Pre-morbid school functioning and trajectories of mental health and social disability in adolescence and young adulthood.

**Adolescent Mental Health PhD Scholarship 2017:** 

School of Psychology, University of Sussex

Supervisor: Professor David Fowler

## Lay Summary:

The ongoing PRODIGY trial is focused on detecting and intervening in cases of adolescents and young adults with severe withdrawal and severe mental health problems. This PhD project builds on this work by gathering data on how participants in the PRODIGY trial who have at risk mental states functioned at school pre-morbidly, using the National Pupil Database. Our aim is to study the course of social disability throughout childhood and adolescence with respect to a range of background factors in terms of school functioning, including attainment, attendance, school exclusion, and special educational needs. This will enable us to examine pre-morbid school functioning with respect to the course of social disability in the early course of psychoses and effects of treatment within the PRODIGY cohort. We also propose to compare this cohort to matched controls to examine the effects of antecedent school factors. We will draw upon our extensive experience using longitudinal modelling in this area.

**Research Student:** Lucie Crowter

Hi, I'm Lucie and I'm due to start a PhD at the School of Psychology, University of Sussex in September 2017. For the past two years I have been working on the NIHR HTA funded PRODIGY youth mental health and social recovery trial (ISRCTN47998710).

I previously attained both my undergraduate degree in Psychology and Masters degree in Foundations of Clinical Psychology and Mental Health at the University of Sussex. For my Masters dissertation I conducted a study

focused on measuring and analysing school children's mental health attitudes.

My research interests focus on the integration of developmental and clinical psychological understandings of social and mental health vulnerabilities and the development of preventative interventions designed to improve the lives of children and young people. I am very happy to have been awarded the Adolescent Mental health scholarship by MHRUK and to have the opportunity to pursue research within this area of interest.

Start Date: September 2017

#### **Scientific Goal:**

Fowler and Banerjee lead an ongoing program of research at the University of Sussex examining the antecedents and course of social disability in young people with and at risk of psychosis. We have a strong track record in this area having completed several trials and cohort studies with young people with psychoses and at risk mental states (Fowler) and investigations of the interface between mental health and social exclusion at school (Banerjee). Our studies have shown that young people with first episode psychosis most at risk of long term social disability often have long histories of difficulties dating back to childhood (e.g., Hodgekins et al., 2015). Related work by Banerjee, including longitudinal analysis, has demonstrated that patterns of social exclusion and withdrawal occur in both primary and secondary school contexts and are associated with specific socio-cognitive, socio-emotional, and mental health profiles.

We currently investigate the emergence of social disability in those with first episode psychosis and at risk mental states (ARMS) presenting to children and young people's mental health services. We have an ongoing randomised full HTA trial (PRODIGY; Fowler Cl and Banerjee co-I) focusing on detecting and intervening in cases with severe withdrawal and mental health problems. We have identified a large cohort of individuals with ARMS (n=270) for whom we examine the course of social disability over 15 months as well as the effects of treatment. The goal of the proposed PhD research is to build upon this project by adding new matched controls who are Not in Education, Employment, or Training, and by tracing back all participants' school functioning as recorded in the National Pupil Database. The work will identify early risk indicators and trajectories in school functioning as antecedents of subsequent patterns of social disability and ARMS.

1. What are the antecedents of ARMS and social disability in terms of functioning at primary and secondary school? Cognitive and academic problems have already been identified as potential risks for the developmental and expression of ARMS, social disability, and psychosis (Allen et al., 2005; Hodgekins et al., 2015; Norman et al., 2008; Strauss et al., 2012). Unfortunately, studies to date have tended to use only retrospective self and/or observer ratings of pre-morbid functioning. However, extensive and detailed data are routinely collected throughout every child's school career, with respect to attendance, attainment, fixed-term or permanent exclusions from school, and any special educational needs (both in terms of type and severity of need). Using contemporaneously recorded data on pre-morbid functioning will offer a substantial novel contribution to our understanding of the risk indicators of ARMS and social disability.

2. What are the trajectories of social activity and disability within ARMS, and can they be predicted by profiles of pre-morbid school functioning? Within ARMS, current activity levels seem especially important in predicting transition to psychosis (Cannon et al., 2008; Yung et al., 2006). In the context of the PRODIGY trial, identifying early school functioning markers of later social functioning trajectories would have two major benefits: a) earlier detection of ARMS cases especially vulnerable to transition to psychosis and to long-term social disability in the context of psychosis; and b) identification of cases most likely to respond to the social recovery treatment tested in the PRODIGY trial.

## Progress Report year 4, 2021

## **Background**

During this PhD, there has been a focus on understanding the development of mental health problems and difficulties with social/occupational functioning in adolescence/young adulthood. Difficulty engaging in meaningful relationships and activities is a key feature of chronic mental health problems and is associated with long-term negative personal, social and economic outcomes. Understanding how these difficulties develop can have implications for the development of appropriate preventive interventions, treatment strategies and the promotion of recovery.

In this PhD, we plan to explore the relationships between functioning and psychological wellbeing in depth. My PhD is linked to a previous NIHR HTA-funded randomised controlled trial:

PRODIGY – a trial which looked at the effect of a novel Social Recovery Therapy for young people (16-25 years) with emerging complex psychological difficulties and social disability (difficulties engaging in social and occupational activities, such as employment, education, voluntary work and leisure activities)

## 2020/21 Update

## SEQual qualitative study

I previously conducted interviews with 11 young people who had taken part in PRODIGY. During these interviews I asked the young people about their time at school and any ways in which they felt their school experiences may have had an impact on their mental health and how they spend their time. Over the past year I have analysed the data from the interviews, which involves looking for themes or patterns across the interviews. The young people talked about a variety of experiences from their time at school, including their relationships with friends and peers, their relationships with teachers, how they felt about the future when they were at school, and their mental health during their schooling. I have written up the findings from these interviews and am preparing a paper for publication.

## **PRODIGY data analyses**

A key area of focus in this PhD is social and occupational functioning. In the PRODIGY study, this functioning was measured using the Time Use Survey, which measures the hours per week that people spend in structured activity. This structured activity is comprised of:

- Paid and voluntary employment,
- · Education and training
- Childcare
- Housework and chores
- Structured sports and leisure activities

Over the past year I have analysed the PRODIGY data to look at the relationships between functioning (time spent in structured activity), feelings of hopefulness and thoughts about the self and others. The aim of these analyses is to better understand social functioning and social disability (severe difficulties engaging in activities that are meaningful to the individual) for young people who are experiencing emerging complex mental health difficulties. The results from these analyses have been written up and I am currently finishing a draft of a paper to be submitted for publication.

## **Next steps**

I am currently writing up my thesis, which involves providing context for the work that has been carried out, explaining what was done and why, what was found, and what the implications of these findings are for current and future research regarding the emergence of mental health problems in the context of difficulties with occupational and social functioning.

#### **Progress Report Year 3, 2020**

#### **Background**

Difficulty with engaging in meaningful relationships and activities is a key feature of chronic mental health problems and is associated with long-term negative personal, social and economic outcomes. Understanding how these difficulties develop, as well as exploring the trajectories of social and occupational functioning over time, can have implications for the development of appropriate preventive interventions, treatment strategies and the promotion of recovery. In this PhD, we plan to explore the relationships between functioning and psychological wellbeing in depth. As part of this, we will investigate the impact of school experiences on later mental health and functioning, by linking research data to school functioning data, as recorded in the National Pupil Database (NPD). My PhD is linked to two research projects:

1) PRODIGY – an NIHR HTA-funded randomised controlled trial, examining the effect of a

novel Social Recovery Therapy for young people with emerging complex psychological difficulties and social disability.

2) TURN-OUT - a research project examining time use and associated wellbeing for young people who are Not in Education, Employment or Training (NEET).

## Matching NPD data to research data

Over the past year I have coordinated a successful application to the Department for Education to access individual school data from the NPD for 81 PRODIGY participants. The application was approved in May 2020 and we are currently awaiting access to the matched data. This application follows a previous approval to access NPD information for ~100 TURN-OUT participants.

With this matched research and NPD data we plan to examine relationships between school functioning and later mental health and social functioning outcomes for young people who are either: i) experiencing emerging complex mental health difficulties; ii) not in education, employment or training; or iii) from a student population. With these analyses, we hope to better understand the early experiences of these groups, and to develop ways to identify and support young people most at risk of chronic difficulties.

# **SEQual qualitative study**

For the SEQual study I conducted interviews with young people who previously took part in PRODIGY. These interviews explored how PRODIGY participants remembered their time at school and any ways in which they felt their school experiences may have shaped their later mental health and how they spend their time. Over the past year I have completed recruitment to SEQual and am currently transcribing and analysing the study data, with a plan to write up the results for publication.

## **PRODIGY data analyses**

This past year I have continued analyses of data from the PRODIGY trial. I have examined relationships between the experience of paranoid thoughts, mood and anxiety symptoms, and negative thoughts about the self and others. Results from these analyses have been written up and are in the process of being submitted for publication. Going forward, I plan to investigate the experiences of social disability (severe difficulties with engaging in meaningful activities) within this group. Participants from the PRODIGY trial were followed up over the course of 2 years, so there is potential to examine the trajectories of social functioning and mental health over time.

## **COVID-19 update**

Recently, I have had the opportunity to support the implementation of an Applied Research Collaboration study examining the mental health and social impacts of the current pandemic on hard-to-reach communities. There will be an opportunity to utilise data from this project within my PhD, which will allow us to explore the impact of COVID-19 and the associated lockdown on social functioning, social connectedness and mental health/wellbeing.

#### **Progress Report Year 2, 2019**

## **Background**

In order to explore the impact of school experiences on later mental health and functioning, we plan to link research data to school functioning data, as recorded in the National Pupil Database. My PhD is linked to two ongoing research projects:

- 1) PRODIGY an NIHR HTA-funded randomised controlled trial, examining the effect of a novel Social Recovery Therapy for young people with emerging complex psychological difficulties and social disability.
- 2) TURN-OUT a research project examining time use and associated wellbeing for young people who are Not in Education, Employment or Training (NEET).

## **Update on progress**

#### Qualitative study:

Over the past year I have been conducting a qualitative study (SEQual), which has been adopted onto the NIHR Clinical Research Network Portfolio. As part of SEQual I have been conducting interviews with young people who previously took part in PRODIGY, asking them about their time at school and any ways in which they think their school experiences may have shaped their later mental health and how they spend their time. I have currently recruited 10 young people to this study, with an aim to recruit a total of 12 participants.

Accessing and linking National Pupil Database information to research data:

TURN-OUT: I have coordinated a successful application to the Department for Education to access individual data from the National Pupil Database (NPD) for TURN-OUT participants. Preliminary analyses on the NPD and TURN-OUT research data have been carried out, with plans to further analyse any associations between school experiences and later wellbeing and functional outcomes for young people who are currently NEET.

PRODIGY: Over the past year, PRODIGY participants have been asked for consent to access their individual National Pupil Database (NPD) from the Department for Education. I have directly obtained participant NPD consents and supervised PRODIGY research assistants with this process (~80 NPD consents obtained across the trial so far). We plan to make an application to the Department for Education to access PRODIGY participants' individual NPD data later this year.

## PRODIGY baseline analyses:

This past year I have also conducted analyses on baseline data from the PRODIGY research trial. One of our initial research aims was to explore the experiences of paranoid thoughts amongst young people, in the context of negative thoughts about the self and others, and the experience of mood and anxiety symptoms. Going forward, we plan to use the follow-up data from PRODIGY to further explore these relationships over time.

## 2018 End of Year 1 report

#### General outline of the body of research:

This PhD is part of a larger body of ongoing work at the University of Sussex, in collaboration with Sussex Partnership NHS Trust. The broad aim of this PhD is to investigate the associations between school experiences and later mental health and functioning. This research has a particular emphasis on the potential to identify, and develop support for, young people most at risk of chronic and severe mental health difficulties.

In order to explore the impact of school experiences on later mental health and functioning, we plan to link research data to school functioning data, as recorded in the National Pupil Database. My PhD is linked to two ongoing research projects:

- 1) PRODIGY (<a href="http://www.sussex.ac.uk/spriglab/research/current/prodigy">http://www.sussex.ac.uk/spriglab/research/current/prodigy</a>) an NIHR HTA-funded randomised controlled trial. PRODIGY is examining the effect of a novel Social Recovery Therapy for young people with emerging complex psychological difficulties and social disability. Extensive mental health and functioning information is collected for PRODIGY participants at baseline, 9, 15 and 24 month follow-ups.
- 2) TURN-OUT a research project examining time use and associated wellbeing for young people who are Not in Education, Employment or Training (NEET). Information regarding wellbeing and functioning is collected for TURN-OUT participants at one time point.

## This year:

I have assisted in the completion of follow-up assessments for the PRODIGY trial and conducted some preliminary analyses on the PRODIGY baseline dataset. We have submitted, and received approval for, a study amendment to ask PRODIGY participants who have completed trial participation whether they provide consent for their individual National Pupil Database (NPD) to be accessed from the Department for Education. Furthermore, this year I have contributed to a submitted publication arising from the PRODIGY baseline data, focused on the added impact of attenuated psychotic symptoms amongst people who also have complex, emerging non-psychotic mental health experiences (Berry et al., under review).

I have liaised with youth services across Sussex in order to promote the TURN-OUT project and have been actively involved in the recruitment of participants. Participants in TURN-OUT are asked to provide consent to access their individual data from the National Pupil Database, and an application to access this data has been submitted to the Department for Education.

To provide context to analyses of school functioning data and research data, a qualitative study has been designed to ask PRODIGY participants about their time at school. We are interested in participants' relationships with peers & teachers, how much they felt a part of the school community and how they felt their school experiences impacted on their mental health. This study has received preliminary sponsorship approval from the University of Sussex and is subject to pending NHS ethical approval.

Over this past year I have conducted a review of the literature regarding functioning and mental health, leading to overall research questions regarding early school functioning and later outcomes. I have also presented this body of research to public and academic audiences.

## What happens next?

Pending successful applications to the Department for Education, we plan to match individual research data from PRODIGY and TURN-OUT to school functioning data (from the NPD), in order to examine associations between time at school and later mental health and functioning. I also plan to conduct the qualitative study with 8-16 people who have completed participation in the PRODIGY trial, in order to better understand their school experiences.