

Mental health in children and adolescents in child welfare institutions

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REVISED PROJECT OUTLINE

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Summary

Background

There is little Norwegian research available on children and adolescents in child welfare institutions and mental health. European and American research, however, shows that mental health complaints amongst children in institutions are extremely widespread and that they do not receive help for this. It is well documented that a large proportion of children who have been subject to child protection measures have major difficulties later in life in regard school attendance and work, but we know very little about their mental health. This project aims to remedy these knowledge gaps in order to provide a research-based aid to young people living in child welfare institutions receiving the health support they need.

Objectives

The project has three main objectives: 1) To gain knowledge about children and adolescents in the age group 12 - 23 years who live in child welfare institution, focusing on mental illness and psychosocial adjustment; 2) To identify institutional circumstances that may be of significance for the health, adjustment and development of the children and the adolescents; and 3) To gain knowledge about the children's and adolescent's need for, and use of, health services for mental health complaints. The project will be able to provide research-based knowledge about what measures may be taken to ensure that these children receive the health support they need, and that the help they receive maximise the probability of positive adjustment and good mental health. The overall aim of the project is to produce knowledge that may be essential to practical policies at the interface between child welfare and child psychiatry.

Methodology

A nationwide selection comprising of 500 young people aged between 12 and 23 and living in child welfare institutions will be studied. In order to achieve qualitatively good data, each individual child will be investigated personally (as opposed to just a questionnaire and records methodology). The following aspects will be studied: history of childhood/adolescence, school and work life, mental health, psychosocial functioning and adjustment, health support, protection factors and institutional influences. Mental health will be examined through a semi-structured diagnostic interview in order to provide ICD-10 and DSM-IV diagnoses. Other information will be collected through test methodology, questionnaires and interview. These data will be linked to various types of records data.

Information about young people will also be collected from the young person's principal contact (in Norwegian 'hovedkontakt', literally 'main contact' – often a nominated staff member within the institution) and teacher. The head of the institution will complete a questionnaire about the institution.

Organisation

The project is a collaboration between researchers at NTNU Samfunnsforskning AS and NTNU. The principal responsibility for its conduct lies with the Regional Child Protection Research Unit for Central Norway (BUS) and the Regional Centre for Child and Adolescent Mental Health for Central Norway (RBUP). A project management group has been established comprising key researchers in the project. The project management group is responsible for the scientific management of the project.

Timeframe

The timeframe for the project is 2010 - 2014.

Contribution

The project aims to establish a research basis for the health support children and adolescents living in child welfare institutions need and the quality of care offered in the institution. In order to meet the substantial need for mental health support expected in this group, it is important to specify the magnitude and type of support these children need. More targeted support could be provided for these children's health complaints and also improved institutional care in order to promote mental health and psychosocial adjustment. It is important to be able to identify aspects of the institution that are linked to future good mental health amongst its residents. Furthermore, it is essential to be able to identify what aspects of the institutions are important for different types of children.

Introduction

It is a belief widely held amongst professionals that a large proportion of children in child welfare institutions have extensive mental health problems, and that they do not receive adequate help for these. Studies from Europe and the USA show that about half of children in child welfare institutions have mental illnesses and that the majority do not receive help for these. From Norway there is a questionnaire survey (CBCL (Achenbach, 2003)) from child welfare institutions in Oslo (Kjelsberg & Nygren, 2004) that indicates that as many as 68% of children may have psychiatric problems. In order for these children to receive the necessary health support it is important that the need for this support, and its existing scale, be documented. Our first objective in the project is therefore to chart how many children in child welfare institutions have mental illnesses, how many are in need of support and how many receive support.

It ought to be an objective for the care of these children and adolescents living in child welfare institutions that this contributes to the best possible psychosocial adjustment and mental health, and at least does not contribute to deterioration in the situation. There is today major variation in the offering to these young people. We do not currently know whether differences in the offering received may have significance for the course of their further development. Our second objective is therefore to investigate what aspects of the institutions and their personnel may be of significance for the psychosocial adjustment and mental health complaints in these youngsters.

Even though it is well documented that many children who have been subject to child welfare measures have major difficulties later in regard to education and work [19], we know nothing about the mental health of these children. Nor do we have an in-depth picture of their subsequent careers other than that provided by records data. It is highly probable that subsequent psychosocial adjustment and mental health varies widely between the children. Which child copes well and what may lie behind this? Our third objective in this project is therefore to produce knowledge about what circumstances seem to underlie both positive and negative courses of development in children and adolescents in child welfare institutions.

In overall terms, the aim of this extensive project is to produce knowledge that may be essential to practical policies at the interface between child welfare and child psychiatry. It is a strength that the project is multidisciplinary and therefore crosses traditional boundaries between child welfare, psychology, child psychiatry and paediatrics. Both psychological and social factors will be investigated in one and the same project. The project will be able to provide research-based knowledge about what potential measures ought to be implemented in order that these children receive the health support they need, and that the measures they receive maximise the probability of positive adjustment and good mental health. Children and adolescents in institutions are current and future major users of public services and only a moderate improvement in their health and adjustment to society may provide significant resource savings.

Research subject

How many children in child welfare institutions have mental illnesses and how many receive mental health support?

We have certain Norwegian studies that touch upon this question. One study showed that children at child welfare institutions in Oslo had scores on a questionnaire about mental com-

plaints just as high as children who had been admitted to children's and young people's psychiatric institutions [40]. However, this sort of questionnaire methodology is not suitable in deciding whether or not a child has a mental illness. For that, much more comprehensive investigation is needed, for example in the form of psychiatric interviews. Studies in which diagnoses have been established show that the incidence varies from 20 % (Denmark, records information) through 50 % (Nutzel, Schmid, Goldbeck, & Fegert, 2005) (Germany, interview), 71 % (Ford, Vostanis, Meltzer, & Goodman, 2007) (England, interview) and 96 % (McCann, James, Wilson, & Dunn, 1996) (England, interview). Such a difference in incidence underlines at the same time the importance of carrying out studies in the relevant country for which knowledge is sought, since legislation, offerings and referrals will vary strongly between the individual countries. In addition little is known about the incidence of double clients, and how many of these children with mental illnesses who need help have received or are receiving such help. It also appears that a substantial proportion of children in institutions who also have mental health complaints do not receive help for these [14, 40].

The inadequacy of information about Norwegian conditions is underlined by what can be deduced from available official statistics. Child welfare statistics show that the child's mental problems are seldom cited as the grounds for initiating child welfare measures. In 2007 only 1% (127) of new cases of children with child welfare measures received help because of their mental problems. Almost half of the children received help because of circumstances at home/special needs. 14% of the children received help because of behavioural problems (for example associated with social deviation and criminality) and 1% received help because of their substance abuse [59]. Both of these categories may be indicative of mental problems. About 2% of children with child welfare measures in the course of 2007 received either psychiatric polyclinic treatment (1.2%) or treatment in "other treatment institutions" (0.9%). The latter category included psychiatric treatment institutions; substance abuse institutions; and residential and working collectives (Kovacs, 2009; SBB, 2008). Note that this is treatment as a child welfare measure and not the proportion of children that receive such help. Statistics from psychiatry (BUP data) show that 2 % (of 53,111 patients) lived in an institution: a category that includes child welfare institutions, but also substance abuse collectives and, for example, homes for the disabled. It cannot therefore be determined how many were in child welfare institutions.

From the point of view of the health service there will not only be a need for an overview of the number of children needing health support, but also what types of illnesses are involved, what causes these problems and what can be done in regard to both prevention and treatment. Our objective in the project is to chart the panorama of illness as widely as possible.

What institutional factors are significant for mental health complaints and different psychosocial adjustment?

There are few studies about the possible effect of institutional placement on the further psychosocial adjustment of child welfare children so placed, but the studies that exist indicate that institutional factors have a certain effect on development [44]. This is significant information since such factors are potentially susceptible to influence. Because knowledge is meagre, it is again essential to carry out national studies since transferability from other countries with other types of institution is uncertain. Research reviews (Andreassen, 2003; Clough, Bullock, & Ward, 2006) have identified a number of predictive factors of the outcome from the period of residence. Our objective in the project is to gain knowledge about what institutional factors have significance for young peoples' psychosocial adjustment. In addition we

shall collect objective data and use questionnaires evaluating the institutions' social atmosphere.

What factors personal to the child, its history and context, are predictive of different courses of mental health complaints and different psychosocial adjustment?

Children in child welfare institutions have been exposed to stresses that, to varying degrees, will challenge their coping ability and make them vulnerable to the development of mental health complaints as well as behavioural and substance abuse problems. In other words, continuing psychosocial adjustment and development of children in institutions follows a variety of courses. As a starting point we can differentiate between four different courses. Even if it is assumed that a significant proportion of these children have mental health complaints, there will be a large group that have only moderate or insignificant complaints. Some of these children will continue a course into adult life with continuing insignificant or moderate complaints. This is the first and "robust" track. On the other hand, other children who have few difficulties to begin with will develop such difficulties in the course of their stay in the institution or later. Other children again will have significant difficulties to start with, but manage to come through these and will have limited, or perhaps just few, mental health complaints or psychosocial adjustment difficulties at the end of their adolescence. A fourth group of youngsters start out with significant difficulties that continue, or are even reinforced, through adolescence and early adult life.

What factors contribute to deciding the different courses of development? We shall base our answer to this complex question on a psychological, social and contextual perspective. This means that we will collect information from several explanatory levels: in detail, psychological factors personal to the child (for example emotional regulation and cognitive ability level); social factors (for example relationships with peers and adults); as well as contextual factors (for example institutional and school life factors).

Explanatory variables - risk and protection factors for development of mental health problems and difficulties in psychosocial adjustment

We assume that in general the factors that affect the mental health of young people in institutions are the same as for other young people. The exception is that institutional factors may contribute. The relationship with parents and parent-child interaction occupy a vital place in explaining the development and continuation of difficulties in adolescence in general. From a historical perspective this will have been an important source of influence for the young people under discussion here, regardless of whether it is a matter of biological parents or foster parents. Some will also have contact with their parental figures while they are at the institution. In any case these young people will have relationships with the staff, and in many ways the staff will act in the parental role for these youngsters. However, the staff work a normal working day, they are away during holidays and there can be a large turnover, meaning that these young people will have much greater problems in developing stable relationships with adults than those who grow up in a family.

Based on previous research on child welfare children and the incidence of different difficulties in this age group, the main weight of mental health problems is covered by (in DSM-IV terminology) behavioural disorders, ADD/ADHD, depression, anxiety, learning difficulties and substance-related disorders. Even though the incidence in the general youth population is

low, there is a clear possibility that a proportion of children in child welfare institutions will also suffer from attachment disruption and post-traumatic stress syndrome/disorder (PTSD). In regard to psychosocial adjustment, difficulties not covered by the illnesses mentioned above, the most important areas will involve adjustment and participation in school and working life, social networks and social functioning in relation to friends and at the institution.

Individual risk and protection factors will be unique for the relevant mental health problem or psychosocial adjustment difficulty. Nevertheless, the rule is that few specific explanatory variables exist for such problems. Even in a broadly pitched project like this, it will not be possible to cover the entire spectrum of potential explanations. In what follows we shall therefore take as a starting point some of the empirically potent explanatory variables for a cluster, or even the majority, of complaints.

Social circumstances and childhood/adolescence

History. A significant proportion of children in institutions may have faced risk factors for the development of mental health problems even at the fetal stage: for example exposure to intoxicants/substance abuse, stress and malnutrition. Unstable attachment factors, for example through changes of carer; inadequately growth-promoting family relationships; abuse and violence in childhood/adolescence; all will further increase the risk weighting. Despite comprising a much burdened group in terms of previous negative impact factors, the quantity and content of these will vary substantially, as will the young people's ability to cope with a difficult starting point.

School. For ordinary young people, completion of schooling is a significant factor in successful transition to adult life and integration into groups of friends. Dropping out from school, on the other hand, is associated with a range of negative factors such as subsequent unemployment [46], use of social security benefits [26], substance abuse [22] and criminality [35]. There are also risk factors that increase the chance of dropping out of school. These are, on the one hand, subject and school-related, such as poor marks, low aspiration/self-belief and low educational motivation, and on the other hand, factors relating to mental health, such as anxiety complaints [24] and behavioural difficulties [10]. Not surprisingly, children in child welfare programs have poorer results at school [8] and generally more unstable linkage to working life than other young adults [19]. It is therefore essential to identify factors that increase the probability of good adjustment to school and of completion of education.

Competence and network. Social competence is fundamental to successful adjustment. Good social abilities protect against the development of mental health problems [15] and seem to contribute to good adjustment to school, even though other factors (for example ability) are controlled [69]. Furthermore, social support is assumed to protect against the development of difficulties, in particular depression, through functioning as a buffer against negative life events [21]. Children in child welfare institutions seem not only to have poorer adult networks, but also less access to friends who can provide different forms of social support [7]. Since access to social support is potentially susceptible to influence, we shall therefore investigate whether reduced social support (and social competence) puts child welfare children further at risk of developing mental health complaints, including when other social and personal factors are controlled.

Psychological factors

Personality. Even early precursors of individual personality traits, i.e. baby and toddler temperament, are predictive of psychopathology in adulthood [51]. In childhood and the adolescent years the connection between personality traits and mental health problems is strong [13, 16, 17]. Personality is generally difficult to modify and one could therefore argue that there is little purpose in measuring factors that cannot be changed. Personality will however dispose for other personal risk and protection factors: for example self-image. It is therefore essential to control for variations in personality traits between child welfare children, so that other differences in personal characteristics are not erroneously seen as the source of protection or risk, when these are a reflection of variations in personality.

Self-image. A low self-image during adolescence seems to predict subsequent increased risk of criminality and poorer psychosocial adjustment, beyond the effect of previous mental health problems [66]. Possibly a more positive view of oneself leads to one not giving up

when one meets resistance, of which child welfare children will meet plenty, and that one therefore more often succeeds [62].

Attachment. Achieving a secure attachment to one or more carers is assumed to be one of the fundamental development tasks in the initial years of life [2, 12]. The quality of the attachment (the emotional bond) between child and parent is assumed to result in the development of forms of *internal working models*: i.e. assumptions about oneself, other people and about the relationship between others and oneself [12]. It is believed that such working models are built up through the interaction with the primary carers early in life. Originally a secure form of attachment (Type B) was described and two insecure forms, avoidant attachment (Type A) and ambivalent attachment (Type C) [2]. A third form of insecure attachment, disorganised attachment (Type D), was described later. This presents as a continual alternation between different attachment styles without the child finding a modus that seems to help in stressful and threatening situations. Insecure attachment seems to be predictive of subsequent mental health problems [45, 61], at least within the childhood/adolescence timeframe. Child welfare children are expected to display an over-frequency of insecure or disorganised attachment in which clinical attachment disturbances are also part of the picture [71]. Nevertheless a proportion of the children will have formed good attachments to one or both parents, to foster parents or to other adults. Surprisingly enough, the incidence of attachment styles and the consequence of any insecure attachment have been studied only to a limited degree in ordinary child welfare children. Therefore we do not know how many of these children have insecure or disorganised attachment and nor do we have knowledge about the relative significance of different attachment styles.

Emotion regulation. Essential to children's social adjustment is their ability to handle emotions, and behaviour that arises out of emotions, in a satisfactory way [18]: in other words effective emotion regulation. Difficulties in emotion regulation (both over-control and under-control) are linked to subsequent mental health complaints [18]. A key factor in emotion regulation is the ability to stabilise oneself after having been in a sad and dysphoric mood ("mood repair"). This ability is related both to neurological factors, in the form of atypical activity in different areas of the brain, and factors in the mother-child interaction [41]. At the same time, good ability to regulate emotions in an adjusted way also seems to protect youngsters against negative environmental factors [41].

Neuropsychological factors and general competence level. The ability to process stimuli is fundamental to our adjustment to the environment. A range of difficulties in recognition, interpretation, storage and retrieval of information is connected with mental health complaints. One of these competences is executive functions: that is to say a higher order construct that comprises three elements: a) the ability to shift between tasks or focus, b) the ability to inhibit prepotent responses, and c) the ability to update and to monitor the content of working memory ("short-term memory") [50]. For example, difficulties with executive functions are linked to depression [57], anxiety [3] and behavioural difficulties [52], and in particular to ADHD [9].

Other neurocognitive difficulties are also risk factors for mental health complaints: language difficulties, and better executive abilities than language abilities, seem to be predictive of behavioural difficulties [63]. Reduced episodic memory is also associated with certain forms of anxiety [3]. Orphanage children who have been subject to early and serious under-stimulation have a range of neurocognitive deficits, even if their IQ is within the normal area [11]. Even though there are some small studies of cognitive functioning in institutionalised children and

those placed in foster homes [53, 56], so far we have no knowledge of how widespread these difficulties are or what types of difficulties dominate the picture. Nor do we know the extent to which these cognitive difficulties, or strengths for those children who have normal skills, represent a risk of/protection against subsequent development of mental health complaints. Even though the extent to which such cognitive skills will be the objective of possible measures is limited, it is essential to clarify the youngsters' limitations so that both residential care and schooling can be adapted to the individual's strengths and difficulties. If not, fundamental cognitive deficiency may be interpreted as inadequate interest, inadequate perseverance or willpower: something that may lead that young person and her/his circle (for examples teachers or staff) into disadvantageous patterns of interaction.

Coping and cognitive style. How we think about others and about ourselves, and how much confidence we have in our own ability to cope with challenges, are predictive of our way of acting, our success in social contexts as well as the development of mental health problems. In this project we shall focus on two areas within this wide field of research, namely interpretation of a) social situations and b) coping style. A negative cognitive attribution style - i.e. to ascribe the cause of negative occurrences to internal, stable characteristics in oneself, whereas success is explained through external factors, is associated with the development of depression [36]. To attribute negative, possibly hostile intentions to others when one faces an ambiguous social situation disposes for subsequent development of antisocial traits [23].

Biological factors

Biological/medical factors may also impact on mental illnesses and psychosocial adjustment in children and adolescents. This also applies to genetic factors and the development, structure and functioning of the brain. It would be desirable to study genetic and organic brain factors in the project in order to gain as wide a knowledge as possible in explaining mental health complaints and adjustment in young people, but for resource reasons this will not be carried out.

In summary we shall answer three overall questions through this study:

1. How widespread are mental health complaints in children in child welfare institutions, and how is their psychosocial adjustment otherwise? How many children in need of health support for mental illnesses receive such health support?
2. What institutional factors contribute to promoting favourable development in the child and what factors can hinder this?
3. What factors in the child's history and life situation seem to promote favourable development in regard to mental health and psychosocial adjustment, and what factors lead to deterioration?

We have a unique opportunity in this study to examine what factors impact on the child's functioning. As far as we are aware such a broad evaluation has not been carried out previously. The study will provide a nuanced picture of what the problem is, what ought to and can be done for the individual child (psychiatric treatment, medication, changed schooling, transfer to another care situation etc.) and what the prognosis is for the individual child. A picture will also be obtained of which children fit into the structure that child welfare institutions have today and whether the institutional offering ought to be expanded or changed.

Method

Design and selection

A nationwide selection.

Since one of the objectives is to chart the situation for children at child welfare institutions in Norway, we shall study a nationwide selection. In order to achieve a thorough enough picture of these children we shall study each individual child, in contrast to studies in which children themselves and/or staff complete a questionnaire. Our methodology is therefore much more time-consuming and costly, and it will therefore not be practicable to study all these children in Norway. Nor is this necessary in order to produce reliable and nationally representative estimates. We aim to study a random selection of 500 children through a cluster selection. We estimate a participation percentage of 70, meaning that 715 children will be asked. By our reckoning this will give us the most reliable estimate within a manageable financial framework. Such an approach means that the test personnel must travel around the country and examine children in different institutions. All children at the selected institution who are aged 12 or older, and for whom the formal requirements for participation are met (including consent), will be studied.

Data collection - procedure

Based on a database covering all the institutions in the country, a list will be prepared of institutions (departments) that will be asked to participate in the study. An estimate has been made to achieve a percentage distribution of children in each geographic region. The departments at the different institutions are arranged randomly and will be contacted in the order in which they are arranged. We shall continue to contact departments on the list until the number of children estimated in each region is reached. The project coordinator will call the institutions to inform that they have been selected to take part in the study. Those institutions wishing to participate will be sent an information package, comprising of an information letters to managers, principal contacts, children/adolescents and parents, and consent declarations. After the necessary consents have been obtained, an investigation will be carried out (test, interview and questionnaire) of residents who have consented. The investigation of a resident will take two half days and we shall therefore ask that the children and adolescents to be released from school or work for this period. The participants will receive a gift card for NOK 500 for their time used. Heads of institutions will complete the questionnaire on the institution's social environment, organisation, operation, structure and professional methodology approaches. The principal contact will be interviewed about the child and complete the questionnaire about health and quality of life. The child's teacher will complete the questionnaire associated with various factors concerning the child and the relationship to the teacher. Cf. "overview of tools" below. Information will also be collected from various relevant records.

Tests and questionnaires	Area	Informant
CAPA	Child psychiatric interview	Young person
CANTABeclipse	Neuropsychology	Young person
WASI	Intellectual ability test	Young person
Supplementary interview of the young person	Care/school/treatment	Young person
Questionnaire SDQ	Emotional/behavioural problems	Young person
SPPA	Self-image	Young person
DERS	Emotion regulation	Young person
KINDL	Quality of life	Young person
SSQ	Social support	Young person
SSRS	Social functioning	Young person/teacher
COPES	Institutional environment	The young person/institution represented by head
Questionnaire about the institution	Objective information	Institution represented by head
Interview about the young person	ADHD/attachment disturbance/Asperger	Institution represented by head
Questionnaire CBCL	Mental health	Institution represented by head
KINDL adult	Quality of life	Institution represented by head
Questionnaire TRF	School - mental health	Teacher
SSRS/Social Coping	Social skills	Teacher
Psychosocial difficulties	Psychosocial difficulties	Teacher
TSRI	Teacher/student relationship	Teacher

Pilot study

The project "Mental health in children in child welfare institutions" demands comprehensive data collection and each young person will go through a comprehensive battery of tests and questionnaires. This should be carried out in a day and is estimated to take between five and seven hours.

To preclude the possibility of data collection being overly burdensome for the children and adolescents, it was decided to carry out a pilot study within an almost identical interview context as in the main project. The aim was to gain knowledge about the burden on the young

people and find whether anything could be improved/adjusted. In addition, the pilot study was to give information about the suitability of the test and questionnaires, the most advantageous sequencing of their use on the young people and logistics in connection with the interviews.

It was decided to select two institutions with a total of 10 young people to participate in the pilot. The three research assistants who will work on the main project were to interview/test under the leadership of the research coordinator. The pilot was followed up by a user survey to obtain the young people's views on what they had experienced, both negative and positive, and obtain advice on what ought to be done differently. The same applied to heads and the young people's principal contacts at each of the institutions, as well as the research assistants who collected the data¹.

Drop-out study

Results from the pilot project showed that the institution could consent to participate in the study at the same time as the institution's management "selected out" (excluded) individual potential informants. This was *inter alia* because the management considered the young people to be too sick to participate and/or that participation became too stressful for them. When institutions selected for the main study were contacted, certain institutions also indicated that they would not participate partly because they considered that their residents, for various reasons, could not cope with this. Since such a drop-out would weaken representativeness and produce a skewed selection in which a number of young people with mental and other difficulties would not be included in the study, it was decided that application should be made to the REC to conduct a drop-out study. This would be by collecting data on these young people using CBCL completed by an adult at the institution who knows the child/young person well: preferably the child's principal contact.

Procedures have been prepared for collecting and storing data from the drop-out study. These ensure full anonymity.

The drop-out study was approved by the REC in a letter dated 23 July 2011.

Ethics

Ethics and protection of personal information for the individual

We are clear that the young people (and other informants) must deal with a lot of questionnaires and tests in this project and we have debated whether this may be too great a burden on the young people. Our experience from previous research at BUS where we have interviewed young people in institutions, is that they like to be involved in projects, they like to be listened to and to be at the centre of attention. We shall provide the young people with comprehensive information about the project in advance and also tell them why we want to carry out just such a project. It will be entirely voluntary whether the young people participate and they can withdraw underway. From general considerations of ethics and with a view to achieving a high participation percentage, it is important to brief the youngsters thoroughly that the information will be treated as confidential. Before the main project starts, a pilot study will be

¹ The pilot was conducted in March/April 2011. The results from the pilot study have been imparted in an internal report from BUS, NTNU Samfunnsforskning AS. The project has been adjusted in accordance with results from this. This covers for example adjustments in logistics and information letters to make the content and objective of the project clearer, as well as to make access to information easier. In addition CAPA and CANTABeclipse have been reduced, and the methodology in the test/interview situation has been changed to accommodate the needs of the informants.

conducted in which the ethical aspects associated with the content and scope of tests and interviewing of the individual young person will be assessed. Necessary permissions will be obtained from REC.

Stigmatisation of child welfare children?

It is probable that the project will conclude that a significant proportion of children in child welfare institutions have mental difficulties. Such factors will naturally enough be discussed in the media. This may be perceived both as further stigmatisation of an already vulnerable group as well as seeming stressful for those who are in child welfare, or have been. The researchers will therefore be particularly careful about what is published, and how. One can never fully guard against sensationalistic reporting. However it is our view that it is more unethical *not* to carry out this research than to do it. To ignore, or to wish not to know anything research-based about the assumed significant health complaints with which these youngsters struggle, may be seen as more ethically dubious than to investigate this thoroughly. The objective must be to improve the life situation of these young people, both now and in the long term. Effective measures to improve the situation must be research-based and not only based on assumptions or unsystematic observations.

Revealing support needs for mental difficulties

Since a thorough interview will be conducted with the young person, we would anticipate that in a number of cases an unmet support need for mental difficulties will be revealed. It will be research assistants who conduct the individual interviews and they will not have competency to take decisions on the need for further measures. Where such possible needs for support are discovered, this will be discussed in a reference group internal to the project, comprising competent health personnel (specialists in clinical psychology, child psychiatry etc.). Where there are considered to be grounds for referral a process towards this will be started. However this in itself raises additional ethical and legal considerations.

Where the participant in the project is under 16 years of age, i.e. under the age of competence to give independent consent, representatives of the project will enter a dialogue with the person having parental responsibility to prepare the ground for referral to the child and adolescent psychiatrist (or others). It is the person with parental responsibility that must contact either a doctor or the head of the child welfare unit, who are the two with the authority to refer onwards. The researchers in the project do not have referral rights.

Where the participant is over 16 years of age we will contact the young person personally. Where the youngster so consents, the person with parental responsibility will be informed, but this is something the young person can reject. The objective will be the same as above. In both cases it applies that the person contacted is of course entitled to abstain from asking for health support. The exception will be where there is serious danger to the life or health of the young person or others, as for example in the event of explicit risk of suicide.

In the following cases the young person/person with appropriate legal authority will be contacted: psychosis or suspected psychosis, serious eating disorders, serious depression and bipolar disorders, extensive developmental disturbances, clear risk of suicide, as well as other conditions with significant dysfunction or illness.

Organisation of the project

The project is a collaboration between a number of research groups at NTNU and NTNU Samfunnsforskning AS. As a whole, these groups have comprehensive experience and

knowledge within the field of child welfare and mental illness in children and young people. The project is multidisciplinary and thus crosses traditional boundaries between child welfare, psychology, child psychiatry and paediatrics. A central research group (project management group) will be responsible for the scientific effort in the project and has the deciding authority in regard to this. This group comprises Professor Ann-Mari Brubakk (Medical Faculty), Associate Professor/Senior Consultant Thomas Jozefiak (Medical Faculty), Head of Research Torill Tjelflaat (NTNU Samfunnsforskning AS) and Professor/Head of Research Lars Wickstrøm (NTNU Samfunnsforskning AS/NTNU). One of the researchers in the group has the day-to-day responsibility/administrative coordination of the content and progress of the project (Torill Tjelflaat). Senior Researcher/Research Coordinator Nanna Kayed, NTNU Samfunnsforskning AS, is not a member of the project management group but is required to attend its meetings. Thomas Jozefiak is responsible for work associated with RBUP's (Medical Faculty) grant, and Torill Tjelflaat has the same responsibility in regard to BUS (NTNU Samfunnsforskning AS). An expanded researcher group has also been established comprising other research colleagues in the project. A data management committee has been established comprising the members of the project management group and the research coordinator.

The project is organised as *one* project, and has joint reporting to the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) and the Norwegian Directorate of Health. A cooperation agreement has been signed between NTNU Samfunnsforskning AS represented by its Managing Director, Bente Aina Ingebrigtsen, and the Department of Neuroscience, Faculty of Medicine, NTNU represented by the Head of Department, Lars Jacob Stovner. A consortium agreement has been prepared between the key parties in the project, entered into by Turid Suzanne Berg-Nielsen, Ann-Mari Brubakk, Torill Tjelflaat and Lars Wichstrøm.

Progress

The project plan for the whole project period 2010-2014 is attached as Appendix 1.

Budget

The budget for the whole project period 2010-2014 is attached as Appendix 2.

15 Nov 2011
Torill Tjelflaat

Literature

- Achenbach, T. M. (2003). *Manual for ASEBA School-Age Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Andreassen, T. (2003). Behandling av ungdom i institusjoner. Hva sier forskningen? Oslo.
- Clough, R., Bullock, R., & Ward, A. (2006). What Works in Residential Child Care. A review of research of research evidence and practical considerations. London.
- Ford, T., Vostanis, P., Meltzer, H., & Goodman, R. (2007). Psychiatric disorder among British children looked after by local authorities: comparison with children living in private households. [Article]. *British Journal of Psychiatry*, *190*, 319-325. doi: 10.1192/bjp.bp.106.025023
- Kjelsberg, E., & Nygren, P. (2004). The prevalence of emotional and behavioural problems in institutionalized childcare clients. [Article]. *Nordic Journal of Psychiatry*, *58*(4), 319-325. doi: 10.1080/08039480410005846
- Kovacs, M. (2009). *Affect regulation, mood repair and juvenile-onset depressions*. Paper presented at the International Conference Sponsored by ESCAP, Budapest.
- McCann, J. B., James, A., Wilson, S., & Dunn, G. (1996). Prevalence of psychiatric disorders in young people in the care system. [Article]. *British Medical Journal*, *313*(7071), 1529-1530.
- Nutzel, J., Schmid, M., Goldbeck, L., & Fegert, J. M. (2005). Psychiatric support for children and adolescents in residential care in a german sample. [Article]. *Praxis Der Kinderpsychologie Und Kinderpsychiatrie*, *54*(8), 627-644.
- SBB. (2008). Statistisk sentralbyrås årlige barnevernstatistikk. Tabell 5 "Barn med barnevernstiltak i løpet av året, etter alder og tiltak i 2007.