

*Parents of grown-up children with
disabilities*

An unknown group of carers



Brä
diak

Brücke diakoni

- A non-profit organization
- Healthcare, disability and elderly care



Project Involvement and support

- For parents to grown-up sons and daughters with disabilities.

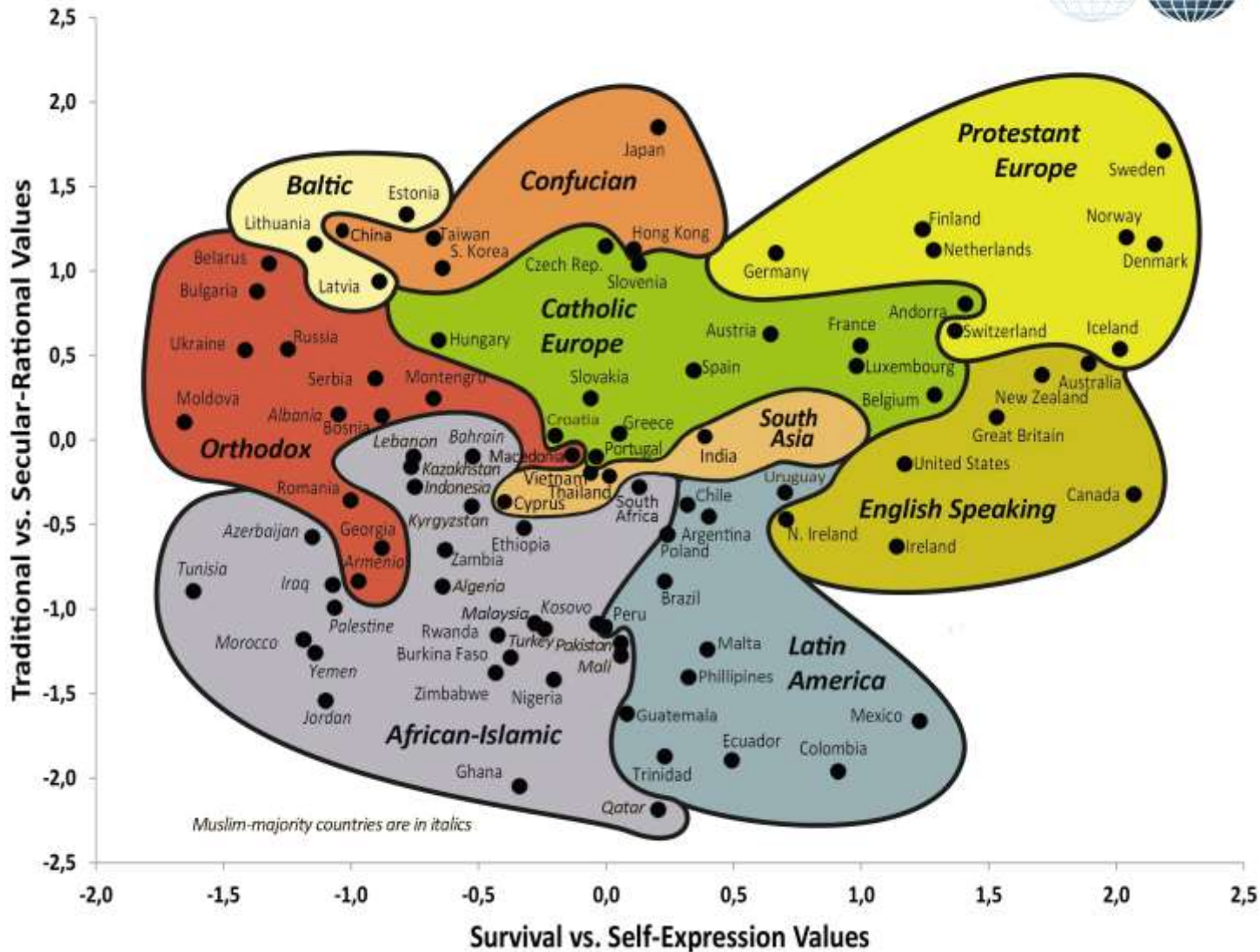


Disability policy

- The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments, 1994
 - Full participation
 - Personal influence
 - Ability to live independently

The culture map

WVS6, 2015



Adulthood

- Independent life
- Many parents continue to help their children after they have become adults.





Project Involvement and support

Parenthood:

- They coordinate efforts.
- They ensure that the son/daughter gets what he/she is entitled to
- They have a medical overview
- They step in when regular staff is ill or not show up
- They maintain contact with authorities and other key agencies
- They support their grown-up children economically

“Who will do all these things when I can’t
or when I no longer live?”

“I wish my child dies before me.”

Studycircle

"When I am no longer here"

- Information and facts
- Reflections
- Opportunity to meet other parents
- Lifestory about their son/daughter



“We need a more nuanced discussion about parents being important carers” (Anna Whitaker 2010)

Parents want:

- *that someone else would coordinate all the interventions the adult child has.*
- *continuity and competence of staff.*
- *the law's intentions to be followed.*
- *to be recognized for what they do.*

Thank you!

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References

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- Anna Whitaker, Forskning om funktionshinder pågår 2/2010, Att åldras med funktionshinder, 2008
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