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**Investigating Activity Levels in Children with Psychotic-like Experiences  
The Role of Emotional, Social and Cognitive Factors**

Tekes, Sinem

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# **VOLUME I**

## **SYSTEMATIC LITERATURE REVIEW AND EMPIRICAL RESEARCH PROJECT**

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**Sinem Tekes**

**Thesis submitted in partial fulfilment of the degree of  
Doctorate in Clinical Psychology**

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Institute of Psychiatry, Psychology and Neuroscience

King's College London

June 2017

*Ji buy diyamin, till min mor.*

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# **Systematic Literature Review**

Stigma experiences in children and young people with mental health difficulties: A systematic review of their relationship with activity levels.

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## **1. Abstract**

Engagement in activity, an aspect of social functioning, is important to good mental health. In adults, perceived mental health stigma has been shown to limit functioning, and is therefore implicated in the development and maintenance of a range of mental health conditions. Recovery-oriented interventions have started to focus on reducing stigma, to promote improved functioning. There is growing interest in early intervention in mental health, to address vulnerability and emerging difficulties, and promote engagement in developmental opportunities, with a view to reducing future morbidity. Stigma-focused interventions could be important components of early support. Despite this, little is known about the impact of self-stigma amongst young people with mental health problems and its association with activity levels and social functioning. This is the first systematic review to investigate this relationship in children and young people. The purpose was to consider the potential for stigma-focused early intervention to promote better functioning in this group. Five electronic data bases were searched up to January 2017; PsychINFO, PubMed, Embase, Medline and Web of Science. A total of 4001 citations were screened and seven quantitative studies were identified that met inclusion criteria. Four studies showed a significant relationship between mental health stigma and aspects of social functioning in young people. However, interpretation of the findings is restricted by the small number and poor methodological quality of identified studies. In particular, the range of conceptualisations of self-stigma and social functioning, and the methods of measurement utilised, limit the potential to compare studies. There is a need for more studies investigating self-stigma experiences with young people with mental health problems, using well-conceptualised, developmentally appropriate measures, of social functioning in particular.

## 2. Overview

There has been increasing interest over the last decade in childhood onset of mental health conditions and early intervention (Department of Health 2007). Early intervention is intended to improve current child wellbeing, and thereby engagement in social and educational opportunities, with consequent benefits to future mental health and functioning (Bertolote & McGorry, 2005; Tolan & Dodge, 2005). Adolescence is a critical period of transition to adulthood during which identity consolidation, development of independence, and the increasing importance of stronger peer relationships occurs (Steinberg & Morris, 2001). Adolescence is also considered a key period of vulnerability for developing serious mental health problems, which, over and above the impact of the health problem per se, interfere with usual developmental opportunities, and may thus create additional vulnerability (Cicchetti & Rogosch, 2002). Therefore early intervention during this key time would be critical, not only to reduce the likelihood of mental health difficulties in vulnerable young people, but also to minimise their impact on the key developmental tasks of adolescence. Reducing adverse impact and additional vulnerability should reduce persistence of mental health problems into adulthood, or their recurrence (e.g. Kim-Cohen et al., 2003) thereby reducing the overall mental health burden (Institute of Medicine, 2009).

One of the key factors contributing to the adverse current and future impact and maintenance of mental health problems is the experience of social rejection and self-stigma (Link & Phelan, 2001). Internalised or self-stigma in adults with mental health problems has been associated with a range of negative outcomes including depression and low self-esteem as well as poor quality of life and reduced activity and social functioning (Lysaker et al., 2007a; 2007b; Moriarty et al., 2012). The impact on functioning is particularly key: inactivity and avoidance are exacerbating factors in a range of mental health conditions, and limit opportunities for rehabilitation and recovery, contributing to a negative cycle of persistence and recurrence of difficulties. However, despite the apparent link within adults, and the particular importance of independent and social activity in adolescence, there is comparatively less research about the relationship between mental health stigma and functioning in children and young people. Therefore the aim of the current review will be to investigate the relationship between stigmatised experiences in young people with mental health problems, and social functioning.

The review begins with an introduction to the particular issues of mental health difficulties in children and adolescents, the nature of stigma, the study of mental health stigma in youth irrespective of its impact on functioning, and the specific impact of mental health stigma on functioning in adults. The specific rationale for the review is then presented, followed by the methodology, a detailed presentation of review findings, and a discussion of the implications, with conclusions regarding future research and clinical need.

### **3. Introduction**

#### **Mental health in adolescence**

The prevalence of mental health problems in children and young people (CYPs) aged between five and fifteen years in the UK has been reported to be as high as ten percent (Meltzer et al., 2003b) and up to twenty percent worldwide (Kieling et al., 2011). There is ample evidence that psychiatric disorders have an onset in early life well before adulthood (Kim-Cohen et al., 2003) and that the disorders manifested in childhood and adolescence often recur in adulthood (Costello, Foley & Angold, 2006). For example CYPs experiencing anxiety are 3.5 times more likely than others to suffer from depression or anxiety disorders in adulthood (Meltzer et al., 2003a).

Furthermore, a prospective longitudinal study that followed a birth cohort since the 1970s, found that 50% of individuals with a psychiatric diagnosis at the age of 26, first had a diagnosable disorder between the ages of 11 and 15 and three quarters before the age of 18 (Kim-Cohen et al., 2003). Mental health problems in youth have been associated with negative effects on educational attainment, chronic disability, and lost productivity (Kieling et al., 2011) as well as increased rates of suicide (Vijayakumar et al., 2005) across adolescence and adulthood. Associations are well replicated cross-culturally (Vijayakumar et al., 2005). The findings highlight the need to further understand the factors that may serve to exacerbate mental health problems in young people.

#### **Adolescence as a critical period of development**

Adolescence and emerging adulthood is a critical period in the development of personal identity (Côté, 2006), during which rapid physical, cognitive and social change occurs (Feldman & Elliott, 1990). This period marks the final phase of a longstanding pattern of growth and brain maturation including for example increases in white matter and decreases in volumes of grey matter possibly representing ‘pruning’ of tissue (Gogtay et al., 2004), which underlie cognitive and social development (Crone & Dahl, 2012).

Furthermore, the formation of social relations plays a significant role during adolescence whereby individuals begin to individuate from their familial context and become more sensitive to peer influences, and more likely to internalise peer opinions, which may lead to pressures to conform (Crosnoe & McNeely, 2008). Therefore, peer relations may create difficulties for adolescents’ adjustment and functioning particularly

during middle adolescence as peer relationships become more influential (Steinberg & Morris, 2001) and they may be particularly susceptible to negative evaluation and potential rejection from others (Donenberg & Pao, 2005).

### **Stigma**

There has been an increase in interest over the last decade in mental health stigma and its adverse impact particularly for people with severe mental illness (Thornicroft et al., 2007). For young people, when mental health issues may be occurring for the first time, in the context of significant neurodevelopmental change, and alongside a developing sense of self, independence, and the importance of the views of others, stigma is a key issue, and may restrict access to appropriate help (Gulliver, Griffiths, & Christensen, 2010). The impact of stigma in adolescence may restrict access to a wide range of development opportunities, and thus perpetuate and create further vulnerability to future mental ill health.

The psychological model of stigma developed Link and Phelan (2001), stated that stigma occurs when aspects of labelling, stereotyping, separation, status loss and discrimination coincide. They suggest that once the labelling and status loss of an individual occurs the process of discrimination and devaluation of the individual takes place. Discrimination is described as a process occurring at both an individual and structural level, which unfolds as the behavioural component of the stigma process. The stigmatised individual responds to the negative stereotype and discrimination based on their beliefs and fears about rejection and discrimination and may subsequently act with less confidence or more defensively, or ultimately avoid social contact (Moses, 2010a). This highlights the possibility that there could be a direct link between stigma and activity levels through the processes described in the Link and Phelan (2001) model, whereby the stigmatised individual engages in less activity and more avoidance, which may further reinforce beliefs about the negative stereotype due to fewer opportunities to gain positive reinforcement. Stigma could therefore be an important factor in reduced activity levels, and given that previous research has shown that activity can significantly impact on recovery in a range of mental health conditions including anxiety and depression (e.g. Link et al., 2001; Sirey et al., 2001), it is increasingly important to further investigate these links. This could help to improve treatment interventions by directly addressing the impact of stigma on reduced activity.

It is important to consider the different types of stigma, particularly the difference between public and self-stigma. Public stigma refers to stigmatising attitudes that have been endorsed by the general population whilst experienced or self-stigma refers to the direct discrimination and stigma endorsed by the individual (Corrigan & Watson, 2004; Ritsher & Phelan, 2004). Within the mental health context, public stigma involves public concepts of mental illness and the negative reactions from individuals or societal groups of people who experience mental health difficulties (Gerlinger et al., 2013). Self-stigma involve individuals with mental health problems endorsing and internalising the negative stereotypes and prejudices held by the general public about mental illness (e.g. Corrigan et al., 2005) and acting in accordance.

Both public stigma and self-stigma have been shown to have detrimental effects on individuals with mental health problems, and associated interventions show promise in reducing stigma. Targeting public stigma requires large-scale interventions and campaigns aimed at improving mental health knowledge and awareness in the general population (Thornicroft et al., 2007). However, recent reviews have found that self-stigma is actually much more likely than public stigma to impact adversely on help seeking, suggesting interventions to support understanding (Wood et al., 2016; Schnyder et al., 2017), increasing quality of life, resilience and recovery by working directly with individuals with mental health problems. This work should complement the public stigma campaigns and interventions in a joint effort to reduce the negative stereotyping and discrimination of individuals with mental health difficulties (Evans-Lacko et al., 2012). Therefore, experiences of self-stigma will form part of the main focus for the current study.

Studies with adult populations have shown that self-stigma has a positive correlation with symptoms of depression and anxiety (Link et al., 1997), a negative impact on self-esteem and social relationships (Corrigan & Watson, 2002; Wood et al., 2017) and causes delays in seeking treatment (Starr, Campbell & Herrick, 2002), all of which may contribute to further avoidances and withdrawals, perpetuating a vicious cycle which can have a negative impact on longer term mental health outcomes (Link & Phelan 2001; Moriarty et al., 2012). Although there is currently growing understanding of public stigma of adolescent mental health (e.g. Moses 2010a; Kaushik, Kostaki & Kyriakopoulos, 2016), there is a noticeable lack of research investigating the impact of self-stigma amongst CYPs who are experiencing mental health problems. Recent

research has highlighted associations between internalised stigma and mental health presentations including depression, social anxiety and unusual experiences in individuals at risk of developing psychosis, highlighting the possible contribution of mental health stigma to depression, which may increase the risk of developing psychosis (Pyle et al., 2015). These findings suggest an important role of self-stigma on the trajectory of mental health difficulties in young people, indicating potential for further investigation.

The majority of the research investigating stigma and mental health difficulties in CYPs has focused on issues of help seeking; given that stigma is one of the main barriers that causes delays for accessing appropriate treatments (Chandra & Minkovitz 2007; Gulliver et al., 2010). Chandra and Minkovitz (2007) highlighted that one of the key factors impacting on young people's willingness to address mental health difficulties included the anticipation of negative responses from family members, peers, and school staff towards mental health care seeking. This was supported by a recent systematic review (Kaushnik et al., 2016) reporting significant evidence of the stigmatisation of young people with mental health problems by peers as well as adults highlighting the presence of fear of rejection and discrimination within this age group.

Whilst reducing the impact of stigma upon help seeking in adolescence is undoubtedly important, there remains scope to better understand the adverse effects of stigma on other behaviours, for example avoidance and withdrawal, that may in turn limit adolescent development opportunities, and increase morbidity. Improving both help-seeking and functioning are key aims of early intervention research and service development. However, whilst the effectiveness of help-seeking is dependent upon the help available and access pathways, improving functioning is associated with positive mental health impact across contexts, particularly for severe mental health conditions. A better understanding of the impact of stigma upon functioning in adolescence is required as it would help to inform clinical interventions to improve outcomes for young people with, or at risk of developing, mental health difficulties.

### **Stigma during critical period of development**

Given that adolescence is a particularly sensitive period whereby individuals begin to develop a sense of self-identity (Feldman & Elliott, 1990) and become more likely to internalise peer (Crosnoe & McNeely, 2008) and family (O'Brien et al., 2006) opinions,

potential negative evaluation and rejection from others can be an increasingly worrying concern (Donenberg & Pao, 2005). This is important because in comparison to adults, adolescents have a less consolidated identity to protect against or neutralise stereotypes and prejudice from peers, family and society and are also more susceptible to worrying about being different from their peers (Kranke et al., 2011), which could lead to increased levels of secrecy (Elkington et al., 2012) and social isolation (Adewuya et al., 2011) into adulthood. This highlights the relationship between mental health stigma and social functioning and the potential impact on longer-term mental health outcomes.

### **Activity and social functioning**

Social functioning is an umbrella term for a range of skills and activities representative of a person's ability to manage themselves, the tasks of daily living, occupational, vocational and relational roles, and meaningful activity (Harvey & Strassing, 2012). Improving social functioning is an important mental health outcome, particularly for conditions characterised by functional deterioration, such as schizophrenia (Lysaker et al., 2007b). Within the psychosis literature, social functioning deficits have been mainly linked to negative symptoms and neurocognitive deficits (e.g. Green et al., 2000), leading to interventions focusing on improving ability or competence through for example remedial learning strategies (e.g. Horan et al., 2011). However, increases in activity levels, including more time spent in meaningful activity with reduced time spent doing nothing and reduced social withdrawal, have also been associated with improvements in mood and positive symptoms compared to cognitive deficits (Wing & Brown, 1970; Olbrich et al., 1993; Purvis et al., 2004). This suggests possible avenues for therapeutic interventions by increasing activity levels through improving mood and distressing experiences. Indeed, re-engaging in self-care, meaningful activity, and relationships is a key target of cognitive behavioural interventions (National Institute for Health and Care Excellence, 2014). Several studies have shown the impact of reduced activity levels in mental wellbeing with young people (e.g. Passmore 2003; Caldwell 2005) however there is still a paucity of research investigating activity levels in young people with mental health difficulties.

There is currently a range of methods used to measure social functioning in young people including quality of life questionnaires (Jörngården, Wettergen & von Essen, 2006), social adjustment inventories focusing on aspects of school, peer and family relationships and leisure activities (Weissman & Bothwell, 1976; John et al., 1987) as

well as social competence questionnaires (LaFreniere & Dumas, 1996). While many studies examine activity as part of a wider construct of functioning, there has been rekindled interest recently in measures focusing exclusively on activity. For example, ‘time budget’ measures of weekly activity have gained increasing favour within the adult literature (Jolley et al., 2006; Killaspy et al., 2015; Cella, Edwards & Wykes, 2016; Velligan et al., 2016). However there have been no studies to date investigating the use of similar hour-by-hour detailed descriptions of activity levels with young people with mental health difficulties. Given that targeting reduced activity levels within therapy has shown reliable improvements in studies with adults, it will be important to investigate firstly whether reduced activity is found in young people with mental health difficulties, and secondly whether targeting activity specifically in therapy will have positive outcomes. However, for the purpose of the current review, in order to assess the possible link between stigma and activity in young people, it will be necessary to investigate the methods currently used within the literature to measure activity. Therefore, although the current study utilises a narrow definition of activity levels, the search will involve a broad focus, as activity is likely to be incorporated into available measures of social functioning.

### **Social functioning and stigma**

Studies of stigma in adults with a range of serious mental health problems have shown its widespread effects on social functioning. For example, a study by Lysaker and colleagues (2007a) looked at the effect of stigma on symptoms and social functioning in a group of adults with schizophrenia. They found that stigma was associated with increased symptoms and fewer social relationships, both at baseline and six month follow up. Similarly, in a systematic review looking at experiences of stigma in patients with schizophrenia, it was found that positive symptoms, depression and general psychopathology often correlated significantly with personal stigma, and psychosocial factors including quality of life was inversely correlated with personal stigma (Gerlinger et al., 2013). Another study looking at self-stigma among mental health patients found that perceived poor social support was the main correlate of increased self-stigma (Adewuya et al., 2011). Moriarty et al. (2012) found that internalised stigma was significantly correlated with reduced activity, which has been supported by other similar studies (Ben-Zeev et al., 2012). The findings indicate that, for adults with severe mental health problems, the fear of what others will think of them and how they will be treated

by others may limit their engagement with activities (Moriarty et al., 2012). The findings from adult studies reporting on the negative impact of self-stigma on social functioning and mental health, as well as its long term impact, raises the question as to whether similar effects would be seen in adolescent populations.

### **Mental health and social functioning**

Studies have highlighted that reduction in functioning in children and adolescents may impact on their academic and social development as well as contribute to greater risk of further mental health difficulties in the future (Fusar-Poli et al., 2010). Various disorders have been associated with reduced social functioning in their earliest stages, particularly early onset psychosis and the psychosis prodrome (Lay et al., 2000; Tarbox & Pogue-Geile, 2008). For example, individuals with first episode psychosis show difficulties in maintaining social relationships prior to initial hospitalisation (Horan et al., 2006), which has been shown to predict post-onset symptoms severity and overall functioning (Addington, van Mastrigt & Addington, 2003; Walshe et al., 2007). Furthermore, positive family relationships predict decreased symptoms and enhanced social functioning among adolescents at risk for psychosis (O'Brien et al., 2006).

In a qualitative study by Moses (2010a) young people with mental health difficulties were interviewed about their stigma experiences and reported that highest levels of experienced stigma were from peers, which led to loss of friendships and the avoidance of stigmatising interactions through concealing their mental health difficulties. Similar findings were shown with a sample of young people at risk of developing psychosis, highlighting that difficulty with interpersonal relationships and subsequent concealment of experiences due to stigma, could contribute to developing unusual experiences (Byrne & Morrison, 2010). Therefore, given the findings that adolescence is a particularly sensitive time for developing mental health difficulties, disruptions of social functioning at this stage of development may have significant impact on the duration and long-term clinical outcomes.

### **3.1. Aims and objectives**

Adolescence is a key time to intervene to reduce current and future mental health difficulties. There is recognition of the importance of activity to good mental health in adults, and growing public awareness and research evidence showing the relationship between stigma and social functioning in adults (e.g. Lysaker et al., 2007a) and the

negative impact of these factors on longer-term outcomes (e.g. Link & Phelan, 2001). There is also interest in the development of stigma-focused interventions (Wood et al., 2016). However, despite this, there is very limited research investigating the impact of self-stigma amongst young people with mental health problems and its association with activity levels and social functioning.

While the adult research highlights the potential importance of understanding the relationship of mental health stigma to activity, there may in adolescence, be differences from the way adults experience and be impacted by self-stigma, that are important to investigate. Adolescence is a critical period for the development and consolidation of identity when young people learn independence and autonomy as well as how to fit in socially with their surroundings (Wisdom, Clarke & Green, 2006). Therefore any impairment in social functioning at this time could be particularly detrimental and increase risk of developing or maintaining mental health difficulties. Mental health difficulties and experiences of stigma are therefore increasingly important to consider at this stage in order to promote understanding of their interactions as well as to intervene early.

Therefore the aim of the current study is to conduct a systematic review investigating the relationship between mental health stigma and activity in children and young people. It is proposed that experiences of mental health stigma will have a negative impact on levels of activity including social functioning in children and young people.

In summary, this review aims to:

- Identify, synthesise and discuss the outcome of studies investigating the impact of self-stigma related to mental health upon activity in children and young people
- Consider the quality of the identified studies.

## **4. Method**

### **4.1. Design**

A systematic review of the literature was conducted following PRISMA guidelines (Moher et al., 2009) with the results described and presented in a qualitative synthesis. The review was registered with PROSPERO (CRD42016050500 (<http://www.crd.york.ac.uk/prospero>)). The PROSPERO registration is available in Appendix A.

### **4.2. Search strategy**

The electronic searches were undertaken using five databases including PsychINFO, PubMed, Embase, Medline and Web of Science. There were no lower date limits for the searches and electronic searches ended on 8th January 2017. The Cochrane Collaboration advises the use of multiple search sources when conducting systematic reviews (Higgins & Green, 2008), therefore reference list screening was undertaken via visual inspection of the collected papers to locate any further potentially relevant cited journals articles. Furthermore, researchers and authors of relevant studies were contacted to advise about any recommendations for published or unpublished studies that they were aware of.

### **4.3. Study selection criteria**

In order to gain a full understanding of the association between mental health stigma and reduced activity, the current study sought to include studies where samples of an ‘at risk’ population were investigated despite not having a confirmed mental health diagnosis. This is based on qualitative research showing that young people with an at risk mental state (ARMS) were concerned about stigma in relation to their unusual psychological experiences, and as a result reported a fear of negative reactions from other people (Byrne & Morrison, 2010). Furthermore, rather than restricting the search to samples comprising exclusively young people under the age of 18 years, the current review will include studies with participant samples with a mean age of 18 years or younger, to accommodate studies extending to late adolescence, whilst retaining the desired focus on youth. The strategy is consistent with reports showing that the critical period for onset of a range of mental health problems extends into early adulthood (e.g. Patel et al., 2007).

Studies were eligible for the review if they: (a) included children and adolescents with a mental health condition or ‘at risk’ presentation; (b) reported on a sample with mean age of 18 years or under; (c) included any measure of mental health related personal stigma including internalised stigma, perceived stigma, experienced stigma and/or self-stigma; (c) measured any aspect of social functioning including activity levels (d) reported peer-reviewed research e) presented results including associations between social functioning and personal stigma. If participants with a mean age of 18 years or under were included as a subset of a broader sample with an older mean age, data on those participants must have been reported separately, as a subgroup, to allow for extraction of findings. There were no restrictions placed on country setting or the methods of measuring stigma and social functioning. Papers not published in English, qualitative studies, reviews (systematic or meta-analytic), non-peer reviewed research including conference proceedings, reviews, editorials and opinion pieces were excluded. Studies investigating the impact of other types of stigma, for example public stigma, where personal stigma could not be differentiated, were also excluded.

#### **4.4. Search criteria**

‘Stigma’ AND ‘Young people’ OR ‘young person’ OR ‘teenager\*’ OR ‘youth\*’ OR ‘adolescen\*’ OR ‘young adult\*’ OR ‘child\*’ OR ‘Pediatric\*’ OR ‘Paediatric\*’ AND ‘Mental illness\*’ OR ‘mental disorder’ OR ‘mental health’. The full search strategies are available in the Appendix section B. No specific terms were included for social functioning, because of the heterogeneity of potentially relevant terms, and so as not to limit the results of the search.

#### **4.5. Data extraction**

The titles and abstracts were screened independently by the author and another reviewer (ST and CH) and any rating disagreements were resolved by consensus or by assistance from a third reviewer, who had a supervisory role (SJ). Wherever there were uncertainties regarding the eligibility of the reference at this stage, they would be retained and assessed for full text screening. Two reviewers (ST and CH) independently screened the full text papers for eligibility, again with any disagreements resolved by consensus or a third reviewer (SJ).

The full data extraction was completed by the author and included extraction of study design, sample characteristics, methods of assessing stigma and social functioning and

relevant study outcomes. A second independent reviewer (CH) followed the same procedure for data extraction for all of the final papers.

#### **4.6. Quality assessment**

The methodological quality of the included studies was appraised independently by two reviewers (ST and CH) using an adapted version of the ‘Evaluation of Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies’ (Effective Public Health Practice Project). For the purposes of the current study, specific items were adapted to include the validity and reliability of the stigma and social functioning measures (see Appendix C for the adapted EPHPP). The EPHPP was used to assess each study across the domains including selection bias; study design; confounders; data collection methods; withdrawals and dropout rates; consideration of missing data; power and suitability of analysis. The ratings across the domains were used to give one global rating for each study with the following descriptors: ‘strong’ = no weak ratings; ‘moderate’ = one weak rating; ‘weak’ = two or more weak ratings on the subscales. The reviewers compared the ratings and any discrepancies were noted, discussed and resolved by consensus rating.

## **5. Results**

### **5.1. Overview of study selection**

There were a total of seven papers included in the review, published up to and including the final search date of 8th January 2017. The initial systematic search using the electronic databases identified 5507 records, with one more identified following a hand reference list screening from the eligible papers (Wiener et al., 2012). There were 4001 papers remaining following the removal of duplicate texts, out of which 646 papers were excluded. The remaining 830 papers were screened for titles and abstracts. The title and abstract screen yielded 184 full texts for review, which led to the further exclusion of 177 papers. The study selection process is described in Figure 1 using the PRISMA Flow Diagram (Moher et al., 2009).

The majority of the papers were excluded due to mean age exceeding 18 years (44.1%), the second most common reason for exclusion was lack of social functioning measure within the studies (15.8%). Of the full text papers 11.3% were non-peer reviewed research including dissertations, conference proceedings or editorials. A tenth of the papers were excluded on the basis of the stigma measure not being mental health related (10.7%) but rather based on a neurological, physical health or social condition, most notably epilepsy, HIV/AIDS or stigmatising experiences of orphanhood or homelessness. Although those papers usually included mental health outcomes showing these populations were at risk or vulnerable to psychological difficulties, the stigma measures focused on the physical health or social concerns, rather than mental health stigma, and therefore they were excluded from the current study. A tenth (10.7%) of the studies examined public attitudes rather than personal stigma, focusing on, for example, stigma reduction interventions in schools. Finally, 4.0% of the full texts were qualitative and 3.4% either systematic or meta-analytic reviews covering topics unrelated to the current study, and were therefore excluded.

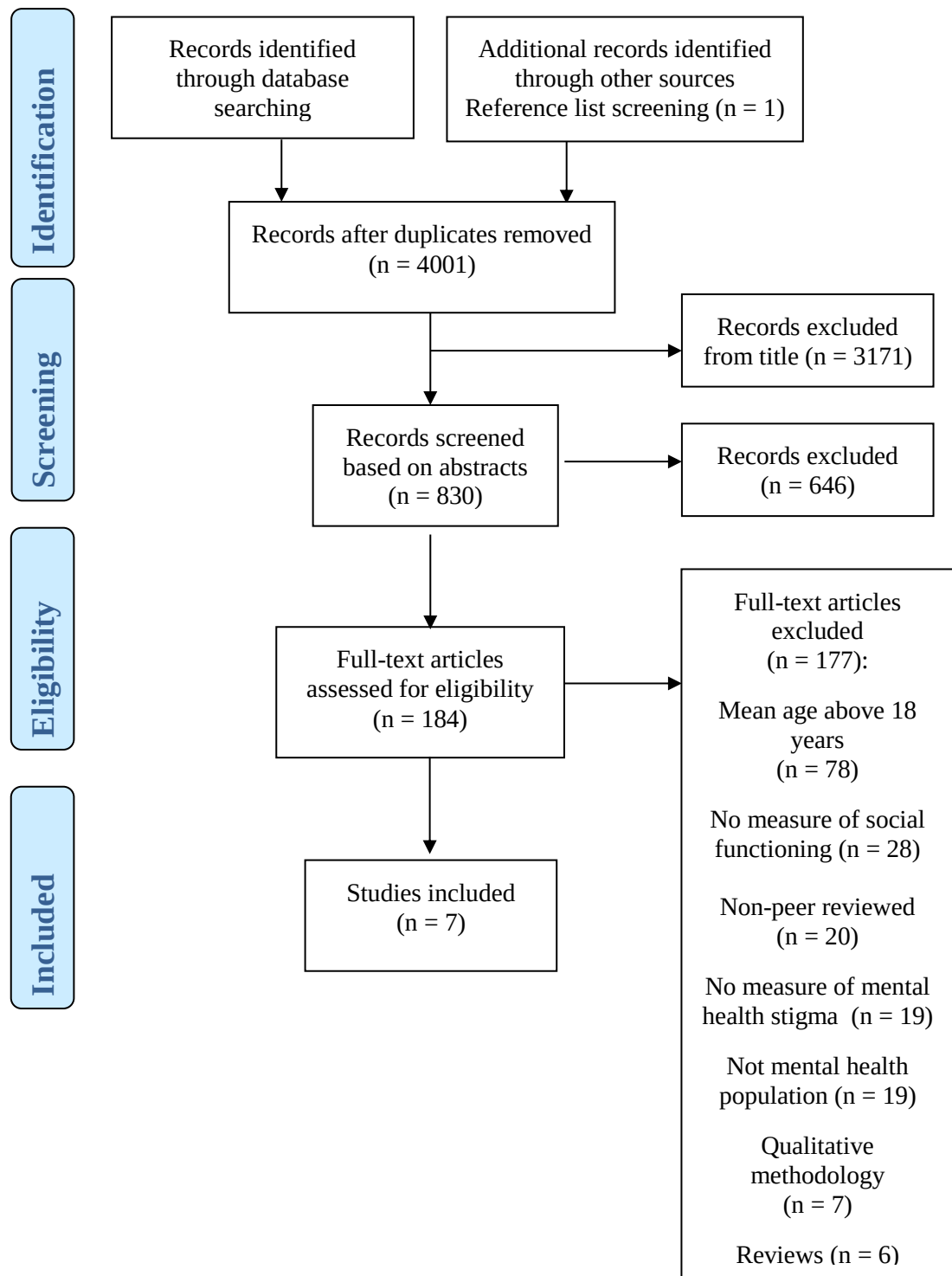


**Figure 1.** PRISMA Flowchart of study selection process.

## 5.2. Reliability of study selection

The studies were rated for eligibility by two independent reviewers and where there were disagreements between the two reviewers (ST and CH) regarding eligibility of studies, a third reviewer (SJ) was consulted. Of the final seven papers, the two

reviewers (ST and CH) were in agreement for six of the seven papers selected, and all of the papers not included. There was disagreement regarding only one of the selected papers (Wiener et al., 2012), related to i) whether Attention Deficit Hyperactivity Disorder (ADHD) should be considered as a mental health condition, and ii) whether the relationship of activity and stigma was directly investigated. Adjudication by the third reviewer indicated inclusion. Clarification from the authors was requested regarding associations between the social functioning items on the scale and stigma, as these were not reported as a separate analysis within the paper. The separate analyses were sent by the authors of the paper (Wiener et al., 2012) and the study was therefore reviewed.

### **5.3. Study characteristics**

The papers included in the current study were all published between 2008 and 2015. As shown in Table 1, there were three studies (Gaziel et al., 2015; Moses, 2009; Moses, 2011) based on a cross sectional design, a further three did not report the design (Kulikowska & Pokorski, 2008; Moses, 2014; Wiener et al., 2012) and the final study used mixed methods (Lindsey et al., 2010). The majority of the studies were conducted in the USA (four), with the remaining studies being from Canada, Israel and Poland. Six out of seven studies used convenience-sampling methods to recruit participants, where recruitment mainly took place within mental health settings including outpatient/community clinics (n = 4) or inpatient wards (n = 2). One study lacked clarification regarding recruitment setting (Kulikowska & Pokorski, 2008).

### **5.4. Participant characteristics**

A total of n = 479 participants across studies were included that either had a diagnosis of a mental health problem or were defined as a 'at risk' sample. Within the total number of participants there were n = 80 young people included in a follow up study (Moses, 2014) who were a subset of the same sample included in the original study (Moses, 2011) therefore taking this into consideration the actual total number of different participants across studies was n = 399. The overall ages of participants ranged from 11 to 18 years, and all studies included both female and male participants apart from one (Lindsey et al., 2010) which consisted of male adolescents only. The majority of the participants in each of the studies were described as 'White' or 'Caucasian' apart from one that included African-American adolescents only (Lindsey et al., 2010).

### Mental health presentations

The current review included papers considering a range of mental health problems as well as ‘at risk’ presentations. The main mental health presentations recorded in each study are presented in Table 1. There were four studies including samples with more than five primary mental health diagnoses (Moses, 2009; Moses, 2011; Moses, 2014; Gaziell et al., 2015), two studies identified as at risk samples with a non-mental health related primary presentation though with mental health comorbidities (Kulikowska & Pokorski, 2008; Wiener et al., 2012), and finally one study looking at depression only (Lindsey et al., 2010). Across these studies, there were five that confirmed diagnoses based on clinician reports from a mental health setting for example psychiatric outpatient or inpatient clinic (Moses, 2009; Moses, 2011; Moses 2014; Gaziell et al., 2015; Wiener et al., 2012), one study used a self-report measure (Lindsey et al., 2010) and the final study employed researcher assessment of mental health presentations (Kulikowska & Pokorski, 2008).

### Chronicity & severity of mental health problems

The majority of studies reported on the duration of mental health problems within their samples, with varied methods of reporting. One study highlighted that their participants had treatment for their mental health problems for an average duration of 11 months (SD = 16.6) and ranging from one to 68 months (Gaziell et al., 2015). Moses (2009) asked parents and/or guardians the age at which the young person first accessed mental health services and reported the average age as 8.5 years (SD = 3.4). Moses (2009) also confirmed that the sample reported high levels of depression during participation in the study, specifically that half of the sample met criteria for clinically significant depression. Two papers reported participants’ average stay in hospital as an indication of mental health presentation severity, which was 7.6 days (SD 4.2) (Moses, 2011) and 7.5 days (SD = 3.6, range 3-28 days) (Moses, 2014). Finally, in Lindsey et al.’s (2010) study, 74% of the participants scored above the clinical cut-off on a depression questionnaire. Two studies (Moses, 2009; Moses, 2011) reported that age at first treatment of mental health problem and stigma were related such that adolescents that were younger when first treated reported higher self-stigma. Wiener et al. (2012) did not find any associations between age and stigma in their sample of ADHD adolescents.

## **5.5. Stigma and Social Functioning measures**

### **5.5.1. Stigma**

A wide range of stigma conceptualisations were used in the papers including stigma tolerance (Lindsey et al., 2010), stigma apprehension (Moses, 2011), enacted social stigma (Moses, 2014) and internalised stigma (Gaziel et al., 2015). One paper looked at both self and public stigma (Moses, 2009) and the final paper conceptualised stigma as the extent to which one might be concerned about the environment's attitude toward their problem (Kulikowska & Pokorski, 2008). Importantly, the stigma terms used across the studies were to some extent describing the young people's personal perceived or self-reported lived experiences of stigma, and thus capturing the essence of the 'personal' stigma construct.

As expected, based on the range of conceptualisations, the papers utilised different tools for measuring stigma within their samples. The majority of studies used selected subscales from established questionnaires (Lindsey et al., 2010; Moses, 2009; Moses, 2014; Wiener et al., 2012). These four studies reported adequate psychometric properties for the stigma measures, and high internal consistencies of above 0.6 as calculated by Cronbach's alpha (Lindsey et al., 2010; Moses, 2009; Moses, 2014; Wiener et al., 2012). Two studies developed novel stigma measures for the purposes of their research (Kulikowska & Pokorski, 2008; Moses, 2011). Though one of them reported adequate Cronbach's alpha of above 0.7 within the paper (Moses, 2011), no further reliability or validation data was provided and further investigation is needed to confirm that the scales employed measure the construct of interest well. Only one paper employed a widely used validated stigma questionnaire (Gaziel et al., 2015).

Three papers (Moses, 2009; 2011; 2014) used multiple stigma measures targeting different aspects of stigma including both self as well as public stigma (the public stigma findings were not included in this review). The remaining four papers (Gaziel et al., 2015; Kulikowska & Pokorski, 2008; Lindsey et al., 2010; Wiener et al., 2012) used a single measure of stigma.

### **5.5.2. Social functioning**

There was also a wide range of methods used to measure social functioning. Three studies conceptualised social functioning with regards to the quality of family or peer relations (experienced or perceived support available from family and peers; Lindsey et

al., 2010; Moses, 2011; 2014). Two studies focused on general functioning using scales targeting aspects of social abilities and functioning (Moses, 2009; Wiener et al., 2012), one study assessed social competence (Kulikowska & Pokorski, 2008) and the final paper measured satisfaction with life (Gaziel et al., 2015). Six out of the seven studies used self-report questionnaires to assess social functioning with the young people as the main informants (Kulikowska & Pokorski, 2008; Lindsey et al., 2010; Moses, 2011; 2014; Wiener et al., 2012). The remaining paper used clinician ratings using a validated measure focusing on general functioning (Moses, 2009).

**Table 1.** Characteristics of included studies and participants

| Study number | Author and year              | Study design                        | Sampling method            | Sample size (n) | Gender                         | Mean age (SD) and range         | Mental Health Problems (MHPs)/at risk sample & method of assessing MH                                                                      | Country (ethnicity)    |
|--------------|------------------------------|-------------------------------------|----------------------------|-----------------|--------------------------------|---------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|------------------------|
| 1            | Gaziel et al. (2015)         | Cross-sectional study               | Convenience sampling       | n=30            | Females: 56.6%<br>Males: 43.4% | 13.9 (1.7)                      | Main MHPs; Major depressive disorder (n=6). Bipolar mood disorder (n=5) disruptive behaviour disorders (n=5)<br>No additional MH measure   | Israel (Israeli)       |
| 2            | Kulikowska & Pokorski (2008) | Not reported                        | Sampling method not stated | n=52            | Females: 61.5%<br>Males: 38.5% | 18.2 (0.6)                      | Self-injuring adolescents with range of MHPs<br>No additional MH measure                                                                   | Poland (Polish)        |
| 3            | Lindsey et al. (2010)        | Mixed methods, triangulation design | Convenience sampling       | n=69            | Males: 100%                    | 15.3 (1.25)<br><br>Range= 13-18 | Range of MHPs<br>Depression measured using the the Centers for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) questionnaire | USA (African-American) |

| Study number | Author and year | Study design          | Sampling method                                                        | Sample size (n) | Gender                         | Mean age (SD) and range        | Mental Health Problems (MHPs)/at risk sample & method of assessing MH                                                                                                                                                                                                                                                                                                                                                                                  | Country (ethnicity)                                                    |
|--------------|-----------------|-----------------------|------------------------------------------------------------------------|-----------------|--------------------------------|--------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------|
| 4            | Moses (2009)    | Cross-sectional study | Convenience sample                                                     | n=60            | Females: 38%<br>Males: 62%     | 14.8 (1.6)<br><br>Range= 12-17 | Range of MHPs: 46% diagnosed with internalising and externalising disorder: ADD/ADHD (53%), depression or anxiety (34%), conduct disorder (31%), bipolar disorder-not otherwise Specified (bipolar NOS; 27%), posttraumatic stress disorder (PTSD; 12 or 20%), alcohol or drug abuse (AODA; 20%), mood disorder NOS (16%), oppositional defiance disorder (19%), reactive attachment disorder (RAD; 12%), and obsessive compulsive disorder (OCD; 5%). | USA (57% White)<br><br>No reported details about other ethnic groups   |
| 5            | Moses (2011)    | Cross-sectional study | Convenience sample. Recent experiences of psychiatric hospitalisation. | n=102           | Females: 62.7%<br>Males: 37.3% | 15.3 (1.5)<br><br>Range= 13-19 | Range of Axis I diagnoses e.g. Depression; 66.7%, Anxiety; 32.4%.<br>Youth Self Report (YSR, Achenbach, 1991) measuring symptom severity.                                                                                                                                                                                                                                                                                                              | USA (74.5% White)<br><br>No reported details about other ethnic groups |

| Study number | Author and year      | Study design                       | Sampling method                                           | Sample size (n)                               | Gender                                                                                        | Mean age (SD) and range                                                     | Mental Health Problems (MHPs)/at risk sample & method of assessing MH                                                                                     | Country (ethnicity)                                                        |
|--------------|----------------------|------------------------------------|-----------------------------------------------------------|-----------------------------------------------|-----------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------|
| 6            | Moses (2014)         | Follow up study from Moses (2011). | Adolescents following six month hospitalisation discharge | n=80 (out of 102 from previous study)         | Females: 65%<br>Males: 35%                                                                    | 15.3 (1.6)<br><br>Range= 13-18                                              | Range of Axis I diagnoses e.g. Depression; 66.7%, Anxiety; 32.4%.<br>Youth Self Report (YSR, Achenbach, 1991).                                            | USA (78.8% Caucasian)<br><br>No reported details about other ethnic groups |
| 7            | Wiener et al. (2012) | Not reported                       | Convenience/community sample                              | ADHD group n=86<br><br>Healthy controls n=152 | ADHD group:<br>Females: 22%<br>Males: 78%<br><br>Control group:<br>Females: 29%<br>Males: 71% | ADHD group 11.46 (1.62)<br><br>Range= 9-14<br><br>Control group 11.8 (1.55) | ADHD and some participants with comorbid learning disabilities (LD) n= 12, LD and depression n=1, oppositional defiant disorder n=3, conduct disorder n=4 | Canada<br><br>No reported details about ethnic groups                      |

## **5.6. Main findings**

### **5.6.1. Associations of stigma and functioning**

Four out of the seven studies reported significant associations between stigma and social functioning. There were 102 adolescents included in the Moses (2011) paper with a range of mental health diagnoses, and who were seen within seven days of first psychiatric hospitalisation discharge. Bivariate correlations were used to assess the relationship between the interpersonal support domains and stigma. The analyses showed significant correlations between one of the interpersonal domains, friendship support, and stigma apprehension, such that those who reported lower quality of friendship support had higher levels of stigma apprehension following hospital discharge ( $r = -0.25, p < .01$ ). The analysis also showed a near significant association between stigma apprehension and lower quality of family functioning ( $r = -0.17, p = .08$ ). Furthermore, Moses (2011) reported on the relationship between school attachment (perceived feelings of closeness and belonging with peers and teachers), and stigma apprehension. However contrary to expectations, reported levels of school attachment were not statistically related to youths' stigma apprehension ( $r = -0.08, ns$ ).

Lindsey and colleagues (2010), in their community sample of 69 male African American youths, reported a significant correlation between quality of relationships (perceived social support) and stigma. The main focus of the study was to assess the relationship between depression and predictor variables, which included stigma and social support. Therefore there were limited details about the strength of the relationship between the variables of interest in the current review.

The main focus of the Gaziel et al. (2015) paper was to examine the relationships among mental health insight, self-stigma, parental insight and the satisfaction of life with a sample of 30 adolescents with mental health difficulties. Using Pearson correlation analyses they reported that experiences of self-stigma were negatively associated with aspects of satisfaction with self and school ( $r = -0.37, p < .05$ ), which suggested that adolescents who had higher levels of internalised stigma of mental illness were less satisfied with life in these domains.

Kulikowska and Pokorski (2008) examined the extent that stigma impacts on social competencies of young people that engage in self-injurious behaviours. They divided their sample of 52 Polish participants in two groups identified as 'stigmatised' and

‘non-stigmatised’ on the basis of whether they had experienced stigma on account of their self-harming. The authors reported that adolescents who self-injured that identified as ‘stigmatised’ had significantly lower social competence across all measured domains compared to those who defined themselves as ‘non-stigmatised’.

#### **5.6.2. Absence of association of stigma with activity**

As shown in Table 2, three out of the seven papers did not show a significant relationship between stigma and social functioning (Moses, 2009; 2014; Wiener et al., 2012). The Moses (2009) paper included a sample of 60 adolescents with severe emotional disturbance covering a range of mental health presentations. There were multiple stigma measures in the study, and using correlational analyses, none of them were significantly correlated with the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1994).

Moses’ (2014) sample included 80 adolescents assessed at six months following their first psychiatric hospitalisation, who had previously been part of the sample examined within the Moses (2011) paper. The study used bivariate associations to investigate the relationship between levels and quality of social support from family and friends with enacted stigma. The analyses did not show any significant associations persisting in the six month follow up to the original paper (Moses, 2011). Interestingly, in a separate analysis, Moses (2014) reported that number of friends was marginally significantly associated with higher stigma ratings, highlighting that more friends was associated with more rather than less enacted stigma which was contrary to the study hypothesis. Furthermore, Moses (2014) investigated the impact of mental health stigma on school functioning including grade achievement and school disciplinary problems. The author reported that youths who experienced disciplinary problems had higher social stigma ( $p < .05$ ), which was in line with study hypotheses. However, contrary to hypothesis, better academic functioning showed marginally significant associations with higher levels of enacted stigma at follow up ( $p = .08$ ).

Finally, Wiener et al. (2012) assessed levels of stigma within their sample of 86 adolescents with ADHD. They used Pearson correlation analyses to investigate the association between stigma and a general functioning measure, which included aspects of activity and social functioning. However, on personal enquiry as to possible associations with specific social functioning subscales of the measure, the authors

confirmed associations were with general functioning that is, ADHD stigma was negatively correlated with the overall total of the Self-Perception of Behavioural Conduct scale ( $r = -0.42, p < .01$ ) rather than activity and social functioning items specifically. The subscales of the Self-Perception of Behavioural Conduct scale are presented in Table 2.

### **5.7. Potential moderating factors**

A few studies looked at other factors that may be impacting on the influence of self-stigma on social functioning (Gaziel et al., 2015; Moses, 2009; 2011; 2014). While not directly part of the current review, these findings are included here for their potential to help make sense of some of the findings. Gaziel et al. (2015) reported on associations between adolescent and parental insight into the youth's mental disorder, self-stigma and satisfaction with life. They found that adolescents with higher insight into their disorder tended to have higher self-stigma specifically measured by alienation ( $r = 0.46, p < .05$ ) and social withdrawal ( $r = 0.46, p < .05$ ) and lower satisfaction with life compared to adolescents who reported less insight into their disorder ( $r = -0.60, p < .05$ ). Furthermore, adolescents whose parents had high insight into their disorder also experienced high self-stigma in comparison to adolescents whose parents had low insight ( $r = 0.42, p < .05$ ).

Two studies investigated the impact of stigma experiences on clinical symptoms including self-esteem (Moses, 2011) and internalising symptoms (Moses, 2014). Moses (2011) found that higher levels of perceived public stigma and self-stigma were associated with lower levels of self-esteem ( $r = -0.31, p < .01$ ). The six-month follow up study (Moses, 2014) examined 'Internalising problems', which included scales of Withdrawn, Somatic complaints and Anxious/Depressed and 'Externalising problems' including Aggressive and Delinquent behaviour. Correlational analyses showed that higher internalising symptom ratings were associated with higher levels of stigma ( $r = 0.29, p = .04$ ), though externalising symptom ratings were not significantly associated with stigma ( $p = ns$ ). Another study investigated the impact of sense of mastery, that is the extent of perceived control over factors that affect their lives as well as future outlook, and found that neither of these were associated with public stigma or self-stigma (Moses, 2009). These studies did not further assess the possible relationships between the clinical symptoms and activity levels with their samples.

**Table 2.** Summary of study findings

| Study number | Author and year              | Method of assessing Stigma                                                                                                                                                                                                                                                                                                                                                                                                                    | Method of assessing Social functioning                                                                                                                                                                                                                                                                                                                                                   | Analysis                                                   | Key findings                                                                                                                                                                                                                                                                                                   | Correlations $p < .05$ | EPHPP global rating |
|--------------|------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------------------|
| 1            | Gaziel et al. (2015)         | <p>'Internalised Stigma of Mental Illness' (ISMI) (Ritsher et al., 2003)</p> <p>Hebrew translation</p> <p>Four subscales following adaptations (originally five):</p> <ul style="list-style-type: none"> <li>• Alienation</li> <li>• Stereotype endorsement</li> <li>• Discrimination experience</li> <li>• Social withdrawal</li> </ul> <p>Twenty-nine items in total.</p> <p>Authors reported high/moderate reliability in all domains.</p> | <p>'Multi-dimensional Students' Life Satisfaction Scale' (MSLSS) (Huebner, 1994)</p> <p>Five dimensions:</p> <ul style="list-style-type: none"> <li>• Relations with close family</li> <li>• Relations with friends</li> <li>• Self-satisfaction</li> <li>• School satisfaction</li> <li>• Living environment satisfaction</li> </ul> <p>Forty items in total (Cronbach alpha = 0.7)</p> | Correlations between MSLSS and self-stigma measures        | <p>There were negative correlations reported between the MSLSS questionnaire and the self-stigma measure (<math>r = -0.37, p &lt; .05</math>)</p> <p>The authors conclude that the more adolescents internalise public stigma of mental illness, the less satisfied they were with school and self domains</p> | Yes                    | Weak                |
| 2            | Kulikowska & Pokorski (2008) | The authors developed a question asking the youths about the environment's attitude toward their self-injuring behaviours, which                                                                                                                                                                                                                                                                                                              | 'Questionnaire of Social Competence' (QSC), (Polish version; Matczak, 2001)                                                                                                                                                                                                                                                                                                              | Group comparisons of Social Competence in 'stigmatised' vs | There were $n = 27$ participants in the 'stigmatised' and $n = 25$ in the 'non-stigmatised' group                                                                                                                                                                                                              | Yes                    | Weak                |

| Study number | Author and year       | Method of assessing Stigma                                                                                                                                                                                                                                                                                    | Method of assessing Social functioning                                                                                                                                                                                              | Analysis                                                                                                                                                                                                                                         | Key findings                                                                                                                                                                                                                                                                                                                                                               | Correlations $p < .05$ | EPHPP global rating |
|--------------|-----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------------------|
|              |                       | led to establishing the following groups: 'stigmatised' and 'non-stigmatised'                                                                                                                                                                                                                                 | Three categories of competence: <ul style="list-style-type: none"> <li>• Interpersonal or intimate relations</li> <li>• Social exposure</li> <li>• Situations requiring assertiveness</li> </ul> Ninety items in total.             | 'non-stigmatised' group using paired or unpaired t-tests                                                                                                                                                                                         | The 'stigmatised' group had a statistically lower result in social competence compared to self-injuring 'non-stigmatised' group                                                                                                                                                                                                                                            |                        |                     |
| 3            | Lindsey et al. (2010) | <p>'The Attitudes Toward Seeking Professional Help Scale' (Fischer &amp; Turner, 1970).</p> <p>'Stigma tolerance' subscale only (originally four subscales) measuring sensitivity to other's perceptions if being seen by a mental health practitioner</p> <p>Five items in total (<math>r = 0.65</math>)</p> | <p>'The Social Support Scale' (Friedman et al., 2006)</p> <p>Assessed perceived availability of emotional and practical support from one's social network</p> <p>Rated on five point Likert scale (internal reliability = 0.90)</p> | <p>Hierarchical regression analyses to determine the degree to which predictor variables were associated with depressive symptoms and whether social support moderated the association between mental health stigma and depressive symptoms.</p> | <p>Both mental health stigma (<math>B = -1.07, p &lt; .05</math>) and social support (<math>B = -1.99, p &lt; .05</math>) were significant negative predictors of depressive symptoms</p> <p>They found that mental health stigma <math>\times</math> social support (<math>B = 0.79, p &lt; .01</math>), was a significant positive predictor of depressive symptoms.</p> | Yes                    | Weak                |

| Study number | Author and year | Method of assessing Stigma                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     | Method of assessing Social functioning                                                                                                                                                                                                                                                                                                           | Analysis                                       | Key findings                                                              | Correlations $p < .05$ | EPHPP global rating |
|--------------|-----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------|---------------------------------------------------------------------------|------------------------|---------------------|
| 4            | Moses (2009)    | <p>Author used four separate scales:</p> <ul style="list-style-type: none"> <li>• 'Social devaluation', adapted from the 'Perceived Devaluation / Discrimination Scale' (Link et al., 1997)</li> </ul> <p>Included fourteen items (alpha coefficient=0.76).</p> <ul style="list-style-type: none"> <li>• 'Personal rejection' adapted from 'Rejection Experiences scale' (Link et al., 1997),</li> </ul> <p>Included eight items (alpha coefficient=0.78)</p> <ul style="list-style-type: none"> <li>• 'Self-stigma' scale adapted from Austin et al's. (2004) 'Child Stigma Scale'</li> </ul> <p>Included five items (alpha coefficient=0.81)</p> <ul style="list-style-type: none"> <li>• 'Secrecy' included four</li> </ul> | <p>Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1994)</p> <p>Measure of functional impairment rated by clinician</p> <p>Five subscales:</p> <ul style="list-style-type: none"> <li>• Role Performance</li> <li>• Behaviour Toward Others</li> <li>• Mood/Self Harm</li> <li>• Substance Abuse</li> <li>• Thinking</li> </ul> | Associations between stigma measures and CAFAS | CAFAS scores were not significantly related to any of the stigma measures | No                     | Weak                |

| Study number | Author and year | Method of assessing Stigma                                                                                                                                                                                            | Method of assessing Social functioning                                                                                                                                                                                                                                                                                                                                   | Analysis                                                                                                | Key findings                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | Correlations $p < .05$ | EPHPP global rating |
|--------------|-----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------------------|
|              |                 | items from a range of measures which were further adapted by the author (alpha coefficient=0.84)                                                                                                                      |                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                        |                     |
| 5            | Moses (2011)    | <p>'Stigma apprehension Scale' developed by the author, targeted concerns about being devalued and rejected due to recent hospitalisation.</p> <p>Four item scale rated from one to five (alpha coefficient=0.75)</p> | <p>The author measured family functioning using the 'General Functioning' subscale of the 'Family Assessment Device' (GFF; Miller et al., 1985).</p> <p>Twelve items rated on a 5-point agreement scale (alpha = 0.89).</p> <p>Quality of relationship with friends measured using the 'Inventory of Parent and Peer Attachment' (F; Armsden &amp; Greenberg, 1987).</p> | The extent to which levels of stigma was related to interpersonal support, using bivariate associations | <p>Findings showed that Stigma correlated with GFF (<math>r = -0.17, p &lt; .10</math>). The association between stigma apprehension and lower quality of family functioning demonstrated a trend toward statistical significance (<math>p = .08</math>).</p> <p>Stigma correlated with F (<math>r = -0.25, p &lt; .01</math>). Friendship support was the only significant correlate of participants' stigma apprehension: lower quality of friendship support related to</p> | Yes                    | Weak                |

| Study number | Author and year | Method of assessing Stigma                                                                                                                                                                                                                              | Method of assessing Social functioning                                                                                                                                                                                                                               | Analysis                                                                                                                                           | Key findings                                                                                                                                                                                             | Correlations $p < .05$ | EPHPP global rating |
|--------------|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------------------|
|              |                 |                                                                                                                                                                                                                                                         | <p>Nine items in total (alpha = 0.89). 'School Attachment Scale' measured the quality of participants' sense of comfort, safety, belonging at school and perceived closeness with peers and teachers.</p> <p>Nine items rated on a 5-point scale (alpha = 0.88).</p> |                                                                                                                                                    | <p>higher stigma apprehension (<math>p = .01</math>).</p> <p>Reported levels of school attachment were not statistically related to youths' stigma apprehension (<math>r = -0.08</math>, <i>ns</i>).</p> |                        |                     |
| 6            | Moses (2014)    | <p>'Enacted social stigma scale': experiences with social exclusion &amp; devaluation by others on account of MH problems and treatment. Items adapted from the 'Rejection Experiences scale' (Link et al., 1997).</p> <p>The author added one item</p> | General Functioning' subscale of the 'Family Assessment Device' (GFF; Miller et al., 1985) and 'Inventory of Parent and Peer Attachment' (F; Armsden & Greenberg, 1987) (as Moses, 2011 study)                                                                       | Follow up from Moses (2011) study (T1). Current study (T2) used bivariate associations between 'enacted stigma' and the predictor variables (at T1 | There were no significant associations between enacted stigma and each of social functioning variables, meaning that effect and size of social support and network did not attenuate levels of stigma    | No                     | Moderate            |

| Study number | Author and year      | Method of assessing Stigma                                                                                                                                                                     | Method of assessing Social functioning                                                                                                                                                                                                                                       | Analysis                                                                                                                             | Key findings                                                                                                                                                                                                                                                                                                  | Correlations $p < .05$ | EPHPP global rating |
|--------------|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------------------|
|              |                      | regarding others' lowered expectations toward oneself.<br><br>Five items in total.                                                                                                             | Number of peer relationships: participants listed up to 10 people whom they considered as a friend in the past few months, scored 0 to 10.                                                                                                                                   | and T2. Multivariate regression analysis was used to explore most robust correlates of adolescents' enacted stigma at 6-months (T2). | Number of friends was marginally significantly associated with higher stigma ratings.                                                                                                                                                                                                                         |                        |                     |
| 7            | Wiener et al. (2012) | The authors used one scale from the one scale from the 'Attributions for ADHD questionnaire' (AAQ; Kaidar, Wiener & Tannock, 2003), assessing ADHD stigmatisation<br><br>Eight items in total. | Self-perception profile for children' (SPPC; Harter, 1985)<br><br>Measures self-esteem and domain-specific areas of competency which included five scales:<br>• Scholastic competence<br>• Social acceptance<br>• Behavioural conduct<br>• Athletic competence<br>• Physical | Associations between stigma and SPPC compared to control group                                                                       | ADHD stigmatisation was negatively correlated with Self-Perception of Behavioural Conduct ( $r = -0.42, p < .01$ ) and Global Self-Worth ( $r = -0.45, p < .01$ ). However once clarified with authors, there were no significant differences between social functioning specific items and levels of stigma. | No                     | Weak                |

| Study number | Author and year | Method of assessing Stigma | Method of assessing Social functioning            | Analysis | Key findings | Correlations $p < .05$ | EPHPP global rating |
|--------------|-----------------|----------------------------|---------------------------------------------------|----------|--------------|------------------------|---------------------|
|              |                 |                            | appearance                                        |          |              |                        |                     |
|              |                 |                            | Thirty items in total within the competency scale |          |              |                        |                     |

## 5.8. Summary of quality assessment

The EPHPP Tool was used in the current review to evaluate the quality of the included studies. As shown in Table 2, a total of six studies were classified as ‘weak’, one study as ‘moderate’ and none achieved an overall ‘strong’ rating. The major limitations that were associated with an overall ‘weak’ rating were biases in participant selection ( $n = 3$ ), inadequate consideration of withdrawal and dropout rates ( $n = 5$ ), failure to take into account missing data and dropouts ( $n = 7$ ), and lack of consideration of the influence of potential confounding variables ( $n = 7$ ). As shown in Figure 2 below, five out of the nine domains (including global rating) had ratings classified as ‘strong’. The inter-rater reliability for the two independent raters on quality ratings was Kappa = 0.82, 95% CI (0.71 – 0.92).

The Kulikowska and Pokorski (2008) paper had the highest number of ‘weak’ ratings across the eight domains ( $n = 6$ ), followed by Gazi et al. (2015) ( $n = 4$ ) and the remaining papers (Lindsey et al., 2010; Moses, 2009; 2011). Wiener et al. (2012) had  $n = 3$  ‘weak’ ratings in total. Finally, Moses (2014) was the only study with ‘moderate’ overall rating. Considering the studies that reported significant associations between stigma and social functioning, they were all given ‘weak’ ratings. The only study that showed ‘moderate’ overall rating reported non-significant relationship between the variables of interest in the current review.

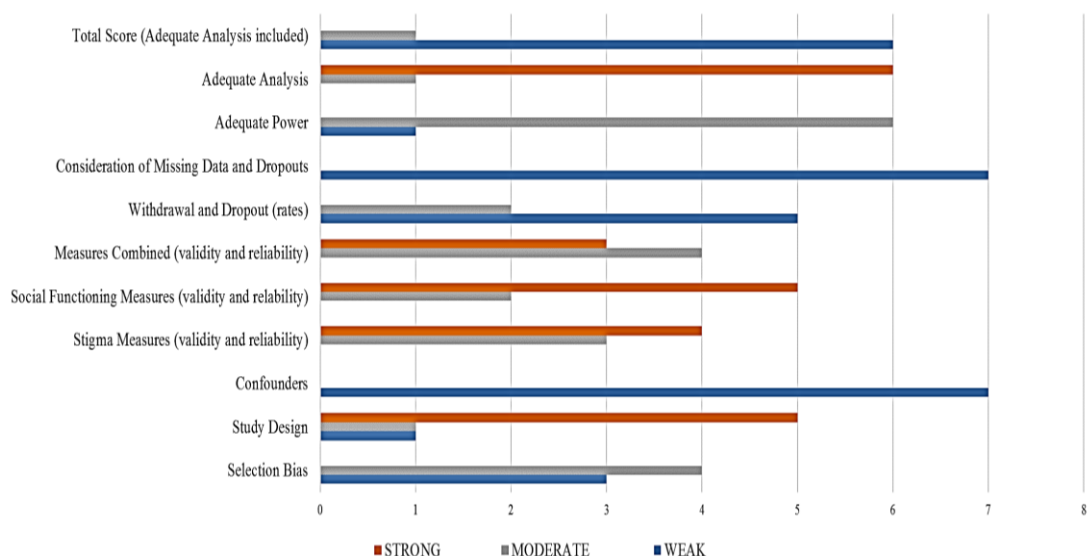


**Figure 2.** Study ratings across domains within the EPHPP Quality Assessment Tool

## 6. Discussion

This systematic review aimed to summarise the association between stigma and activity levels in young people with, or ‘at risk’ of experiencing, mental health difficulties. Specifically, it was predicted that there would be a significant association between levels of mental health stigma and activity levels such that higher levels of stigma would be associated with reduced levels of activity. This is the first review to date investigating these associations within a child and adolescent mental health sample. The current study has summarised the findings based on seven peer-reviewed studies whereby four papers, reported significant correlations between higher levels of stigma and aspects of reduced social functioning including activity, thereby supporting the hypothesised relationship, while three did not support it. The quality of the majority of papers was rated as ‘weak’, whilst one study had an overall ‘moderate’ rating. The interpretation of the findings therefore need to be understood within the context of the number and quality of identified studies as well as the methods and conceptualisations utilised to measure self-stigma and social functioning. The limitations of these studies will be discussed in further detail in this section, followed by recommendations for future research and clinical implications of the findings.

In the current review, only one out of the seven papers used a well-established validated stigma measure (Gaziel et al., 2015) and two used novel measures developed for the purposes of their study. The remaining papers used subscales from a range of stigma measures and reported adequate psychometric properties (Cronbach’s  $\alpha > 0.6$ ) for the final measures used within the respective studies. The use of subscales from a range of measures and adapting to suit the studies may also highlight the range of conceptualisations of stigma that were measured within the studies, for example enacted and anticipated stigma. Part of the complexity in researching the relationship between stigma and social functioning amongst young people is the lack of validated methods of measuring stigma and consistent use of the measures.

One of the key issues within this review involved lack of clear conceptualisations of the stigma and social functioning within the research literature. There are often problems disentangling the concepts of stigma and social functioning, as they tend to overlap or be mentioned interchangeably. For example in Moses (2009) several measures of stigma were used that could be related to aspects of social functioning for example ‘secrecy’. Importantly secrecy can be conceptualised by its impact on the relationship

quality, which would be an aspect of social functioning or alternatively the fear of judgement, which would make it an aspect of stigma. Moses (2011) comment that one of the stigma measures used, specifically within the personal rejection scale, had aspects of social functioning and activities within the items and could have been part of assessing social functioning. These concepts are also used interchangeably within the research therefore there is little clarity around the extent to where stigma becomes a concern for activity levels including social support and functioning. This appears to be the common issue in psychosocial research looking at social functioning and mental health.

The current study utilised the definition of stigma proposed by Link and Phelan (2001), which suggests that stigmatised individuals respond to negative stereotype based on their beliefs and fears about rejection and discrimination and may subsequently act with less confidence or more defensively, or ultimately avoid social contact (Moses, 2010a). This highlights the possible impact of stigma on levels of activity, whereby perceived discrimination and negative evaluation may be reinforced through reduced self-regard and defensive coping strategies including withdrawal and disengagement, which can contribute to levels of isolation and therefore the maintenance of a range of mental health conditions.

The majority of papers reviewed in the current study referred to the Link and Phelan (2001) model to assess the links between stigma and aspects of activity or social functioning. For example, the papers by Moses (2009; 2011; 2014) as well as Lindsey et al. (2010) and Gaziel et al. (2015) drew on the aforementioned model in their studies, out of which three papers in total showed a positive association between stigma and social functioning. Wiener et al. (2012) conceptualised stigma using Major and O'Brien's (2005) model which highlights the expectancy confirmation process of stigmatisation whereby specific negative behaviours result in differential treatment of the individual which may increase the likelihood of problematic behaviours and functioning and subsequently impact on self-esteem and functioning. Finally, Kulikowska and Pokorski (2008) defined stigma as proposed by Smith (2002) focusing on the stigmatisation of individuals who self-harm and the experiences of stigma specifically resulting in rejection and decreases in social functioning and competence. All three models postulate similar mechanisms by which stigma may impact on activity or social functioning outcomes.

The methods used to measure social functioning varied significantly across the identified studies. Despite previous research showing the importance of engagement with activities particularly within this critical period of development (e.g. 'Aiming high' report, United Kingdom Government Department; DCSF) and the impact reduced social functioning has on psychological wellbeing (Asarnow, Jaycox & Tompson, 2001), there is no single definition of social functioning and there is a limited number of valid questionnaires to measure this concept. Given that measures of activity levels are often incorporated into methods of assessing social functioning, it was necessary that the current study utilised a broad search in order to allow for a wider range of identification of papers and understanding of the measures currently available within the child and adolescent literature. However, despite utilising a broad search, only seven papers were identified for the current review. The issues highlighted in the current review therefore emphasise the importance of future research exploring issues of mental health stigma with young people, as well as to develop and utilise validated measures of stigma and social functioning to clarify the relationship between these areas.

### **Family and peer relationships**

There were some inconsistencies with regards to the associations between perceived family support and stigma. One of the studies showed that family members were more likely the first source of support for mental health difficulties rather than peers (Lindsey et al., 2010). The preference for adolescents to disclose to family about mental health concerns has been supported by previous studies showing that positive family relationships predict decreased symptoms and enhanced social functioning among adolescents at risk for psychosis (O'Brien et al., 2006). However another study reported that family support and school attachment levels were not significantly associated with levels of stigma (Moses, 2009).

Two studies included in the current review (Lindsey et al., 2010; Moses, 2009) showed that lower quality of friendship support was associated with higher levels of stigma apprehension and reinforced the reluctance for those young people to seek help as result. On the contrary, Moses (2014) reported that having a larger number of friends was marginally significantly associated with higher stigma ratings. These findings highlight that it may not be the number of friends that is protective against stigma, but rather the significance of group identification and affiliation (Moses, 2011; Moses,

2014). Previous studies have shown that larger social network may provide increased opportunities for rejection or criticisms by some of those friends (Hughes, 2005). With regards to quality of friendships, it has been suggested that having friends belonging to a similarly low status or stigmatised group may be an effective strategy for coping with stigma (Moses, 2010a) as this helps to preserve one's positive self-concept through exchange of social validation and emotional support (Major, 2006). Furthermore, youths who self-harm (Kulikowska & Pokorski, 2008) were shown to experience stigma specifically related to the social rejection following disclosure of the self-harming, highlighting possible reinforcement for using secrecy as a coping strategy (Moses, 2009).

### **School functioning**

Gaziel et al. (2015) found that adolescents who had higher levels of internalised stigma of mental illness were less satisfied with themselves, and with school. This is in contrast to the findings from the Moses (2011) paper whereby affiliation with school was not impacted by levels of stigma. Although these may be limited in comparison by the measures used to report social functioning, it nonetheless shows discrepancies in terms of the relationship with stigma and perceptions of school experiences. Given that gaining educational competence during school years is an important factor in achieving success in future employment and productivity (Hinshaw, 2005), the relationship between stigma and school functioning should be a focus of future research.

### **Chronicity of mental health difficulties**

Another potentially important factor in the study of stigma emerging from this review involves the duration or chronicity of mental health problems. Some of the current studies found that those who presented to mental health services at a younger age (Moses, 2011; 2014) reported higher levels of stigma and more experiences of personal rejection (Moses, 2009) at the time of the studies. Although Wiener et al. (2012) did not find an association between age and stigma, their sample was much younger (mean age = 11.5) and also did not present with the severity of mental health presentations as in the studies by Moses (2011; 2014), where the participants had a history of inpatient admission. Adult studies have found that patients with longer duration of illness were significantly more likely to report higher levels of self-stigma and are more likely to experience enacted stigma (Adewuya et al., 2011) leading individuals to constrict their

social networks which further exacerbates stigma experiences (Stuart, 2004). It will be critical for future research to further investigate the impact of the duration of mental health difficulties on self-stigma with young people, in order to understand its longer term impact on social functioning.

### **6.1. Strengths and limitations of the review**

The current study was conducted within the guidelines available for systematic reviews (Higgins & Green, 2008) in order to reduce the impact of biases. Part of this involved the process of including two independent raters from the initial search stages through to reading titles and abstracts, full texts, as well as quality assessment review. Furthermore, six databases were used for the initial search process as well as systematic hand and reference list screening, which minimise the risk of not identifying possible relevant studies. However, there are a number of limitations that warrant caution in interpreting the findings.

Importantly within this research context, although the causality could not be explained through the methodology and analysis using correlations, one must consider whether the findings reported here indicate whether stigma impacts on social functioning, or whether it is the mental health presentation that limits social functioning. It could also be the impact of both these factors in a complex maintenance cycle.

The studies varied extensively with regards to the heterogeneity of mental health presentations and severity of illness within the samples as well as methods of conceptualising and measuring stigma and social functioning. Importantly, there was a wide range of mental health presentations within the samples included in the current review. Adult studies have shown that specific mental health problems including schizophrenia is a more stigmatising label held by the general public compared to major depression (Angermeyer & Matschinger, 2003). Young people are less likely to receive such diagnoses however it would be useful to consider the impact of stigma experiences with young people with for example unusual experiences. The heterogeneity of the samples included in the reviewed papers may limit the understanding of stigma experiences as based on specific mental health presentations.

Only seven papers were identified, utilising various measures of activity and identified associations were shown to be highly variable across studies. As the current review deliberately utilised search terms that did not restrict identified studies on the basis of

specific aspects of functioning (leaving this open, and employing a second rater to determine inclusion), it is likely that this is an accurate reflection of the available literature in this area. The low number of studies identified limits the conclusions that can be made about whether stigma is an important factor in reduced activity levels in young people and whether it should be targeted in therapy. However, given that reduced activity levels are a well-known maintenance factor across a range of mental health conditions with adults (e.g. Wing & Brown, 1970; Olbrich et al., 1993; Purvis et al., 2004), this research needs to be extended to child and adolescent populations.

Furthermore, it is important to consider the methodological quality of future studies. The current review showed that the quality of the included papers was significantly low, specifically that six out of the seven papers were rated as ‘weak’. These ratings were mainly limited by ratings on three domains on the EPHPP Tool including ‘consideration of missing data’, ‘withdrawals and dropout rates’, and ‘confounders’.

## **6.2. Future directions**

Given that research aiming to establish a relationship between mental health stigma and social functioning with young people is in its infancy, perhaps it is not surprising that further understanding is necessary. Future research would benefit from developing clearer conceptualisation of stigma in order to provide a framework for better interpretation of various empirical findings. Relatedly, social functioning is currently conceptualised as encompassing a wide range of factors and would benefit from more specific definitions, which would also facilitate methods of measuring the concept. Furthermore, as mentioned previously the heterogeneity of mental health samples in previous research makes interpretation of findings difficult. Given that experiences of stigma have been shown to vary widely depending on the specific label mental health label (e.g. Angermeyer & Matschinger, 2003), future research would benefit from investigating stigma within specific mental health samples. Finally, this review has highlighted that the primary aims of the majority of the identified papers were not to directly assess the relationship between stigma and activity, therefore this relationship was often investigated as a secondary analysis. The current review calls on future research to address the relationship between stigma and activity more directly by investigating these as a primary focus of studies.

### **6.3. Clinical implications**

The number of studies looking at stigma experiences with young people with mental health problems are very limited. In a recent systematic review (Kaushik et al., 2016) looking at the prevalence of stigma in young people, only three out of 32 studies were identified looking at self-stigma and the majority were based on studies investigating public stigma. Although exploring aspects of public stigma is crucial, more studies are needed to investigate the impact of self-stigma with young people's experiences of mental health difficulties to enable targeting these experiences directly in clinical intervention.

The relationship between young people and parents and wider family appears to be at times protective with regards to seeking support for mental health problems (Lindsay et al., 2010), whilst alternatively, these relationships could be reinforcing messages about concealing mental health difficulties which leads the young person to internalising a negative meaning about having a mental health problem, resulting in increased levels of self-stigma (Moses, 2010b). Therefore, clinical interventions should focus on increasing coping strategies and resources to manage stigmatising experiences by for example supporting young people to attribute prejudices to external factors in order to minimise the process of internalising them. For individuals who are 'at risk' of developing mental health difficulties, psychological distress could be ameliorated through supportive and helpful communication and disclosure of unusual experiences, which has shown to improve emotional wellbeing and reduced risk for developing psychosis (Byrne & Morrison, 2010). Furthermore, it would be particularly important for family members to take part in the intervention process to help internalise these messages to enable generalisation of these approaches outside the clinic.

In addition, it will be important to consider aspects of activity and social functioning directly within therapeutic intervention with young people. Fowler et al. (2009; 2010) developed an intervention focusing on increasing time spent in meaningful activities with improving psychological well-being. The trial was developed with adults in early phase of psychosis and aimed to improve recovery by increasing engagement in meaningful activity including education, household chores, voluntary work and social activities. The trial was found to have a significant and positive effect on the functional outcome of hours spent each week in structured activity (Fowler et al., 2009). Given that youth engagement with positive activity has been shown to improve educational,

social and emotional outcomes in adulthood ('Aiming High'; DCSF, 2010) and that reduced activity has been described as a risk factor for developing mental health difficulties in young people (Fusar-Poli et al., 2010), it is fundamental that similar methods are considered for application within interventions with young people.

Two studies included in the current review reported on the relationship between stigma and impact of concealing mental health difficulties. Kulikowska and Pokorski (2008) showed that the experiences of stigma were specifically related to the social rejection following disclosure of the self-harming. Similarly, Moses (2009) reported that higher self-stigma ratings were associated with more experiences of personal rejection and greater secrecy levels. The impact of secrecy or non-disclosure of mental health problems due to fear of rejection and discrimination has been widely reported amongst adults (e.g. Luoma et al., 2007) as well as young people with mental health problems (Byrne & Morrison, 2010; Moses, 2010; Elkington et al., 2012).

Given that adolescence and young adulthood are critical periods of development of self-identity (Hinshaw, 2005) the need for social belonging and acceptance may make young people more vulnerable to negative perception and rejection (Donenberg & Pao, 2005) therefore stigmatising experiences at this age can have significant impact. Researchers have suggested that coping with stigma experiences by concealing problems in the longer term could lead to anticipatory anxiety and reduced levels of opportunities for social support (Crocker & Garcia, 2006). Furthermore, more recent findings suggest that difficulties with interpersonal relationships leading to concealment of experiences due to stigma, could be a risk factor for developing unusual experiences in an at risk sample (Byrne & Morrison, 2010). It is necessary for clinical interventions to focus on aspects of secrecy as a coping strategy at an early age, and to help young people to consider situations where this may be adaptive but also where it may impact on their mental health negatively in the longer term as possible safety behaviour or avoidance of activities due to fears about what others may think of them.

Link and Phelan's (2001) model of stigma highlighted that reduced social support occurs following experiences of stigma. However, within the current context of young people with mental health problems, it is difficult to make any firm conclusions about causality or the direction of the impact of stigma and social functioning on mental health outcomes. The evidence present within adult studies (e.g. Moriarty et al., 2012), and young people with physical health problems (e.g. Cluver et al., 2008; Asante et al.,

2015; Caserta et al., 2016) showing the relationship between stigma and reduced social functioning should encourage more research within mental health contexts.

#### **6.4. Conclusion**

The current systematic review is the first to date to assess studies investigating the association between stigma and social functioning in young people with or at risk of mental health difficulties. Seven studies were identified out of which four showed significant relationships between mental health stigma and aspects of social functioning. Despite this, interpretation of the findings is limited due to the number and quality of identified studies as well as the methods and conceptualisations utilised to understand and measure self-stigma and social functioning as related to young people. Recommendations for future research have been outlined throughout, including more studies investigating self-stigma experiences with young people with mental health problems and the need for validated measures of social functioning in particular. This would help to clarify the link between mental health stigma and social functioning and its impact on mental health presentations, as has been shown in adult studies, and inform the development of potential early intervention strategies.

## 7. References

- Achenbach, T. M., & Edelbrock, C. S. (1991). *Youth Self-report and Profile*. University of Vermont, Department of psychiatry.
- Addington, J., van Mastrigt, S., & Addington, D. (2003). Patterns of premorbid functioning in first-episode psychosis: Initial presentation. *Schizophrenia Research*, 62, 23–30.
- Adewuya, A. O., Owoeye, A. O., Erinfolami, A. O., & Ola, B. A. (2011). Correlates of self-stigma among outpatients with mental illness in Lagos, Nigeria. *International Journal of Social Psychiatry*, 57(4), 418-427.
- Addington, J., van Mastrigt, S., & Addington, D. (2003). Patterns of premorbid functioning in first-episode psychosis: Initial presentation. *Schizophrenia Research*, 62, 23–30
- Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, 108(4), 304-309.
- Armsden, G. C., & Greenberg, M. T. (1987). The inventory of parent and peer attachment: Individual differences and their relationship to psychological well-being in adolescence. *Journal of youth and adolescence*, 16(5), 427-454.
- Asarnow, J. R., Jaycox, L. H., & Tompson, M. C. (2001). Depression in youth: Psychosocial interventions. *Journal of Clinical Child Psychology*, 30(1), 33-47.
- Austin, J. K., MacLeod, J., Dunn, D. W., Shen, J., & Perkins, S. M. (2004). Measuring stigma in children with epilepsy and their parents: instrument development and testing. *Epilepsy & Behavior*, 5(4), 472-482.
- Ben-Zeev, D., Frounfelker, R., Morris, S. B., & Corrigan, P. W. (2012). Predictors of self-stigma in schizophrenia: New insights using mobile technologies. *Journal of dual diagnosis*, 8(4), 305-314.
- Bertolote, J., & McGorry, P. (2005). Early intervention and recovery for young people with early psychosis: consensus statement. *The British Journal of Psychiatry*, 187(48), s116-s119.
- Brook, U., & Geva, D. (2001). Knowledge and attitudes of high school pupils towards peers' attention deficit and learning disabilities. *Patient Education and Counseling*, 43(1), 31-36.
- Byrne, R., & Morrison, A. P. (2010). Young people at risk of psychosis: A user- led exploration of interpersonal relationships and communication of psychological difficulties. *Early Intervention in Psychiatry*, 4(2), 162-168.

- Cella, M., Edwards, C., & Wykes, T. (2016). A question of time: A study of time use in people with schizophrenia. *Schizophrenia Research*, 176(2), 480-484.
- Chandra, A., & Minkovitz, C. S. (2007). Factors that influence mental health stigma among 8th grade adolescents. *Journal of Youth and Adolescence*, 36(6), 763-774.
- Cicchetti, D., & Rogosch, F. A. (2002). A developmental psychopathology perspective on adolescence. *Journal of consulting and clinical psychology*, 70(1), 6.
- Collishaw, S. (2015). Annual research review: secular trends in child and adolescent mental health. *Journal of Child Psychology and Psychiatry*, 56(3), 370-393.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self- stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35-53.
- Corrigan, P. W., Watson, A. C., Heyrman, M. L., Warpinski, A., Gracia, G., Slopen, N., & Hall, L. L. (2005). Structural stigma in state legislation. *Psychiatric Services*, 56(5), 557-563.
- Costello, E. J., Foley, D. L., & Angold, A. (2006). 10-year research update review: the epidemiology of child and adolescent psychiatric disorders: II. Developmental epidemiology. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(1), 8-25.
- Côté, J. (2006). Emerging adulthood as an institutionalized moratorium: Risks and benefits to identity formation. In J. J. Arnett & J. L. Tanner (Eds.), *Coming of age in the 21st century: The lives and contexts of emerging adults* (pp. 85-116). Washington, DC: American Psychological Association.
- Crocker, J., & Garcia, J. A. (2006). Stigma and the social basis of the self: A synthesis. *Stigma and group inequality: Social psychological perspectives*, 287-308.
- Crone, E. A., & Dahl, R. E. (2012). Understanding adolescence as a period of social-affective engagement and goal flexibility. *Nature Reviews Neuroscience*, 13(9), 636-650.
- Crosnoe, R., & McNeely, C. (2008). Peer relations, adolescent behavior, and public health research and practice. *Family & Community Health*, 31, S71-S80.
- Department of Health. (2007). *National service framework for children, young people and maternity services. The Mental health and psychological well-being of children and young people*. London: DH.
- Dolphin, L., & Hennessy, E. (2014). Adolescents' perceptions of peers with depression: An attributional analysis. *Psychiatry research*, 218(3), 295-302.
- Donenberg, G., & Pao, M. (2005). Youths and HIV/AIDS: Psychiatry's role in a changing epidemic. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 728-747.

Effective Public Health Practice Project (EPHPP) “Quality Assessment Tool for Quantitative) Studies”. <http://www.ephpp.ca/tools.html>

Elkington, K. S., Hackler, D., McKinnon, K., Borges, C., Wright, E. R., & Wainberg, M. L. (2012). Perceived mental illness stigma among youth in psychiatric outpatient treatment. *Journal of Adolescent Research*, 27(2), 290-317.

Evans-Lacko, S., Brohan, E., Mojtabai, R., & Thornicroft, G. (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological medicine*, 42(8), 1741.

Feldman, S. S., & Elliott, G. R. (Eds.). (1990). *At the threshold: The developing adolescent*. Cambridge, MA: Harvard University Press.

Fischer, E. H., & Turner, J. I. (1970). Orientations to seeking professional help: development and research utility of an attitude scale. *Journal of consulting and clinical psychology*, 35(1p1), 79.

Friedman, M. S., Koeske, G. F., Silvestre, A. J., Korr, W. S., & Sites, E. W. (2006). The impact of gender-role nonconforming behavior, bullying, and social support on suicidality among gay male youth. *Journal of Adolescent Health*, 38(5), 621-623.

Fusar-Poli, P., Byrne, M., Valmaggia, L., Day, F., Tabraham, P., Johns, L., ... & OASIS Team. (2010). Social dysfunction predicts two years clinical outcome in people at ultra high risk for psychosis. *Journal of psychiatric research*, 44(5), 294-301.

Gaziel, M., Hasson-Ohayon, I., Morag-Yaffe, M., Schapir, L., Zalsman, G., & Shoval, G. (2015). Insight and satisfaction with life among adolescents with mental disorders: Assessing associations with self-stigma and parental insight. *European Psychiatry*, 30(2), 329-333.

Gerlinger, G., Hauser, M., Hert, M., Lacluyse, K., Wampers, M., & Correll, C. U. (2013). Personal stigma in schizophrenia spectrum disorders: a systematic review of prevalence rates, correlates, impact and interventions. *World Psychiatry*, 12(2), 155-164.

Gillberg, C., Gillberg, I. C., Rasmussen, P., Kadesjö, B., Söderström, H., Råstam, M., ... & Niklasson, L. (2004). Co-existing disorders in ADHD—implications for diagnosis and intervention. *European child & adolescent psychiatry*, 13(1), i80-i92.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Penguin, London.

Gogtay, N., Giedd, J. N., Lusk, L., Hayashi, K. M., Greenstein, D., Vaituzis, A. C., Nugent, T.F., Herman, D.H., Clasen, L.S., Toga, A.W., Rapoport, J.L., & Rapoport, J. L. (2004). Dynamic mapping of human cortical development during childhood through early adulthood. *Proceedings of the National academy of Sciences of the United States of America*, 101(21), 8174-8179.

- Gowers, S. G., & Rowlands, L. (2005). Inpatient services. *Current opinion in psychiatry*, 18(4), 445-448.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC psychiatry*, 10(1), 113.
- Harter, S. (1985). *Manual of the Self-Perception Profile for Children*. University of Denver.
- Harvey, P. D., & Strassing, M. (2012). Predicting the severity of everyday functional disability in people with schizophrenia: cognitive deficits, functional capacity, symptoms, and health status. *World Psychiatry*, 11(2), 73-79.
- Higgins, J.P.T. & Green, S. (2008). *Cochrane Handbook for Systematic Reviews of Interventions: Cochrane Book Series*. The Cochrane Collaboration: Wiley-Blackwell
- Hill, R., & Fortenberry, J. (1992). Adolescence as a culture bound syndrome. *Social Science & Medicine*, 35(1), 73-80.
- Hinshaw, S. P. (2005). The stigmatization of mental illness in children and parents: Developmental issues, family concerns, and research needs. *Journal of Child Psychology and Psychiatry*, 46(7), 714-734.
- Hodges, K. (1994). *Child and Adolescent Functional Assessment Scale*. Ypsilanti: Eastern Michigan University, Department of Psychology.
- Horan, W. P., Subotnik, K. L., Snyder, K. S., & Nuechterlein, K. H. (2006). Do recent-onset schizophrenia patients experience a “social network crisis”? *Psychiatry: Interpersonal and Biological Processes*, 69(2), 115-129.
- Huebner, E. S. (1994). Preliminary development and validation of a multidimensional life satisfaction scale for children. *Psychological assessment*, 6(2), 149.
- Hughes, B. M. (2005). Support as intimidation: when social interaction elevates stress-related blood pressure. *The Irish Journal of Psychology*, 26(1-2), 75-86.
- Institute of Medicine (2009). *Preventing mental, emotional and behavioral disorders among young people: progress and possibilities*. Washington DC: National Academies Press.
- John, K., Gammon, D. G., Prusoff, B. A., & Warner, V. (1987). The Social Adjustment Inventory for Children and Adolescents (SAICA): Testing of a new semistructured interview. *Journal of the American Academy of Child & Adolescent Psychiatry*, 26(6), 898-911.
- Jörngården, A., Wettergen, L., & von Essen, L. (2006). Measuring health-related quality of life in adolescents and young adults: Swedish normative data for the SF-36 and the HADS, and the influence of age, gender, and method of administration. *Health and quality of life outcomes*, 4(1), 91.

- Kaidar, I., Wiener, J., & Tannock, R. (2003). The attributions of children with Attention-Deficit/Hyperactivity Disorder for their problem behaviors. *Journal of Attention Disorders*, 6(3), 99-109.
- Kaushik, A., Kostaki, E., & Kyriakopoulos, M. (2016). The stigma of mental illness in children and adolescents: A systematic review. *Psychiatry Research*, 243, 469-494.
- Kieling, C., Baker-Henningham, H., Belfer, M., Conti, G., Ertem, I., Omigbodun, O. & Rahman, A. (2011). Child and adolescent mental health worldwide: evidence for action. *The Lancet*, 378(9801), 1515-1525.
- Killaspy, H., Marston, L., Green, N., Harrison, I., Lean, M., Cook, S., Mundy, T., Craig, T., Holloway, F., Leavey, G., Koeser, L., McCrone, P., Arbutnott, M., Omar, R.Z., King, M. & Koeser, L. (2015). Clinical effectiveness of a staff training intervention in mental health inpatient rehabilitation units designed to increase patients' engagement in activities (the Rehabilitation Effectiveness for Activities for Life [REAL] study): single-blind, cluster-randomised controlled trial. *The Lancet Psychiatry*, 2(1), 38-48.
- Kim-Cohen, J., Caspi, A., Moffitt, T. E., Harrington, H., Milne, B. J., & Poulton, R. (2003). Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. *Archives of general psychiatry*, 60(7), 709-717.
- Kranke, D. A., Floersch, J., Kranke, B. O., & Munson, M. R. (2011). A qualitative investigation of self-stigma among adolescents taking psychiatric medication. *Psychiatric Services*, 62(8), 893-899.
- Kulikowska, A., & Pokorski, M. (2008). Self-injuries in adolescents: social competence, emotional intelligence and stigmatization. *Journal of physiology and pharmacology*, 59(6), 383-392.
- LaFreniere, P. J., & Dumas, J. E. (1996). Social competence and behavior evaluation in children ages 3 to 6 years: the short form (SCBE-30). *Psychological assessment*, 8(4), 369.
- Lay, B., Blanz, B., Hartmann, M., & Schmidt, M. H. (2000). The psychosocial outcome of adolescent-onset schizophrenia: a 12-year followup. *Schizophrenia bulletin*, 26(4), 801-816.
- Lindsey, M. A., Joe, S., & Nebbitt, V. (2010). Family matters: The role of mental health stigma and social support on depressive symptoms and subsequent help seeking among African American boys. *Journal of Black Psychology*, 36(4), 458-482.
- Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, 96-112.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American sociological review*, 400-423.

- Link, B. G., Struening, E. L., Rahav, M., Phelan, J. C., & Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, 177-190.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 27(1), 363-385.
- Link, B. G., Struening, E. L., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric services*, 52(12), 1621-1626.
- Lysaker, P. H., Davis, L. W., Warman, D. M., Strasburger, A., & Beattie, N. (2007a). Stigma, social function and symptoms in schizophrenia and schizoaffective disorder: associations across 6 months. *Psychiatry research*, 149(1), 89-95.
- Lysaker, P. H., Roe, D., & Yanos, P. T. (2007b). Toward understanding the insight paradox: internalized stigma moderates the association between insight and social functioning, hope, and self-esteem among people with schizophrenia spectrum disorders. *Schizophrenia bulletin*, 33(1), 192-199.
- O'Brien, M. P., Gordon, J. L., Bearden, C. E., Lopez, S. R., Kopelowicz, A., & Cannon, T. D. (2006). Positive family environment predicts improvement in symptoms and social functioning among adolescents at imminent risk for onset of psychosis. *Schizophrenia research*, 81(2), 269-275.
- Matczak, A. (2001). Podrecznik do Kwestionariusza Kompetencji Społecznych. *Test of the Polish Psychological Society, Warszawa*. (Handbook in Polish).
- Major, B. (2006). *New perspectives on stigma and psychological well-being*. In S. Levin, & C. van Laar (Eds.), *Stigma and group inequality: Social psychological perspectives* (pp. 193–210). Mahwah, NJ: Lawrence Erlbaum Associates Publishers.
- Meltzer, H., Gatward, R., Corbin, T., Goodman, R., & Ford, T. (2003a). *Persistence, onset, risk factors and outcomes of childhood mental disorders*. London: TSO.
- Meltzer, H., Gatward, R., Goodman, R., & Ford, T. (2003b). Mental health of children and adolescents in Great Britain. *International review of Psychiatry*, 15(1-2), 185-187.
- Miller, I. W., Epstein, N. B., Bishop, D. S., & Keitner, G. I. (1985). The McMaster family assessment device: reliability and validity. *Journal of Marital and Family Therapy*, 11(4), 345-356.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., 2009. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement (The PRISMA Group). *PLoS Med* 6 (6), e1000097. <http://dx.doi.org/10.1371/journal.pmed1000097>.
- Moriarty, A., Jolley, S., Callanan, M.M., & Garety, P. (2012). Understanding reduced activity in psychosis: The roles of stigma and illness appraisals. *Social Psychiatry Psychiatric Epidemiology*, 47, 1685–1693.

Moses, T. (2009). Stigma and self-concept among adolescents receiving mental health treatment. *American Journal of Orthopsychiatry*, 79(2), 261.

Moses, T. (2011). Stigma apprehension among adolescents discharged from brief psychiatric hospitalization. *The Journal of nervous and mental disease*, 199(10), 778-789.

Moses, T. (2010a). Being treated differently: Stigma experiences with family, peers, and school staff among adolescents with mental health disorders. *Social science & medicine*, 70(7), 985-993.

Moses, T. (2010b). Adolescent mental health consumers' self- stigma: associations with parents' and adolescents' illness perceptions and parental stigma. *Journal of community psychology*, 38(6), 781-798.

Moses, T. (2014). Determinants of mental illness stigma for adolescents discharged from psychiatric hospitalization. *Social Science & Medicine*, 109, 26-34.

Muñoz, M., Sanz, M., Pérez-Santos, E., & de los Ángeles Quiroga, M. (2011). Proposal of a socio-cognitive-behavioral structural equation model of internalized stigma in people with severe and persistent mental illness. *Psychiatry Research*, 186(2), 402-408.

National Institute for Health and Clinical Excellence (Great Britain). (2009). *Schizophrenia: Core interventions in the treatment and management of schizophrenia in adults in primary and secondary care*. National Institute for Health and Clinical Excellence.

National Institute for Clinical Excellence. (2014). Psychosis and schizophrenia in adults: prevention and management. *NICE guidelines [CG178]*.

O'Brien, M. P., Gordon, J. L., Bearden, C. E., Lopez, S. R., Kopelowicz, A., & Cannon, T. D. (2006). Positive family environment predicts improvement in symptoms and social functioning among adolescents at imminent risk for onset of psychosis. *Schizophrenia research*, 81(2), 269-275.

Passmore, A., & French, D. (2000). A model of leisure and mental health in Australian adolescents. *Behaviour Change*, 17(03), 208-220.

Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental health of young people: a global public-health challenge. *The Lancet*, 369(9569), 1302-1313.

Pyle, M., Stewart, S. L., French, P., Byrne, R., Patterson, P., Gumley, A., ... & Morrison, A. P. (2015). Internalized stigma, emotional dysfunction and unusual experiences in young people at risk of psychosis. *Early intervention in psychiatry*, 9(2), 133-140.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement*, 1(3), 385-401.

- Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry research*, 121(1), 31-49.
- Ritsher, J. B., & Phelan, J. C. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry research*, 129(3), 257-265.
- Sanz, M., Constable, G., Lopez-Ibor, I., Kemp, R., & David, A. S. (1998). A comparative study of insight scales and their relationship to psychopathological and clinical variables. *Psychological medicine*, 28(2), 437-446.
- Sibitz, I., Amering, M., Unger, A., Seyringer, M. E., Bachmann, A., Schrank, B., ... & Woppmann, A. (2011). The impact of the social network, stigma and empowerment on the quality of life in patients with schizophrenia. *European Psychiatry*, 26(1), 28-33.
- Sirey, J. A., Bruce, M. L., Alexopoulos, G. S., Perlick, D. A., Friedman, S. J., & Meyers, B. S. (2001). Stigma as a barrier to recovery: Perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatric services*, 52(12), 1615-1620.
- Starr, S., Campbell, L. R., & Herrick, C. A. (2002). Factors affecting use of the mental health system by rural children. *Issues in Mental Health Nursing*, 23(3), 291-304.
- Schnyder, N., Panczak, R., Groth, N., & Schultze-Lutter, F. (2017). Association between mental health-related stigma and active help-seeking: systematic review and meta-analysis. *The British Journal of Psychiatry*, bjp-bp.
- Steinberg, L., & Morris, A. S. (2001). Adolescent development. *Annual review of psychology*, 52(1), 83-110.
- Tarbox, S. I., & Pogue-Geile, M. F. (2008). Development of social functioning in preschizophrenia children and adolescents: a systematic review. *Psychological bulletin*, 134(4), 561.
- Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: ignorance, prejudice or discrimination?. *The British Journal of Psychiatry*, 190(3), 192-193.
- Tolan, P. H., & Dodge, K. A. (2005). Children's mental health as a primary care and concern: a system for comprehensive support and service. *American Psychologist*, 60(6), 601.
- U.S. Census Bureau. (2001). Census 2000 PHC-T-9. Population by age, sex, race, and Hispanic or Latino origin for the United States: 2000. Census 2000 Summary File 1. <http://factfinder.census.gov>. Retrieved April 5, 2002.
- Velligan, D. I., Mintz, J., Sierra, C., Martin, M. L., Fredrick, M., Maglinte, G. A., & Corey-Lisle, P. K. (2016). The Daily Activity Report (DAR) a novel measure of functional outcome for serious mental illness. *Schizophrenia bulletin*, 42(3), 579-587.

Vijayakumar, L., John, S., Pirkis, J., & Whiteford, H. (2005). Suicide in developing countries (2): risk factors. *Crisis: The Journal of Crisis Intervention and Suicide Prevention*, 26(3), 112.

Walshe, M., Taylor, M., Schulze, K., Bramon, E., Frangou, S., Stahl, D., ... & McDonald, C. (2007). Familial liability to schizophrenia and premorbid adjustment. *The British Journal of Psychiatry*, 191(3), 260-261.

Weissman, M. M., & Bothwell, S. (1976). Assessment of social adjustment by patient self-report. *Archives of general psychiatry*, 33(9), 1111-1115.

Wisdom, J.P., Clarke, G.N., & Green, C.A. (2006). What teens want: Barriers to seeking care for depression. *Administration and Policy in Mental Health and Mental Health Services Research*, 33, 133–145.

Yanos, P. T., Rosenfield, S., & Horwitz, A. V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community mental health journal*, 37(5), 405-419.

Wiener, J., Malone, M., Varma, A., Markel, C., Biondic, D., Tannock, R., & Humphries, T. (2012). Children's perceptions of their ADHD symptoms: Positive illusions, attributions, and stigma. *Canadian Journal of School Psychology*, 27(3), 217-242.

Wood, L., Byrne, R., Varese, F., & Morrison, A. P. (2016). Psychosocial interventions for internalised stigma in people with a schizophrenia-spectrum diagnosis: A systematic narrative synthesis and meta-analysis. *Schizophrenia research*, 176(2), 291-303.

Wood, L., Byrne, R., Burke, E., Enache, G., & Morrison, A. P. (2017). The impact of stigma on emotional distress and recovery from psychosis: The mediatory role of internalised shame and self-esteem. *Psychiatry Research*, 255, 94-100.

## 8. Appendices

### Appendix A - PROSPERO Registration

#### PROSPERO International prospective register of systematic reviews

##### Review title and timescale

- 1 Review title  
Give the working title of the review. This must be in English. Ideally it should state succinctly the interventions or exposures being reviewed and the associated health or social problem being addressed in the review.  
**Stigma experiences in children and young people with mental health disorders: a systematic review of their relationship with social functioning**
- 2 Original language title  
For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.
- 3 Anticipated or actual start date  
Give the date when the systematic review commenced, or is expected to commence.  
**19/08/2016**
- 4 Anticipated completion date  
Give the date by which the review is expected to be completed.  
**31/10/2017**
- 5 Stage of review at time of this submission  
Indicate the stage of progress of the review by ticking the relevant boxes. Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. This field should be updated when any amendments are made to a published record.

The review has not yet started ☒

| Review stage                                                    | Started | Completed |
|-----------------------------------------------------------------|---------|-----------|
| Preliminary searches                                            | Yes     | Yes       |
| Piloting of the study selection process                         | Yes     | Yes       |
| Formal screening of search results against eligibility criteria | Yes     | No        |
| Data extraction                                                 | No      | No        |
| Risk of bias (quality) assessment                               | No      | No        |
| Data analysis                                                   | No      | No        |

Provide any other relevant information about the stage of the review here.

##### Review team details

- 6 Named contact  
The named contact acts as the guarantor for the accuracy of the information presented in the register record.  
**Sinem Tekes**
- 7 Named contact email  
Enter the electronic mail address of the named contact.  
**sinem.tekes@kcl.ac.uk**
- 8 Named contact address  
Enter the full postal address for the named contact.  
**Institute of Psychiatry, Psychology & Neuroscience King's College London Denmark Hill London SE5 8AF**
- 9 Named contact phone number  
Enter the telephone number for the named contact, including international dialing code.  
**+44 (0)7964 247132**
- 10 Organisational affiliation of the review  
Full title of the organisational affiliations for this review, and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Institute of Psychiatry, Psychology & Neuroscience, King's College London

Website address:

- 11 Review team members and their organisational affiliations  
Give the title, first name and last name of all members of the team working directly on the review. Give the organisational affiliations of each member of the review team.

| Title | First name | Last name | Affiliation                                                              |
|-------|------------|-----------|--------------------------------------------------------------------------|
| Miss  | Sinem      | Tekes     | Institute of Psychiatry, Psychology & Neuroscience King's College London |

- 12 Funding sources/sponsors  
Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Any unique identification numbers assigned to the review by the individuals or bodies listed should be included.

Doctorate in Clinical Psychology Program, Institute of Psychiatry, Psychology & Neuroscience King's College London

- 13 Conflicts of interest  
List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

Are there any actual or potential conflicts of interest?

None known

- 14 Collaborators  
Give the name, affiliation and role of any individuals or organisations who are working on the review but who are not listed as review team members.

| Title | First name | Last name | Organisation details |
|-------|------------|-----------|----------------------|
|-------|------------|-----------|----------------------|

## Review methods

- 15 Review question(s)  
State the question(s) to be addressed / review objectives. Please complete a separate box for each question.  
What is the relationship of personal stigma with social functioning and activity in children and adolescents with, or at risk of developing, serious mental health problems?

- 16 Searches  
Give details of the sources to be searched, and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.  
Searches will be conducted on electronic databases, websites and the hand searching of reviews and reference lists. Electronic searches will be carried out on • PsycINFO (Online database of psychological literature) • MEDLINE (Online database of health and medical journals and other news sources) • EMBASE (Online database of health and medical journals) • Web of Science (Online multidisciplinary database covering all sciences) Searching other resources • Reference list screening of included studies • Citation tracking of included studies in Google Scholar and Web of Science • Expert recommendations English language restrictions will be used.

- 17 URL to search strategy  
If you have one, give the link to your search strategy here. Alternatively you can e-mail this to PROSPERO and we will store and link to it.

I give permission for this file to be made publicly available

Yes

- 18 Condition or domain being studied  
Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.  
Stigma (self-stigma, perceived stigma, internalised stigma, experienced stigma, self-labelling, anticipated stigma, stigma stress, consumer stigma), Mental health or 'at risk' (including but not limited to anxiety, depression, psychosis),

Physical activity and Social functioning (social network, engagement in leisure and recreational activities, social activities, quality of life, life satisfaction, social rejection, social participation, social relationships).

- 19 Participants/population  
Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.  
Inclusion: children and adolescents aged up to (mean age of) 18 years with a mental health disorder or 'at risk'.  
Exclusion: adults over the age of 18.
- 20 Intervention(s), exposure(s)  
Give full and clear descriptions of the nature of the interventions or the exposures to be reviewed  
Exposure: experience of stigma in young people aged below 18.
- 21 Comparator(s)/control  
Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group).  
Girls and boys with mental health problem or 'at risk' aged under 18 with stigma experiences
- 22 Types of study to be included  
Give details of the study designs to be included in the review. If there are no restrictions on the types of study design eligible for inclusion, this should be stated.  
Inclusion: published peer-reviewed research based on the following study designs: cross-sectional survey; prospective study; cohort study; experimental study with baseline measures for the outcomes of interest. Exclusion: single case study or qualitative design. Doctoral theses and dissertations, general discussion papers, comments and letters, book chapters, and conference papers, will be also be excluded.
- 23 Context  
Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.
- 24 Primary outcome(s)  
Give the most important outcomes.  
No restrictions will be placed on the method of measuring physical/activity and social functioning health outcomes.  
  
Give information on timing and effect measures, as appropriate.
- 25 Secondary outcomes  
List any additional outcomes that will be addressed. If there are no secondary outcomes enter None.  
None.  
  
Give information on timing and effect measures, as appropriate.
- 26 Data extraction (selection and coding)  
Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.  
Titles and abstracts of studies will be independently screened by the lead researcher and an additional reviewer based on the inclusion criteria outlined earlier. The same procedure will follow for the full text reviews. Data will be extracted from all studies, which have been selected for inclusion in the review. The lead researcher will be responsible for the data extraction, and it will also be completed by a second independent researcher for 100% of included studies. If any discrepancies arise, further dual extraction will proceed.
- 27 Risk of bias (quality) assessment  
State whether and how risk of bias will be assessed, how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.  
The methodological quality of studies will be appraised using an adapted version of the Effective Public Health Practice Project (EPHPP; 2007) 'Quality Assessment Tool for Quantitative Studies' checklist. Overall study quality will be assessed according to the percentage of the maximum possible quality score attained. Quality will be appraised independently by two researchers, with a third reviewer opinion in cases where consensus could not be reached.
- 28 Strategy for data synthesis

Give the planned general approach to be used, for example whether the data to be used will be aggregate or at the level of individual participants, and whether a quantitative or narrative (descriptive) synthesis is planned. Where appropriate a brief outline of analytic approach should be given.

Information about the study sample, sample characteristics, and method of measurement as well as study outcomes will be summarised in a table.

29 Analysis of subgroups or subsets

Give any planned exploration of subgroups or subsets within the review. 'None planned' is a valid response if no subgroup analyses are planned.

None planned.

Review general information

30 Type and method of review

Select the type of review and the review method from the drop down list.

Systematic review

31 Language

Select the language(s) in which the review is being written and will be made available, from the drop down list. Use the control key to select more than one language.

English

Will a summary/abstract be made available in English?

Yes

32 Country

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved. Use the control key to select more than one country.

England

33 Other registration details

Give the name of any organisation where the systematic review title or protocol is registered together with any unique identification number assigned. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here.

34 Reference and/or URL for published protocol

Give the citation for the published protocol, if there is one.

Give the link to the published protocol, if there is one. This may be to an external site or to a protocol deposited with CRD in pdf format.

I give permission for this file to be made publicly available

Yes

35 Dissemination plans

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

Publication in peer reviewed journal.

Do you intend to publish the review on completion?

Yes

36 Keywords

Give words or phrases that best describe the review. (One word per box, create a new box for each term)

37 Details of any existing review of the same topic by the same authors

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38 Current review status

Review status should be updated when the review is completed and when it is published.

Ongoing

- 39 Any additional information  
Provide any further information the review team consider relevant to the registration of the review.
- 40 Details of final report/publication(s)  
This field should be left empty until details of the completed review are available.  
Give the full citation for the final report or publication of the systematic review.  
Give the URL where available.

## Appendix B - Search Strategies

### 1. PsychINFO, PubMed, Embase, Medline:

1. Stigma.mp.
2. Young people.mp.
3. Young person\*.mp.
4. Teenager\*.mp.
5. Youth\*.mp.
6. Adolescen\*.mp.
7. Young adult\*.mp.
8. Child\*.mp.
9. Paediatric\*.mp.
10. Pediatric\*.mp.
11. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12. mental\* ill\*.mp.
13. mental\* disorder\*.mp.
14. mental\* health\*.mp.
15. 12 or 13 or 14
16. 1 and 11 and 15
17. limit 16 to english language
18. limit 17 to humans
19. remove duplicates from 18
20. remove duplicates from 18
21. remove duplicates from 18

### 2. Web of Science:

- #17 #15 AND #14 AND #1  
Refined by: LANGUAGES: (ENGLISH)  
DocType=All document types; Language=All languages;
- #16 #15 AND #14 AND #1  
DocType=All document types; Language=All languages;
- #15 #13 OR #12 OR #11  
DocType=All document types; Language=All languages;
- #14 #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2  
DocType=All document types; Language=All languages;
- #13 TOPIC: (mental\* health\*)  
DocType=All document types; Language=All languages;
- #12 TOPIC: (mental\* disorder\*)

DocType=All document types; Language=All languages;  
 #11 TOPIC: (mental\* ill\*)  
 DocType=All document types; Language=All languages;  
 #10 TOPIC: (Pediatric\*)  
 DocType=All document types; Language=All languages;  
 #9 TOPIC: (Paediatric\*)  
 DocType=All document types; Language=All languages;  
 #8 TOPIC: (Child\*)  
 DocType=All document types; Language=All languages;  
 #7 TOPIC: (Young adult\*)  
 DocType=All document types; Language=All languages;  
 #6 TOPIC: (Adolescen\*)  
 DocType=All document types; Language=All languages;  
 #5 TOPIC: (Youth\*)  
 DocType=All document types; Language=All languages;  
 #4 TOPIC: (Teenager\*)  
 DocType=All document types; Language=All languages;  
 #3 TOPIC: (Young person\*)  
 DocType=All document types; Language=All languages;  
 #2 TOPIC: (Young people)  
 DocType=All document types; Language=All languages;  
 #1 TOPIC: (stigma)  
 DocType=All document types; Language=All languages;

## Appendix C - Adapted EPHPP Quality Assessment Tool

Reference:

Date:

### **Domain 1: Selection Bias**

Q1: Are the individuals selected to participate in the study likely to be representative of the target population?

- 1: Very likely (random selection of list of individuals in the target population)
- 2: Somewhat likely (selected from source (clinic) in systematic manner)
- 3: Not likely (self-referred)
- 4: Can't tell

Q2: What percentage of selected individuals agreed to participate?

- 1: 80 - 100% agreement
- 2: 60 – 79% agreement
- 3: less than 60% agreement
- 4: Not applicable
- 5: Can't tell

### ***Selection Bias Global Rating:***

Strong: The selected individuals are very likely to be representative of the target population (Q1 is 1) and there is greater than 80% participation (Q2 is 1).

Moderate: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); and there is 60 - 79% participation (Q2 is 2).

'Moderate' may also be assigned if Q1 is 1 or 2 and Q2 is 5 (can't tell).

Weak: The selected individuals are not likely to be representative of the target population (Q1 is 3); or there is less than 60% participation (Q2 is 3) or selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

### **Domain 2: Study Design**

Q1: Rationale given for selection of sample with regard to developmental stage.

- 1: Rationale provided
- 2: No rationale provided

Q2: Rationale given for duration of follow up

- 1: Rationale provided
- 2: No rationale provided

### ***Design Global Rating:***

Strong: Rationale is given for both developmental stage and length of follow up (Q1 and Q2 have a rating of 1)

OR

Rationale was provided for either the length of follow up or developmental stage of the sample (either Q1 or Q2 have a rating of 1).

Moderate: A score of 1 on either of the two questions

Weak: A rating of 2 on Q1 and Q2

### **Domain 3: Confounders**

Q1: Were confounders considered and a rationale was provided for inclusion or exclusion?

- 1: Rationale provided or analyses reported with and without confounders (Strong)
- 2: No rationale provided and analyses not reported without confounders (Weak)

### **Domain 4.1: Stigma Measure (validity and reliability)**

Stigma tools, validity and reliability of measures demonstrated for their stated purpose in this sample

Q1: Stigma validity

- 1: Yes
- 2: Face validity
- 3: No/questionable face validity

Q2: Stigma reliability

- 1: Yes
- 2: No
- 3: Can't tell

#### ***Stigma Measure Global Rating:***

Strong: The data collection tools have been shown to be valid (Q1 is 1); and the data collection tools have been shown to be reliable (Q2 is 1).

Moderate: The data collection tools have been shown to be valid (Q1 is 1) or have been shown to have face validity (Q1 is 2); and the data collection tools have not been shown to be reliable (Q2 is 2) or reliability is not described (Q2 is 3).

Weak: The data collection tools have not been shown to be valid (Q1 is 2) or both reliability and validity are not described (Q1 is 3 and Q2 is 3).

### **Domain 4.2 Social functioning Measure (validity and reliability)**

Q1: Social functioning validity

- 1: Yes
- 2: Face validity
- 3: No/questionable face validity

Q2: Social functioning reliability

- 1: Yes
- 2: No
- 3: Can't tell

#### ***Social functioning Measure Global Rating:***

Strong: The data collection tools have been shown to be valid (Q1 is 1); and the data collection tools have been shown to be reliable (Q2 is 1).

Moderate: The data collection tools have been shown to be valid (Q1 is 1) or have been shown to have face validity (Q1 is 2); and the data collection tools have not been shown to be reliable (Q2 is 2) or reliability is not described (Q2 is 3).

Weak: The data collection tools have not been shown to be valid (Q1 is 2) or both reliability and validity are not described (Q1 is 3 and Q2 is 3).

#### **Domain 4.3: Measures (combined) validity and reliability**

##### ***All Measure Global Rating:***

Strong: Both the stigma and social functioning tools have been rated as strong.

Moderate: Both the stigma and social functioning tools have been rated as moderate, or one has been rated as moderate and the other as strong.

Weak: Either the stigma and social functioning tools have been rated as weak.

#### **Domain 5: Withdrawals and Dropouts (rates)**

Q1: Were withdrawals and drop-outs reported in terms of numbers per group?

- 1: Yes
- 2: No
- 3: Can't tell

Q2: Indication of the percentage of participants completing the study.

- 1: 80% - 100%
- 2: 60 – 79%
- 3: Less than 60%
- 4: Can't tell

##### ***Withdrawals and Dropouts Global Rating:***

Strong: will be assigned when the follow-up rate is 80% or greater (Q2 is 1).

Moderate: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) OR Q2 is 5 (N/A).

Weak: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q2 is 4).

#### **Domain 6: Consideration of Missing Data and Dropouts**

Q1: Some consideration for missing data and differences in drop out analysed

- 1: both (Strong)
- 2: one (Moderate)
- 3: none (Weak)

#### **Domain 7: Adequate Power**

Q1: Consideration for and discussion of power of analyses conducted

- 1: discussed and all analyses powered
- 2: discussed
- 3: not mentioned

Q2: Multiple testing considered/p-value adjusted or justified why not adjusted

1: considered

2: not considered

***Adequate Power Global Rating:***

Strong: Analyses powered or power only discussed (Q1 is 1 or 2) and Multiple testing considered (Q2 is 1)

Moderate: Either analyses powered/ power discussed (Q1 is 1 or 2) or Multiple testing considered (Q2 is 1)

Weak: Neither analyses powered/power discussed (Q1 is 3) or Multiple testing considered (Q2 is 2)

**Domain 8: Adequate Analyses**

1: Analysis most likely to yield most accurate parameters (modelling entire data sets) (Strong)

2: Analysis appropriate but not modelling entire datasets, not taking into account predictors' effects over and above effects of other predictors (all predictors in the same model) (Moderate)

3: Analyses inadequate or information presented on analyses inconclusive (Weak)

Total Score (adapted from EPHPP)

Rated across 5 domains: selection bias, study design, *confounders*, data collection method and withdrawals and dropouts

STRONG (no WEAK ratings)

MODERATE (one WEAK rating)

WEAK (two or more WEAK ratings)

Total Score (Adequate Analysis included instead of confounders)

Rated across 5 domains: selection bias, study design, data collection method, withdrawals and dropouts and *adequacy of analysis*

STRONG (no WEAK ratings)

MODERATE (one WEAK rating)

WEAK (two or more WEAK ratings)

# **Empirical Study**

## **Investigating Activity Levels in Children with Psychotic-like Experiences: The Role of Emotional, Social and Cognitive Factors**

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Not Applicable.

## 1. Abstract

**Background:** Reduced activity is implicated in the development and maintenance of a range of mental health problems. Adolescence is a critical period of development and also a period of vulnerability for the onset of serious mental health problems. Early preventative and ameliorative interventions are therefore crucial at this time, to reduce the impact of mental illness on developmental opportunities, and thereby, the risks of persistence and recurrence. Previous studies have shown associations between positive symptom distress and activity levels in adults with psychosis however less is known about these relationships in young people.

**Aims:** This study aimed to investigate the influence of emotional, cognitive and social factors, on levels of activity in adolescents with unusual experiences. The purpose is to inform early mental health intervention with young people who are at risk of developing serious mental health problems.

**Design:** A cross-sectional design was employed, and a correlational analysis.

**Method:** A sample of young people attending community mental health teams (n= 183) completed a range of measures assessing activity levels, unusual experiences, mood, stigma, adverse life events and schemas.

**Results:** Correlational analyses showed significant associations between reduced activity levels and higher unusual experiences severity, emotional symptoms and stigma, as well as negative self-schemas with reduced activity levels. However, this was notwithstanding the influence of demographic factors including age, gender, ethnicity and clinical setting, and patterns of associations changed once these were controlled.

**Conclusions:** Firm conclusions cannot therefore be drawn without further research specifically addressing the association of activity, and its potential correlates, with demographic variables. The current study highlights potential clinical implications of the findings, and a number of recommendations for future research.

## **2. Introduction**

### **2.1. Overview**

Numerous studies and governmental reports highlight the association between engagement in youth activities and successful outcomes in adulthood (e.g. ‘Aiming high’ report, United Kingdom Government Department; DCSF)<sup>1</sup>. Taking part in meaningful activities including interacting with family and peers, developing skills, attending school and pursuing spare-time interests have all been recognised as contributing to general wellbeing, cross culturally and for young people with mental health problems (John, 2001). Indeed, reduced activity is a key factor in the development and maintenance of a range of mental health problems, including psychosis (e.g. Garety et al., 2001). As the time when young people start to develop a sense of identity, and independence of functioning and relationships (Harter, 1999), and a key period of vulnerability for the onset of serious mental health problems (Kim-Cohen et al., 2003), adolescence is considered to be a critical period for early preventative and ameliorative interventions.

Adolescence is therefore a particularly significant time to investigate relationships between activity and psychopathology, and the psychological mechanisms potentially influencing activity levels in order to inform early intervention for young people at risk of mental health problems. Previous research has highlighted associations between positive symptom distress and activity in adults with psychosis, with a strong influence of perceived stigma on activity levels. The aim of the current study is to investigate these associations in adolescents with distressing unusual experiences (UEDs), a potential early vulnerability factor for the later development of a mental state at risk for psychosis (van Os & Reininghaus, 2016). The study will also evaluate, for the first time, the influence of past adverse life events, and beliefs about the self and others, on levels of activity in adolescents with UEDs. Identified relationships will inform the potential to intervene to improve engagement in activity by addressing distress associated with unusual experiences, emotional problems, stigma, the psychological sequelae of adversity, and self and other schemas, pending further longitudinal research. This section of the thesis describes the study, commencing with an introductory review of the

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<sup>1</sup> The Department for Children, Schools and Families Publications was disbanded in 2010.

relevant literature, a description of the methods and study findings, and a critical discussion of their implications for clinical practice and future research. The introduction will outline the impact of activity levels within mental health, focusing on the adult psychosis literature, particularly unusual experiences and early intervention services. There will then be an overview of the impact of emotional, cognitive and social factors on activity levels in young people. This section ends with an outline of the specific rationale for the current study.

### **Activity and wellbeing**

Engagement in activities has shown benefits on physical, social, emotional and cognitive wellbeing through improving resilience and ability to cope with stress and negative life events (Caldwell, 2005). Passmore (2003) investigated the impact of leisure activities on mental health outcomes amongst adolescents and found that leisure participation had a positive influence on self-efficacy, competence, self-worth and a positive relationship with better mental health. Furthermore, youth engagement in positive activities has been shown to improve educational, social and emotional outcomes in adulthood (e.g. 'Aiming high' report, United Kingdom Government Department; DCSF, 2010). For example, it has been found that young people who engaged in socialising and self-development activities (e.g. playing a musical instrument, doing community work) achieved on average 10-20% higher GCSE point scores (Cebulla & Tomaszewski, 2009). Several mental health presentations including depression, anxiety and psychosis have been associated in adult research with reduced activity levels and social functioning through amotivation and avoidance, which have been shown to exacerbate and maintain difficulties due to lack of opportunities to obtain positive reinforcement (Veale, 2008; Lutgens, Garipey & Malla, 2017). A key focus of cognitive behavioural therapies is on increasing levels of activity in order to gain positive reinforcement and subsequently improved mood (e.g. Kanter & Baruch, 2006).

### **Unusual experiences**

Unusual experiences are similar to symptoms of psychosis such as having odd beliefs and altered perceptions, though by comparison are reduced in frequency and intensity. Research suggests that unusual experiences are common (Van Os et al., 2009) and may constitute part of a spectrum of normative development (Laurens et al., 2012). However, unusual experiences can be impairing and distressing for a minority of

children (Kelleher et al., 2013). The likelihood of developing psychosis and a range of other mental health problems following unusual experiences is associated with persistence of symptoms as well as limited protective and coping strategies (Asher et al., 2013). Studies have highlighted that reductions in functioning in young people at risk of developing psychosis may have an adverse effect on their academic and social development, thus increasing their vulnerability, as well as contributing to greater risk of further mental health difficulties in the future (Fusar-Poli et al., 2010). This highlights the need to investigate potential risk factors and focus on early intervention strategies especially with young people with UEDs.

### **Mental health and activity levels**

Reduced activity levels can be understood as a pivotal part of mental health conditions, with mechanistic influence such that increased activity levels exerts an impact on the core of the disorder by providing direct and indirect opportunities for reward and positive reinforcement (Kanter et al., 2010). It is well established that this facilitates the challenging of negative thoughts and beliefs about ability, coping, enjoyment and perception of danger, which often leads to avoidances particularly within depression, anxiety and psychosis (Hopko et al., 2003; Jolley et al., 2006). Furthermore, engagement in activities provides distraction, which helps to reduce rumination and worry as well as offering opportunities for engagement with social aspects within the community, which helps to reduce isolation (Mahoney et al., 2005). A number of studies have shown preliminary relationships between unusual experiences and functioning (e.g. Yung et al., 2006; 2009). Therefore, reductions in activity levels and functioning have been shown to be a potential early vulnerability factor for the later development of a mental state at risk for psychosis.

One of the main aims of primary mental health services is to promote and increase activity and social inclusion for people with psychosis. This is also one of the basic principles of Cognitive Behavioural Therapy (CBT), which is recommended for treating psychosis and has shown to improve social functioning outcomes and activity levels (NICE, 2009). According to the basic principles of CBT, engagement in any pleasurable and rewarding activities is recommended particularly within the early stages of therapy. This may involve scheduling activities especially with other people that give a sense of positive reinforcement (Rupke, Blecke & Renfrow, 2006).

Furthermore, the relationship between mood and number of pleasant activities engaged in is well established such that people with depression engage in fewer activities, less frequently and as a result access less positive reinforcement compared to other individuals (Lewinsohn & Graf, 1973; Cuijpers, Van Straten & Warmerdam, 2007). This has been shown to maintain depression in both adults (e.g. Kawachi & Berkman, 2001) and young people (Asarnow, Jaycox & Tompson, 2001). Depression has been shown to increase the risk for onset of psychosis (Yung et al., 2009) and a number of studies have found an association between depression and positive psychotic experiences in young people (e.g. Van Rossum et al., 2011; Barragan et al., 2011). In a study by Barragan and colleagues (2011) unusual experiences were investigated in a community sample of adolescents and young people and they reported a positive relationship between social withdrawal and avolition with depression. Therefore the current study will investigate levels of unusual experiences with distress (UEDs) as well as presence of mood on the relationship with activity levels.

### **Early intervention services**

Early intervention (EI) services have been developed with the aim of offering support to individuals who have experienced a first episode psychosis or by intervening at an earlier stage by identifying people who may be at risk of developing psychosis and offering preventative intervention (e.g. Fusar-Poli et al., 2013). Individuals defined as ‘at risk’ may have experiences of attenuated sub-clinical positive symptoms or family history of psychosis (Yung et al., 2006). Studies have shown that out of those individuals identified in the first established services as ‘at risk’ 40% experienced a first episode psychosis within one year (Yung et al., 2003). Rates of transition have since declined, possibly due to the success of these services, but also potentially due to wider inclusion criteria and the transdiagnostic nature of the key risk factors (Simon et al., 2014).

The EI services offer a wide range of treatment types with CBT showing to be particularly effective (Morrison et al., 2004). The CBT approach to the EI clinical services focuses on the inability of individuals to generate alternative explanations for unusual experiences, and that lack of supportive friendships and trusting social relationships prevents facilitation of normalising those interpretations. It is well established that increased social withdrawal and isolation follows from the onset of mental health difficulties (Repper & Perkins, 2003) particularly within psychosis, which

may lead to reduced quality of life and impaired social functioning (Gaite et al., 2002). Therefore, identifying young people who are at risk of developing psychosis, including those with unusual experiences with distress (UEDs) should be a priority in order to intervene early and prevent transition to psychosis.

### **Psychosis and activity levels**

Aspects of social functioning and activity related to mood and positive symptoms may have an impact on quality of life by reducing levels of anxiety and depression, or managing distressing voices or beliefs through dropping safety seeking behaviours (Moriarty et al., 2012). A few studies have focused specifically on improving social functioning and activity levels by adding components such as vocational case management as part of a standard CBT treatment (Fowler et al., 2009). However the results are mixed (e.g. Hogarty et al., 1974; 1997) and psychological mechanisms of reduced activity is still under-researched particularly within adolescent samples.

Jolley and colleagues (2006) found that out of various cognitive, emotional and social mediators of activity levels in adults with psychosis, only negative symptoms and positive symptom distress correlated with activity levels. This was measured using a Time Budget diary and semi structured interview developed specifically to assess level of activity and functioning in a typical week. This measure has been adapted and tested with young people experiencing psychotic like symptoms and will be used in the current study as the main outcome measure.

### **Stigma**

Moriarty et al. (2012) found that internalised stigma was significantly correlated with reduced activity in adults with psychosis. The authors concluded that the fear of what others will think of them and how they will be treated may limit the activities that people with psychosis engage with. Other studies looking at the experiences of stigma in adults have shown positive correlations between self-stigma and symptoms of depression and anxiety (Link et al., 1997) as well as negative impact on self-esteem and social relationships (Corrigan & Watson, 2002). These may all contribute to further avoidances and withdrawals, perpetuating a vicious cycle which can have a negative impact on longer term mental health outcomes (Link & Phelan, 2001; Moriarty et al., 2012).

Although there is limited research investigating the experiences of stigma and social functioning in young people experiencing mental health difficulties, there is some development in this area, which has been highlighted in the previous chapter ('Stigma experiences in children and young people with mental health disorders: A systematic review of their relationship with social functioning'). For example, young people with mental health difficulties have reported that stigma experiences from peers led to loss of friendships and subsequent avoidance to prevent further stigmatising interactions (Moses, 2010) and qualitative research indicated that young people at risk of developing psychosis reported fear of negative reactions from other people because they had unusual psychological experiences (Byrne & Morrison, 2010). Therefore, the current study will investigate the association between stigma perception and levels of activity.

### **Adverse life events**

According to the cognitive model for psychosis (e.g. Garety et al., 2001) the appraisals about psychotic experiences as external and threatening increase levels of distress. The distress about the experiences may subsequently impact on activity levels and social functioning due to persecutory beliefs about others which may cause avoidances for example of going outside (Jolley et al., 2006). The impairments of social functioning may be impacted by other symptoms of psychosis however there is currently limited understanding about the relationship between UEDs and social functioning. Therefore, a better understanding of the factors that contribute to reduced activity levels and social withdrawal with young people experiencing UEDs is paramount as it could potentially have important long-term effects on prognosis. Furthermore, bullying experiences in childhood has gained attention over the recent years and studies have shown that a history of being bullied and poor social relationships predict the onset of unusual experiences (Campbell & Morrison, 2007) as well as other mental health difficulties including depression and anxiety in a sample of adolescents (Bond et al., 2001).

Studies have shown that individuals at risk of developing psychosis tend to experience heightened emotional reactivity to minor stressors in day-to-day situations (e.g. Palmier-Claus, Dunn & Lewis, 2012), therefore difficulties in social interactions may further exacerbate their vulnerabilities. Various models of psychosis posit that the stressors are mediated by emotional problems as well as by the development of cognitive schemas indicating threat of others and a vulnerable sense of self (Garety et al., 2001). Understanding the links between UEDs and social avoidance may influence

the way experiences of victimisation is treated within interventions aimed at addressing mental health problems in adolescents. Therefore the current study will investigate the potential link between UEDs and social functioning as well as adverse life events in young people.

### **Schemas**

Given the evidence about the significance of social relations during adolescence whereby individuals are more likely to internalise peer opinions which could lead to pressures to conform (Crosnoe & McNeely, 2008), adolescents may be particularly susceptible to the negative evaluation and potential rejection from others (Donenberg & Pao, 2005). According to Campbell and Morrison (2007) children with unusual experiences may be more likely to interpret interpersonal relationships and interactions as rejecting and hostile, which may cause longstanding social avoidance due to perceived threat by others (Freeman, Garety & Kuipers, 2001). These experiences can trigger a strong stress response (Jones & Fernyhough, 2007) and may also play a role in the development of negative schemas about self and others (Garety et al., 2001). Schematic beliefs have not been widely assessed with young people experiencing UEDs and therefore the current study will investigate the potential association between schemas and activity levels.

## **2.2. The Current Study**

It is well established that involvement in activities including extracurricular activities and after school programs are important aspects of adolescent development (Passmore 2003; Caldwell 2005) during which significant physical, cognitive and social change occurs (Feldman & Elliott, 1990). Studies have shown widespread benefits gained from engagement in activities particularly in emotional and cognitive wellbeing through improving resiliency and coping with stress and negative life events (Caldwell 2005).

Given that young people with mental health problems are at a greater risk of social exclusion and poor interpersonal relationships (Feinstein, Bynner & Duckworth, 2005) the impact of reduced functioning and engagement in leisure activities may exacerbate the risk and negatively impact on mental health prognosis and recovery. Early intervention treatments for childhood onset of mental illness have gained increasing support (Department of Health; DoH, 2007) to reduce the risk of problems recurring

into adulthood (e.g. Kim-Cohen et al., 2003) therefore it is paramount to research the factors that may be associated with mental health problems in youth.

Previous research in adult populations has shown significant relationships between mood, psychosis, perceived stigma and activity levels (Jolley et al., 2006; Moriarty et al., 2012) as well as cognitive and social factors including schemas and experiences such as adverse life events and later social functioning (e.g. Freeman et al., 2001; Palmier-Claus et al., 2012). The current study aims to extend this emerging model of activity in adults to an adolescent population, firstly to understand levels of activity in young people in relation to experiences of psychotic like symptoms and secondly to examine its association with cognitive, social and emotional factors to inform future treatment.

The specific hypotheses for this project will be:

1. As based on the adult psychosis literature, reduced levels of activity and functioning will be associated with higher levels of:
  - Severity of unusual experiences with distress (UEDs)
  - Depression and anxiety
  - Perceived stigma
2. Higher levels of adverse life events and bullying experiences will be associated with reduced activity levels
3. Negative schemas about the self and about others will be associated with reduced activity levels

### **3. Methods**

#### **3.1. Statement of Contribution**

The author (ST), with consultation from supervisors (SJ and SB) developed the research question and selected the questionnaires used for the current study, which included baseline data from two studies of cognitive behavioural therapy for distressing childhood unusual experiences (the CUES and CUES+ studies). The author assessed a number of the young people and families that were recruited to the CUES+ study, which included the measures for the current study as part of a larger assessment battery. The author was also involved in delivering CBT intervention to a young person taking part in the CUES+ study, using manualised 16-week therapy protocol. The author checked and cleaned all activity data (which had not previously been part of any analysis from the main studies) from both the CUES and CUES+ studies, and created a new database, solely for the purpose of this study, using activity data from the combined studies, including demographic variables and hypothesised emotional social and cognitive correlates. Power analyses, statistical analysis plans, and final analyses were conducted by the author in consultation with statisticians. The write-up of the study and the interpretation of results and their implications is the work of the author in consultation with the supervisory team.

#### **3.2. Research context**

The current study employed baseline data from two separate studies, both investigating unusual experiences and therapy outcomes in young people; the Coping with Unusual ExperienceS for Children (CUES) study (ISRCTN13766770), and the Coping with Unusual ExperienceS for 12 to 18-year olds (CUES+) study (ISRCTN21802136). Both studies were based in community Child and Adolescent Mental Health Services (CAMHS) within the South London and Maudsley NHS Foundation Trust (SLaM).

#### **3.3. Participant information for the CUES study**

The CUES (Coping with Unusual Experiences for Children) project was a pilot evaluation to assess the effectiveness of an adapted Cognitive Behavioural Therapy (CBT) programme in reducing distress in young people (YP) who report unusual experiences and emotional problems. The study recruited from July 2011 to April 2014 with a total of 110 participants.

### **3.3.1. Inclusion criteria**

Children referred to CAMHS Tier 2 services (emotional and behavioural difficulties) that were aged between 8 and 14 years were invited to take part in the study. They were also required to live locally for the duration of the study (in order to complete therapy and measures). The exclusion criteria were unstable living arrangements or insufficient command of English to complete the measures.

CUES was awarded ethical approval by the London Hampstead Research Ethics Committee (Ref: 11/LO/0023).

### **3.3.2. Participant recruitment and procedure**

The young people were recruited directly from the waiting list for CAMHS for young people with emotional and behavioural problems not usually reaching criteria for a formal mental health diagnosis ('Tier 2'). Young people on the waiting list had been screened for urgent need for support, or more serious mental health or developmental conditions by service clinicians. The young people and families referred to the service were sent information sheets as well as consent and assent forms. The research team contacted them two weeks later to assess interest in participating, and arranged to meet interested families to discuss participation. Parents/carers gave informed consent and children gave assent to take part in the study. All consenting young people completed baseline assessments, therefore not all participants from the CUES study had unusual experiences.

## **3.4. Participant information for the CUES+ study**

The CUES+ project was a randomised controlled trial of the effectiveness of cognitive therapy in reducing distress associated with unusual experiences in older children (12-18 year olds) with mental health difficulties. The study is ongoing until September 2017. The current study employed baseline data collected until the end of January 2017.

### **3.4.1. Inclusion criteria**

The inclusion criteria for CUES+ were that the individual presented to CAMHS services for young people with mental health difficulties requiring secondary care (usually a degree of risk to their presentation, 'Tier 3'), and, in the routine screening battery employed by the service, reported a current unusual experience, either with self-rated distress, or with a score within the clinical range on the emotional symptom

subscale of the Strengths & Difficulties Questionnaire (SDQ; Goodman et al., 2000), was within the 12 to 18 year old age range and with sufficient English language skills to be able to complete the measures and therapy, with interpreter support offered where appropriate. Furthermore it was necessary that they could confirm availability for the study duration. Exclusion criteria were a previously identified learning disability of an IQ below 70, a known neurological condition with the UEDs identified as a secondary phenomenon (e.g. occurring only during epileptic seizures) or UEDs solely due to intoxication or withdrawal in the context of substance misuse.

CUES+ was awarded ethical approval by London Hampstead Research Ethics Committee (Ref: 14/LO/1970).

### **3.4.2. Participant recruitment and procedure**

The young people that reported UEDs were given information sheets and consent forms, with the parents informed as appropriate and also given the study information with a follow up call from the research team following approximately two to four weeks, offering a meeting for families and young people interested in participation. The procedure for those under age 16 years was to secure parental consent and child assent and for those over age 16 to initially seek young person (YP) consent with parent consent following if the YP agrees to the familial participation. This enabled the participant to ask any questions about the research and explained to them that they could withdraw from the study at any time if they so wished. Baseline assessments were completed following consent, with randomisation following the assessment.

### **3.5. CUES and CUES+ baseline assessments**

Trained researchers within both CUES and CUES+ research teams administered the measures with the young person as the main informant, whilst the demographic information was obtained from parents or carers, clinical records and/or from the young person. The assessments covered a large battery of measures and tasks assessing UEDs and associated cognitions, emotion, coping strategies and social functioning. Participation or otherwise in either study did not affect the young person's treatment from CAMHS in any way. A careful risk assessment protocol was in place, ensuring that the necessary agencies and the clinical team were informed if any risk or other new information emerged as part of the research assessment or treatment.

### **3.6. The Current Study**

The current study utilised only the baseline data that was collected for both the CUES and CUES+ studies. The primary focus of the current study was activity levels, therefore only those participants across both the CUES and CUES+ studies who completed the activity measure (that is the Time Budget) were included in the current study. The CUES study recruited a total of 110 participants, 80 of whom completed the Time Budget and CUES+ study had a total of 104 participants, 102 of whom completed the time budget.

#### **3.6.1. Design**

The current study was an observational, cross-sectional design with activity levels as the main dependent measure, and unusual experiences, mood, adverse life events and schema as independent variables.

Permission from the original Research Ethics Committees and the local sponsor was granted for the Chief Investigator (CI; CI and sponsor were common to the two studies) to create a fully anonymised combined dataset, which was used by the author of the current study, within the same organisation as the CI. Datasets of the common variables required for this study were created from baseline data for both studies. Datasets were labelled with their study of origin and each participant given a numerical code that was not associated with their original participant identifier. Participant identifiers were then deleted to create anonymised databases. The anonymised databases were then combined specifically for the current study. Up to the present time, the activity data employed in the current study has not been combined or analysed for any other purpose. Moreover, the proposed research questions and hypotheses for this study have not been addressed by any research arising from either of the larger two studies.

#### **3.6.2. Measures**

The measures are outlined separately for activity levels, unusual experiences, mood, stigma, adverse life events and schemas.

##### **3.6.2.1. Activity**

*Time budget (adapted from Jolley et al., 2006)*

The Time Budget used in this study is an adaptation of the version developed by Jolley and colleagues (2006). The original Time Budget comprises a weekly activity record,

completed by semi-structured interview with a researcher, with each day split into four time periods (morning, lunchtime, afternoon and evening), and the activities completed during that time period rated for intensity and complexity from 1 to 4. Adaptations for young people were made following a period of piloting as part of the CUES study and were: the inclusion of only one ‘typical’ weekday, as school weekdays usually follow a similar pattern; the collapsing of afternoon and evening, into one ‘after lunch’ section, as piloting indicated that children found it hard to differentiate these time periods; and the inclusion of ratings of after-school activities, bedtime and sleep (not part of this study). Piloting also indicated a change to scoring criteria, in that the highest category, for a time period filled with complex, demanding, independent activities, did not apply to younger children’s lifestyles, therefore categories 3 and 4 were collapsed. See Appendix A for the adapted Time Budget measure. The frequency of each score (0 – 3) is indicative of the range of activity undertaken over the week. The total Time budget score is derived by summing the ratings across the three time points, yielding a maximum score of 27. Full details on rating criteria for the adapted Time budget are available in Appendix B. The measure shows good inter-rater reliability (intraclass correlation:  $r = 0.99$ ,  $p = .001$ ) and test–retest reliability ( $r = 0.83$ ,  $p < .001$ ) amongst people with psychosis (Jolley et al., 2005).

### **3.6.2.2. Unusual experiences**

*Unusual experiences questionnaire (UEQ; Laurens et al., 2007)*

The UEQ consists of nine items with each unusual experience (UE) rated on a three-point scale of conviction (0 = Not True, 1 = Somewhat True, 2 = Certainly True). The UE items that were rated by the young person as either ‘somewhat’ or ‘certainly true’, were followed up with questions relating to frequency, distress and functional impact of the UE over the preceding two-week period (see Appendix C for the UEQ). These were rated on a four-point scale ranging from 0 to 3 with higher scores indicating greater levels of frequency, distress and impact. Totalling the scores for those items rated  $> 0$  on the distress and impact scales gives an overall measure of severity of UEs with distress or adverse impact (UEDs), with scores ranging from 0 to 99, greater severity indicated by higher scores. The UEQ has been shown to have good internal consistency ( $\alpha = 0.82$ ) and satisfactory construct validity as well as satisfactory agreement with clinical interview (Laurens et al., 2007).

### **3.6.2.3. Mood**

*The Strengths & Difficulties Questionnaire (SDQ; Goodman et al., 2000)*

The SDQ (Appendix D) is a screening tool that measures behavioural and emotional difficulties in young people aged between 3 and 16 years of age. The measure consists of 25 items describing positive and negative attributes and can be allocated to five subscales with five items each; emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviours. The items are rated on a three point scale ranging from 0 = not true, 1 = somewhat true, 2 = certainly true, giving a subscale score from summing the five items (0 - 10). A total difficulties score can be derived from summing each item (except the prosocial behaviour subscale) giving a score ranging from 0 to 40. The SDQ has been reported to have valid and reliable psychometric properties (Goodman, 2001). The measure is routinely used in local services and recent studies have indicated it is suitable for young people up to the age of 19 years (Van Roy, Veenstra & Clench-Aas, 2008). The current study utilised the data from the Emotional subscale of the SDQ only. The Emotional subscale consists of five items measuring internalising symptoms, which have been associated with the DSM-IV diagnoses of anxiety or depression: scores of 6 or more indicate levels of emotional problems in the borderline or clinical range (Goodman, 2001).

### **3.6.2.4. Stigma**

*Self-stigma of Mental Illness scale (ISMI; Ritsher, Otilingam & Grajales, 2003)*

Stigma was measured using an adapted version of the Self-stigma of Mental Illness scale (ISMI; Ritsher et al., 2003). The original questionnaire has 29 items consisting of statements about subjective experiences of stigma, which are measured on a Likert scale. It consists of five subscales including alienation, stereotype endorsement, discrimination experience, social withdrawal and stigma resistance. The responses can both be totaled and averaged to give an overall score or otherwise separate totals for each of the subscales. The measure has shown to have good psychometric properties in adults including test-retest reliability ( $r = 0.92$ ) and internal consistency ( $\alpha = 0.90$ ) (Ritsher et al., 2003). A shorter version was developed with clinicians and young people (Bradley, 2013) based on selecting the two highest loading items for each subscale. Therefore the finalised self-stigma measure consisted of 10 items about the young

people's experiences in coming into contact with services (see Appendix E for the adapted ISMI). Each item was rated on a Likert scale ranging from 1 'strongly disagree' (1) to 'strongly agree' (5) with scores summed and averaged and higher scores suggesting greater self-stigma. The internal consistency within that sample was reported to be satisfactory ( $\alpha = 0.81$ ).

### **3.6.2.5. Social factors**

*Life Events Inventory (LEI; Wilkinson et al., 2009)*

This questionnaire assesses the occurrence of ten different life events within the last year including bereavements, losses and danger to self and others, with one final item asking about any other adverse life events within same timescale (Appendix F). The endorsed items were subsequently rated for emotional impact (rated from 1 = very good to 5 = very bad) and chronicity (whether distress persisted over more than two weeks). The events that were rated as having moderately or severely negative impact and lasted more than two weeks were summed to produce a total life events score, which ranged from 0 to 11.

*Bullying experiences (adapted from Schonert-Reichl et al., 2010)*

Experiences of bullying were assessed using items about victimisation at school taken from the Middle Years Development Instrument (MDI; Schonert-Reichl et al., 2010). These items require participants to identify the frequency (0 = never, 1 = rarely, 2 = sometimes, 3 = often) of experienced bullying including physical, verbal, social and cyber and other forms, totaling a sum of 12 (see Appendix G). At the point of administration of the scale within the current context, participants were given a brief definition of bullying and asked about experiences of bullying during the current school year.

### **3.6.2.6. Cognitive Factors**

*The Brief Core Schema Scale (BCSS; adapted from Fowler et al., 2006)*

The BCSS measures beliefs/schemas about the self and others and was designed specifically for use with people with psychosis (Fowler et al., 2006). The measure consists of four scales, each of six items: negative-self, positive-self, negative-others, and positive-others. Each item is first endorsed Yes/No, with endorsed items rated for strength of belief on a scale from one to four (1 = believe it slightly, 2 = believe it

moderately, 3 = believe it very much, 4 = believe it totally). The scale was very slightly adapted for young people based on a subset of CUES study data (Noone et al., 2015); the adaptations were re-ordering of the items to start and end with positive self content, and clarifying the word ‘devious’ as ‘devious or liars’ (see Appendix H for the BCSS). The current study utilised the data from the negative self and negative other items of the BCSS only. The BCSS has been shown to have good psychometric properties and construct validity (Fowler et al., 2006).

### **3.6.3. Sample size and power considerations**

The current study was designed to test associations between activity and UEDs, mood, stigma, social and cognitive factors using correlational analyses. Previous studies (Moriarty et al., 2012) have reported associations of medium size ( $r = 0.4$ ) in adults, and this was used as the basis for a power calculation. Using G\*Power 3 (Faul et al., 2009), with alpha set at 0.001 to take account of multiple testing, a sample of 99 participants would be required to give 80% power to detect a correlation of 0.4.

### **3.6.4. Planned analyses**

All analyses will be carried out using IBM SPSS Statistics Version 22. Cross-sectional analyses will be conducted with the baseline data collected from the young people who took part in the CUES and CUES+ study settings. Normality checks are described separately in the section below.

The aim of the current study is to assess the relationship between activity levels and the hypothesised contributory variables including unusual experiences with distress, mood, stigma, adverse life events and schemas. The Time Budget will be the primary outcome measure.

The planned analysis firstly involves characterising the sample, followed by assessing the relationships between activity levels and the hypothesised contributory variables using Pearson’s correlation coefficient ( $r$ ) or the equivalent Spearman’s rank ( $r_s$ ) for non-parametric data. The correlational analyses will be conducted separately for the emotional, social and cognitive factors. Thirdly, an assessment of the differences according to demographic variables and the clinical settings (that is CUES and CUES+) will be conducted. The latter analyses will firstly involve assessment of associations of activity with demographic variables, and secondly, associations with the hypothesised

predictor variables. If necessary, regression analyses will be used to repeat hypothesis-testing, in order to control for potential confounding factors.

#### **3.6.4.1. Distribution**

The distribution of data across the whole sample was examined by visually inspecting histograms and calculating z- scores for skewness and kurtosis (dividing each by its standard error). This was completed for each measure separately. In order to consider the normal distribution of the variables, a cut off of z scores of above 3.29 was applied (Kim, 2013) which showed that all variables were within the acceptable range of normality (Field, 2013). The visual inspection of the variables all appeared to be within normal distribution, though the Time budget data was slightly negatively skewed. Visual inspection of Q-Q plots showed that the Time budget was sufficiently normally distributed. Therefore the statistical analyses will be conducted using parametric tests and there will be no need to repeat the analyses using the equivalent non-parametric tests.

#### **3.6.4.2. Outliers**

Similarly, the possibility of outliers within the data set was examined by converting all scores across the measures to z- scores for each participant separately. A cutoff of z- scores greater than 3.29 was used to detect outliers (Kim, 2013). Using this criterion revealed a total of five outliers, two outliers in the UEQ (scores of 76 and 81 out of the range possible range of 0 to 99), two in Life events (scores of 7 out of the possible range of 0 to 11) and one in Time budget total (score of 1 out of possible range of 0 to 27). The statistical analyses were conducted following removal of the outliers on the specific measures showing that four out of the five outliers did not have a significant influence on the overall findings, and were therefore retained in the analyses. The outlier on the Time budget total score did however show to significantly impact on the findings such that when the outlier was present in the analyses, the Time budget significantly correlated with BCSS negative other schema ( $r = -0.156$ ,  $p = 0.04$ ) whereas when excluded the correlation was no longer significant ( $r = -0.118$ ,  $p = 0.12$ ). No other differences in results were apparent. Analyses are therefore reported with the participant excluded ( $n = 183$ ).

#### **3.6.4.3. Missing data**

Missing data was managed primarily by prorating the data. The requirement for prorating the Time budget data was if up to two ratings were missing across the nine time points. In the event that more than two cells were to be missing then the data would be excluded from the statistical analyses. One participant was excluded due to missing more than one third of the data (that is two ratings) for the Time budget. There were instances where certain measures were not administered, partially completed, or not completed, due to participants withdrawing consent ( $n = 1$ ) or disengaging from the study. The stigma measure was introduced late into the CUES study battery, and therefore not administered to the first cohort of participants. There was missing data (number shown in brackets) for the following variables; age (1), ethnicity (1), SDQ-E (3), ISMI (23), BCSS negative self (2), BCSS negative other (7), Life events (2). Gender, UED and Bullying experiences total had no missing data. There were no further participants excluded due to missing datasets therefore there was no need to statistically correct for any bias introduced by omitting participants because of missing data.

## **4. Results**

### **4.1. Demographic and clinical characteristics of the sample**

A total of 183 participants (76 male, 107 female) were included in the current study, 43% (n = 79) from CUES and 56.8% (n = 104) from CUES+ setting. The combined demographic data for both settings is shown in Table 1 below, including the sample age, ethnicity and gender. The majority of participants were female (58.5%) and there were a balanced number of participants from Non-BME (49.2%) and BME (50.3%) groups.

There were 153 participants within the sample with reported UEDs. Approximately 16% (n = 30) did not have UEDs. In a general population sample including young people aged between 9 and 12 years, approximately 60% reported having unusual experiences, and 25% of them with distress (15% in total) (Barragan et al., 2011). Approximately 70% (n = 126) of participants scored at or above the clinical cutoff for self-reported emotional problems on the SDQ-E (score  $\geq 6$ ) with the whole sample scoring at a mean of 6.31 (SD = 2.42). These can be compared to the general population norms conducted with children between ages 8 and 13 years (Muris et al., 2004) and 11 and 15 years (Meltzer et al., 2000) with means of 2.6 (SD = 2.1) and 2.8 (SD = 2.1) respectively. Similar norms have been extended to a sample of pre-, early and late adolescents between ages 10 and 19 years (Van Roy et al., 2008). Scores were higher amongst the present sample compared to the general population studies, which would be expected within a clinical sample.

The normative BCSS and bullying experiences means presented in Table 1 were taken from non-clinical samples (Fowler et al., 2006; Schonert-Reichl et al., 2010). The ISMI scores were compared to an adult sample with reported item means ranging from 1.8 to 2.6, and standard deviations ranging from 0.65 to 0.85 (Ritsher, Otilingam & Grajales, 2003). There were no normative means available for the adverse life events questionnaire however Wilkinson and colleagues (2009) showed that within their clinical and non-clinical sample of young people, 32% reported experiencing at least one unpleasant life event.

**Table 1.** Demographic and clinical characteristics of the sample (total n = 183)

|                            | n   | Mean               | SD    | Range   | Possible Range | Comparison group Mean | Comparison group SD |
|----------------------------|-----|--------------------|-------|---------|----------------|-----------------------|---------------------|
| Age (years)                | 182 | 13.39              | 2.38  | 8 - 17  | 8 - 18         |                       |                     |
| Gender                     |     |                    |       |         |                |                       |                     |
| Male                       | 76  | 19.13              | 4.48  |         |                |                       |                     |
| Female                     | 107 | 16.57              | 4.69  |         |                |                       |                     |
| Ethnicity                  |     |                    |       |         |                |                       |                     |
| Non-BME                    | 90  | 18.32              | 4.99  |         |                |                       |                     |
| BME                        | 92  | 16.93              | 4.46  |         |                |                       |                     |
| Time budget total score    | 183 | 17.64              | 4.76  | 1 - 27  | 0 - 27         |                       |                     |
| UED severity               | 183 | 19.75              | 16.72 | 0 - 81  | 0 - 99         |                       |                     |
| SDQ Emotional subscale     | 180 | 6.31               | 2.42  | 0 - 10  | 0 - 10         | 2.60 - 2.80           | 2.10                |
| ISMI                       | 160 | 29.21 <sup>a</sup> | 8.28  | 10 - 49 | 0 - 50         | 1.80 - 2.60           | 0.65 - 0.85         |
| Bullying experiences total | 183 | 3.21               | 3.22  | 0 - 12  | 0 - 12         | 1.70                  | 0.80                |
| Adverse life events        | 181 | 1.65               | 1.57  | 0 - 7   | 0 - 11         |                       |                     |
| BCSS negative self         | 181 | 7.01               | 6.31  | 0 - 24  | 0 - 24         | 3.55                  | 3.55                |
| BCSS negative other        | 176 | 9.06               | 6.43  | 0 - 24  | 0 - 24         | 4.07                  | 4.04                |

*UED Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), SDQ Strength and Difficulties Questionnaire (Goodman et al., 2000), ISMI Self-stigma of Mental Illness scale (Ritsher et al., 2003), Bullying experiences (adapted from Schonert-Reichl et al., 2010), Adverse life events Life Events Questionnaire (Wilkinson et al., 2009), BCSS Brief Core Schema Scale (Fowler et al., 2006)*

*BME Black and Minority Ethnic*

n differs for each measure due to varying completions rates and missing data

<sup>a</sup>The total raw scores were prorated when one or two scale items were missing

## 4.2. Activity levels within the sample

The mean score on the Time budget measure was 17.64 (SD = 4.76) with a spread of scores across the range of the measure from 6 to 27, with a possible range of 0 to 27. With regards to levels of activity this range varied from sleeping most of the day to functioning well at school, spending time with friends and family and engagement with afterschool activities. The range of activity levels measured using the Time budget generally indicated that those with lower scores on the scale spent most of their time doing nothing, or engaged in passive activities with little or no social contact. On the other hand, those scoring higher on the Time budget spent most of their time engaging in a range of complex activities, with little time doing nothing. As demonstrated in Table 2, within the current sample, there was a generally low frequency of zero ratings, with the majority of participants engaging in active but simple and brief activities (ratings of 2 on the Time budget). Overall, 37.7% of the sample (n = 58) reported activities rated as inactive (score of '0') during at least one time point out of nine total time points.

**Table 2.** Time budget activity (n = 183)

|                | Mean (SD)    | Range  | Possible range |
|----------------|--------------|--------|----------------|
| TB week total  | 17.64 (4.76) | 6 - 27 | 0 - 27         |
| TB frequency 0 | .51 (.84)    | 0 - 3  | 0 - 9          |
| TB frequency 1 | 1.85 (1.93)  | 0 - 8  | 0 - 9          |
| TB frequency 2 | 3.89 (1.93)  | 0 - 9  | 0 - 9          |
| TB frequency 3 | 2.78 (2.49)  | 0 - 9  | 0 - 9          |

*TB* Time Budget

*SD* Standard deviation

### 4.3. Main analyses

Each hypothesis was tested in a primary, uncontrolled correlational analysis.

**Hypothesis 1:** There would be associations between activity levels, and measures of unusual experiences with distress (UEDs), mood and stigma. Specifically, reduced levels of activity and functioning would be associated with higher levels of severity of UEDs, depression and anxiety and stigma.

Significant correlations were found between activity and UED severity (see Table 3), such that higher levels of UED severity were associated with lower levels of activity ( $r = -0.16, p < .05$ ). Significant correlations were found between the SDQ-E and activity ( $r = -0.20, p < .01$ ) such that having more emotional symptoms (lower mood and higher anxiety) was associated with reduced activity levels. Furthermore, there were significant correlations between stigma and activity ( $r = -0.20, p < .05$ ) such that higher stigma was associated with reduced activity levels.

**Hypothesis 2:** There would be associations between activity levels and life events such that higher levels of bullying experiences and adverse life events would be associated with reduced activity levels.

Pearson's  $r$  correlations showed that there were no significant associations between activity levels and adverse life events ( $r = 0.02, p > .05$ ) or experiences of bullying ( $r = 0.04, p > .05$ ).

**Hypothesis 3:** Schemas would be associated with activity levels such that negative schemas would be associated with reduced activity levels.

There were significant correlations between activity and negative schemas about the self. Specifically, the results showed that negative self-schemas were associated with

reduced activity levels ( $r = -0.29, p < .001$ ). There was no significant association between activity and negative schemas about others ( $r = -0.12, p > .05$ ).

**Table 3.** The association of activity levels with emotional, social and cognitive factors.

| Variable                   | n   | Time budget ( $r$ ) |
|----------------------------|-----|---------------------|
| UED severity               | 183 | -0.16*              |
| SDQ Emotional subscale     | 180 | -0.20**             |
| ISMI                       | 160 | -0.20*              |
| Bullying experiences total | 183 | 0.04                |
| Adverse life events scale  | 181 | 0.02                |
| BCSS negative self         | 181 | -0.29**             |
| BCSS negative other        | 176 | -0.12               |

*UED* Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), *SDQ* Strength and Difficulties Questionnaire (Goodman et al., 2000), *ISMI* Self-stigma of Mental Illness scale (Ritsher et al., 2003), *Bullying experiences* (adapted from Schonert-Reichl et al., 2010), *Adverse life events Life Events Questionnaire* (Wilkinson et al., 2009), *BCSS Brief Core Schema Scale* (Fowler et al., 2006)

\*  $p < .05$

\*\*  $p < .01$

#### 4.4. Activity levels and demographic factors

Independent samples T-tests were conducted to examine whether there were any differences in Time budget scores according to the categorical demographic factors, specifically of the Time budget score between males and females, the two ethnic groups, and the service setting from which participants were recruited. Pearson correlation analyses were conducted to examine the relationship between activity levels and age. The analyses showed that there was a significant difference in Time budget scores between male and females ( $t(181) = 3.70, p < .001$ ) such that the male participants scored significantly higher (Mean = 19.13, SD = 4.48) than the female participants (Mean = 16.57, SD = 4.69), indicating greater levels of activity within males relative to females. There was a significant difference between ethnic groups ( $t(180) = 1.97, p < .05$ ) such that Non-BME participants scored significantly higher (Mean = 18.32, SD = 4.99) than the BME group (Mean = 16.93, SD = 4.46). The analyses also showed a significant difference between clinical settings ( $t(181) = 7.65, p < .01$ ) such that participants in CUES scored significantly higher (Mean = 20.33, SD = 4.13) compared to participants in the CUES+ setting (Mean = 15.59, SD = 4.16).

Furthermore, age was shown to have a significant negative correlation with activity levels ( $r = -0.37, p < .01$ ) such that older participants engaged in less activity.

#### **4.5. Predictor variables and demographic factors**

Independent samples T-tests were conducted to examine whether there were any differences in the hypothesised correlates of activity according to the demographic factors including gender, ethnicity and clinical setting, and Pearson correlation analyses were conducted to examine their relationship with age. The analyses showed significant differences between all the demographic factors (gender, age and settings) apart from ethnicity ( $p > .05$ ), and SDQ-E, UED, ISMI and negative self-schemas ( $p < .01$ ) with  $t$  values ranging from 2.84 to 7.75, and  $r$  values ranged from 0.32 to 0.44, such that female participants scored significantly higher than males, older participants scored higher and CUES+ participants scored higher than CUES participants. There were no significant differences between the demographic factors and negative schemas about others, bullying experiences and adverse life events (all  $p > .05$ ).

#### **4.6. Post hoc analyses**

##### **4.6.1. Investigating the role of demographic factors**

The findings above show that the study settings confound severity of several of the predictor variables as well as differences in activity levels, however they also confound the demographic variables, therefore there is a need to examine the study settings separately in order to disentangle the demographic influences. Further analyses were conducted in order to clarify the influence of age, gender, ethnicity and clinical setting upon the findings as well as the possible differences between the samples from the CUES and CUES+ settings.

Independent t-tests were conducted to assess differences between the studies and Pearson Chi squared tests were used for categorical variables. The Levene's Test for Equality of Variances was significant for age, negative self-schema and stigma indicating that equal variances could not be assumed. Therefore the appropriately adjusted statistical values were reported for those variables (Satterthwaite, 1946).

With regards to clinical differences, the results showed that participants in CUES+ had more severe UEDs ( $t(181) = -5.02, p < .001$ ), were more anxious and depressed on the SDQ-E ( $t(178) = -5.80, p < .001$ ), reported higher levels of stigma ( $t(91.83) = -5.91, p$

< .001) and more negative self-schemas ( $t(178.63) = -7.75, p < .001$ ). Negative schemas about others showed a trend towards significance; again with CUES+ participants showing higher levels of negative schemas compared to CUES participants. Participants in CUES+ were significantly older ( $t(148.62) = -11.85, p < .001$ ) and female participants were more highly represented within the CUES+ setting (75%) whilst CUES had a higher proportion of male participants (63.3%). As the CUES+ sample also had lower activity levels ( $t(181) = 7.65, p < .001$ ) compared to participants in the CUES setting, two further sets of analyses were conducted to test hypotheses separately for each sample (i.e. for CUES and for CUES+). Table 4 shows the means and standard deviations for each variable across the two clinical settings, with gender and ethnicity reported as frequencies.

**Table 4.** Differences between CUES and CUES+ participants across variables

|                        | Clinical setting |       |       |       |       |       | Test         |
|------------------------|------------------|-------|-------|-------|-------|-------|--------------|
|                        | CUES             |       |       | CUES+ |       |       |              |
|                        | n                | Means | SD    | n     | Means | SD    |              |
| Age (years)            | 79               | 11.57 | 1.96  | 104   | 14.78 | 1.61  | $p < .001$   |
| Gender (n)             |                  |       |       |       |       |       | $X^2 < .001$ |
| Male                   | 50               |       |       | 26    |       |       |              |
| Female                 | 29               |       |       | 78    |       |       |              |
| Ethnicity (n)          |                  |       |       |       |       |       | $X^2 = ns$   |
| Non-BME                | 42               |       |       | 48    |       |       |              |
| BME                    | 37               |       |       | 55    |       |       |              |
| Time budget            | 79               | 20.33 | 4.13  | 104   | 15.59 | 4.16  | $p < .001$   |
| UED severity           | 79               | 13.06 | 15.41 | 104   | 24.83 | 15.94 | $p < .001$   |
| SDQ Emotional subscale | 77               | 5.19  | 2.40  | 103   | 7.14  | 2.08  | $p < .001$   |
| ISMI                   | 56               | 24.14 | 8.58  | 104   | 31.94 | 6.70  | $p < .001$   |
| Bullying experiences   | 79               | 3.27  | 3.03  | 104   | 3.16  | 3.37  | $ns$         |
| Adverse life events    | 77               | 1.42  | 1.32  | 104   | 1.82  | 1.72  | $ns$         |
| BCSS negative self     | 77               | 3.48  | 4.41  | 104   | 9.63  | 6.25  | $p < .001$   |
| BCSS negative other    | 72               | 8.04  | 6.11  | 104   | 9.76  | 6.59  | $p = .082$   |

*UED* Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), *SDQ* Strength and Difficulties Questionnaire (Goodman et al., 2000), *ISMI* Self-stigma of Mental Illness scale (Ritsher et al., 2003), *Bullying experiences* (adapted from Schonert-Reichl et al., 2010), *Adverse life events* *Life Events Questionnaire* (Wilkinson et al., 2009), *BCSS* *Brief Core Schema Scale* (Fowler et al., 2006)

*BME* Black and Minority Ethnic

n differs for each measure due to varying completions rates and missing data

Each hypothesis was tested again in each sample separately, using Pearson correlation analyses. Within the CUES sample, only ethnicity was associated with activity levels suggesting that those from BME groups had lower levels of activity ( $r = -0.24, p < .05$ ), otherwise  $r$  values were all  $\leq -0.16, p$  values  $> .05$ . For the CUES+ participants, stigma

and adverse life events were associated with activity levels, such that, directly contrary to hypothesis, higher levels of stigma were associated with higher levels of activity ( $r = 0.20, p < .05$ ), and greater levels of adverse life events were associated with higher levels of activity ( $r = 0.21, p < .05$ ), otherwise the  $r$  values were all  $\leq 0.08$ ,  $p$  values  $> .05$ . However, given that splitting the sample reduces power and removes variances these results have to be interpreted with some caution.

#### **4.6.2. Associations of activity with emotional, social, cognitive and demographic variables for each sample**

A series of multiple linear regression analyses were conducted firstly with the sample as a whole, followed by separate analyses for each clinical setting, with activity as the dependent variable, and the emotional, social and cognitive variables entered firstly in combination, and then, in a second regression series, each variable separately, in seven separate analyses, into a model also including the three demographic variables that is age, gender and ethnicity. Multicollinearity was assessed using collinearity statistics on SPSS to check whether predictor variables were highly correlated. This included examining the variance inflation factor (VIF) and tolerance statistic within the correlation matrixes. The values for VIF ranged from 1.01 to 2.20, and were all below the cutoff of 10 suggested by Myers (1990). Tolerance values ranged from 0.46 to 0.99, and were all above the cutoff of 0.2 suggested by Menard (1995).

##### **i) Associations of activity with emotional, social, cognitive and demographic factors in the whole sample (n = 154)**

The first regression model with activity as the dependent variable and each emotional, social and cognitive factor entered in combination, excluding the demographic variables, significantly predicted activity levels ( $r = 0.36, F(7,147) = 2.99, p < .001$ ), with negative schemas about self showing significant associations with activity ( $\beta = -0.25, p = .011$ ) and adverse life events approaching significance ( $p = 0.075$ ). Table 5 below shows the  $\beta$  and  $p$  values for each variable. However, when each independent variable was entered one at a time (shown in Table 6) along with the four demographic factors (age, gender, ethnicity and clinical setting) all the models were significant but the variance in activity was only accounted for by the influence of the demographic variables on each model. Specifically, clinical setting (that is CUES and CUES+) was

the only variable that significantly predicted activity across all analyses ( $\beta$  values all  $\leq -4.66$ ,  $p$  values  $< .05$ ). The regression models have been included in Appendix I, highlighting the statistical parameters of the demographic variables within each of the separate regression analyses. Given that the planned correlations are no longer significant due to confounds in severity across the two clinical settings, the clinical settings are assessed separately, below, using similar regression analysis approach.

**Table 5.** Whole sample regression without demographic variables (n = 154)

| Variable               | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|------------------------|----------|-------------|---------|----------|-------|
|                        |          |             |         |          | 0.08  |
| UED severity           | -.02     | .03         | -.06    | .56      |       |
| SDQ Emotional subscale | -.06     | .19         | -.03    | .75      |       |
| ISMI                   | -.05     | .06         | -.09    | .39      |       |
| Bullying experiences   | .16      | .13         | .11     | .22      |       |
| Adverse life events    | .44      | .25         | .15     | .08      |       |
| BCSS negative self     | -.18     | .07         | -.25    | .01      |       |
| BCSS negative other    | -.03     | .07         | -.04    | .65      |       |

*UED* Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), *SDQ* Strength and Difficulties Questionnaire (Goodman et al., 2000), *ISMI* Self-stigma of Mental Illness scale (Ritsher et al., 2003), *Bullying experiences* (adapted from Schonert-Reichl et al., 2010), *Adverse life events* *Life Events Questionnaire* (Wilkinson et al., 2009), *BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

**Table 6.** Whole sample regression with demographic variables entered one at a time with each predictor

| Variable               | n   | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|------------------------|-----|----------|-------------|---------|----------|-------|
| UED severity           | 181 | .01      | .02         | .03     | .71      | .25   |
| SDQ Emotional subscale | 179 | .09      | .15         | .04     | .55      | .27   |
| ISMI                   | 158 | .05      | .04         | .08     | .30      | .31   |
| Bullying experiences   | 181 | .04      | .10         | .03     | .67      | .25   |
| Adverse life events    | 179 | .27      | .20         | .09     | .18      | .27   |
| BCSS negative self     | 179 | -.03     | .06         | -.05    | .56      | .26   |
| BCSS negative other    | 174 | -.02     | .05         | -.03    | .69      | .24   |

*UED* Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), *SDQ* Strength and Difficulties Questionnaire (Goodman et al., 2000), *ISMI* Self-stigma of Mental Illness scale (Ritsher et al., 2003), *Bullying experiences* (adapted from Schonert-Reichl et al., 2010), *Adverse life events* *Life Events Questionnaire* (Wilkinson et al., 2009), *BCSS Brief Core Schema Scale* (Fowler et al., 2006)

Demographic variables included age, gender, ethnicity, setting (CUES and CUES+)

$r^2$  (adjusted)

ii) Associations of activity with emotional, social, cognitive and demographic factors in the CUES sample (n = 79)

The first regression model did not significantly predict activity levels ( $r = 0.27$ ,  $F(7,44) = 0.49$ ,  $p > .05$ ), with no single predictor variable showing a significant association with activity. Table 7 includes the Standardised Beta Coefficient ( $\beta$ ) values for each variable. Similarly, when each independent variable was entered one at a time, along with the three demographic factors (age, gender and ethnicity), no model significantly predicted activity levels and no predictor showed a significant association with activity, with the exception of ethnicity, which significantly predicted activity across all analyses ( $\beta$  values all  $\leq -0.29$ ,  $p$  values  $< .05$ ), apart from that for stigma alone ( $\beta = -0.11$ ,  $p > .05$ ). The CUES regression models have been included in Appendix J, highlighting the statistical parameters of the demographic variables within each of the separate regression analyses.

**Table 7.** CUES sample regression without demographic variables (n = 51)

| Variable               | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|------------------------|----------|-------------|---------|----------|-------|
|                        |          |             |         |          | -.08  |
| UED severity           | -.01     | .05         | -.05    | .81      |       |
| SDQ Emotional subscale | .23      | .26         | .16     | .38      |       |
| ISMI                   | -.06     | .09         | -.15    | .50      |       |
| Bullying experiences   | .07      | .22         | .06     | .76      |       |
| Adverse life events    | .22      | .49         | .07     | .66      |       |
| BCSS negative self     | -.13     | .14         | -.18    | .34      |       |
| BCSS negative other    | -.03     | .11         | -.05    | .80      |       |

*UED* Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), *SDQ* *Strength and Difficulties Questionnaire* (Goodman et al., 2000), *ISMI* Self-stigma of Mental Illness scale (Ritsher et al., 2003), *Bullying experiences* (adapted from Schonert-Reichl et al., 2010), *Adverse life events* *Life Events Questionnaire* (Wilkinson et al., 2009), *BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

iii) Associations of activity with emotional, social, cognitive and demographic factors in the CUES+ sample (n = 102)

The third regression model did not significantly predict activity levels ( $r = 0.30$ ,  $F(7,95) = 1.29$ ,  $p > .05$ ), though there was a trend towards an association of activity with stigma ( $p = .094$ ) and adverse life events showed a significant association with activity levels

( $p < .05$ ). Table 8 includes the  $\beta$  values for each variable. When each independent variable was entered into the model one at a time, along with the three demographic factors (age, gender and ethnicity), the model including stigma was marginally significant in predicting activity levels ( $r = 0.29$ ,  $F(4,98) = 2.20$ ,  $p = 0.075$ ) and stigma contributed significantly to the model ( $\beta = 0.22$ ,  $p < .05$ ). Similarly, the model for adverse life events was marginally significant ( $r = 0.28$ ,  $F(4,98) = 2.10$ ,  $p = 0.087$ ); and as a single predictor variable it also contributed significantly to the model ( $\beta = 0.21$ ,  $p < .05$ ). The model for SDQ-E was non-significant, however gender was a marginally significant predictor of activity levels ( $p = 0.08$ ). The remaining models, which separately included the independent variables UED, Bullying, Negative self and other schemas were all non-significant with no predictor showing a significant association with activity ( $\beta$  values all  $\leq 0.14$ ,  $p$  values  $> .05$ ). The CUES+ regression models have been included in Appendix K, highlighting the statistical parameters of the demographic variables within each of the separate regression analyses.

**Table 8.** CUES+ sample regression without demographic variables (n = 102)

| Variable               | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|------------------------|----------|-------------|---------|----------|-------|
|                        |          |             |         |          | .02   |
| UED severity           | .01      | .03         | .02     | .85      |       |
| SDQ Emotional subscale | -.03     | .23         | -.01    | .92      |       |
| ISMI                   | .12      | .07         | .20     | .09      |       |
| Bullying experiences   | .02      | .14         | .01     | .92      |       |
| Adverse life events    | .53      | .26         | .22     | .04      |       |
| BCSS negative self     | -.06     | .08         | -.09    | .44      |       |
| BCSS negative other    | -.06     | .07         | -.10    | .40      |       |

*UED* Unusual experiences with distress rated using the UEQ (Laurens et al., 2007), *SDQ* Strength and Difficulties Questionnaire (Goodman et al., 2000), *ISMI* Self-stigma of Mental Illness scale (Ritsher et al., 2003), *Bullying experiences* (adapted from Schonert-Reichl et al., 2010), *Adverse life events* Life Events Questionnaire (Wilkinson et al., 2009), *BCSS* Brief Core Schema Scale (Fowler et al., 2006)

$r^2$  (adjusted)

## 5. Discussion

This is the first study to investigate levels of activity in young people in relation to experiences of psychotic like symptoms and emotional, social and cognitive factors. Adolescence is a key stage for the onset of mental health difficulties, and the development of future mental health vulnerabilities. Activity can be considered a proxy measure of the impact on young people's ability to negotiate the key developmental tasks of adolescence, by engaging with opportunities to develop both peer relations, and their sense of self as an independent agent interacting with the world. Restricting these opportunities may perpetuate current mental health difficulties, and increase future vulnerability. Understanding the factors impacting on activity may inform the development of interventions specifically designed to promote functioning at this critical stage.

Three hypotheses concerning psychosocial correlates of activity levels were tested in a large sample of young people aged 8 to 18 years, recruited from mental health services as part of two different pre-existing studies. The first hypothesis was that reduced levels of activity would be associated with higher levels of severity of unusual experiences (UED severity), depression and anxiety and perceived stigma. The second hypothesis was that higher levels of trauma and adverse life events would be associated with reduced activity levels. Finally, it was hypothesised that negative schemas about the self and others would be associated with reduced activity levels. The results showed support for associations between reduced activity levels and higher UED severity, emotional symptoms and stigma, as well as negative self-schemas with reduced activity levels. The prediction that social factors and negative schemas about others would be associated with activity levels was not supported by the main findings. However, whilst the main hypotheses were supported by significant associations, this was notwithstanding the influence of demographic factors including age, gender, ethnicity and clinical setting, which were also associated with activity levels, and with many of the hypothesised emotional, social and cognitive predictors. Age, gender, and severity of presentation also differed systematically between clinical settings, necessitating investigation of the samples separately to clarify the role of demographic variables. When participants from the two pre-existing study settings were considered separately and demographic variables were controlled, the pattern of findings changed markedly, possibly as a result of reducing the variance in activity and severity of presentation in

the subsamples, and reducing power. Associations within each setting subsample were inconsistent. However, when participants from the two pre-existing study settings were considered separately and demographic variables were controlled, the pattern of findings changed markedly, possible as a result of reducing the variance in activity and severity of presentation in the subsamples, and reducing power. Associations within each setting subsample were inconsistent, but not supportive of any of the three main hypotheses. Overall, therefore, firm conclusions cannot be drawn from the current data: whole sample findings may be confounded by demographic variation, and subsample analyses may be insufficiently powered to detect associations. Findings will be discussed in further detail, followed by recommendations for future research and clinical implications.

The current study found that higher levels of UED severity, stigma and emotional symptoms were significantly associated with reduced activity levels. These findings are in support of the study hypotheses and also consistent with previous research showing significant relationship between reduced activity levels and positive and negative symptoms distress in adults with psychosis (e.g. Jolley et al., 2006). The relationship with increased levels of depression and anxiety suggest that similarly to the adult literature (e.g. Lewinsohn & Graf, 1973; Cuijpers et al., 2007) engagement in fewer activities with young people may be associated with an overall lack of positive reinforcements gained which could exacerbate mood difficulties, though further research is required in order to understand the direction of these relationships. Furthermore, given that young people with unusual experiences may be more vulnerable to developing fear of rejection by others, the relationship between perceived stigma and activity levels may subsequently result in avoidances of social interaction and activities (Brewin 1995).

Previous research has highlighted that a history of adverse life events, including bullying experiences, predict the onset of unusual experiences with distress (Campbell & Morrison, 2007) which can subsequently impact on activity levels due to persecutory beliefs about others and cause avoidances (Jolley et al., 2006). The current findings showed however that there were no significant relationships between activity levels and adverse life events and bullying. This is a somewhat surprising finding given the relatively high levels of bullying experiences within the current sample compared to the normative sample. An explanation for this could be issues highlighted with the

demographic factors and study samples, and that an association would be found with a differently comprised sample or possibly, that the impact of adverse life events with young people presents a different picture. This may suggest that adverse life events within this developmental stage do not impact on general functioning and activities per se, which could possibly be explained by the dependent position of young people within their systems. Previous research has highlighted the significant role of family involvement and school with regards to youth engagement in activities (e.g. Mahoney et al., 2005), which serves as a protective factor.

The current study also showed a significant relationship between increased negative self-schemas and reduced activity levels. There are limited previous studies investigating the impact of schemas on activity, however the current findings are consistent with the cognitive model of psychosis suggesting negative self-schemas and resultant emotional distress may lead to less engagement with activities, which can contribute to maintaining distress and social isolation (e.g. Garety et al., 2001). Given the significant role of low-self esteem in maintaining difficulties in adults with psychosis (e.g. Corrigan & Watson, 2002), negative schemas with young people should be further considered in future research.

### **Activity levels in the current sample compared to adults with psychosis**

An interesting finding in the current study is that although the older participants engaged in significantly fewer activities, very few participants scored within the 'inactive' range on the Time budget measure, suggesting that the sample as a whole were more active compared to studies investigating inactivity with adults with psychosis. For example Moriarty and colleagues (2012) reported inactivity means (frequency of zero ratings on the Time budget) as 3.18 (SD = 3.50, possible range 0 to 27, around 10% of ratings) and Jolley et al. (2006) reported means of 8.40 (SD = 5.60, around 30% of ratings), which suggest higher levels of inactivity compared to the figures reported in the current study (Mean = 0.52, SD = 0.84, possible range 0 to 9, around 5% of ratings). There are a number of possible explanations to the differences in activity levels between young people with UEDs and adults with psychosis. Firstly inactivity may be more significant within clinical psychosis compared to mental health difficulties and UEDs where reduced activity levels may be more an aspect of impairment of general functioning rather than an aspect of poorer prognosis and maintenance factor as shown in psychosis (e.g. Carpenter & Strauss, 1991; Garety et al.,

2001). Secondly, young people may be more able to access opportunities for engagement in activities through living at home, engaging in family activities as well from attending school (e.g. Mahoney et al., 2005). This can be contrasted with adults with psychosis, who may have limited familial involvement, reduced social network and live alone making them more at risk of reduced activity levels and social isolation (e.g. Evert et al., 2003).

Furthermore, part of these discrepancies could be explained by the adapted differences in the Time budget measure, for example fewer time points in the current version, and method of scoring within the current study, however a number of additional factors could account for this. Lastly, the current findings could be explained by differences in child and adult cultural activities. It is possible that the impact of social media and ability to socialise with friends and family via online games and social networks means young people are generally more active than adults (e.g. Shaw & Gant, 2002). The findings from the current study however are limited with regards to making any inferences regarding these factors.

### **Activity levels and demographic factors**

With regards to the demographic factors, the current sample as a whole showed that male participants reported higher levels of activity relative to females, non-BME participants scored significantly higher than the BME group and older participants were shown to have lower activity levels. However, as demographic variables differed according to clinical setting, although the initial analyses indicated a possible strong relationship between the demographic variables and activity levels, they may have been a confound of the different participant populations with different levels of severity of mental health presentation. Generally, previous studies with adults tend to find associations of psychosocial factors with activity irrespective of gender, age, ethnic group and severity of mental health presentation (Jolley et al., 2006; Moriarty et al., 2012). The current study on the other hand showed mixed results in this regard, and this was an unanticipated finding.

The two study samples were different with respect to severity of difficulties, in that participants from the CUES study were recruited from Tier 2 and CUES+ from Tier 3 CAMH clinical settings, indicating more severe mental health difficulties within the latter group. Furthermore, the ages of participants ranged from eight to fourteen in the

CUES study and twelve to eighteen in CUES+, highlighting different developmental stages across the span of childhood through to adolescence. The older adolescents in the current study engaged in significantly less activity overall compared to the younger participants, which is a finding reported in previous studies (e.g. Mahoney & Vest 2012). Research investigating the role of activity levels in child and adolescent development, has mainly focused on the role of out of school and organised activities (e.g. Feinstein et al., 2005). Although it has been well established that participation in organised activities peak during early adolescence and diminishes with age (e.g. Simpkins et al., 2005), a paucity of research have investigated the developmental implications of this decline, particularly with young people experiencing mental health difficulties. Therefore although further discussion of the association of demographic factors with activity levels is currently limited and tentative, the sections below aim to summarise the current findings in the context of the available adolescent literature.

### **Age differences**

During the transition into adolescence the need for social acceptance leads to young people spending increased amounts of time interacting with peers and progressively less time with parents and family (Larson et al., 1996; Youniss et al., 1997). It is well established that adolescence is a time of significant change within school particularly as transition from primary to secondary school occurs (Pellegrini & Long 2002), highlighting potentially increased stressors for the older adolescents as pressures for autonomy increases following the school years (Sirsch, 2003). These transitions could make it more difficult for young people with mental health difficulties to adjust to, making them more vulnerable through these developmental stages. Mahoney and colleagues (2005) suggest that differences in engagement of activities across adolescence may reflect fewer organised activities available for young people, changed interests with age as well as uptake of employment during non-school hours. However future research needs to further explore the factors that may impact on reduced activity levels with young people with mental health difficulties, across the developmental stages.

### **Gender differences**

Within the whole sample, gender differences did not appear to contribute significantly to the regression models, however the preliminary analyses showed that female

participants engaged in significantly less activity in total compared to the male participants. Previous studies have shown mixed results with regards to gender disparities and engagement with activities suggesting differing interests between males and females (e.g. Feinstein, Bynner & Duckworth, 2005). Although studies have shown different developmental trajectories for males and females with regards to onset of mental health difficulties (e.g. Cicchetti & Rogosch, 2002) suggesting that females tend to internalise difficulties during adolescence whilst males tend to express feelings of distress externally, there is very limited research investigating the impact of these differing pathways on social functioning and activity levels. The current study did not find any further significant relationships between gender and activity levels, and given the overrepresentation of females within the CUES+ study, future studies should consider more balanced representation of males and females when assessing these relationships.

### **Ethnicity**

The findings highlighted that non-BME participants reported significantly higher levels of activity compared to the BME group and that ethnicity significantly contributed to the separate regression models. According to Mahoney et al. (2005) availability of activities, economy of family and culture interact and are likely to account for low uptake of activities within economically disadvantaged children as well as those from minority ethnic groups. Factors including availability of activity, economic status and culture often interrelate and account for the lower participant rates of children from low socioeconomic backgrounds and minority groups (Hultsman 1992; Jackson & Rucks 1993). This could potentially explain some of the findings here with regards to the differences between ethnic groups, however future research would need to investigate more specifically.

### **5.1. Limitations**

There are a number of limitations in the current study that merit caution in interpreting the results. The first limitation is that the design of the study is cross-sectional therefore it is not possible to draw inferences regarding causation. The bidirectional relationships found within the main analyses may imply that increased UED severity, emotional symptoms and stigma leads to reduced activity levels, but equally these factors could

increase through limited engagement in activity and increased social avoidances as a result of low mood, UED severity and perceived stigma.

Associations found in uncontrolled correlational analyses may have been influenced by demographic factors, which were associated with both activity levels and hypothesised correlates of activity. Further investigation of the influence of demographic factors was limited by the demographic and clinical differences between the clinical setting-based subsamples comprising the study population, for example, severity of unusual experiences and activity were confounded by age and gender. Further research will be required to clarify this, employing samples selected for the purpose.

The current study samples were comparable on the basis that they were recruited from CAMH services, the young people had emotional and behavioural difficulties and they also overlapped in age. However despite this the analyses highlighted significant differences between the study groups with regards to activity levels, demographic and clinical factors, showing that CUES+ participants had higher levels of stigma, more negative self-schemas and lower activity levels compared to participants in the CUES study. For these purposes they were distinct enough to warrant further separate analyses. Furthermore, approximately 30 participants did not have unusual experiences, which indicate heterogeneity of the study sample. This may have confounded some of the current findings.

The sample size was determined according to previously reported effect sizes from other studies, however following the separation of the two samples, there were smaller sample sizes included within the regression analyses. This was particularly true for the CUES sample which was reduced to  $n = 56$  for analyses including the stigma measure and only included  $n = 79$  participants in the final analyses compared to  $n=104$  within the CUES+. The sample sizes were therefore significantly smaller than the amount indicated from the initial power analyses ( $n = 99$ ). Larger sample sizes are therefore needed to help clarify interpretation of factors impacting on activity levels.

Studies suggest that the benefits of engaging in activity may be impacted by socio-economic status (e.g. Mahoney et al., 2005), specifically that higher income families spend more money on children's activities who as a result show increased engagement compared to children from low-income families (Jackson & Rucks 1993). The current

study did not examine this possible relationship therefore the extent to which socioeconomic status may have impacted on the current findings is unclear.

## **5.2. Future research**

The current study has highlighted the significant role of demographic factors, which warrant further investigation in future research. Studies examining activity levels with young people should consider the possibility of significant variations within gender, ethnicity, age and severity of symptoms on the findings, together with socioeconomic status. A large population based study may be indicated to establish patterns in activity outside the clinical setting, which can then be tested in clinical settings. Should associations be robustly demonstrated, it would be necessary to ensure a representative mix of age, gender and ethnicity, and specify the population to whom the findings apply, in any subsequent research.

The impact of the demographic variables on the findings suggest that more longitudinal research is necessary to understand the trajectory of activity levels throughout adolescence with young people experiencing mental health difficulties, as well as to clarify the relationships between activity and the social, emotional and cognitive variables. Furthermore, the heterogeneity of study samples should be considered in order to assess potential demographic differences separately from the impact of different mental health presentations and severities. Specifically, future research to clarify the role of demographic variables requires a sample where severity of mental health presentation (expected to impact on activity) is not directly confounded with gender and age differences. Alternatively, if severity of presentation is found to be inextricably confounded with age or gender, this should be noted, and further demographic variability should be assessed within a sample with consistent severity of mental health presentation.

There is a significant lack of methods available for measuring activity levels and social functioning with young people. The Time budget has shown helpful benefits in the use with adults and therefore the current study utilised an adapted version for young people. There is now a strong need for normative data for the Time budget to assess activity levels within the general population to validate the measure with young people and to produce norms for future studies.

Furthermore, previous studies have indicated the influence of family socioeconomic status on activity levels particularly highlighting the impact of low-income families on youth's engagement with activities (Jackson & Rucks 1993). This would be particularly relevant for studies sampling participants within deprived inner city boroughs, as environmental adversity may confound findings (e.g. Kirkbride et al., 2008). Future studies investigating activity levels with young people with mental health difficulties therefore need to consider the possible relationship between family income and youth's engagement with activities.

### **5.3. Clinical implications**

The current findings suggest that is less about 'inactivity' when it comes to young people and perhaps increasingly about 'reduced' activity levels. The low levels of inactivity within this sample could suggest that young people with mental health difficulties have generally impaired functioning rather than inactivity as shown with adults with psychosis. This could potentially encourage a dimensional approach of functioning, where inactivity is understood as a consequence of clinical illness and which as a result of prolonged mental ill health becomes a maintaining factor. The understanding of impaired functioning versus inactivity will be important to consider in future research particularly with regards to understanding the implications for this with a vulnerable sample of young people as well as the trajectory of this with regards to development of psychosis.

On the other hand it may be that inactivity is less important in vulnerable young people or in childhood compared to adults with mental health difficulties. It is possible that looking at activity levels within this client group is not required until, or if they do go on to develop psychosis. It is well established that engaging in activity is beneficial for general wellbeing including better self-esteem, educational attainment and social skills development (DCFS, 2010), however in psychosis, activity is particularly important given the findings that reduced social contact and work functioning leads to poorer prognosis (e.g. Carpenter & Strauss, 1991) and may serve to maintain negative schemas which can exacerbate psychotic symptoms (Garety et al., 2001). Furthermore, the onset of a psychotic illness with young people heightens the challenges of fulfilling the developmental roles, and of engaging in activities and relationships with peers (MacDonald et al., 2005). Investigating these factors further will have important

implications for clinical interventions, particularly with young people with an ‘at risk’ mental state.

The current study found that, before controlling for demographic variables, reduced activity levels within the whole sample were associated with higher levels of UED, stigma and emotional symptoms. There was also a significant relationship between increased negative self-schemas and reduced activity levels. Should these associations be replicated in larger studies, with better controls for demographic associations, this may indicate specific strategies for targeting aspects of activity and social functioning within psychological interventions with young people with mental health difficulties, in order to improve wellbeing and reduce the distress associated with unusual experiences and perceived stigma. Improving coping strategies and functioning may help to increase resilience to the future development of an ‘at risk’ mental state which has been shown with adults (Addington et al., 2011). In particular, the associations with negative self schemas and reduced activity levels could indicate potential targets for treatment using cognitive behavioural approaches to help vulnerable young people at an early stage before the negative schematic models of the self leads to external attributions of threat and increased levels of distress (Garety et al., 2001). The cognitive model for psychosis (e.g. Garety et al., 2001) suggests that resultant persecutory beliefs may be exacerbated by social isolation due to reduced exposure to more normalising explanations (White et al., 2000). The findings reported here need to be replicated in future research, in order to clarify the factors to be adapted within clinical interventions and the role of activity levels in improving mental health.

#### **5.4. Conclusion**

The current study has for the first time investigated the relationship between activity levels and social, emotional and cognitive factors in a sample of young people with unusual experiences. The findings showed support for the majority of the main hypotheses, however as there were strong associations with demographic variables, associations may have arisen artifactually. Further research is needed to highlight patterns of activity in young people in the general population and clinical samples and associations with demographic and socio-economic variables. Thereafter, longitudinal research, with samples selected to adequately represent relevant demographic variables is needed to adequately test these hypotheses. It may be that activity is a less important indicator of poor recovery in childhood compared to adulthood, or, that activity is only

important once mental illness is diagnosed, and there are diagnosis- specific differences in social, emotional and cognitive predictors. Despite the unclear findings of the current study, functioning is an important outcome, and a number of points to clarify have been highlighted. Findings are insufficiently robust at this stage to inform strong treatment recommendations; investigation of changes in activity following existing CAMHS interventions may help to inform future developments.

## 6. References

- Addington, J., Cornblatt, B. A., Cadenhead, K. S., Cannon, T. D., McGlashan, T. H., Perkins, D. O., ... & Heinssen, R. (2011). At clinical high risk for psychosis: outcome for nonconverters. *American Journal of Psychiatry*, 168(8), 800-805.
- Asarnow, J. R., Jaycox, L. H., & Tompson, M. C. (2001). Depression in youth: Psychosocial interventions. *Journal of Clinical Child Psychology*, 30(1), 33-47.
- Asher, L., Zammit, S., Sullivan, S., Dorrington, S., Heron, J., & Lewis, G. (2013). The relationship between psychotic symptoms and social functioning in a non-clinical population of 12 year olds. *Schizophrenia Research*, 150, 404-409.
- Barragan, M., Laurens, K. R., Navarro, J. B., & Obiols, J. E. (2011). Psychotic-like experiences and depressive symptoms in a community sample of adolescents. *European Psychiatry*, 26(6), 396-401.
- Bebbington, P. E., Bhugra, D., Brugha, T., Singleton, N., Farrell, M., Jenkins, R., ... & Meltzer, H. (2004). Psychosis, victimisation and childhood disadvantage. *The British Journal of Psychiatry*, 185(3), 220-226.
- Bond, L., Carlin, J. B., Thomas, L., Rubin, K., & Patton, G. (2001). Does bullying cause emotional problems? A prospective study of young teenagers. *British Medical journal*, 323(7311), 480-484.
- Bradley, J. (2013). *Predictors of distress and coping in children with unusual experiences: the role of stigma and appraisal*. Unpublished Doctorate in Clinical Psychology Thesis, King's College London.
- Brewin, C. R. (1995). Cognitive aspects of social support processes. *Social Support and Psychiatric Disorder: Research findings and guidelines for clinical practice*, 96-116.
- Byrne, R., & Morrison, A. P. (2010). Young people at risk of psychosis: A user- led exploration of interpersonal relationships and communication of psychological difficulties. *Early Intervention in Psychiatry*, 4(2), 162-168.
- Caldwell, L. L. (2005). Leisure and health: why is leisure therapeutic?. *British Journal of Guidance & Counselling*, 33(1), 7-26.
- Campbell, M. L. C., & Morrison, A. P. (2007). The relationship between bullying, psychotic-like experiences and appraisals in 14-16-year olds. *Behaviour Research and Therapy*, 45, 1579-1591.
- Carpenter, W.T., & Strauss, J.S. (1991). The prediction of outcome in schizophrenia. IV: Eleven-year follow-up of the Washington IPSS cohort. *Journal of Nervous and Mental Disease*, 179, 517-525.
- Cebulla, A. & Tomaszewski, W. (2009). Risky Behaviour and Social Activities, *DCSF Research Report 173*.

- Cicchetti, D., & Rogosch, F. A. (2002). A developmental psychopathology perspective on adolescence. *Journal of consulting and clinical psychology*, 70(1), 6.
- Collip D, Nicolson NA, Lardinois M, Lataster T, van Os J, Myin-Germeys I; G.R.O.U.P. Daily cortisol, stress reactivity and psychotic experiences in individuals at above average genetic risk for psychosis. *Psychol Med*. 2011;41:2305–2315.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self- stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35-53.
- Crosnoe, R., & McNeely, C. (2008). Peer relations, adolescent behavior, and public health research and practice. *Family Community Health*, 31, S71-S80.
- Cuijpers, P., Van Straten, A., & Warmerdam, L. (2007). Behavioral activation treatments of depression: A meta-analysis. *Clinical psychology review*, 27(3), 318-326.
- Department of Health. (2007). *National service framework for children, young people and maternity services. The Mental health and psychological well-being of children and young people*. London: DH.
- Donenberg, G., & Pao, M. (2005). Youths and HIV/AIDS: Psychiatry's role in a changing epidemic. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44, 728-747.
- Evert, H., Harvey, C., Trauer, T., & Herrman, H. (2003). The relationship between social networks and occupational and self-care functioning in people with psychosis. *Social psychiatry and psychiatric epidemiology*, 38(4), 180-188.
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G\* Power 3.1: Tests for correlation and regression analyses. *Behavior research methods*, 41(4), 1149-1160.
- Feinstein, L., Bynner, J., & Duckworth, K. (2005). *Leisure Contexts in Adolescence and their Effects on Adult Outcomes* London: Centre for Research on the Wider Benefits of Learning.
- Feldman, S. S., & Elliott, G. R. (Eds.). (1990). *At the threshold: The developing adolescent*. Cambridge, MA: Harvard University Press.
- Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. Sage.
- Freeman, D., Garety, P. A. & Kuipers, E. (2001). Persecutory delusions: developing the understanding of belief maintenance and emotional distress. *Psychological Medicine*, 31, 1293-1306.
- Fowler, D., Freeman, D., Smith, B., Kuipers, E., Bebbington, P., Bashforth, H., Coker, S., Hodgekins, J., Gracie, A., Dunn, G. & Garety, P. (2006). The Brief Core Schema Scales (BCSS): psychometric properties and associations with paranoia and grandiosity in non-clinical and psychosis samples. *Psychological Medicine*, 36, 749 - 759.
- Fowler, D., Hodgekins, J., Painter, M., Reilly, T., Crane, C., Macmillan, I., ... & Jones, P. B. (2009). Cognitive behaviour therapy for improving social recovery in psychosis: a

report from the ISREP MRC Trial Platform study (Improving Social Recovery in Early Psychosis). *Psychological medicine*, 39(10), 1627-1636.

Fusar-Poli, P., Byrne, M., Valmaggia, L., Day, F., Tabraham, P., Johns, L., et al. (2010). Social dysfunction predicts two years clinical outcome in people at ultra high risk for psychosis. *Journal of Psychiatric Research*, 44, 294- 301.

Fusar-Poli, P., Borgwardt, S., Bechdolf, A., Addington, J., Riecher-Rössler, A., Schultze-Lutter, F., ... & Valmaggia, L. (2013). The psychosis high-risk state: a comprehensive state-of-the-art review. *Journal of the American Medical Association psychiatry*, 70(1), 107-120.

Gaite, L., Vázquez- Barquero, J. L., Borra, C., Ballesteros, J., Schene, A., Welcher, B., ... & Herran, A. (2002). Quality of life in patients with schizophrenia in five European countries: the EPSILON study. *Acta Psychiatrica Scandinavica*, 105(4), 283-292.

Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. E. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological medicine*, 31(02), 189-195.

Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. (2000). Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *The British Journal of Psychiatry*, 177(6), 534-539.

Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(11), 1337-1345.

Harter, S. (1999). *The construction of the self: A developmental perspective*. Guilford Press.

Hogarty, G. E., Goldberg, S. C., Schooler, N. R., & Ulrich, R. F. (1974). Drug and sociotherapy in the aftercare of schizophrenic patients: II. Two-year relapse rates. *Archives of General Psychiatry*, 31(5), 603-608.

Hogarty, G.E., Kornblith, S.J., Greenwald, P., DiBarry, A.L., Cooley, S., Ulrich, R.F., Carter, M., & Flesher, S. (1997). Three-year trials of personal therapy among schizophrenic patients living with or independent of family, II: Effects on adjustment of patients. *American Journal of Psychiatry*, 154(11), 1514-1524.

Hopko, D. R., Lejuez, C. W., Ruggiero, K. J., & Eifert, G. H. (2003). Contemporary behavioral activation treatments for depression: Procedures, principles, and progress. *Clinical psychology review*, 23(5), 699-717.

Howes, O. D., & Kapur, S. (2009). The dopamine hypothesis of schizophrenia: version III—the final common pathway. *Schizophrenia bulletin*, 35(3), 549-562.

Hultsman, W. Z. (1992). Constraints to activity participation in early adolescence. *The Journal of Early Adolescence*, 12(3), 280-299.

- Jackson, E. L., & Rucks, V. C. (1993). Reasons for ceasing participation and barriers to participation: Further examination of constrained leisure as an internally homogeneous concept. *Leisure Sciences*, 15(3), 217-230.
- Jolley, S., Garety, P.A., Ellett, L., Kuipers, E., Freeman, D., Bebbington, P.E., Fowler, D.G., & Dunn, G. (2006). A validation of a new measure of activity in psychosis. *Schizophrenia research*, 85(1), 288-295.
- John, K. (2001). Measuring children's social functioning. *Child Psychology and Psychiatry Review*, 6(4), 181-188.
- Jones, S. R., & Fernyhough, C. (2009). Rumination, reflection, intrusive thoughts, and hallucination-proneness: towards a new model. *Behaviour research and therapy*, 47(1), 54-59.
- Kanter, J. W., Manos, R. C., Bowe, W. M., Baruch, D. E., Busch, A. M., & Rusch, L. C. (2010). What is behavioral activation?: A review of the empirical literature. *Clinical psychology review*, 30(6), 608-620.
- Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban health*, 78(3), 458-467.
- Kelleher, I., Harley, M., Lynch, F., Arseneault, L., Fitzpatrick, C., & Cannon, M. (2008). Associations between childhood trauma, bullying and psychotic symptoms among a school-based adolescent sample. *The British Journal of Psychiatry*, 193(5), 378-382.
- Kelleher, I., Corcoran, P., Keeley, H., Wigman, J.T., Devlin, N., Ramsay, H., Wasserman, C., Carli, V., Sarchiapone, M., Hoven, C., Wasserman, D., & Cannon, M. (2013). Psychotic symptoms and population risk for suicide attempt: a prospective cohort study. *Journal of the American Medical Association Psychiatry*, 70(9), 940-8.
- Kim, H. Y. (2013). Statistical notes for clinical researchers: assessing normal distribution (2) using skewness and kurtosis. *Restorative dentistry & endodontics*, 38(1), 52-54.
- Kim-Cohen, J., Caspi, A., Moffitt, T. E., Harrington, H., Milne, B. J., & Poulton, R. (2003). Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. *Archives of general psychiatry*, 60(7), 709-717.
- Kirkbride, J. B., Barker, D., Cowden, F., Stamps, R., Yang, M., Jones, P. B., & Coid, J. W. (2008). Psychoses, ethnicity and socio-economic status. *The British Journal of Psychiatry*, 193(1), 18-24.
- Larson, R. W., Richards, M. H., Moneta, G., Holmbeck, G., & Duckett, E. (1996). Changes in adolescents' daily interactions with their families from ages 10 to 18: Disengagement and transformation. *Developmental Psychology*, 32(4), 744.

- Laurens, K. R., Hodgins, S., Maughan, B., Murray, R. M., Rutter, M. L., & Taylor, E. A. (2007). Community screening for psychotic-like experiences and other putative antecedents of schizophrenia in children aged 9–12 years. *Schizophrenia research*, 90(1), 130-146.
- Laurens, K. R., Hobbs, M. J., Sunderland, M., Green, M. J., & Mould, G. L. (2012). Psychotic-like experiences in a community sample of 8000 children aged 9 to 11 years: an item response theory analysis. *Psychological medicine*, 42(07), 1495-1506.
- Lewinsohn, P. M., & Graf, M. (1973). Pleasant activities and depression. *Journal of consulting and clinical psychology*, 41(2), 261.
- Link, B. G., Struening, E. L., Rahav, M., Phelan, J. C., & Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, 177-190.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 27(1), 363-385.
- Lutgens, D., Garipey, G., & Malla, A. (2017). Psychological and psychosocial interventions for negative symptoms in psychosis: systematic review and meta-analysis. *The British Journal of Psychiatry*, bjp-bp.
- Lysaker, P. H., Davis, L. W., Warman, D. M., Strasburger, A., & Beattie, N. (2007). Stigma, social function and symptoms in schizophrenia and schizoaffective disorder: associations across 6 months. *Psychiatry research*, 149(1), 89-95.
- MacDonald, E., Sauer, K., Howie, L., & Albiston, D. (2005). What happens to social relationships in early psychosis? A phenomenological study of young people's experiences. *Journal of Mental Health*, 14(2), 129-143.
- Mahoney, J. L., Larson, R. W., Eccles, J. S., & Lord, H. (2005). Organized activities as developmental contexts for children and adolescents. *Organized activities as contexts of development: Extracurricular activities, after-school and community programs*, 3-22.
- Meltzer, H., Gatward, R., Goodman, R., and Ford, F. (2000). *Mental health of children and adolescents in Great Britain*. London: The Stationery Office.
- Menard, S. (1995). *Applied logistic regression analysis: Sage University Paper Series on Quantitative Applications in the Social Sciences*. Thousand Oaks, CA; Sage.
- Mills, C., Guerin, S., Lynch, F., Daly, I., & Fitzpatrick, C. (2004). The relationship between bullying, depression and suicidal thoughts/behaviour in Irish adolescents. *Irish Journal of Psychological Medicine*, 21(04), 112-116.
- Moriarty, A., Jolley, S., Callanan, M. M., & Garety, P. (2012). Understanding reduced activity in psychosis: the roles of stigma and illness appraisals. *Social psychiatry and psychiatric epidemiology*, 47(10), 1685-1693.

Morrison, A. P., French, P., Walford, L., Lewis, S. W., Kilcommons, A., Green, J., ... & Bentall, R. P. (2004). Cognitive therapy for the prevention of psychosis in people at ultra-high risk. *The British Journal of Psychiatry*, 185(4), 291-297.

Myers, R. (1990). *Classical and modern regression with applications*. (2nd ed.). Boston, MA; Duxbury.

Muris, P., Meesters, C., Eijkelenboom, A., & Vincken, M. (2004). The self-report version of the Strengths and Difficulties Questionnaire: Its psychometric properties in 8- to 13- year- old non- clinical children. *British Journal of Clinical Psychology*, 43(4), 437-448.

National Institute for Clinical Excellence (2009) Core interventions in the treatment and management of schizophrenia in primary and secondary care. NICE, London

Niemi, L. T., Suvisaari, J. M., Tuulio-Henriksson, A. & Lonnqvist, J. K. (2003). Childhood developmental abnormalities in schizophrenia: evidence from high-risk studies. *Schizophrenia Research* 60, 239–258.

Noone, D., Ames, C., Hassanali, N., Browning, S., Bracegirdle, K., Corrigan, R., Laurens, K.R., Hirsch, C.R., Kuipers, E., Maddox, L., Fowler, D & Jolley, S. (2015). A preliminary investigation of schematic beliefs and unusual experiences in children. *European Psychiatry*, 30(5), 569-575.

Owens, D. C., & Johnstone, E. C. (2006). Precursors and prodromata of schizophrenia: findings from the Edinburgh High Risk Study and their literature context. *Psychological medicine*, 36(11), 1501-1514.

Palmier-Claus, J. E., Dunn, G., & Lewis, S. W. (2012). Emotional and symptomatic reactivity to stress in individuals at ultra-high risk of developing psychosis. *Psychological medicine*, 42(5), 1003.

Passmore, A. (2003). The occupation of leisure: Three typologies and their influence on mental health in adolescence. *OTJR: Occupation, Participation and Health*, 23(2), 76-83.

Pellegrini, A. D., & Long, J. D. (2002). A longitudinal study of bullying, dominance, and victimization during the transition from primary school through secondary school. *British journal of developmental psychology*, 20(2), 259-280.

Read J, Perry BD, Moskowitz A, Connolly J: The contribution of early traumatic events to schizophrenia in some patients: a traumagenic neurodevelopmental model. *Psychiatry* 2001; 64:319–345

Repper, J., & Perkins, R. (2003). *Social inclusion and recovery: A model for mental health practice*. Elsevier Health Sciences.

Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry research*, 121(1), 31-49.

Rupke, S. J., Blecke, D., & Renfrow, M. (2006). Cognitive therapy for depression. *Am Fam Physician*, 73(1), 83-86.

Satterthwaite, F. E. (1946). An approximate distribution of estimates of variance components. *Biometrics bulletin*, 2(6), 110-114.

Schlosser, D. A., Jacobson, S., Chen, Q., Sugar, C. A., Niendam, T. A., Li, G., ... & Cannon, T. D. (2012). Recovery from an at-risk state: clinical and functional outcomes of putatively prodromal youth who do not develop psychosis. *Schizophrenia bulletin*, 38(6), 1225-1233.

Schonert-Reichl, K.A., Guhn, M., Hymel, S., Hertzman, C., Sweiss, L., et al. (2010). *Our children's voices. The Middle Years Development Instrument. Measuring the developmental health and well-being of children in middle childhood*. Human early Learning Partnership. Vancouver.

Shaw, L. H., & Gant, L. M. (2002). In defense of the Internet: The relationship between Internet communication and depression, loneliness, self-esteem, and perceived social support. *Cyberpsychology & behavior*, 5(2), 157-171.

Simon, A. E., Umbricht, D., Lang, U. E., & Borgwardt, S. (2014). Declining transition rates to psychosis: the role of diagnostic spectra and symptom overlaps in individuals with attenuated psychosis syndrome. *Schizophrenia research*, 159(2), 292-298.

Sirsch, U. (2003). The impending transition from primary to secondary school: Challenge or threat?. *International Journal of Behavioral Development*, 27(5), 385-395.

Veale, D. (2008). Behavioural activation for depression. *Advances in Psychiatric Treatment*, 14(1), 29-36.

van Os, J., Linscott, R. J., Myin-Germeys, I., Delespaul, P., & Krabbendam, L. (2009). A systematic review and meta-analysis of the psychosis continuum: evidence for a psychosis proneness-persistence-impairment model of psychotic disorder. *Psychological Medicine*, 39, 179-195.

van Os, J., & Reininghaus, U. (2016). Psychosis as a transdiagnostic and extended phenotype in the general population. *World Psychiatry*, 15(2), 118-124.

van Rossum, I., Lieb, R., Wittchen, H. U., & van Os, J. (2011). Affective dysregulation and reality distortion: a 10-year prospective study of their association and clinical relevance. *Schizophrenia bulletin*, 37(3), 561-571.

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(12), 1304-1312.

White, R., Bebbington, P., Pearson, J., Johnson, S., & Ellis, D. (2000). The social context of insight in schizophrenia. *Social psychiatry and psychiatric epidemiology*, 35(11), 500-507.

Wilkinson, P., Dubicka, B., Kelvin, R., Roberts, C., & Goodyer, I. (2009). Treated depression in adolescents: predictors of outcome at 28 weeks. *The British Journal of Psychiatry*, 194(4), 334-341.

Yanos, P.T., Rosenfield, S., & Horwitz, A.V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal*, 37, 405-419.

Youniss, J., McLellan, J. A., & Yates, M. (1997). What we know about engendering civic identity. *American Behavioral Scientist*, 40(5), 620-631.

Yung, A. R., Phillips, L. J., Yuen, H. P., Francey, S. M., McFarlane, C. A., Hallgren, M., & McGorry, P. D. (2003). Psychosis prediction: 12-month follow up of a high-risk ("prodromal") group. *Schizophrenia research*, 60(1), 21-32.

Yung, A. R., Buckby, J. A., Cotton, S. M., Cosgrave, E. M., Killackey, E. J., Stanford, C., ... & McGorry, P. D. (2006). Psychotic-like experiences in nonpsychotic help-seekers: associations with distress, depression, and disability. *Schizophrenia Bulletin*, 32(2), 352-359.

Yung, A. R., Nelson, B., Baker, K., Buckby, J. A., Baksheev, G., & Cosgrave, E. M. (2009). Psychotic-like experiences in a community sample of adolescents: implications for the continuum model of psychosis and prediction of schizophrenia. *Australian and New Zealand Journal of Psychiatry*, 43(2), 118-128.

## 7. Appendices

### APPENDIX A: Adapted Time Budget Measure

#### Time budget v1 CHILD 26/09/14

We want to find out a bit more about what you do. Please tell us about what you do at school or home. We would like to know about time you spend with friends and family, groups you go to, and what you do with your spare time-like watching TV, reading, or going shopping. We are especially interested in things you do with other people, seeing or going out with friends and talking on the 'phone, and times when you feel bored or lonely.



Thinking about the past week, can you tell me:

1. What you do at the weekend?
2. What a typical school, working or weekday is like for you?
3. How you feel you get on with other people?
4. Groups or activities you do in the evening after school/in the week.

*Ask about new activities and resumed activities; who they spend time with when doing this activities and level of social interaction e.g. online or face-to face, active communication with another person or mere presence of another; for schooldays gauge engagement in the lesson and playtimes, e.g. what were you doing? Who with? How long were you doing it that for? What kind of game were you playing, what did it involve? Did you enjoy it?*

| SATURDAY        |                   |                 |                                                                       |
|-----------------|-------------------|-----------------|-----------------------------------------------------------------------|
| Morning (N & R) | Lunchtime (N & R) | Evening (N & R) | Sleep                                                                 |
|                 |                   |                 | Bed Time:<br><br>Asleep by:<br><br>Sleep through the night:<br>Yes/No |
| SUNDAY          |                   |                 |                                                                       |
| Morning (N & R) | Lunchtime (N & R) | Evening (N & R) | Sleep                                                                 |
|                 |                   |                 | Bed Time:<br><br>Asleep by:<br><br>Sleep through the night:<br>Yes/No |
| WEEKDAY         |                   |                 |                                                                       |
| Morning (N & R) | Lunchtime (N & R) | Evening (N & R) | Sleep                                                                 |
|                 |                   |                 | Bed Time:<br><br>Asleep by:<br><br>Sleep through the night:<br>Yes/No |

## APPENDIX B: Time Budget Scoring Instructions

### Introduction

This measure has been designed to assess activity levels in children. It was originally designed for adults with psychosis. It should be completed as a structured interview with respondents. It is designed to be individualised, and to be sensitive to change. Child norms are in development. Adult norms are given in:

Jolley, S. Garety P. Dunn G. White J. Aitken M. Challacombe F. Griggs M. Wallace M. Craig T. (2005) A pilot validation study of a new measure of activity in psychosis. *Social Psychiatry & Psychiatric Epidemiology*. 40(11):905-11

Jolley, S., Garety, P.A., Ellett, L., Kuipers, E., Freeman, D., Bebbington, P.E., Fowler, D.G., & Dunn, G. (2006). A validation of a new measure of activity in psychosis. *Schizophrenia research*, 85(1), 288-295.

The following guidelines should be read before administration.

1. The measure should be completed for a typical weekday and weekend (e.g. not one when the respondent was unusually unwell, or in hospital) unless an atypical week is particularly required.
2. Ask the participant what they did today or yesterday – this should be easier for participants to remember. Prompt if memory is poor. Ask about any known activities, or activities emerging as a pattern (e.g. ‘when did you get up’; ‘did you have breakfast?’; ‘what did you do then?’). Most respondents will be at school – useful to check how they get there, when they arrive and how much they contribute and interact during the day. If the days are very repetitive, it is OK to say – was that morning the same? Anything different? Normalise lack of activity or socialising, empathise with difficulties particularly if the child is upset by loneliness or lack of activity. Normalise difficulty remembering. Try to help the respondent as much as possible. See Table below for prompt questions.
3. Stick to usual times of day when determining which box to complete. For example, if the young person does not get up until lunchtime, score the morning as sleeping (0) and fill in the rest of the day from lunchtime onwards. If the young person goes to bed late with lots of evening activities, these should still go in the ‘evening’ box, and can only achieve a maximum score of 3.
4. All activities should be noted, without judgement. Even where activities are deemed inappropriate by the interviewer, these should still be added and scored. It is quite usual for people of any age to have 0 and 1 scores for time periods in their week, even when functioning quite highly. E.g. common behaviours such as having a lie in will receive a 0, and watching TV a 1.
5. Complete the additional questions. Note new and resumed activities (Q1) in the relevant columns.

6. Each time period is given a score. Scoring is based on the degree of engagement, personal effort and sought social contact required. For example, sitting through the school day as a passive recipient of learning would score '2' – actively asking questions, or finding other people to play games with would score a '3'.
7. Young people are scored for the highest type of activity achieved, so if they engage actively for part of their school week, but are otherwise passive, the school week would score a '3'. Similarly, if they get a group of friends together to play football after school, but then sit in front of the TV, the time period is scored '3'. However, the activity should be of reasonable duration (20-30 minutes plus, not five minutes). If a higher rated activity is present but of very short duration, composite scores may be estimated (e.g. mostly '1' with a very short period of '3' could rate '1.5').
8. Ask lots of questions to determine level of engagement; the rater is looking for evidence of independent interest, self-motivation, and active enjoyment, rather than just passively being along for the ride with an organised peer group or family. Ask questions like: 'how do you get there?'; 'who decided that?'; 'what do you do when you do that?'; 'tell me about xx'; 'what is your favourite xx?'; 'who do you talk to?'; 'what do you say?'. For example, sitting in front of whatever is on the TV with family and only responding when spoken to, is a '2'; actively telling jokes, or playing games, or engaging with the TV (e.g. programmes are exciting, or funny, or just watched avidly) is a '3'. Do they generally seem enthusiastic about their week? Do they engage well with their family or do they prefer to spend time alone in their room?
9. Ascertain general information on bedtime routine, as well as sleep pattern. Are they watching TV, on their phone or reading before? Are they able to sleep through the night?-
10. If currently not attending school due to school refusal, what are they doing in their day instead?
11. If rater is undecided due to limited information between a 2 or 3 score 2.5.
12. If the activity is insufficiently specified to decide any score, even after intra-group consultation, rate is it as missing.

| Level of activity                                                                                                        | Example                                                                                                                                                                                                                  | Prompting question                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|--------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| None (0)<br>nothing                                                                                                      | Lying<br>Thinking<br>Sleeping                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Low (1)<br>Undemanding,<br>passive and<br>solitary<br>activity/brief<br>or no social<br>interaction                      | Watching TV/<br>Listening to the<br>Radio/Eating/Basic<br>self-care -<br>showering etc                                                                                                                                   | <p>Where you watching TV - alone (1) or with the family (2)?<br/>Were you talking? What about?<br/>(On-going discussion with family about the show(3) or sitting in silence (2))</p> <p>Food: What did you have? Did somebody cook it for you? Did you eat it on your own? What were you doing while you ate? (eating prepared meal alone (1); eating with family but not very engaged (2); active conversation or activity during mealtime (3))<br/>Did you prepare it yourself? (Self-prepared, but easy, e.g. biscuits, something from fridge (2); prepared something carefully, with interest (3))</p>                                                                                                                                                                                                                                                                                                                       |
| <p>Medium (2)<br/>Routine activities.</p> <p>Activities determined by the family.</p> <p>Easier social interactions.</p> | <p>Going to school &amp; Sitting through classes.</p> <p>Spending time in the playground / Having a lunch break at school</p> <p>Playing computer game</p> <p>Surfing the internet</p> <p>Chatting to friends/family</p> | <p>Passively sitting in the classroom (2) vs. actively engaging in the classroom/lesson (3).</p> <p>Was there anybody with you then?<br/>Talking to friends when spoken to in the playground; with but not really part of the group (2); active engagement with group (3); going to the library just to sit (2); active reading (3); enthusiastically playing 'it'/sports with friends (3)</p> <p><u>Check the level of complexity:</u> Name of the game. What kind of game is it? What do you have to do in that game? How many players are involved in it? Do you play with other friends online? Simple/repetitive (2) vs. complex strategy/logic game/interact with friends online (3) Competitive/High score/High levels of concentration (3)</p> <p><u>Check the aim:</u> What did you do?<br/>Social networking/scrolling through internet pages, YouTube (2) vs. searching particular information for assignment (3)</p> |

|                                                                                                                                                                                                                                            |                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                                                                                                                                            | Going/Visited by family                                                                                                                                                | <p><u>Check the Type:</u> online, BBM, Whatsapp (2) face-to-face, phone call conversation (3).<br/> <u>Duration:</u> Brief (2) longer (3). Where you messaging/talking consistently? Is this a friend you also see face-to-face?</p> <p>Check type of interaction: Watching a movie together at home with some conversation with others (2) Playing with cousins/friends (2/3 pending on type of play &amp; duration) Going for a walk (2) their idea (3)</p>                                                                                                                                                                                          |
| <p>Engaged (3)<br/>Complex demanding activity requiring effort.</p> <p>Motivation, enthusiasm and commitment.</p> <p>High levels of social interaction (part of the group).</p> <p>Or multiple 2 rated activities in a period of time.</p> | <p>Reading/Drawing<br/>Piano Practice/<br/>Homework/Playing sports outside of school/After school club/Going to the park with friends/Tidying bedroom/House chores</p> | <p><u>Check the level of effort and complexity:</u> What did you read/draw? Did you learn something new? Did you motivate yourself to do your homework (3) Reminded to do homework (2) Gazing at the book page while thinking about something else (1) vs. Reading a magazine/comic (2) learning new info/novel (3).</p> <p>Do you actively engage in the club/ sport? How do you spend your time when you are there?</p> <p><u>Check for duration:</u> brief less than 30 minutes (2) longer 30minutes + (3)</p> <p><u>Check the level of involvement:</u> Did you do it on your own? (if yes – 3; if not (2) determine the role of other person)</p> |

## APPENDIX C: Unusual Experiences Questionnaire

# Unusual Experiences 1

*Circle the answers that apply to you.*

|                                                                                                                              |                 |                      |                              |
|------------------------------------------------------------------------------------------------------------------------------|-----------------|----------------------|------------------------------|
| <b>1. Some people believe that their thoughts can be read. Have other people ever read your thoughts?</b><br><b>If true:</b> | <b>Not true</b> | <b>Somewhat true</b> | <b>Certainly true</b>        |
| How often has it happened over the last 2 weeks?                                                                             | Not at all      | Only once            | 2-4 times<br>5 or more times |
| How much has it upset you?                                                                                                   | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| How much has it made things hard at home or school?                                                                          | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| <b>2. Have you ever believed that you were being sent special messages through the television?</b><br><b>If true:</b>        | <b>Not true</b> | <b>Somewhat true</b> | <b>Certainly true</b>        |
| How often has it happened over the last 2 weeks?                                                                             | Not at all      | Only once            | 2-4 times<br>5 or more times |
| How much has it upset you?                                                                                                   | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| How much has it made things hard at home or school?                                                                          | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| <b>3. Have you ever thought that you were being followed or spied upon?</b><br><b>If true:</b>                               | <b>Not true</b> | <b>Somewhat true</b> | <b>Certainly true</b>        |
| How often has it happened over the last 2 weeks?                                                                             | Not at all      | Only once            | 2-4 times<br>5 or more times |
| How much has it upset you?                                                                                                   | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| How much has it made things hard at home or school?                                                                          | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| <b>4. Have you ever heard voices that other people could not hear?</b><br><b>If true:</b>                                    | <b>Not true</b> | <b>Somewhat true</b> | <b>Certainly true</b>        |
| How often has it happened over the last 2 weeks?                                                                             | Not at all      | Only once            | 2-4 times<br>5 or more times |
| How much has it upset you?                                                                                                   | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| How much has it made things hard at home or school?                                                                          | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| <b>5. Have you ever felt that you were under the control of some special power?</b><br><b>If true:</b>                       | <b>Not true</b> | <b>Somewhat true</b> | <b>Certainly true</b>        |
| How often has it happened over the last 2 weeks?                                                                             | Not at all      | Only once            | 2-4 times<br>5 or more times |
| How much has it upset you?                                                                                                   | Not at all      | Only a little        | Quite a lot<br>A great deal  |
| How much has it made things hard at home or school?                                                                          | Not at all      | Only a little        | Quite a lot<br>A great deal  |

UNUSUAL EXPERIENCES

|                                                                                                                                 |                 |               |                      |                 |                       |
|---------------------------------------------------------------------------------------------------------------------------------|-----------------|---------------|----------------------|-----------------|-----------------------|
| <b>6. Have you ever known what another person was thinking even though that person wasn't speaking?</b><br><b>If true:</b>      | <b>Not true</b> |               | <b>Somewhat true</b> |                 | <b>Certainly true</b> |
| How often has it happened over the last 2 weeks?                                                                                | Not at all      | Only once     | 2-4 times            | 5 or more times |                       |
| How much has it upset you?                                                                                                      | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| How much has it made things hard at home or school?                                                                             | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| <b>7. Have you ever felt as though your body had been changed in some way that you could not understand?</b><br><b>If true:</b> | <b>Not true</b> |               | <b>Somewhat true</b> |                 | <b>Certainly true</b> |
| How often has it happened over the last 2 weeks?                                                                                | Not at all      | Only once     | 2-4 times            | 5 or more times |                       |
| How much has it upset you?                                                                                                      | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| How much has it made things hard at home or school?                                                                             | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| <b>8. Do you have any special powers that other people don't have?</b><br><b>If true:</b>                                       | <b>Not true</b> |               | <b>Somewhat true</b> |                 | <b>Certainly true</b> |
| How often has it happened over the last 2 weeks?                                                                                | Not at all      | Only once     | 2-4 times            | 5 or more times |                       |
| How much has it upset you?                                                                                                      | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| How much has it made things hard at home or school?                                                                             | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| <b>9. Have you ever seen something or someone that other people could not see?</b><br><b>If true:</b>                           | <b>Not true</b> |               | <b>Somewhat true</b> |                 | <b>Certainly true</b> |
| How often has it happened over the last 2 weeks?                                                                                | Not at all      | Only once     | 2-4 times            | 5 or more times |                       |
| How much has it upset you?                                                                                                      | Not at all      | Only a little | Quite a lot          | A great deal    |                       |
| How much has it made things hard at home or school?                                                                             | Not at all      | Only a little | Quite a lot          | A great deal    |                       |

## APPENDIX D: Strengths & Difficulties Questionnaire

### Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name .....

Male/Female

Date of Birth.....

|                                                                  | Not<br>True              | Somewhat<br>True         | Certainly<br>True        |
|------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
| I try to be nice to other people. I care about their feelings    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am restless, I cannot stay still for long                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I get a lot of headaches, stomach-aches or sickness              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I usually share with others (food, games, pens etc.)             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I get very angry and often lose my temper                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am usually on my own. I generally play alone or keep to myself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I usually do as I am told                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I worry a lot                                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am helpful if someone is hurt, upset or feeling ill            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am constantly fidgeting or squirming                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have one good friend or more                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I fight a lot. I can make other people do what I want            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am often unhappy, down-hearted or tearful                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other people my age generally like me                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am easily distracted, I find it difficult to concentrate       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am nervous in new situations. I easily lose confidence         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am kind to younger children                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am often accused of lying or cheating                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other children or young people pick on me or bully me            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I often volunteer to help others (parents, teachers, children)   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I think before I do things                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I take things that are not mine from home, school or elsewhere   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I get on better with adults than with people my own age          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have many fears, I am easily scared                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I finish the work I'm doing. My attention is good                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## APPENDIX E: Adapted Stigma Measure (ISMI)

Here are some sentences about problems. Please circle how much you agree with each sentence about your problems.

1. People ignore me or take me less seriously just because I have problems

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

2. I am annoyed at myself for having these problems

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

3. I avoid trying to be friends with people who don't have my kind of problems because they wouldn't want to be friends with me

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

4. I don't mix with friends as much as I used to because my problems might make me look or behave 'weird'

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

5. Having these problems has spoiled my life

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

6. Others think that I can't do very much because I have these problems

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

7. I need others to make more decisions for me because of my problems

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

8. People with my kind of problems are usually violent

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

9. People with my kind of problems cannot live a good, happy life

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

10. I feel OK being out with a person who obviously has my kind of problems

|                      |                      |            |                |                |
|----------------------|----------------------|------------|----------------|----------------|
| Strongly<br>Disagree | Slightly<br>Disagree | Don't Know | Slightly Agree | Strongly Agree |
|----------------------|----------------------|------------|----------------|----------------|

## APPENDIX F: Life Events Questionnaire

### Life Events Measure (v1 26/09/14)

*These questions are all about the last **year**. We would like to know about things that have happened to you and your family over the last year. Some of the questions are about difficult and upsetting things that sometimes happen to people. You don't have to answer if you don't want to. Tell the researcher if you feel upset.*

Please score each event on a scale of 1 to 5 for how it felt to you at the time it happened.

- 1 = very good/pleasant/happy
- 2 = quite good/pleasant/happy
- 3 = neither good or bad
- 4 = quite bad/unpleasant/sad/painful
- 5 = very bad/unpleasant/sad/painful

1. Have you changed school in the past year? YES NO (Please circle)

Date(s) Rate (circle)

If YES, give reason: \_\_\_\_\_ 1 2 3 4 5

If you have circled 4 or 5, were you upset about this for more than 2 weeks? YES NO (Please circle)

1a. Who lives in your house? \_\_\_\_\_

2. Have there been any changes in the number of people in your household in the past year? Has anyone left or joined your family? YES NO (Please circle)

Date(s) Rate (circle)

If YES, describe changes: \_\_\_\_\_ 1 2 3 4 5

If you have circled 4 or 5, were you upset about this for more than 2 weeks? YES NO (Please circle)

3. Have you moved house in the last 12 months? YES NO (Please circle)

Date(s) Rate (circle)

If YES, describe moves: \_\_\_\_\_ 1 2 3 4 5

If you have circled 4 or 5, were you upset about this for more than 2 weeks? YES NO (Please circle)

## APPENDIX G: Bullying Experiences Questionnaire

*Definition of BULLY - There are lots of different ways to bully someone, but a bully has some advantage (stronger, more popular, or something else), wants to hurt the other person (it's not an accident), and does so repeatedly and unfairly. Sometimes a group of students will bully another student.*

1. This school year, how often, if at all, have you been bullied in the following ways?

- i. Physical Bullying (for example, someone hit, shoved, or kicked you, spat at you, beat you up, or damaged or took your things without permission)

NEVER RARELY SOMETIMES OFTEN

If yes, who was it?

---

- ii. Verbal Bullying (for example, someone called you names, teased, embarrassed, threatened you, or made you do things you didn't want to do)

NEVER RARELY SOMETIMES OFTEN

If yes, who was it?

---

- iii. Social Bullying (for example, someone left you out, excluded you, gossiped and spread rumours about you, or made you look foolish)

NEVER RARELY SOMETIMES OFTEN

If yes, who was it?

---

- iv. Cyber Bullying (for example, someone used the computer or text messages to exclude, threaten, embarrass you, or hurt your feelings)

NEVER RARELY SOMETIMES OFTEN

If yes, who was it?

---

## APPENDIX H: Brief Core Schema Scale (BCSS)

### What I think about myself and other people

Here is a list of things people can think about themselves and other people. For each one, put a circle around 'yes' if you think it is true and 'no' if you think it is not true. If you think it is true, then put a circle round a number to show how much you think it is true. Don't spend too long on any question. It is OK to put the first thing that comes into your mind. There are no right or wrong answers.

|                                        |    |      | Believe it<br>slightly | Believe it<br>moderately | Believe it<br>very much | I believe<br>it totally |
|----------------------------------------|----|------|------------------------|--------------------------|-------------------------|-------------------------|
| <i>ME</i>                              |    |      |                        |                          |                         |                         |
| I am respected                         | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am valuable                          | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am talented                          | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am successful                        | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am unloved                           | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am worthless                         | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am weak                              | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am vulnerable                        | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am bad                               | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am a failure                         | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am good                              | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| I am interesting                       | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| <i>OTHER PEOPLE</i>                    |    |      |                        |                          |                         |                         |
| Other people are hostile or unfriendly | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are unkind                | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are unforgiving           | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are bad                   | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are devious or liars      | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are nasty                 | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are fair                  | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are good                  | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are trustworthy           | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are accepting             | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are supportive            | NO | YES→ | 1                      | 2                        | 3                       | 4                       |
| Other people are truthful              | NO | YES→ | 1                      | 2                        | 3                       | 4                       |

## APPENDIX I: Whole sample regression with demographic variables

**Table 6.1** Whole sample regression with UED severity and demographic variables

| Variable                                                                                | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | <i>r</i> <sup>2</sup> |
|-----------------------------------------------------------------------------------------|----------|-------------|---------|----------|-----------------------|
|                                                                                         |          |             |         |          | .25                   |
| UED severity                                                                            | .01      | .02         | .03     | .71      |                       |
| Age                                                                                     | -.20     | .18         | -.10    | .27      |                       |
| Gender                                                                                  | -.71     | .68         | -.07    | .30      |                       |
| Ethnicity                                                                               | -1.12    | .63         | -.12    | .08      |                       |
| Setting (CUES and CUES+)                                                                | -3.91    | .87         | -.41    | .00      |                       |
| <i>UED</i> Unusual experiences with distress rated using the UEQ (Laurens et al., 2007) |          |             |         |          |                       |
| <i>r</i> <sup>2</sup> (adjusted)                                                        |          |             |         |          |                       |

**Table 6.2** Whole sample regression with SDQ Emotional subscale and demographic variables

| Variable                                                                  | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | <i>r</i> <sup>2</sup> |
|---------------------------------------------------------------------------|----------|-------------|---------|----------|-----------------------|
|                                                                           |          |             |         |          | .27                   |
| SDQ Emotional subscale                                                    | .09      | .15         | .04     | .55      |                       |
| Age                                                                       | -.17     | .18         | -.09    | .33      |                       |
| Gender                                                                    | -.79     | .72         | -.08    | .27      |                       |
| Ethnicity                                                                 | -1.11    | .63         | -.12    | .08      |                       |
| Setting (CUES and CUES+)                                                  | -4.18    | .88         | -.43    | .00      |                       |
| <i>SDQ</i> Strength and Difficulties Questionnaire (Goodman et al., 2000) |          |             |         |          |                       |
| <i>r</i> <sup>2</sup> (adjusted)                                          |          |             |         |          |                       |

**Table 6.3** Whole sample regression with ISMI stigma scale and demographic variables

| Variable                                                               | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | <i>r</i> <sup>2</sup> |
|------------------------------------------------------------------------|----------|-------------|---------|----------|-----------------------|
|                                                                        |          |             |         |          | .31                   |
| ISMI                                                                   | .05      | .04         | .08     | .30      |                       |
| Age                                                                    | -.19     | .19         | -.09    | .31      |                       |
| Gender                                                                 | -1.29    | .71         | -.13    | .07      |                       |
| Ethnicity                                                              | -.47     | .65         | -.05    | .47      |                       |
| Setting (CUES and CUES+)                                               | -4.66    | .95         | -.47    | .00      |                       |
| <i>ISMI</i> Self-stigma of Mental Illness scale (Ritsher et al., 2003) |          |             |         |          |                       |
| <i>r</i> <sup>2</sup> (adjusted)                                       |          |             |         |          |                       |

**Table 6.4** Whole sample regression with Bullying experiences and demographic variables

| Variable                                                                | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | <i>r</i> <sup>2</sup> |
|-------------------------------------------------------------------------|----------|-------------|---------|----------|-----------------------|
|                                                                         |          |             |         |          | .25                   |
| Bullying experiences                                                    | .04      | .10         | .03     | .67      |                       |
| Age                                                                     | -.19     | .18         | -.10    | .28      |                       |
| Gender                                                                  | -.69     | .68         | -.07    | .31      |                       |
| Ethnicity                                                               | -1.11    | .63         | -.12    | .08      |                       |
| Setting (CUES and CUES+)                                                | -3.84    | .86         | -.40    | .00      |                       |
| <i>Bullying experiences</i> (adapted from Schonert-Reichl et al., 2010) |          |             |         |          |                       |
| <i>r</i> <sup>2</sup> (adjusted)                                        |          |             |         |          |                       |

**Table 6.5** Whole sample regression with Adverse life events and demographic variables

| Variable                 | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|--------------------------|----------|-------------|---------|----------|-------|
|                          |          |             |         |          | .27   |
| Adverse life events      | .27      | .20         | .09     | .18      |       |
| Age                      | -.16     | .18         | -.08    | .36      |       |
| Gender                   | -.71     | .68         | -.07    | .30      |       |
| Ethnicity                | -1.07    | .63         | -.11    | .09      |       |
| Setting (CUES and CUES+) | -4.18    | .86         | -.43    | .00      |       |

*Adverse life events Life Events Questionnaire* (Wilkinson et al., 2009)

$r^2$  (adjusted)

**Table 6.6** Whole sample regression with BCSS negative self and demographic variables

| Variable                 | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|--------------------------|----------|-------------|---------|----------|-------|
|                          |          |             |         |          | .26   |
| BCSS negative self       | -.03     | .06         | -.05    | .56      |       |
| Age                      | -.17     | .18         | -.08    | .36      |       |
| Gender                   | -.46     | .70         | -.05    | .52      |       |
| Ethnicity                | -1.26    | .63         | -.13    | .05      |       |
| Setting (CUES and CUES+) | -3.82    | .89         | -.40    | .00      |       |

*BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

**Table 6.7** Whole sample regression with BCSS negative other and demographic variables

| Variable                 | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|--------------------------|----------|-------------|---------|----------|-------|
|                          |          |             |         |          | .24   |
| BCSS negative other      | -.02     | .05         | -.03    | .69      |       |
| Age                      | -.19     | .18         | -.09    | .30      |       |
| Gender                   | -.60     | .70         | -.06    | .39      |       |
| Ethnicity                | -1.27    | .64         | -.13    | .05      |       |
| Setting (CUES and CUES+) | -3.77    | .89         | -.39    | .00      |       |

*BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

## APPENDIX J: CUES sample regression with demographic variables

**Table 7.1** CUES sample regression with UED severity and demographic variables

| Variable                                                                                | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|-----------------------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                                         |          |             |         |          | .01   |
| UED severity                                                                            | -.01     | .03         | -.05    | .70      |       |
| Age                                                                                     | -.15     | .25         | -.07    | .55      |       |
| Gender                                                                                  | -.08     | .97         | -.01    | .94      |       |
| Ethnicity                                                                               | -2.09    | .95         | -.25    | .03      |       |
| <i>UED</i> Unusual experiences with distress rated using the UEQ (Laurens et al., 2007) |          |             |         |          |       |
| $r^2$ (adjusted)                                                                        |          |             |         |          |       |

**Table 7.2** CUES sample regression with SDQ Emotional subscale and demographic variables

| Variable                                                                  | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|---------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                           |          |             |         |          | .02   |
| SDQ Emotional subscale                                                    | -.13     | .21         | -.08    | .53      |       |
| Age                                                                       | -.12     | .25         | -.06    | .63      |       |
| Gender                                                                    | .19      | 1.02        | .02     | .85      |       |
| Ethnicity                                                                 | -2.09    | .96         | -.26    | .03      |       |
| <i>SDQ</i> Strength and Difficulties Questionnaire (Goodman et al., 2000) |          |             |         |          |       |

**Table 7.3** CUES sample regression with ISMI stigma scale and demographic variables

| Variable                                                               | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                        |          |             |         |          | -.02  |
| ISMI                                                                   | -.07     | .06         | -.15    | .28      |       |
| Age                                                                    | .00      | .27         | .00     | .99      |       |
| Gender                                                                 | -.87     | 1.06        | -.12    | .42      |       |
| Ethnicity                                                              | -.79     | 1.06        | -.11    | .46      |       |
| <i>ISMI</i> Self-stigma of Mental Illness scale (Ritsher et al., 2003) |          |             |         |          |       |
| $r^2$ (adjusted)                                                       |          |             |         |          |       |

**Table 7.4** CUES sample regression with Bullying experiences and demographic variables

| Variable                                                                | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|-------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                         |          |             |         |          | .01   |
| Bullying experiences                                                    | -.05     | .16         | -.04    | .76      |       |
| Age                                                                     | -.14     | .25         | -.07    | .57      |       |
| Gender                                                                  | -.08     | .98         | -.01    | .94      |       |
| Ethnicity                                                               | -2.10    | .96         | -.26    | .03      |       |
| <i>Bullying experiences</i> (adapted from Schonert-Reichl et al., 2010) |          |             |         |          |       |
| $r^2$ (adjusted)                                                        |          |             |         |          |       |

**Table 7.5** CUES sample regression with Adverse life events and demographic variables

| Variable            | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|---------------------|----------|-------------|---------|----------|-------|
|                     |          |             |         |          | .02   |
| Adverse life events | -.24     | .36         | -.08    | .50      |       |
| Age                 | -.13     | .25         | -.06    | .61      |       |
| Gender              | .07      | .98         | .01     | .95      |       |
| Ethnicity           | -2.03    | .96         | -.25    | .04      |       |

*Adverse life events Life Events Questionnaire* (Wilkinson et al., 2009)

$r^2$  (adjusted)

**Table 7.6** CUES sample regression with BCSS negative self and demographic variables

| Variable           | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|--------------------|----------|-------------|---------|----------|-------|
|                    |          |             |         |          | .06   |
| BCSS negative self | -.16     | .11         | -.18    | .13      |       |
| Age                | -.09     | .24         | -.05    | .70      |       |
| Gender             | .34      | .96         | .04     | .72      |       |
| Ethnicity          | -2.39    | .94         | -.29    | .01      |       |

*BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

**Table 7.7** CUES sample regression with BCSS negative other and demographic variables

| Variable            | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|---------------------|----------|-------------|---------|----------|-------|
|                     |          |             |         |          | .05   |
| BCSS negative other | -.08     | .08         | -.12    | .30      |       |
| Age                 | -.12     | .26         | -.06    | .63      |       |
| Gender              | -.01     | 1.01        | -.00    | .99      |       |
| Ethnicity           | -2.42    | 1.00        | -.29    | .02      |       |

*BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

## APPENDIX K: CUES+ sample regression with demographic variables

**Table 8.1** CUES+ sample regression with UED severity and demographic variables

| Variable                                                                                | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|-----------------------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                                         |          |             |         |          | .00   |
| UED severity                                                                            | .02      | .03         | .08     | .42      |       |
| Age                                                                                     | -.29     | .26         | -.11    | .27      |       |
| Gender                                                                                  | -1.41    | .96         | -.15    | .15      |       |
| Ethnicity                                                                               | -.29     | .84         | -.04    | .73      |       |
| <i>UED</i> Unusual experiences with distress rated using the UEQ (Laurens et al., 2007) |          |             |         |          |       |
| $r^2$ (adjusted)                                                                        |          |             |         |          |       |

**Table 8.2** CUES+ sample regression with SDQ Emotional subscale and demographic variables

| Variable                                                                  | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|---------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                           |          |             |         |          | .01   |
| SDQ Emotional subscale                                                    | .28      | .21         | .14     | .18      |       |
| Age                                                                       | -.27     | .26         | -.10    | .30      |       |
| Gender                                                                    | -1.77    | 1.00        | -.19    | .08      |       |
| Ethnicity                                                                 | -.34     | .83         | -.04    | .69      |       |
| <i>SDQ</i> Strength and Difficulties Questionnaire (Goodman et al., 2000) |          |             |         |          |       |
| $r^2$ (adjusted)                                                          |          |             |         |          |       |

**Table 8.3** CUES+ sample regression with ISMI stigma scale and demographic variables

| Variable                                                               | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                        |          |             |         |          | .05   |
| ISMI                                                                   | .13      | .06         | .22     | 2.23     |       |
| Age                                                                    | -.32     | .26         | -.12    | -1.25    |       |
| Gender                                                                 | -1.50    | .94         | -.16    | -1.60    |       |
| Ethnicity                                                              | -.31     | .82         | -.04    | -.38     |       |
| <i>ISMI</i> Self-stigma of Mental Illness scale (Ritsher et al., 2003) |          |             |         |          |       |
| $r^2$ (adjusted)                                                       |          |             |         |          |       |

**Table 8.4** CUES+ sample regression with Bullying experiences and demographic variables

| Variable                                                                | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|-------------------------------------------------------------------------|----------|-------------|---------|----------|-------|
|                                                                         |          |             |         |          | -.00  |
| Bullying experiences                                                    | .06      | .12         | .05     | .61      |       |
| Age                                                                     | -.25     | .26         | -.10    | .35      |       |
| Gender                                                                  | -1.32    | .96         | -.14    | .18      |       |
| Ethnicity                                                               | -.29     | .84         | -.04    | .74      |       |
| <i>Bullying experiences</i> (adapted from Schonert-Reichl et al., 2010) |          |             |         |          |       |
| $r^2$ (adjusted)                                                        |          |             |         |          |       |

**Table 8.5** CUES+ sample regression with Adverse life events and demographic variables

| Variable            | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|---------------------|----------|-------------|---------|----------|-------|
|                     |          |             |         |          | .04   |
| Adverse life events | .50      | .23         | .21     | .03      |       |
| Age                 | -.24     | .25         | -.09    | .34      |       |
| Gender              | -1.41    | .94         | -.15    | .14      |       |
| Ethnicity           | -.15     | .83         | -.02    | .86      |       |

*Adverse life events Life Events Questionnaire* (Wilkinson et al., 2009)

$r^2$  (adjusted)

**Table 8.6** CUES+ sample regression with BCSS negative self and demographic variables

| Variable           | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|--------------------|----------|-------------|---------|----------|-------|
|                    |          |             |         |          | -.00  |
| BCSS negative self | .04      | .07         | .06     | .59      |       |
| Age                | -.29     | .26         | -.11    | .27      |       |
| Gender             | -1.53    | 1.01        | -.16    | .13      |       |
| Ethnicity          | -.29     | .84         | -.04    | .73      |       |

*BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)

**Table 8.7** CUES+ sample regression with BCSS negative other and demographic variables

| Variable            | <i>B</i> | <i>SE B</i> | $\beta$ | <i>p</i> | $r^2$ |
|---------------------|----------|-------------|---------|----------|-------|
|                     |          |             |         |          | -.00  |
| BCSS negative other | .03      | .06         | .04     | .69      |       |
| Age                 | -.26     | .26         | -.10    | .32      |       |
| Gender              | -1.44    | .98         | -.15    | .15      |       |
| Ethnicity           | -.34     | .84         | -.04    | .68      |       |

*BCSS Brief Core Schema Scale* (Fowler et al., 2006)

$r^2$  (adjusted)