

**Please refer to Tilahun et al. (2016) when using this scale in your own research and publications following from this research.**

**Adapted Family Interview Schedule to assess experienced stigma in caregivers of children with developmental disorders in Ethiopia**

Scale reported in Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y. & Hoekstra, R. A., 2016. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. BMC Health Services Research 16(1):152. doi: 10.1186/s12913-016-1383-9.

**Scale notes (cited from Tilahun et al., 2016):**

*Scale adaptation:* The family’s experience of stigma in the community was measured using an adapted version of the Family Interview Schedule (FIS; Sartorius & Janca, 1996). The FIS includes 14 questions about the family’s experience of stigma in the community. The original version of the FIS was developed for relatives of people with schizophrenia and was therefore adapted for use in this study to focus on caregivers of children with developmental disorders. An adapted version of the FIS has previously been used in Ethiopia to assess stigma in relatives of individuals with schizophrenia or major affective disorder (Shibre et al., 2001). In keeping with the version used in that study (and in contrast to the original FIS, which used a visual analogue scale), each FIS question in our survey was rated on a four-point scale where experiencing stigma in the community ‘a lot’ was given a score of 3, ‘often’ a score of 2, ‘sometimes’ a score of 1, and ‘not at all’ a score of 0. To assess the distribution of responses between groups, a total score was computed by summing the item scores, with a minimum score of 0 and a maximum score of 42. The internal consistency of this adapted FIS scale was good (Cronbach’s Alpha = 0.92).

*Data collection:* The questionnaire was prepared in English, translated into Amharic and then back-translated into English to ensure consistency. The instrument was pre-tested by the first author in caregivers of children with ASD and/or ID in attendance at the child mental health clinic at Yekatit 12 Hospital and also in a group of caregivers of children attending the Nehemia Autism Centre, a centre for children with ASD in Addis Ababa. A final version of the questionnaire was established following feedback from the pre-test. Psychiatric nurses were trained to administer the questionnaire by conducting face-to-face interviews with respondents. Training was given over two days to ensure that the psychiatric nurses were familiar with the data collection procedures, the questionnaire, information sheets and consent forms.

<b>Questions about your family and your child</b>					
Can you please tell me whether any of the following things have happened since your child developed problems?					
		Not at all (0)	Sometimes (1)	Often (2)	A lot (3)
301	Worried about being treated differently	0	1	2	3
302	Worried other people would find out about it	0	1	2	3
303	Felt the need to hide this problem from people (i.e. that your child has problems)	0	1	2	3

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304	Helping other people to understand what it is like to have a child with slow development	0	1	2	3
305	Have you made an effort to keep this problem a secret?	0	1	2	3
306	Worried about being avoided	0	1	2	3
307	Explaining to others that your child isn't like their picture of "crazy" people	0	1	2	3
308	Worried that people would blame you for his or her problems	0	1	2	3
309	Worried that a person looking to marry would be reluctant to marry into your family	0	1	2	3
310	Worried about taking him or her out	0	1	2	3
311	Felt ashamed or embarrassed about it	0	1	2	3
312	Sought out people who also have a child with similar problems with developing slowly	0	1	2	3
313	Felt grief or depression because of it	0	1	2	3
314	Felt that somehow it might be your fault	0	1	2	3