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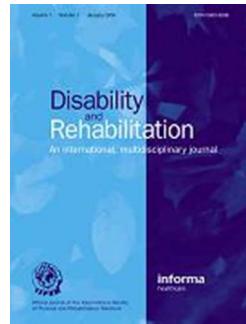
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## **Experiences of employment amongst young people with juvenile idiopathic arthritis: a qualitative study.**

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Manuscript ID	TIDS-04-2016-041.R2
Manuscript Type:	Research Paper
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Manuscripts

1 Young people, employment and arthritis.  
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3 **Experiences of employment amongst young people with juvenile idiopathic arthritis: a  
4 qualitative study.**

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10 **Abstract**  
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13 Purpose: This study explored expectations and experiences of employment amongst young  
14 people with **JIA**juvenile idiopathic arthritis, and the role of health professionals in promoting  
15 positive employment outcomes.  
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18 Methods: Semi-structured interviews (n=13) and three focus groups (n=9,n=4,n=3) were  
19 conducted with young people (16-25y) and adults (26-31y) with juvenile idiopathic arthritis JIA  
20 and semi-structured interviews (n=9) were conducted with health professionals. Transcripts were  
21 analysed thematically.  
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23

24 Results: Young people with juvenile idiopathic arthritis JIA have concerns about employers'  
25 attitudes towards employees with long-term health conditions and lack knowledge of anti-  
26 discrimination legislation. Young people not in education, employment or training identify  
27 arthritisJIA as a key barrier. Challenges associated with JIA-arthritis (e.g. pain, psychological  
28 distress) may not be visible to employers. Decisions about disclosing arthritisJIA are challenging  
29 and cause anxiety. Young people associate good disease management and access to flexible and  
30 convenient care with their capacity to succeed in employment. Psycho-social and vocational  
31 interventions have benefited some young people, but are not routinely available.  
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34 Conclusions: Low expectations of employers may affect young people's decisions about  
35 disclosure and seeking appropriate support in the work place. Health professionals can equip  
36 young people with knowledge and skills to negotiate appropriate support, through signposting to  
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3 anti-discrimination information and offering practice of transferable skills such as disclosure in  
4 consultations.  
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## 10 **Introduction** 11

12 Young people with childhood-onset chronic conditions, such as juvenile idiopathic arthritis  
13 (JIA), are less likely to be employed in adulthood<sup>1-4</sup>. This link between poor health in  
14 adolescence and lower employment rates in adulthood, has been recorded in both physical<sup>1-4</sup> and  
15 mental health conditions<sup>4</sup>. JIA is the most common inflammatory joint disease in childhood and  
16 persists into adulthood in at least a third of young people<sup>5</sup>. It serves as a useful exemplar of a  
17 relapsing and remitting long-term health condition which can be visible or invisible and can  
18 cause varying levels of disability over time<sup>5</sup>. The management of JIA has improved rapidly in  
19 recent decades, with effective new drugs and multi-disciplinary care<sup>6</sup>. This has led to an  
20 improvement in clinical outcomes for many patients<sup>7</sup>, which may facilitate~~should enable~~ more  
21 young people with JIA to work.  
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The majority of the literature about employment for people with chronic conditions focuses on adult-onset disease and young people's needs may be different. For example, adult onset inflammatory arthritis is associated with increased unemployment compared to controls<sup>8</sup> and significant adult rheumatology literature is devoted to understanding employment experiences<sup>9</sup> and evaluating interventions towards maintaining or resuming work<sup>10-12</sup>. While this literature may be of some relevance, the employment related experiences and needs of young people with JIA are not well understood. In 2012, a thematic synthesis of 27 qualitative studies of experiences of JIA<sup>13</sup> found only one study focussing on employment<sup>14</sup>. Most of the adolescents

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in this study worried about discrimination and those in whom JIA was not visible felt a dilemma about disclosing their condition to potential employers<sup>14</sup>. Canadian surveys of work experiences amongst young adults with rheumatic disease (including JIA) reported significant disease related absenteeism, job disruptions and productivity loss<sup>15</sup>. Entering the workplace with a long-term health condition and no prior work experience is likely to present different or additional challenges, compared to developing a long-term health condition as an adult during a career of work. This may explain why adults with childhood-onset systemic lupus erythematosus (jSLE) were less likely to be employed than those with adult-onset SLE, independent of demographic and disease characteristics<sup>16</sup>.

Professionals caring for young people with JIA appear uncertain how best to support this group into employment<sup>17-19</sup>. A key component of the care of young people is their transition to adult-centred services<sup>20</sup>. Addressing vocational issues during this time is integral to transitional care programmes, for example by asking about career plans, work experience and participation in household chores to promote vocational readiness<sup>20-23</sup>. However, a study exploring adolescents' perspectives of their pre-vocational and early employment needs reported limited, uncoordinated services<sup>14</sup> and several studies have reported unmet training needs amongst paediatric and adult health professionals with respect to vocational issues<sup>17-19</sup>. The objectives of this study were to explore the expectations and experiences of employment amongst young people with JIA, and the actual and potential role of the multi-disciplinary team in promoting positive employment outcomes. This study focuses primarily on young people aged between 16 and 25 years, when a majority of young people in the UK complete full time education and many enter employment<sup>24</sup>.

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5 **Methods**  
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7 The methodological approach taken was *qualitative description*, as described by Sandelowski  
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9<sup>25,26</sup>. This is a naturalistic and pragmatic approach to qualitative research, which aims to produce  
10 low-inference descriptions of data in everyday language, and leads to minimally theorized  
11 findings, of practical value to practitioners and policy-makers.  
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14 Interviews and focus groups were used in three phases of data collection. The *exploratory phase*  
15 involved semi-structured interviews with i) young people with JIA and ii) health professionals  
16 engaged in their care. All participants for this phase were recruited from a large, UK teaching  
17 hospital with an established adult JIA service<sup>27</sup>. The *validation phase* entailed focus groups with  
18 young people with JIA at this and two further teaching hospitals in other UK cities. The aim of  
19 this phase was to test whether different geographical settings or group dynamics would produce  
20 additional or contrasting perspectives. The *final phase* comprised interviews with i) young  
21 people with JIA, ii) adults with JIA and iii) health professionals at all three sites to test and refine  
22 the emerging themesories.  
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25 To be eligible for this study, young people were aged from 16 to 25 years, had a diagnosis of JIA  
26 and were under the care of a rheumatologist; adults were aged 26 years or over, had a diagnosis  
27 of JIA and were under the care of a rheumatologist. This study focussed on young people aged  
28 16 to 25 years, reflecting the age group attending UK young adult rheumatology services and  
29 encompassing the period of leaving full time education and entering employment for many  
30 young people. Adults aged 26 to 31 years were included to take into account trends towards  
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3 longer periods in education and training<sup>24</sup>. Patients were invited to participate at a routine follow  
4 up appointment by their rheumatologist or another member of the multi-disciplinary team,  
5 between December 2012 and May 2014. Initially, patient participants were chosen to provide  
6 maximum variation of age, gender, disease severity, educational attainment and employment  
7 status. Health professional participants were recruited to represent the key disciplines involved in  
8 their care. As themes emerged, theoretical sampling<sup>28</sup> was undertaken, seeking cases-were  
9 sought to revise, challenge or add to the analysis.

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The initial interview schedule was developed using a review of relevant literature and unreported data from a previous questionnaire<sup>29</sup>. That questionnaire, which was un-validated, used both multiple choice and open ended questions to collect exploratory data on education and employment histories and experiences in an adult JIA population. The researchers adopted a conversational style for both interviews (HH) and focus groups (HH and RH), to encourage a comfortable and fluent dialogue rich in detail, while using a schedule as a reference to ensure that key topics were covered. HH is a research nurse with experience of working in specialist young adult JIA services and known to the majority of participants at one of the centres but not currently involved in their clinical care. RH is a research associate, not previously known to many of the participants. Recordings were transcribed verbatim and given a unique study number to preserve participants' anonymity. The transcripts were analysed in an iterative cycle, the analysis carried out concurrently with data collection, which allowed for new lines of enquiry to be followed in subsequent interviews<sup>30</sup>. Initial analysis involved familiarisation with the data: listening to the audio recordings alongside active reading of the transcripts, making notes and highlighting issues of interest. Initial coding (simple codes, preserving action, staying close to

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the text) was applied to the transcripts from the first data collection phase<sup>28</sup>. As data collection and analysis progressed, more focussed coding was employed: using the most significant or frequent earlier codes to sift large amounts of data<sup>28</sup>. Mapping (creating visual representations of relationships among codes and themes) was used to assist the grouping of codes into themes<sup>28</sup>. The analysis was conducted by the researcher (HH), with sections of the transcripts co-coded and discussed with other team members. Emerging themes were debated and challenged at data analysis workshops involving the wider research team, of including researchers, health professionals and patient representatives. The group reviewed, discussed and reached agreement on the initial data analysis work of the researcher (HH), through reference to extracts of the raw data. Ethical approval was obtained from the National Research Ethics Service (NRES) Committee North West – Greater Manchester East, UK (Ref 12/NW/0690). Written, informed consent was obtained from each participant.

## Results

### *Sample*

A total of 10 young people with JIA were interviewed, a further 16 young people attended focus groups and three adults with JIA were interviewed. There were a total of 29 patient participants, with a median age of 22 years (range from 16 to 31 years) and two thirds of participants were female (19/29). Many (21/29) were being treated with traditional and/or biological disease modifying anti-rheumatic drugs (DMARDs). Three quarters of participants (22/29) were in full or part-time employment (see table 1). Nine health professionals, including rheumatology

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3 specialist nurses, rheumatologists, occupational therapists, physiotherapists and psychologists,  
4  
5 were interviewed (see table 2).  
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7 [Tables 1 and 2]  
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10 There were some similarities in young people's experiences of education and training as  
11 compared to employment, but also some marked differences. Where similarities existed, the  
12 results have been reported collectively, using the term education, employment or training (EET).  
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14 Conversely, where there were differences between participants' experiences of education and  
15 employment, these results have been reported separately.  
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24 ***Expectations of employment***  
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26 ***Determination to work***  
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28 The young people in this sample wanted to work, irrespective of current occupation, disease  
29 severity or duration. Most wanted to work full time, with the exception of planned breaks for  
30 study or child care. Some young people demonstrated significant commitment to their career  
31 choice and willingness to surmount barriers caused by JIA. For example a nurse recalls learning  
32 to perform chest compressions with restricted wrist flexion:  
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35 *It's my hands that have caused me the most problem. But I didn't want it to stop me from  
36 being a nurse. We [nurse educator and I] had a discussion about it, we tried various  
37 different ways and then we worked out what would be best to sustain an effective  
38 compression. (participant 2:13)*  
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41 Others had chosen or changed jobs and careers in order to accommodate aspects of their disease.  
42 Due to the effects of their disease certain young people with JIA felt they could not pursue more  
43 physically demanding jobs such as sports coach, military or fire service. Missing a significant  
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amount of schooling was another reason some young people changed their aspirations. Those interviewees not engaged in EET identified their diagnosis as a key barrier.

10 *Low expectations and limited knowledge of anti-discrimination legislation*  
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12 Young people in this sample had concerns about employers' attitudes towards employees with  
13 long-term health conditions. Most young people were offered additional support in education and  
14 training, though not all had accepted the assistance. Examples of support included extra time in  
15 exams, flexible hours and use of a lap top computer. Young people did not expect equivalent  
16 assistance in the workplace, expressing concerns about employers' willingness to support  
17 employees with long-term health conditions.  
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26 *A lot of places wouldn't adapt something [for employee with JIA]. Obviously they're going  
27 to have to put in money and time. I think a lot of places wouldn't even think about it.*  
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30 (participant 2:11)  
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33 Examples of additional support and concessions in EET were collated from the phase one  
34 interviews and presented at the phase two focus groups. The examples tended to be simple and  
35 inexpensive, such as altering work patterns to switch task or take a break more frequently (see  
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40 appendix 1supplementary material). Focus group participants were asked to say which examples  
41 they would expect as standard from an employer. There was no consensus on this minimum  
42 standard of support, but all the groups identified very few examples. Some participants explained  
43 that their views were based on their own experiences of highly varied support in different roles  
44 or working for different line managers, sometimes even within the same organisation. Where  
45 employers had been supportive, young people often characterised themselves as 'lucky' and did  
46 not expect this always to be the case.  
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3 *I'm quite lucky because I get on with my managers so they're understanding, I know in  
4 some places it's not so understanding. (participant 2:10)*

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6 Many young people worried about active discrimination, particularly during recruitment and few  
7 were prepared to state their JIA on a job application form (see figure 1).  
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15 Young people in this study were not aware of their rights and employers' obligations under anti-  
16 discrimination legislation; few had received any guidance and patient information leaflets are  
17 unclear. As in many other countries, UK employers have a legal obligation (under the Equality  
18 Act 2010<sup>31</sup>) not to discriminate against and to provide reasonable adjustments for an employee  
19 with a disability. While the majority of this sample would qualify as having a disability under  
20 this legislation, few were aware of their status. Only two of the 13 interviewees identified  
21 themselves as 'disabled'. Young people rarely received guidance from health professionals or  
22 others on their entitlement under anti-discrimination legislation<sup>31</sup> and advice was sometimes  
23 inaccurate. Health professionals struggled to maintain up to date, comprehensive information on  
24 EET issues and most addressed EET in consultations chiefly when patients raised specific  
25 problems. One young man had needed time off for hospital appointments, infusions and surgery.  
26 Worries that his poor sickness record could affect his future job prospects prompted him to look  
27 into whether his arthritis classed as a disability and what difference this would make to him.  
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*I've learnt about different people's rights and things like that and if your arthritis classes  
as a disability (I know a lot of people's doesn't and mine doesn't) it actually affects the  
way they count your absence for things like absence based redundancies. So if you have a  
certain amount of sick days and they're making redundancies you're more likely to be  
made redundant. If you have a disability none of those days count towards that.*

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3 Researcher: *But you say that yours doesn't count?*  
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5 *No, I have asked if it does, and I don't think it does. I think I just talk myself down and*  
6  
7 *think, "It's not that bad." (participant 2:15)*

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10 This young man in a professional career accepted erroneous advice from his employer. Armed  
11 with new information following a focus group discussion concerning relevant anti-discrimination  
12 legislation<sup>31</sup>, he was able to persuade the company of their error and correct his sickness absence  
13 record. This positive outcome nevertheless highlights a shortcoming in information provision to  
14 this group.  
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#### 24 ***Experiences of employment*** 25

##### 26 ***Hidden impacts and limited disclosure of JIA*** 27

28 At times, JIA prevented young people in this sample attending EET or caused effects noticeable  
29 to others such as swollen joints or limping. These effects tended to be transient and associated  
30 with disease flares. Young people also described on-going hidden impacts of JIA (see appendix  
31 2supplementary material), such as pain, stiffness and fatigue, which were often exacerbated by  
32 EET activities (e.g. standing, lifting, typing, commuting) or environment (e.g. cold, footwear,  
33 furniture, equipment).  
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42 *washing up the sinks were really low... so you had to bend which was really sore on my*  
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44 *knees and my back. So I'd come home from a shift and just crash (participant 2:01)*  
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47 Long hours and repetitive tasks without breaks caused the most difficulty and these were  
48 common experiences particularly in temporary, unskilled jobs. Some young people experienced  
49 psychological as well as physical impacts associated with JIA, including anxiety, effects on  
50 mood and altered body image. Young people responded to on-going hidden symptoms, most  
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4 commonly pain, in different ways, rarely seeking formal support and more often relying on the  
5 informal support of co-workers or, as one young person put it, 'just suffer in silence'.  
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10 As young people may have few outward signs of JIA, they must make the difficult decision  
11 whether or not to disclose their condition to employers or educators. In phases one and two, a  
12 majority of young people described opting not to disclose their condition or to disclose in very  
13 restricted ways. Examples of this included telling a trusted co-worker but not their line manager,  
14 or disclosing only their diagnosis without explaining symptoms and their impact. Young people  
15 tended to disclose their condition less frequently and in more limited ways to employers as  
16 compared to educators. Few of the young people participating in phases one and two had  
17 described their employment circumstances as secure or permanent. To explore the significance  
18 of employment security in relation to disclosure decisions, young people and adults in permanent  
19 employment were purposefully sought to interview in phase three. Adults were included as  
20 relatively few young people achieve secure, permanent employment by the age of 25 years. Four  
21 overlapping themes were identified in young people's accounting for limited disclosure (see  
22 figure 1). Disclosure decisions provoked huge anxiety, particularly in relation to being perceived  
23 as different and fearing discrimination. Young people characterised the decision as 'choosing the  
24 lesser of two evils', describing worries associated both with others knowing and not knowing  
25 about their condition. Job security in terms of a permanent contract did not appear to facilitate  
26 disclosure.  
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29 [Figure 1]  
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#### ***Role of the multi-disciplinary team in promoting positive employment outcomes***

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3 Young people must overcome physical, psychological and social challenges presented by JIA to  
4 succeed in EET. The pyramid in figure 2 shows the support from healthcare providers that young  
5 people in this study have found reported as helpful, based on the firm foundation of optimal  
6 disease management. These categories emerged from reported need and support within the  
7 transcripts. Young people valued flexible and convenient care and have found it particularly  
8 important at significant times such as during exams or beginning a new job. Positive experiences  
9 included rapid access to treatment for disease flares and efforts to minimise visits by combining  
10 appointments. Health professionals reported the introduction of evening clinics and telephone  
11 consultations, though none of the young people in our study had yet experienced these initiatives.  
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14 [Figure 2]  
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16 Psycho-social and vocational interventions (figure 2 – additional support) benefited some young  
17 people, but were not routinely available. For example, advice and coaching on disclosure from a  
18 psychologist helped one young person to build confidence and improve relationships with  
19 teachers and peers (figure 2 - skills training). The multidisciplinary rheumatology team included  
20 a psychologist (part-time) at one of the three centres. One centre has provided mock interview  
21 practice for some young people, though not to any individuals participating in this study. Young  
22 people from one participating centre had met other young people with JIA at social events and on  
23 group holidays <sup>32</sup> and reported this as a positive experience, contributing to confidence and  
24 emotional well-being (figure 2 - social and emotional support). Several young people without  
25 opportunities to meet others their age with JIA expressed a strong desire to do so.  
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The foundation levels of support (figure 2) can only be provided by health professionals. The  
additional levels of support (figure 2) may be provided by health professionals or others such as

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3 parents, peers, teachers or voluntary organisations. Young people have experienced varying  
4 levels of support with some lacking support. For example, all of the interviewees not in EET had  
5 also previously failed to complete a course or training programme. Their narratives indicated a  
6 lack of guidance to make sensible choices or assistance to negotiate appropriate support to  
7 succeed.  
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## 19 Discussion

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21 Despite widespread agreement on the social and economic value of employment for individuals  
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23<sup>33</sup>, to date little attention has been given to the employment related experiences and needs of  
24 young people with JIA. Shaw<sup>14</sup> explored the pre-vocational needs of adolescents with JIA aged  
25 12 to 17 years. This research with young people (aged 16-25) and adults (aged up to 31 years)  
26 extends and complements Shaw's work. Two novel findings of this study relate to young  
27 people's **expectations of employment**. The young people in the study lacked knowledge of anti-  
28 discrimination legislation and they had low expectations of employers' willingness to provide  
29 support for employees with a long term condition. As in Shaw's study, they feared  
30 discrimination in the work place<sup>14</sup>. This lack of knowledge and low expectations may be factors  
31 in the tendency to disclose less to employers compared to educators and trainers, particularly as  
32 'not expecting to benefit' was a key reason young people gave for not disclosing their condition  
33 (figure 1).  
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| Living with JIA had a marked impact on the **experiences of employment** of the young people in  
the study and was identified as a key barrier for young people not in EET. This finding was

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2  
3 expected, given the lower reported employment rates for young people with JIA and other  
4 childhood-onset conditions<sup>1-4</sup>. This study has added important insights, by describing the  
5 ongoing disease related challenges faced by young people not only obtaining but also sustaining  
6 EET. These challenges included coping with physical impacts of pain, stiffness, fatigue and  
7 psychological impacts such as anxiety and low mood. Such factors were rarely obvious to  
8 employers, educators and peers, giving the young people discretion over whether, how and when  
9 to disclose their condition. The young people experienced uncertainty and anxiety associated  
10 with disclosure decisions, with similar results previously reported for young people with JIA<sup>14</sup>  
11 and cancer<sup>34</sup>, as well as for adults with rheumatoid arthritis<sup>35</sup>. This study adds the range of  
12 reasons young people give for not disclosing JIA (see figure 1). Awareness and understanding of  
13 these reasons may enable health professionals to target support appropriately. For example, a  
14 young person finding it difficult to explain the diagnosis of JIA may find it helpful to practice  
15 these conversations with employers or educators through role play.  
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Job autonomy and flexibility have been shown to be key predictors of continued employment in adults with rheumatoid arthritis<sup>35</sup>, enabling employees to adapt work schedules or environments to accommodate their condition. Young people are more likely to have unskilled, temporary and entry level jobs compared to older adults<sup>24</sup> and may consequently have less autonomy. This potentially disadvantaged position in the workforce, may increase the need for support among young people with JIA, for example to be able to identify practical solutions and negotiate their implementation.

1 Young people, employment and arthritis.  
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3 The **role of the multi-disciplinary team in promoting positive employment outcomes** was  
4 found to be heterogeneous, as described by both patient and professional participants in this  
5 study. Many young people had experience of health professionals providing optimal disease  
6 management and flexible and convenient care (see table 3). While optimal disease management  
7 is already a key goal for health professionals, it is nevertheless informative to highlight the link  
8 many young people made between having well managed disease and their capacity to succeed in  
9 employment. Similarly, flexible and convenient care for young people is already widely  
10 advocated. In England, for example, this forms part of the government's quality criteria for  
11 young people friendly health services<sup>36</sup>.  
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26 The psycho-social and vocational interventions, constituting the additional level of support  
27 described in table 3, have benefitted some young people, but these services are not routinely  
28 available. Such interventions have not been evaluated individually, but as part of effective  
29 transitional care programmes. Such programmes involve the nurturing of transferable skills for  
30 the workplace such as communication skills with professionals, disclosure and vocational  
31 planning<sup>23</sup>. The HEEADDSSS framework<sup>37</sup> for consultations with adolescents also prompts the  
32 inclusion of EET issues. Through regularly asking young people about EET and their existing  
33 support, for example from parents, peers, teachers and voluntary organisations, health  
34 professionals may identify unmet support needs. Many of the challenges faced by the young  
35 people with JIA, such as anxiety about disclosure, are not disease specific and have been found  
36 in other childhood-onset chronic conditions<sup>34</sup>. Thus, there may be scope to develop and test  
37 generic interventions jointly across specialties with occupational therapists likely to play a key  
38 role<sup>19</sup>, though unmet training needs of health professionals remain a barrier<sup>17-19</sup>. Positively  
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1 Young people, employment and arthritis.  
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3 evaluated examples from other specialties of such interventions include role play<sup>38</sup>, hospital-  
4 based vocational readiness counselling and group programmes both for young people themselves  
5 and for parents or carers<sup>39</sup>.  
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### ***Strengths and limitations***

13 Including two data collection methods strengthened this study. Some of the most disadvantaged  
14 young people with JIA are those not currently in EET. Such young people were perhaps less  
15 willing to attend a focus group to discuss an area of their lives in which they considered they had  
16 not succeeded; only one young person not in EET attended a focus group (n=1/16). Recruiting  
17 young people not in EET for interview proved more successful (n=3/13) enabling some  
18 exploration of the experiences of this group. Greater use of interviews or a dedicated focus group  
19 may have increased representation of this hard to reach group. Such targeting of recruitment  
20 strategies should be a priority for future work as young people not in EET potentially have the  
21 greatest need for support.  
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50 In an innovative and effective approach to involving patients as research partners, a data analysis  
51 session was conducted with a group of patients with JIA and health professionals. The group  
52 reviewed, discussed and reached agreement on the initial data analysis work of the researcher  
53 (HH) alongside extracts of the raw data. This activity shifted the focus of subsequent data  
54 analysis towards a greater awareness of the impact on EET of psychological and social factors  
55 such as self-esteem. The inclusion of the ‘social and emotional support’ category in figure 2,  
56 arose from this activity.  
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1 Young people, employment and arthritis.  
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3 Participants were recruited from specialist young adult rheumatology clinics in large teaching  
4 hospitals, where staff are more likely to have had training in adolescent and young adult issues.  
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6 There is therefore selection bias towards specialist clinics and the experiences of young people  
7 cared for in other settings and without age appropriate clinics are not known. In spite of  
8 involving three UK cities, all participants were Caucasian and therefore the experiences of young  
9 people of other ethnicities could not be explored. The interviews and focus groups were held at a  
10 time of economic recession and high youth unemployment in the UK<sup>24</sup> which may have affected  
11 young people's views on, for example, the willingness of employers to employ and make  
12 adaptions for a young person with a health condition. Employers' attitudes were not explored or  
13 compared to young peoples' expectations.

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28 ***Future research***  
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30 This study focused on understanding the perspectives of young people and health professionals.  
31 Future work should i) focus on the experiences of young people from ethnic minorities or not in  
32 EET and ii) explore the perspectives of employers and promote collaboration between employers  
33 and health professionals to support young people with JIA or other long-term conditions.  
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42 In conclusion, most young people with JIA in our study had limited knowledge of anti-  
43 discrimination laws and expectations of support from employers if they disclosed their disease  
44 were low. Many had chosen not to disclose their condition to employers, despite experiencing  
45 difficulties during education, training or employment. Flexible healthcare scheduling was  
46 considered helpful in supporting their education and employment, but employment-specific  
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support from healthcare providers such as signposting to anti-discrimination legislation or hands-  
on practice on disclosure and other communication skills may have additional benefits.  
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## 17 Acknowledgments 18

19 We would like to thank all the participants in this study.  
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## 27 Declaration of Interest 28

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31 for Health Research through the Comprehensive Clinical Research Network.  
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34 The authors report no conflicts of interest.  
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5 **Table 1 Characteristics and circumstances of patient participants**  
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The first digit of the participant number refers to the phase of the project the person took part in.

**Definitions**

DMARD	Disease Modifying Anti-Rheumatic Drug (either synthetic or biological)
GCSE	General Certificate of Secondary Education, qualification in a specific subject typically achieved aged 15-16 years in the UK
A' Level	Advanced Level, qualification in a specific subject, at a level above GCSE, typically achieved aged 17-18 years in the UK
FE	Further Education: study below bachelor's degree level for people above school age
HE	Higher Education: study at bachelor's degree level
NEET	Not in Education, Employment or Training

**Table 2 Health professionals interviewed**

Profession		Interviewees
Rheumatology specialist nurse	Adult	2
	Paediatric	0
Consultant rheumatologist	Adult	1
	Paediatric	1
Occupational therapist	Adult	2
	Paediatric	1
Physiotherapist	Adult	1
	Paediatric	0
Psychologist	Adult and paediatric	1
Total		9

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3 **Figure 1 How young people account for selective and limited disclosure of JIA**

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5 Participant number from table 1 in brackets.  
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11 **Figure 2 Types of support from health professionals benefitting some young people**  
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13 Participant number from table 1 in brackets.  
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Table 1 Characteristics and circumstances of patient participants

Participant Number	Age (years)	Gender	Main Occupation	Additional Part Time Work?	Level of Educational Attainment (or equivalent)	Disease Duration (years)	Currently on DMARD Treatment?
3:01	16	F	School pupil	No	No qualifications	5	Yes
2:01	17	F	FE student	Yes	5 or more GCSEs	16	No
1:01	18	F	FE student	No	5 or more GCSEs	8	Yes
2:02	19	M	NEET	No	3 or more A'levels	8	Yes
2:03	19	M	HE student	No	3 or more A'levels	4	No
2:04	19	M	Factory worker	No	3 or more A'levels	4	Yes
2:05	19	F	Retail worker	No	5 or more GCSEs	4	Yes
1:02	19	M	NEET	No	5 or more GCSEs	14	Yes
1:03	19	F	NEET	No	No qualifications	17	Yes
1:04	19	M	HE student	Yes	3 or more A'levels	13	Yes
1:05	19	F	HE student	Yes	3 or more A'levels	16	Yes
2:06	20	F	HE student	Yes	3 or more A'levels	16	No
2:07	21	F	Accounts clerk	No	3 or more A'levels	16	No
2:08	22	F	Retail worker	No	3 or more A'levels	20	Unknown
2:09	22	F	Bar worker	No	Bachelor's degree	10	Yes
3:02	22	M	Chef	No	1-4 GCSEs	11	Yes
2:10	23	F	Retail worker	No	Bachelor's degree	9	No
2:11	23	F	Payment processor	No	3 or more A'levels	15	Yes
2:12	23	F	Home care worker	No	3 or more A'levels	21	Yes
1:06	23	F	Administrator	No	3 or more A'levels	8	Yes
2:13	24	F	Nurse	No	3 or more A'levels	20	Unknown
2:14	24	M	Technical drawer	No	3 or more A'levels	10	No
1:07	24	F	HE student	Yes	Bachelor's degree	22	Yes
2:15	25	M	Trainee accountant	No	Bachelor's degree	12	Yes
1:08	25	F	Bar worker	No	3 or more A'levels	Unknown	Yes
2:16	25	F	Administrator	No	Bachelor's degree	11	Yes
<b>Young people</b>	<b>Mean 21.1</b>					<b>Mean 12.4</b>	
3:03	29	F	Pharmacist	No	Bachelor's degree	24	Yes
3:04	29	M	Postman	No	Bachelor's degree	18	Yes
3:05	31	M	NEET	No	1-4 GCSEs	18	Yes
<b>Adults</b>	<b>Mean 29.7</b>					<b>Mean 20</b>	

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#### Definitions

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FE	Further Education: study below bachelor's degree level for people above school age
HE	Higher Education: study at bachelor's degree level
NEET	Not in Education, Employment or Training

### IMPLICATIONS FOR REHABILITATION

- Young people with juvenile idiopathic arthritis JA encounter challenges with regard to employment; many lack the knowledge and skills to negotiate appropriate support from employers.
- Rehabilitation professionals could play a more substantial role in equipping them with relevant knowledge and skills by signposting to anti-discrimination information and nurturing transferable skills, such as disclosure, in consultations.
- Potentially helpful interventions, such as group activities or assessment by a psychologist, have benefited some but need more evaluative scrutiny with respect to employment outcomes.

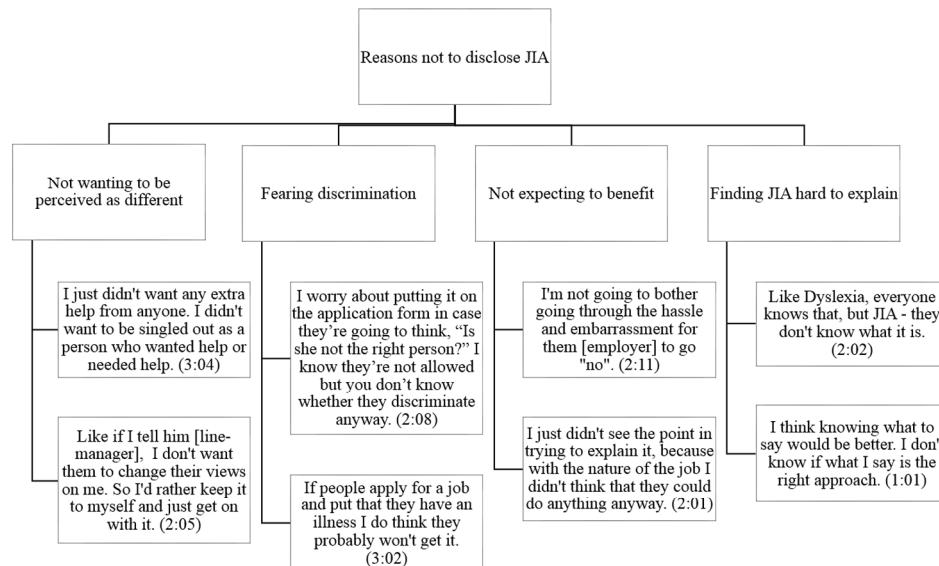


Figure 1 How young people account for selective and limited disclosure of JIA.  
+ (Participant number from table 1 in brackets.)

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Figure 2 Types of support from health professionals benefitting some young people!! + !! + .  
(Participant number from table 1 in brackets.)

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3      Supplementary List S1  
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6      **Examples of additional support and concessions in education, employment or training,**  
7      **discussed in focus groups.**

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11      Advice on rights  
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14      Time to attend medical appointments  
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17      Adapted equipment  
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20      Work station assessment and improvement (e.g. adjustable chair, gel wrist supports)  
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23      Allocation of tasks in a way which recognises condition (and its fluctuating nature)  
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26      Extended deadlines  
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29      Help with physical tasks  
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32      Flexible working hours  
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## Supplementary Figure S1

**Hidden impacts of JIA in education, employment or training.**