wellbeing, capability to run own household, mobility, social contacts, participation in activities outside the home
- Preferences/desires regarding activities of daily living
Addendum

Local Wmo, seeking solutions to persisting needs
Contact and experience with Stichting MEE
Contact with local voluntary organisations, Wmo-loket, social work
Alternative offer by local authorities
Familiarity with and opinion of the Social Support Act
Reasons for/against, and experience with, participation in client boards

Informal care, seeking solutions to persisting needs
Way of informing private network about cuts to their entitlements
Whether or not asked private network to take over the previously received (day)care; from whom (not) and why
Whether or not received offers from private network to take over the previously received (day)care
Contacts with other affected clients
Comparison of personal situation to that of other affected clients
Possible, shared solutions to persisting needs with other affected clients

Informal care, possible request scruple and care ideals
General easiness/difficulty of requesting care from the personal network
Relative easiness/difficulty of requesting care from family, friends, neighbours
Personal preferences regarding care-giving relations
Feelings of indebtedness when receiving care; norms regarding reciprocity

Hypothetical dilemmas
Storyline 1: Lisa, old age

1a) Lisa (80) lives independently in a senior flat. 4 years ago her husband died. She was very depressed and at risk of loneliness. A social worker requested daycare for her. Now she can go there for 3 days per week.
    Do you think this is a proper solution to Lisa’s problem?

1b) In 2009 Lisa receives a re-assessment for daycare. She tells the assessor that she is very satisfied with the daycare and that her situation has much improved. Now it is decided she is entitled to only one day of daycare per week.
    What do you think that this decision means to Lisa?

1c) Lisa notices that a co-resident flat member in a comparable situation has also been affected by the measure, but in her case, daycare was reduced from 3 to 0 days.
    How do you think Lisa should feel, now that she learns that her flatmate is affected even more?
**Storyline 2: Jan, psychiatric disorder**

2a) Jan (42) has a psychiatric disorder. He cannot do his own administration. That is why for years he received individual support. This support has now ended. The care assessment authority judges that he is no longer eligible, because he only has a mild disability.

*What do you think that Jan should do?*

i. Make a formal appeal against the measure
ii. Ask a relative to help him out
iii. Try to find out to what extent he can manage by himself

2b) His father offers to take over the administration. But Jan finds this difficult, because he feels it undermines his autonomy. He also feels it could change his relationship with his father.

*Do you agree on his line of reasoning?*

2c) Jan decides to accept his father's offer. After some time the relation with his father becomes tensed, because he interferes with Jan's lifestyle.

*Do you think that:*

i. Jan should continue to express gratitude?
ii. Jan should express his discomfort?

**Storyline 3: Jesse, cognitive disability**

3a) Jesse (12) has a mild cognitive disability, and finds it hard to interact with peers. That is why he receives individual support in his participation in the scouting club. Due to the cuts this support is now lost, and his parents search for an alternative. They go to a voluntary organisation, where they find a 19-year student who is prepared to support Jesse.

*Do you think this is a proper solution?*

3b) It is decided that Jess will support Jesse for the whole academic year. Everything goes well. But after 4 months the student receives an offer for a paid partime job which he wants to take on due to financial need. He explains his dilemma to Jesse's parents.

*Do you think that Jesse's parents should request the student to stick to the agreement?*

3c) The parents decided to offer payment to Jesse for his volunteer work, but nevertheless, he still decides to quit. They find another volunteer for Jesse, but they lack a personal click. The parents give up finding another volunteer and the mother considers to take over the care task herself, at the cost of her work.

*Do you think this is a good idea of the mother?*
Personal information
Age, marital status, household composition, religion, political affiliation, education, (volunteer)work, social network

Extension interviews with clients' representatives

Involvement in the care situation
Amount and type of care given
Recognition of boundaries to customary/non-customary care
Pathway to requesting publicly financed care
In case of personal budget; reasons, budget administration, way of spending

Personal impact of cuts to publicly financed care
Assumed more care responsibilities or not after reform
Ways/attempts to redivide mounting care responsibilities
Experience of mounting care-giving duties
Consequences for own activities, such as (volunteer)work and free time
Attitude towards increased informal care norm