

Patient-reported outcomes in child and adolescent mental health services (CAMHS): Use of idiographic and standardized measures

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Abstract

Background: There is increasing emphasis on use of patient-reported outcome measures (PROMs) in mental health but little research on the best approach, especially where there are multiple perspectives.

Aims: To present emerging findings from both standardized and idiographic child-, parent- and clinician-rated outcomes in child and adolescent mental health services (CAMHS) and consider their correlations.

Method: Outcomes were collected in CAMHS across the UK. These comprised idiographic measures (goal-based outcomes) and standardized measures (practitioner-rated Children's Global Assessment Scale; child- and parent-rated Strengths and Difficulties Questionnaire).

Results: There was reliable positive change from the beginning of treatment to later follow-up according to all informants. Standardized clinician function report was correlated with standardized child difficulty report ($r = -0.26$), standardized parent report ($r = -0.28$) and idiographic joint client-determined goals ($r = 0.38$) in the expected directions.

Conclusions: These results suggest that routine outcome monitoring is feasible, and suggest the possibility of using jointly agreed idiographic measures alongside particular perspectives on outcome as part of a PROMs approach.

Keywords: *routine outcome monitoring, patient-reported outcomes, CAMHS*

Introduction

Assessing outcomes in health settings has featured in healthcare research for many decades (Jefford et al., 2003) and has become an increasing policy priority worldwide (Department of Health, 2010; Manchinkanti & Hirsh, 2009; Patterson et al., 2006) but the literature identifies many challenges in relation to how best to implement routine outcome evaluation in mental health (Busch & Sederer, 2000). This paper examines two particular areas of interest (a) in relation to whose views should take precedence and (b) in relation to the relative merits of standardized as opposed to idiographic approaches.

Typically, there is statistically significant but low concordance between different reporters of mental health symptoms (Brown et al., 2006; Zahner & Daskalakis, 1998). This raises questions about whose viewpoint to prioritize when considering outcomes of treatment. While the practitioner's perspective may be most likely to correspond to symptom-based criteria for illness and recovery, practitioners are reliant on information from clients and, in a context where outcomes may determine service funding, may be subject to biases.

There has been a growing interest in patient-reported outcome measures (PROMs) (Hansen et al., 2010; Shipley et al., 2000; Whelan et al., 2010), but in child mental health contexts there are issues of different perspectives with low concordance between, e.g. children and their parents (Verhulst & Van der Ende, 2008) and with each perspective alone having strengths and weaknesses. Thus, whilst parent reports are often relied upon when children are considered too young to provide self-reports (Levitt et al., 2007) there may be some possibility of bias due to parents' own mental health status (Cornah et al., 2003) or parents' lack of awareness of internalizing difficulties (Verhulst & Van der Ende, 2008). Child self-report may be desirable, but children with a range of behavioural and emotional problems may be less self-aware of these than others around them and younger children have been found to be less differentiated in reports about the mental health problems that they experience than older children (Van Roy et al., 2008).

There has also been a growing interest in the relative merits and demerits of idiographic PROMs – such as goal-based outcomes (GBOs) or top problems as defined by the child and family as opposed to more standardized pre-defined measures (Weisz et al., 2011). There are many reasons why GBOs may be more acceptable to service users and practitioners (Weisz et al., 2011), focussing as they do on the particular concerns of the individual and removing the sense of tick box exercise that both practitioners and service users are concerned about (Moran et al., 2012). It may be that a focus on GBOs, and in particular tracking progress across sessions, can be a powerful way to improve effectiveness and efficiency (Weisz et al., 2011). However, whilst GBOs may provide information about change most relevant to the particular concerns of the service users, standardized measures may allow more meaningful comparisons across groups.

In this paper, we investigate the use of both standardized and idiographic data from the perspective of children, parents and clinicians to explore the correlations between them and what they can tell us about outcomes in child and adolescent mental health services (CAMHS).

Method

Participants

This paper is based on data on 16 115 episodes of care submitted by 41 CAMHS, mostly from across England along with 6% from Scotland. The majority of cases were from the Nation Health Service (NHS) (79%) with most of the remaining coming from the voluntary sector. Fifty-two percent related to children aged 6–12, and 42% to 13–18-year-olds. More than half (55%) were boys. The most common presenting problems were emotional (55%), conduct (18%), autism (18%) and hyperkinesis (12%), which are consistent with national trends (www.camhsmapping.org.uk).

These episodes of care were taken from a dataset of 67 898 collected through a learning collaboration of practitioners, managers, commissioners and researchers whose primary aim is to foster the effective use of routine outcome measures: the CAMHS Outcomes Research Consortium (CORC; CAMHS Review, 2008). Of this larger dataset, 24% had

outcome data 4–8 months after outset (see Table I). It is not possible to know exactly how many of those episodes of care without outcome data related to families choosing not to complete questionnaires and how many had not been asked to complete the questionnaires. The gender, age profile and duration of problems in those who had completed outcome measures and those who had not was similar, but there was an indication that the level of initial problem severity was higher for those cases without outcome data. For the parent-rated Strengths and Difficulties Questionnaire (SDQ), mean total score at Time 1 was higher for cases with missing Time 2 data (19.7 versus 18.7, $t = 10.3$, $p < 0.001$) similar to the child-rated SDQ (18.1 versus 17.2; $t = 8.0$, $p < 0.001$). It is possible that some of the families attending participating services did not have any data submitted to the consortium by the services. As such we are unable to make accurate hypotheses about how this group may differ from others for which data exist.

Measures

The following key perspectives on outcome were taken:

- (a) Standardized PROMs
- (b) Standardized clinician-rated outcomes
- (c) Idiographic GBOs jointly agreed by family members

All measures were selected for validity, reliability and feasibility (CORC, 2011a, 2011b; Slade et al., 1999) and are summarized in Table II.

Standardized PROMs

Parents or carers and young people aged 11 and older completed the SDQ at baseline and again 6 months later. This 25-item measure assesses emotional symptoms, conduct problems, hyperactivity, peer relationship difficulties and pro-social behaviour (Goodman, 2001). The higher the score on either of these summed scales, the worse the child's problems (with the exception of pro-social behaviour).

Table I. Number of measures returned to the CORC central team by measure and informant.

Type of measure	Measure	Measures completed at outset	Measures completed at 6-month follow-up	Paired outset and follow-up data	Services with paired data
Standardized PROM	Parent SDQ (total diffs)	36579	8640	7542	38
Standardized PROM	SDQ Added Value	N/A	5296	N/A	32
Standardized PROM	Child SDQ (total diffs)	19899	5172	4263	36
Idiographic GBO	Goals	401	218	171	5
Standardized clinician-rated symptom measure	CGAS	24552	7469	6767	31
Standardized clinician-rated symptom measure	HoNOSCA	2640	635	621	8

Note: Total diffs denotes the SDQ total difficulties score.

Table II. The core CORC protocol.

Measure	Type of measure	Outset data	Follow-up data
Parent or Child SDQ	PROM	Completed by parents and child before or during the first meeting	Completed by parents and child at 6 months after first meeting (no less than 4 months, no more than 8 months)
Goals	Goal attainment	Completed by practitioner following discussions with the child and family (usually within first three meetings)	Completed by practitioner 6 months after first meeting or at end of contact if this is sooner
CGAS or HoNOSCA	Clinician-rated symptom measure	Completed by practitioner after the first meeting	Completed by practitioner 6 months after first meeting or at end of contact if this is sooner

The SDQ added value score (AVS) estimates the impact of active intervention at the clinic by comparing the observed mean parental SDQ total difficulties score with the score predicted from baseline scores assuming the child is untreated (Ford et al., 2009; Youth in Mind Ltd., 2011a, 2011b). Scores derived translate to a standardized effect size with higher scores, suggesting that the parental reports of the mental health of children going through the CAMHS is better than would have been expected if support were not received.

Standardized clinician-rated outcomes

Practitioner measures include the widely used Children's Global Assessment Scale (CGAS) and the Health of the Nation Scale for Children and Adolescents (HoNOSCA). The CGAS provides an estimate of the global level of emotional and behavioural function for children aged 4–16, on a scale of 1 (poor functioning) to 100 (high functioning) (Shaffer et al., 1983; Sourander et al., 1996). The HoNOSCA was developed to monitor outcomes in CAMHS and can discriminate well between young people accessing different intensity of services (Gowers et al., 1999). The higher the score on this scale, the greater the problems the child is experiencing.

Idiographic GBOs

The GBOs attempt to measure progress towards the specific goals young persons or their family have chosen to work on with CAMHS. Up to three goals are identified collaboratively by practitioners, service users and their families and these are rated in terms of how close the family are to achieving each goal out of 10. The outcome is the difference between the start and end ratings, where a positive value indicates progress towards achieving the goal (Law, 2006).

Procedure

Measures were completed within the first three meetings with the service user and again either at case closure or between 4 and 8 months into treatment. Services submit these data in a pseudonymized format annually for collation (CORC, 2011a).

Results

Standardized PROMs

The mean SDQ AVS, based on parent-report SDQ scores and pooling data from all age groups, was 0.19 (95% confidence interval of the mean = 0.16–0.22), which translates to a modest but statistically robust effect size.

Figure 1 demonstrates that, across four consecutive years, mean AVS for services has been consistently and reliably greater than 0, suggesting that on average children and young people for whom there were outcome data show greater reduction in symptoms than would have been expected without service contact.

Standardized clinician-reported outcomes

Figure 2 shows changes in scores on clinician-reported measures (CGAS and HoNOSCA) from baseline to follow-up. While these scales are on opposite scoring systems (i.e. CGAS: high scores = high levels of functioning; HoNOSCA: high scores = high levels of problems), both measures indicate an overall improvement in children's mental health from baseline to follow-up (CGAS: mean difference of 9.2 points, $t = 61.5$, $p < 0.001$; HoNOSCA: mean difference -5.5 points, $t = 27.0$, $p < 0.001$).

Idiographic GBOs

GBOs are a relatively recent addition to the CORC protocol; so the available data are limited at this stage ($n = 173$). The data that have been collected show a significant average change of 3.6 (out of a possible 10) towards reaching the goals set at the beginning of an intervention ($t = 17.8$, $p < 0.001$).

Correlations between measures

To consider the correlation between child-, parent- and clinician-reported outcomes and the GBOs, differences scores were computed for each measure based on Time 1 scores minus Time 2 scores (see Table III). Therefore, a positive change score indicates an improvement over time for SDQ measures but not for GBOs or CGAS, which are scored differently such that negative scores indicate improvement.

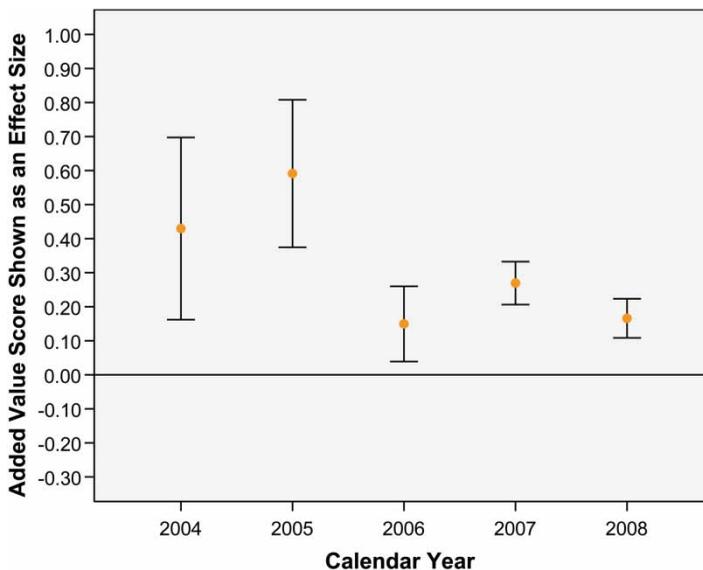


Figure 1. The SDQ AVS over time from 41-member groupings submitting Time 1 and Time 2 parental SDQ data (2004, $n = 64$; 2005, $n = 120$; 2006, $n = 433$; 2007, $n = 1310$; 2008, $n = 1565$).

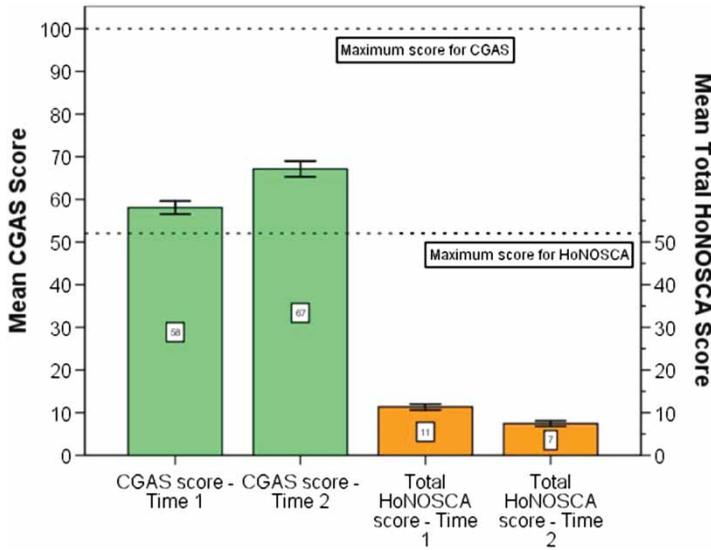


Figure 2. Practitioner measures of outcome at Time 1 and Time 2. Note: HoNOSCA ($N = 621$): lower score indicates fewer problems; CGAS ($N = 6767$): higher score indicates fewer problems).

Table III. Bivariate correlations (Pearson’s r) between T1 – T2 difference measures.

	Child SDQ	Parent SDQ	CGAS	Goal 1	Goal 2
Parent SDQ	0.29***, $n = 4046$				
CGAS	-0.26***, $n = 1679$	-0.28***, $n = 2947$			
Goal 1	-0.10, $n = 64$	-0.27**, $n = 109$	0.38***, $n = 154$		
Goal 2	-0.13, $n = 57$	-0.38***, $n = 88$	0.37***, $n = 123$	0.71***, $n = 200$	
Goal 3	-0.26, $n = 25$	-0.29, $n = 42$	0.39***, $n = 70$	0.57***, $n = 129$	0.54***, $n = 129$

** $p < 0.01$.

*** $p < 0.001$.

The goal measure differences correlated with each other, between $r = 0.54$ and $r = 0.71$, suggesting that progress with one goal is associated with progress on another. There were also correlations between difference scores for goals 1 and 2, and the parent SDQ difference scores, and the strongest correlations were between all three goal difference scores and the clinician-rated CGAS difference (around $r = 0.4$). No statistically significant correlation was found between any of the goal difference scores and the child SDQ total difference scores, though the sample estimate of the correlation between these variables is positive. The smaller sample size ($n < 70$) and the resulting lack of statistical power may explain the lack of a statistically significant correlation.

Discussion

Outcome data presented in this paper from the CORC dataset across parent-, child- and clinician-reported outcomes all suggested an overall reduction in mental health problems for children seen by participating services in England and Scotland. These findings are consistent with research in showing modest but significant improvements in mental health

outcomes after intervention from mental health services (Ford et al., 2009; Pirkis et al., 1999; Stiles et al., 2007).

For many of the measures used, it is not possible to assess to what extent these reductions over time are accounted for by regression to the mean (Bland & Altman, 1994). However, the SDQ AVS estimates the extent of change observed to be over that which would be expected if the children had not been seen by services (Ford et al., 2009) and so adjusts for regression to the mean, attenuation and the natural fluctuations in the level of psychopathology. The mean AVS over 5 years suggested that outcome improvements were greater than would be expected according to epidemiological data (Ford et al., 2009), which suggest that, overall, services are having a positive impact on children's mental health problems.

Correlations between the difference scores from baseline to follow-up for the GBOs and the other parent- and clinician-rated measures were statistically significant and of a similar magnitude to those observed between clinician- and parent-rated measures, giving an indication of good construct validity. This suggests that such idiographic measures may have some utility alongside more standardized measures and may be of particular help in that they combine perspectives.

Correlations between child-reported SDQ and goals were not significant. However, it is important to note the very small number of children providing data. These findings may be due to a lack of statistical power or a lack of correspondence between GBOs and child-reported outcomes, and need to be replicated in a larger sample. The findings could equally be explained by the GBOs more closely reflecting adults' aims, particularly those of clinicians', a hypothesis suggested by the fact that the strongest correlations existed between GBOs and the clinician-rated CGAS. This merits further investigation.

Limitations

Clearly these results need to be treated with caution for a number of reasons. The lack of accurate information on response rates, and the likely limited response rate to the follow-up measurement, is a major limitation that members of the collaboration are striving to overcome in future data collection. We cannot know whether these results reflect the experience of the majority of people seen by services. The literature suggests that those who do not complete post-treatment measures have more severe problems at the outset (Stiles et al., 2003) and this would be consistent with the known skew in our dataset. In addition, there is evidence that those who fail to complete post-treatment data – one of the causes of missing data in the present dataset – might have made worse progress than those who completed both pre- and post-questionnaires, which may lead to a positive bias in outcome estimates (Clark et al., 2008). On the other hand, the use of general measures to cover as many children as possible means that effect sizes will be smaller than those that would be obtained with disorder-specific measures (Lee et al., 2005) and so may underestimate the extent of change.

Conclusion

These results suggest that a range of PROMs may provide useful information on outcomes in child mental health services. The parent-reported measures, in particular using the SDQ, can be used to make comparisons of change with an untreated population and thus can allow services to benchmark themselves against a naturally occurring "control" group. Whilst the strengths and limitations of this measure and its associated added value estimation warrant further investigation, the SDQ does provide some possibility of use in terms of service development and improvement.

Whilst the correlations between the GBOs and the standardized measures were modest, they were significant and they were in line with concordance between perspectives based on standardized measures. These results suggest the possibility of using jointly agreed idiographic measures alongside particular perspectives on outcome as part of a PROMs approach.

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References

- Bland, J.M., & Altman, D.G. (1994). Statistic notes: Regression towards the mean. *British Medical Journal*, 308 (6942), 1499.
- Brown, J.D., Wissow, L.S., Gadowski, A., Zachary, C., Bartlett, E., & Horn, I. (2006). Parent and teacher mental health ratings of children using primary-care services: Interrater agreement and implications for mental health screening. *Ambulatory Pediatrics*, 6(1), 347–351.
- Busch, A.B., & Sederer L.I. (2000). Assessing outcomes in psychiatric practice: Guidelines, challenges, and solutions. *Harvard Review of Psychiatry*, 8(6), 323–327.
- CAMHS Review. (2008). *Children and Young People in Mind; the Final Report of the National CAMHS Review*. Retrieved June 17, 2010, from www.dcsf.gov.uk/CAMHSreview/downloads/CAMHSReview-Bookmark.pdf
- Clark, D.M., Fairburn, C.G., & Wessely, S. (2008). Psychological treatment outcomes in routine NHS services: A commentary on Stiles et al. (2007). *Psychological Medicine*, 38(5), 629–634.
- CORC (CAMHS Outcomes Research Consortium). (2011a). *CORC Measures*. Retrieved February 2011, from <http://www.corc.uk.net/index.php?contentkey=81>
- CORC (CAMHS Outcomes Research Consortium). (2011b). *CORC Protocol*. Retrieved February 2011, from <http://www.corc.uk.net/index.php?contentkey=12>
- Cornah, D., Sonuga-Barke, E., Stevenson, J., & Thompson, M. (2003). The impact of maternal mental health and child's behavioural difficulties on attributions about child behaviours. *British Journal of Clinical Psychology*, 42(1), 69–79.
- Department of Health. (2010). *Transparency in Outcomes: A Framework for the NHS*. London: Stationery Office.
- Ford, T.J., Hutchings, J., Bywater, T., Goodman, A., & Goodman, R. (2009). Evaluation of the Strengths and Difficulties Questionnaire Added Value Score as a method for estimating effectiveness in child mental health interventions. *The British Journal of Psychiatry*, 194, 552–557.
- Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire (SDQ). *Journal of the American Academy of Child & Adolescent Psychiatry*, 40, 1337–1345.
- Gowers, S.G., Harrington, R.C., Whitton, A., Lelliott, P., Beevor, W., Wing, J., et al. (1999). Brief scale for measuring outcomes of children with emotional and behaviour disorders. The Health of the Nations Outcome Scale for Children and Adolescents (HoNOSCA). *The British Journal of Psychiatry*, 174, 413–416.
- Hansen, L.K., Vincent, S., Harris, S., David, E., Surafudheen, S., & Kingdon, D. (2010). A patient satisfaction rating scale for psychiatric service users. *Psychiatric Bulletin*, 34, 485–488.
- Jefford, M., Stockler, M.R., & Tattersall, M.H.N. (2003). Outcomes research: What is it and why does it matter? *Internal Medicine Journal*, 33, 110–118.
- Law, D. (2006) *Goal Based Outcomes (GBOs): Some Useful Information*. London: Internal CORC publication. Retrieved from www.corc.uk.net

- Lee, W., Jones, L., Goodman, R., & Heyman, I. (2005). Broad outcome measures may underestimate effectiveness; an instrument comparison survey. *Child and Adolescent Mental Health, 10*, 143–144.
- Levitt, J.M., Saka, N., Romanelli, L.H., & Hoagwood, K. (2007). Early identification of mental health problems in schools: The status of instrumentation. *Journal of School Psychology, 45*(2), 163–191.
- Manchinkanti, L., & Hirsh, J.A. (2009). Obama health care for all Americans: Practical implications. *Pain Physician, 12*, 289–304.
- Moran, P., Kelesidi, K., Guglani, S., Davidson, S., & Ford, T. (2012). What do parents and careers think about routine outcome measures and their use? A focus group study of CAMHS attenders. *Clinical Child Psychology and Psychiatry, 17*(1), 65–79.
- Patterson, P., Matthey, S., & Baker, M. (2006). Using mental health outcome measures in everyday clinical practice. *Australasian Psychiatry, 14*, 133–136.
- Pirkis, J., Burgess, P., Dunt, D., & Henry, L. (1999). *Measuring Quality in Australian Mental Health Services*. Melbourne: Centre for Health Program Evaluation, Health Economics Unit.
- Shaffer, D., Gould, M.S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., et al. (1983). A Children's Global Assessment Scale (CGAS). *Archives of General Psychiatry, 40*, 1228–1231.
- Shipley, K., Hilborn, B., Hansell, A., Tyrer, J., & Tyrer, P. (2000). Patient satisfaction: A valid index of quality of care in a psychiatric service. *Acta Psychiatrica Scandinavica, 101*, 330–333.
- Slade, M., Thornicroft, G., & Glover, G. (1999). The feasibility of routine outcome measures in mental health. *Social Psychiatry and Psychiatric Epidemiology, 34*, 243–249.
- Sourander, A., Helenius, H., & Piha, J. (1996). Child psychiatric short term inpatient treatment: CGAS as a follow-up measure. *Child Psychiatry and Human Development, 27*, 93–104.
- Stiles, W.B., Leach, C., Barkham, M., Lucock, M., Iveson, S., Shapiro, D.A., et al. (2003). Early sudden gains in psychotherapy under routine clinic conditions: Practice-based evidence. *Journal of Consulting and Clinical Psychology, 71*, 14–21.
- Stiles, W.B., Barkham, M., Mellor-Clark, J., & Connell, J. (2007). Effectiveness of cognitive-behavioural, person-centred, and psychodynamic therapies in UK primary-care routine practice: Replication in a larger sample. *Psychological Medicine, 38*, 677–688.
- Van Roy, B., Veenstra, M., & Clench-Aas, J. (2008). Construct validity of the five-factor Strengths and Difficulties Questionnaire (SDQ) in pre-, early, and late adolescence. *Journal of Child Psychology and Psychiatry, 49*, 1304–1312.
- Verhulst, F.C., & Van der Ende, J. (2008). Using rating scales in a clinical context. In M. Rutter, D. Bishop, D. Pine, S. Scott, J. Stevenson, E. Taylor, & A. Thapar (Eds.), *Rutter's Child and Adolescent Psychiatry* (pp. 289–298). Oxford: Blackwell.
- Weisz, J.R., Chorpita, B.F., Frye, A., Ng, F.Y., Lau, N., Bearman, S.K., et al. (2011). Youth top problems: Using idiographic, consumer-guided assessment to identify treatment needs and to track change during psychotherapy. *Journal of Consulting and Clinical Psychology, 79*, 369–380.
- Whelan, P., Andrews, T., Patel, S., & Lewis, A. (2010). Taking the Cinderella speciality to the PROM: Developing a patient related outcome measure for an older adult mental health service. *Quality in Ageing and Older Adults, 11*, 51–55.
- Youth in Mind Ltd. (2011a). *Questionnaires in English. Strengths and Difficulties Questionnaires*. Retrieved February 2011, from <http://www.sdqinfo.com/b2.html>
- Youth in Mind Ltd. (2011b). *Scoring the SDQ. Strengths and Difficulties Questionnaires*. Retrieved February 2011, from <http://www.sdqinfo.com/b4.html>
- Zahner, G.E.P., & Daskalakis, C. (1998). Modeling sources of informant variance in parent and teacher ratings of child psychopathology. *International Journal of Methods in Psychiatric Research, 7*(1), 3–16.