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

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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  
11 **Abstract**  
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13  
14 Purpose: This study explored expectations and experiences of employment amongst young  
15  
16 people with [JA juvenile idiopathic arthritis](#), and the role of health professionals in promoting  
17  
18 positive employment outcomes.  
19

20  
21 Methods: Semi-structured interviews (n=13) and three focus groups (n=9,n=4,n=3) were  
22  
23 conducted with young people [\(16-25y\)](#) and adults [\(26-31y\)](#) with [juvenile idiopathic arthritis JA](#)  
24  
25 and semi-structured interviews (n=9) were conducted with health professionals. Transcripts were  
26  
27 analysed thematically.  
28  
29

30  
31 Results: Young people with [juvenile idiopathic arthritis JA](#) have concerns about employers'  
32  
33 attitudes towards employees with long-term health conditions and lack knowledge of anti-  
34  
35 discrimination legislation. Young people not in education, employment or training identify  
36  
37 [arthritis JA](#) as a key barrier. Challenges associated with [JA-arthritis](#) (e.g. pain, psychological  
38  
39 distress) may not be visible to employers. Decisions about disclosing [arthritis JA](#) are challenging  
40  
41 and cause anxiety. Young people associate good disease management and access to flexible and  
42  
43 convenient care with their capacity to succeed in employment. Psycho-social and vocational  
44  
45 interventions have benefited some young people, but are not routinely available.  
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51 Conclusions: Low expectations of employers may affect young people's decisions about  
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53 disclosure and seeking appropriate support in the work place. Health professionals can equip  
54  
55 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 Young people with childhood-onset chronic conditions, such as juvenile idiopathic arthritis  
12 (JIA), are less likely to be employed in adulthood<sup>1-4</sup>. This link between poor health in  
13 adolescence and lower employment rates in adulthood, has been recorded in both physical<sup>1-4</sup> and  
14 mental health conditions<sup>4</sup>. JIA is the most common inflammatory joint disease in childhood and  
15 persists into adulthood in at least a third of young people<sup>5</sup>. It serves as a useful exemplar of a  
16 relapsing and remitting long-term health condition which can be visible or invisible and can  
17 cause varying levels of disability over time<sup>5</sup>. The management of JIA has improved rapidly in  
18 recent decades, with effective new drugs and multi-disciplinary care<sup>6</sup>. This has led to an  
19 improvement in clinical outcomes for many patients<sup>7</sup>, which ~~may facilitate~~ **should enable** more  
20 young people with JIA to work.  
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38 The majority of the literature about employment for people with chronic conditions focuses on  
39 adult-onset disease and young people's needs may be different. For example, adult onset  
40 inflammatory arthritis is associated with increased unemployment compared to controls<sup>8</sup> and  
41 significant adult rheumatology literature is devoted to understanding employment experiences<sup>9</sup>  
42 and evaluating interventions towards maintaining or resuming work<sup>10-12</sup>. While this literature  
43 may be of some relevance, the employment related experiences and needs of young people with  
44 JIA are not well understood. In 2012, a thematic synthesis of 27 qualitative studies of  
45 experiences of JIA<sup>13</sup> found only one study focussing on employment<sup>14</sup>. Most of the adolescents  
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3 in this study worried about discrimination and those in whom JIA was not visible felt a dilemma  
4 about disclosing their condition to potential employers <sup>14</sup>. Canadian surveys of work experiences  
5 amongst young adults with rheumatic disease (including JIA) reported significant disease related  
6 absenteeism, job disruptions and productivity loss <sup>15</sup>. Entering the workplace with a long-term  
7 health condition and no prior work experience is likely to present different or additional  
8 challenges, compared to developing a long-term health condition as an adult during a career of  
9 work. This may explain why adults with childhood-onset systemic lupus erythematosus (jSLE)  
10 were less likely to be employed than those with adult-onset SLE, independent of demographic  
11 and disease characteristics <sup>16</sup>.

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

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## 2 3 4 5 **Methods**

6  
7 The methodological approach taken was *qualitative description*, as described by Sandelowski  
8  
9 <sup>25,26</sup>. This is a naturalistic and pragmatic approach to qualitative research, which aims to produce  
10  
11 low-inference descriptions of data in everyday language, and leads to minimally theorized  
12  
13 findings, of practical value to practitioners and policy-makers.  
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19 Interviews and focus groups were used in three phases of data collection. The *exploratory phase*  
20  
21 involved semi-structured interviews with i) young people with JIA and ii) health professionals  
22  
23 engaged in their care. All participants for this phase were recruited from a large, UK teaching  
24  
25 hospital with an established adult JIA service <sup>27</sup>. The *validation phase* entailed focus groups with  
26  
27 young people with JIA at this and two further teaching hospitals in other UK cities. The aim of  
28  
29 this phase was to test whether different geographical settings or group dynamics would produce  
30  
31 additional or contrasting perspectives. The *final phase* comprised interviews with i) young  
32  
33 people with JIA, ii) adults with JIA and iii) health professionals at all three sites to test and refine  
34  
35 the emerging themes.  
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42 To be eligible for this study, young people were aged from 16 to 25 years, had a diagnosis of JIA  
43  
44 and were under the care of a rheumatologist; adults were aged 26 years or over, had a diagnosis  
45  
46 of JIA and were under the care of a rheumatologist. This study focussed on young people aged  
47  
48 16 to 25 years, reflecting the age group attending UK young adult rheumatology services and  
49  
50 encompassing the period of leaving full time education and entering employment for many  
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52 young people. Adults aged 26 to 31 years were included to take into account trends towards  
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1 Young people, employment and arthritis.

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3 longer periods in education and training<sup>24</sup>. Patients were invited to participate at a routine follow  
4  
5 up appointment by their rheumatologist or another member of the multi-disciplinary team,  
6  
7 between December 2012 and May 2014. Initially, patient participants were chosen to provide  
8  
9 maximum variation of age, gender, disease severity, educational attainment and employment  
10  
11 status. Health professional participants were recruited to represent the key disciplines involved in  
12  
13 their care. As themes emerged, theoretical sampling<sup>28</sup> was undertaken, seeking cases~~were~~  
14  
15 sought to revise, challenge or add to the analysis.  
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21 The initial interview schedule was developed using a review of relevant literature and unreported  
22  
23 data from a previous questionnaire<sup>29</sup>. That questionnaire, which was un-validated, used both  
24  
25 multiple choice and open ended questions to collect exploratory data on education and  
26  
27 employment histories and experiences in an adult JIA population. The researchers adopted a  
28  
29 conversational style for both interviews (HH) and focus groups (HH and RH), to encourage a  
30  
31 comfortable and fluent dialogue rich in detail, while using a schedule as a reference to ensure  
32  
33 that key topics were covered. HH is a research nurse with experience of working in specialist  
34  
35 young adult JIA services and known to the majority of participants at one of the centres but not  
36  
37 currently involved in their clinical care. RH is a research associate, not previously known to  
38  
39 many of the participants. Recordings were transcribed verbatim and given a unique study number  
40  
41 to preserve participants' anonymity. The transcripts were analysed in an iterative cycle, the  
42  
43 analysis carried out concurrently with data collection, which allowed for new lines of enquiry to  
44  
45 be followed in subsequent interviews<sup>30</sup>. Initial analysis involved familiarisation with the data:  
46  
47 listening to the audio recordings alongside active reading of the transcripts, making notes and  
48  
49 highlighting issues of interest. Initial coding (simple codes, preserving action, staying close to  
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2  
3 the text) was applied to the transcripts from the first data collection phase<sup>28</sup>. As data collection  
4  
5 and analysis progressed, more focussed coding was employed: using the most significant or  
6  
7 frequent earlier codes to sift large amounts of data<sup>28</sup>. Mapping (creating visual representations of  
8  
9 relationships among codes and themes) was used to assist the grouping of codes into themes<sup>28</sup>.

10  
11 The analysis was conducted by the researcher (HH), with sections of the transcripts co-coded and  
12  
13 discussed with other team members. Emerging themes were debated and challenged at data  
14  
15 analysis workshops involving the wider research team, of including researchers, health  
16  
17 professionals and patient representatives. The group reviewed, discussed and reached agreement  
18  
19 on the initial data analysis work of the researcher (HH), through reference to extracts of the raw  
20  
21 data. Ethical approval was obtained from the National Research Ethics Service (NRES)  
22  
23 Committee North West – Greater Manchester East, UK (Ref 12/NW/0690). Written, informed  
24  
25 consent was obtained from each participant.  
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## 35 Results

### 36 *Sample*

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38 A total of 10 young people with JIA were interviewed, a further 16 young people attended focus  
39  
40 groups and three adults with JIA were interviewed. There were a total of 29 patient participants,  
41  
42 with a median age of 22 years (range from 16 to 31 years) and two thirds of participants were  
43  
44 female (19/29). Many (21/29) were being treated with traditional and/or biological disease  
45  
46 modifying anti-rheumatic drugs (DMARDs). Three quarters of participants (22/29) were in full  
47  
48 or part-time employment (see table 1). Nine health professionals, including rheumatology  
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1 Young people, employment and arthritis.

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3 specialist nurses, rheumatologists, occupational therapists, physiotherapists and psychologists,  
4  
5 were interviewed (see table 2).  
6

7 [Tables 1 and 2]  
8  
9

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).  
13  
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***

#### 25 *Determination to work*

26  
27 The young people in this sample wanted to work, irrespective of current occupation, disease  
28 severity or duration. Most wanted to work full time, with the exception of planned breaks for  
29 study or child care. Some young people demonstrated significant commitment to their career  
30 choice and willingness to surmount barriers caused by JIA. For example a nurse recalls learning  
31 to perform chest compressions with restricted wrist flexion:  
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39  
40 *It's my hands that have caused me the most problem. But I didn't want it to stop me from*  
41 *being a nurse. We [nurse educator and I] had a discussion about it, we tried various*  
42 *different ways and then we worked out what would be best to sustain an effective*  
43 *compression. (participant 2:13)*  
44  
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49 Others had chosen or changed jobs and careers in order to accommodate aspects of their disease.  
50 Due to the effects of their disease certain young people with JIA felt they could not pursue more  
51 physically demanding jobs such as sports coach, military or fire service. Missing a significant  
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3 amount of schooling was another reason some young people changed their aspirations. Those  
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5 interviewees not engaged in EET identified their diagnosis as a key barrier.  
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### 10 *Low expectations and limited knowledge of anti-discrimination legislation*

11  
12 Young people [in this sample](#) had concerns about employers' attitudes towards employees with  
13  
14 long-term health conditions. Most young people were offered additional support in education and  
15  
16 training, though not all had accepted the assistance. Examples of support included extra time in  
17  
18 exams, flexible hours and use of a lap top computer. Young people did not expect equivalent  
19  
20 assistance in the workplace, expressing concerns about employers' willingness to support  
21  
22 employees with long-term health conditions.  
23  
24  
25

26 *A lot of places wouldn't adapt something [for employee with JIA]. Obviously they're going*  
27  
28 *to have to put in money and time. I think a lot of places wouldn't even think about it.*

29  
30  
31 *(participant 2:11)*  
32

33 Examples of additional support and concessions in EET were collated from the phase one  
34  
35 interviews and presented at the phase two focus groups. The examples tended to be simple and  
36  
37 inexpensive, such as altering work patterns to switch task or take a break more frequently (see  
38  
39 [appendix 1 supplementary material](#)). Focus group participants were asked to say which examples  
40  
41 they would expect as standard from an employer. There was no consensus on this minimum  
42  
43 standard of support, but all the groups identified very few examples. Some participants explained  
44  
45 that their views were based on their own experiences of highly varied support in different roles  
46  
47 or working for different line managers, sometimes even within the same organisation. Where  
48  
49 employers had been supportive, young people often characterised themselves as 'lucky' and did  
50  
51 not expect this always to be the case.  
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1 Young people, employment and arthritis.

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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

7 Many young people worried about active discrimination, particularly during recruitment and few  
8 were prepared to state their JIA on a job application form (see figure 1).  
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14  
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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44 *I've learnt about different people's rights and things like that and if your arthritis classes*  
45 *as a disability (I know a lot of people's doesn't and mine doesn't) it actually affects the*  
46 *way they count your absence for things like absence based redundancies. So if you have a*  
47 *certain amount of sick days and they're making redundancies you're more likely to be*  
48 *made redundant. If you have a disability none of those days count towards that.*  
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1 Young people, employment and arthritis. 10

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3 Researcher: *But you say that yours doesn't count?*

4  
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)*  
8  
9

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 *Hidden impacts and limited disclosure of JIA*

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27 At times, JIA prevented young people [in this sample](#) attending EET or caused effects noticeable  
28 to others such as swollen joints or limping. These effects tended to be transient and associated  
29 with disease flares. Young people also described on-going hidden impacts of JIA (see [appendix](#)  
30 [2supplementary material](#)), such as pain, stiffness and fatigue, which were often exacerbated by  
31 EET activities (e.g. standing, lifting, typing, commuting) or environment (e.g. cold, footwear,  
32 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*  
43  
44 *knees and my back. So I'd come home from a shift and just crash (participant 2:01)*  
45  
46

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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1 Young people, employment and arthritis.

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3 commonly pain, in different ways, rarely seeking formal support and more often relying on the  
4 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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49 [Figure 1]  
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54 ***Role of the multi-disciplinary team in promoting positive employment outcomes***  
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1 Young people, employment and arthritis. 12

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3 Young people must overcome physical, psychological and social challenges presented by JIA to  
4  
5 succeed in EET. The pyramid in figure 2 shows the support from healthcare providers that young  
6  
7 people in this study have found reported as helpful, based on the firm foundation of optimal  
8  
9 disease management. These categories emerged from reported need and support within the  
10  
11 transcripts. Young people valued flexible and convenient care and have found it particularly  
12  
13 important at significant times such as during exams or beginning a new job. Positive experiences  
14  
15 included rapid access to treatment for disease flares and efforts to minimise visits by combining  
16  
17 appointments. Health professionals reported the introduction of evening clinics and telephone  
18  
19 consultations, though none of the young people in our study had yet experienced these initiatives.  
20  
21  
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23

24 [Figure 2]

25  
26 Psycho-social and vocational interventions (figure 2 – additional support) benefited some young  
27  
28 people, but were not routinely available. For example, advice and coaching on disclosure from a  
29  
30 psychologist helped one young person to build confidence and improve relationships with  
31  
32 teachers and peers (figure 2 - skills training). The multidisciplinary rheumatology team included  
33  
34 a psychologist (part-time) at one of the three centres. One centre has provided mock interview  
35  
36 practice for some young people, though not to any individuals participating in this study. Young  
37  
38 people from one participating centre had met other young people with JIA at social events and on  
39  
40 group holidays <sup>32</sup> and reported this as a positive experience, contributing to confidence and  
41  
42 emotional well-being (figure 2 - social and emotional support). Several young people without  
43  
44 opportunities to meet others their age with JIA expressed a strong desire to do so.  
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51 The foundation levels of support (figure 2) can only be provided by health professionals. The  
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53 additional levels of support (figure 2) may be provided by health professionals or others such as  
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1 Young people, employment and arthritis.

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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  
6 levels of support with some lacking support. For example, all of the interviewees not in EET had  
7  
8 also previously failed to complete a course or training programme. Their narratives indicated a  
9  
10 lack of guidance to make sensible choices or assistance to negotiate appropriate support to  
11  
12 succeed.  
13

## 19 Discussion

20  
21 Despite widespread agreement on the social and economic value of employment for individuals  
22  
23 <sup>33</sup>, to date little attention has been given to the employment related experiences and needs of  
24  
25 young people with JIA. Shaw <sup>14</sup> explored the pre-vocational needs of adolescents with JIA aged  
26  
27 12 to 17 years. This research with young people (aged 16-25) and adults (aged up to 31 years)  
28  
29 extends and complements Shaw's work. Two novel findings of this study relate to young  
30  
31 people's **expectations of employment**. The young people in the study lacked knowledge of anti-  
32  
33 discrimination legislation and they had low expectations of employers' willingness to provide  
34  
35 support for employees with a long term condition. As in Shaw's study, they feared  
36  
37 discrimination in the work place <sup>14</sup>. This lack of knowledge and low expectations may be factors  
38  
39 in the tendency to disclose less to employers compared to educators and trainers, particularly as  
40  
41 'not expecting to benefit' was a key reason young people gave for not disclosing their condition  
42  
43 (figure 1).  
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51 | Living with JIA had a marked impact on the **experiences of employment** of the young people in  
52  
53 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  
5 childhood-onset conditions <sup>1-4</sup>. This study has added important insights, by describing the  
6  
7 ongoing disease related challenges faced by young people not only obtaining but also sustaining  
8  
9 EET. These challenges included coping with physical impacts of pain, stiffness, fatigue and  
10  
11 psychological impacts such as anxiety and low mood. Such factors were rarely obvious to  
12  
13 employers, educators and peers, giving the young people discretion over whether, how and when  
14  
15 to disclose their condition. The young people experienced uncertainty and anxiety associated  
16  
17 with disclosure decisions, with similar results previously reported for young people with JIA <sup>14</sup>  
18  
19 and cancer <sup>34</sup>, as well as for adults with rheumatoid arthritis <sup>35</sup>. This study adds the range of  
20  
21 reasons young people give for not disclosing JIA (see figure 1). Awareness and understanding of  
22  
23 these reasons may enable health professionals to target support appropriately. For example, a  
24  
25 young person finding it difficult to explain the diagnosis of JIA may find it helpful to practice  
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27 these conversations with employers or educators through role play.  
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35 Job autonomy and flexibility have been shown to be key predictors of continued employment in  
36  
37 adults with rheumatoid arthritis <sup>35</sup>, enabling employees to adapt work schedules or environments  
38  
39 to accommodate their condition. Young people are more likely to have unskilled, temporary and  
40  
41 entry level jobs compared to older adults <sup>24</sup> and may consequently have less autonomy. This  
42  
43 potentially disadvantaged position in the workforce, may increase the need for support among  
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45 young people with JIA, for example to be able to identify practical solutions and negotiate their  
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47 implementation.  
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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

1 Young people, employment and arthritis. 16  
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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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### 11 ***Strengths and limitations***

12 Including two data collection methods strengthened this study. Some of the most disadvantaged  
13 young people with JIA are those not currently in EET. Such young people were perhaps less  
14 willing to attend a focus group to discuss an area of their lives in which they considered they had  
15 not succeeded; only one young person not in EET attended a focus group (n=1/16). Recruiting  
16 young people not in EET for interview proved more successful (n=3/13) enabling some  
17 exploration of the experiences of this group. Greater use of interviews or a dedicated focus group  
18 may have increased representation of this hard to reach group. Such targeting of recruitment  
19 strategies should be a priority for future work as young people not in EET potentially have the  
20 greatest need for support.  
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38 In an innovative and effective approach to involving patients as research partners, a data analysis  
39 session was conducted with a group of patients with JIA and health professionals. The group  
40 reviewed, discussed and reached agreement on the initial data analysis work of the researcher  
41 (HH) alongside extracts of the raw data. This activity shifted the focus of subsequent data  
42 analysis towards a greater awareness of the impact on EET of psychological and social factors  
43 such as self-esteem. The inclusion of the 'social and emotional support' category in figure 2,  
44 arose from this activity.  
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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  
8 cared for in other settings and without age appropriate clinics are not known. In spite of  
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10 involving three UK cities, all participants were Caucasian and therefore the experiences of young  
11  
12 people of other ethnicities could not be explored. The interviews and focus groups were held at a  
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14 time of economic recession and high youth unemployment in the UK <sup>24</sup> which may have affected  
15  
16 young people's views on, for example, the willingness of employers to employ and make  
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18 adaptations for a young person with a health condition. Employers' attitudes were not explored or  
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20 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.  
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32 Future work should i) focus on the experiences of young people from ethnic minorities or not in  
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34 EET and ii) explore the perspectives of employers and promote collaboration between employers  
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36 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-  
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44 discrimination laws and expectations of support from employers if they disclosed their disease  
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46 were low. Many had chosen not to disclose their condition to employers, despite experiencing  
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48 difficulties during education, training or employment. Flexible healthcare scheduling was  
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50 considered helpful in supporting their education and employment, but employment-specific  
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1 Young people, employment and arthritis. 18

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3 support from healthcare providers such as signposting to anti-discrimination legislation or hands-  
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5 on practice on disclosure and other communication skills may have additional benefits.  
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## 8 9 10 **Acknowledgments**

11 We would like to thank all the participants in this study.  
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## 15 16 17 **Declaration of Interest**

18  
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20  
21 CRP) 2012 [grant number WS2307342]. This work was supported by the UK National Institute  
22  
23 for Health Research through the Comprehensive Clinical Research Network.  
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26 The authors report no conflicts of interest.  
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## 33 **References**

- 34  
35  
36 1. Jetha A. The impact of arthritis on the early employment experiences of young adults: A  
37 literature review. Disability and Health Journal 2015;8:317-324.  
38  
39 2. Diaz-Mendoza AC, Modesto Caballero C, Navarro-Cendejas J. Analysis of employment  
40 rate and social status in young adults with childhood-onset rheumatic disease in  
41 Catalonia. Pediatr Rheumatol Online J 2015;13:29.  
42  
43 3. Maslow GR, Haydon A, McRee AL, Ford CA, Halpern CT. Growing up with a chronic  
44 illness: social success, educational/vocational distress. J Adolesc Health 2011;49(2):206-  
45 12.  
46  
47 4. Hale DR, Bevilacqua L, Viner RM. Adolescent Health and Adult Education and  
48 Employment: A Systematic Review. Pediatrics 2015;136(1):128-40.  
49  
50 5. Selvaag AM, Aulie HA, Lilleby V, Flato B. Disease progression into adulthood and  
51 predictors of long-term active disease in juvenile idiopathic arthritis. Ann Rheum Dis  
52 2016;75(1):190-5.  
53  
54  
55  
56  
57  
58  
59  
60

## Young people, employment and arthritis.

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6. Coulson E, Hanson H, Foster H. What does an adult rheumatologist need to know about juvenile idiopathic arthritis? *Rheumatology (Oxford)* 2014;53(12):2155-66.
7. Minden K, Niewerth M, Zink A, Seipelt E, Foeldvari I, Girschick H, Ganser G, Horneff G. Long-term outcome of patients with JIA treated with etanercept, results of the biologic register JuMBO. *Rheumatology (Oxford)* 2012;51:1407-1415.
8. Verstappen S, Bijlsma J, Verkleij H, Buskens E, Jacobs J. Overview of work disability in rheumatoid arthritis patients as observed in cross-sectional and longitudinal surveys. *Arthritis Rheum* 2004;51(3):488-497.
9. Hoving JL, van Zwieten MC, van der Meer M, Sluiter JK, Frings-Dresen MH. Work participation and arthritis: a systematic overview of challenges, adaptations and opportunities for interventions. *Rheumatology (Oxford)* 2013;52(7):1254-64.
10. Carruthers EC, Rogers P, Backman CL, Goldsmith CH, Gignac MA, Marra C, Village J, Li LC, Esdaile JM, Lacaille D. "Employment and arthritis: making it work" a randomized controlled trial evaluating an online program to help people with inflammatory arthritis maintain employment (study protocol). *BMC Med Inform Decis Mak* 2014;14:59.
11. Vlieland TP, de Buck PD, van den Hout WB. Vocational rehabilitation programs for individuals with chronic arthritis. *Curr Opin Rheumatol* 2009;21(2):183-8.
12. Mahalik J, Shigaki CL, Baldwin D, Johnstone B. A review of employability and worksite interventions for persons with rheumatoid arthritis and osteoarthritis. *Work* 2006;26(3):303-11.
13. Tong A, Jones J, Craig JC, Singh-Grewal D. Children's experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. *Arthritis Care & Research* 2012;64(9):1392-404.
14. Shaw KL, Hackett J, Southwood TR, McDonagh JE. The prevocational and early employment needs of adolescents with juvenile idiopathic arthritis: the adolescent perspective. *Br J Occupational Therapy* 2006;69(3):98-105.
15. Jetha A, Badley E, Beaton D, Fortin PR, Shiff NJ, Gignac MA. Unpacking early work experiences of young adults with rheumatic disease: An examination of absenteeism, job disruptions and productivity loss. *Arthritis Care Res* 2015;67(9):1246-1254.
16. Lawson E, Hersh A, Trupin L, von Scheven E, Okumura M, Yazdany J, Yelin E. Educational and vocational outcomes of adults with childhood- and adult-onset systemic lupus erythematosus: nine years of followup. *Arthritis Care Res* 2014;66(5):717-724.
17. McDonagh JE, Minnaar G, Kelly K, O'Connor D, Shaw KL. Unmet education and training needs in adolescent health of health professionals in a UK children's hospital. *Acta Paediatr* 2006;95(6):715-9.

1 Young people, employment and arthritis. 20

- 2  
3 18. McDonagh JE, Southwood TR, Shaw KL. Unmet education and training needs of  
4 rheumatology health professionals in adolescent health and transitional care.  
5 Rheumatology (Oxford) 2004;43(6):737-43.  
6  
7 19. Shaw K, Hackett J, Southwood T, McDonagh J. The prevocational and early employment  
8 needs of adolescents with juvenile idiopathic arthritis: The occupational therapy  
9 perspective. Br J Occupational Therapy 2006;69(11):497-504.  
10  
11 20. McDonagh JE. Young people first, juvenile idiopathic arthritis second: transitional care in  
12 rheumatology. Arthritis Rheum 2008;59(8):1162-70.  
13  
14 21. Royal College of Nursing. Adolescent Transition Care: RCN Guidance for Nursing Staff.  
15 London: RCN; 2013.  
16  
17 22. Department of Health. Transition: Moving on well. London: Crown; 2008.  
18  
19 23. McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care  
20 programme on adolescents with juvenile idiopathic arthritis. Rheumatology (Oxford)  
21 2007;46(1):161-8.  
22  
23 24. Office for National Statistics. Young People in the Labour Market, 2014.  
24 [http://www.ons.gov.uk/ons/rel/lmac/young-people-in-the-labour-market/2014/rpt-](http://www.ons.gov.uk/ons/rel/lmac/young-people-in-the-labour-market/2014/rpt-young-people.html#tab-Youth-Unemployment)  
25 [young-people.html#tab-Youth-Unemployment](http://www.ons.gov.uk/ons/rel/lmac/young-people-in-the-labour-market/2014/rpt-young-people.html#tab-Youth-Unemployment) ( 23 Dec 2016, date last accessed).  
26  
27 25. Sandelowski M. What's in a name? Qualitative description revisited. Research In Nursing  
28 & Health 2010;33(1):77-84.  
29  
30 26. Sandelowski M. Whatever happened to qualitative description? Research In Nursing &  
31 Health 2000;23(4):334-40.  
32  
33 27. Foster HE, Marshall N, Myers A, Dunkley P, Griffiths ID. Outcome in adults with juvenile  
34 idiopathic arthritis: a quality of life study. Arthritis Rheum 2003;48(3):767-75.  
35  
36 28. Charmaz K. Constructing Grounded Theory: A Practical Guide Through Qualitative  
37 Analysis. London: Sage; 2006.  
38  
39 29. Malviya A, Foster HE, Rushton S, Hanson H, Ferris C, Muthumayandi K, Deehan D.  
40 Exploring the relationships between adult juvenile idiopathic arthritis and employment  
41 Arthritis and Rheumatism 2012;64(9):3016-3024.  
42  
43 30. Rapley T. Some Pragmatics of Data Analysis. In: Silverman D, editor. Qualitative  
44 Research: Theory, Method & Practice. third ed. London Sage 2010.  
45  
46 31. Equality Act. London: HMSO; 2010.  
47  
48 32. Hackett J, Johnson B, Shaw KL, McDonagh JE. Friends united: an evaluation of an  
49 innovative residential self-management programme in adolescent rheumatology. Br J  
50 Occupational Therapy 2005;68 (12): 567-573.;68(12):567-573.  
51  
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- 1 Young people, employment and arthritis. 21
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- 3 33. Waddell G, Burton KA. Is work good for your health and well-being? London 2006.
- 4
- 5 34. CLIC Sargent. No Young Person with Cancer Left Out. 2013.
- 6 [http://www.clicsargent.org.uk/sites/files/clicsargent/13092a\\_No\\_young\\_person\\_with\\_c](http://www.clicsargent.org.uk/sites/files/clicsargent/13092a_No_young_person_with_cancer_left_out.pdf)
- 7 [ancer\\_left\\_out.pdf](http://www.clicsargent.org.uk/sites/files/clicsargent/13092a_No_young_person_with_cancer_left_out.pdf) (23 Dec 2016, date last accessed).
- 8
- 9
- 10 35. Mancuso C, Paget S, Charlson M. Adaptations made by rheumatoid arthritis patients to
- 11 continue working: A pilot study of workplace challenges and successful adaptations.
- 12 Arthritis Care Res 2000;13:89-99.
- 13
- 14 36. Department of Health. You're welcome: Quality criteria for young people friendly health
- 15 services. 2011
- 16 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/2163](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216350/dh_127632.pdf)
- 17 [50/dh\\_127632.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216350/dh_127632.pdf) (23 Dec 2016, date last accessed).
- 18
- 19
- 20 37. Goldenring J, Rosen D. Getting into adolescent heads: an essential update.
- 21 Contemporary Pediatrics 2004;21(1):64-90.
- 22
- 23 38. Lindsay S, McDougall C, Sanford R, Menna-Dack D, Kingsnorth S, Adams T. Exploring
- 24 employment readiness through mock job interview and workplace role-play exercises:
- 25 comparing youth with physical disabilities to their typically developing peers. Disability
- 26 And Rehabilitation 2014;Oct 17:1-13.
- 27
- 28
- 29 39. Wolf-Branigin M SV, White P. . Improving quality of life and career attitudes of youth
- 30 with disabilities: experiences from the Adolescent Employment Readiness Centre. .
- 31 Research on Social Work Practice 2007;17: (3):324-333.
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3 **Table 1 Characteristics and circumstances of patient participants**

4 (separate document)

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8 The first digit of the participant number refers to the phase of the project the person took part in.

9 **Definitions**

10 DMARD Disease Modifying Anti-Rheumatic Drug (either synthetic or biological)

11 GCSE General Certificate of Secondary Education, qualification in a specific subject  
12 typically achieved aged 15-16 years in the UK

13 A' Level Advanced Level, qualification in a specific subject, at a level above GCSE,  
14 typically achieved aged 17–18 years in the UK

15 FE Further Education: study below bachelor's degree level for people above school  
16 age

17 HE Higher Education: study at bachelor's degree level

18 NEET Not in Education, Employment or Training

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34 **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



1 Young people, employment and arthritis.

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

4  
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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For Peer Review

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

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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

For Peer Review

## IMPLICATIONS FOR REHABILITATION

- Young people with juvenile idiopathic arthritis~~HA~~ 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.

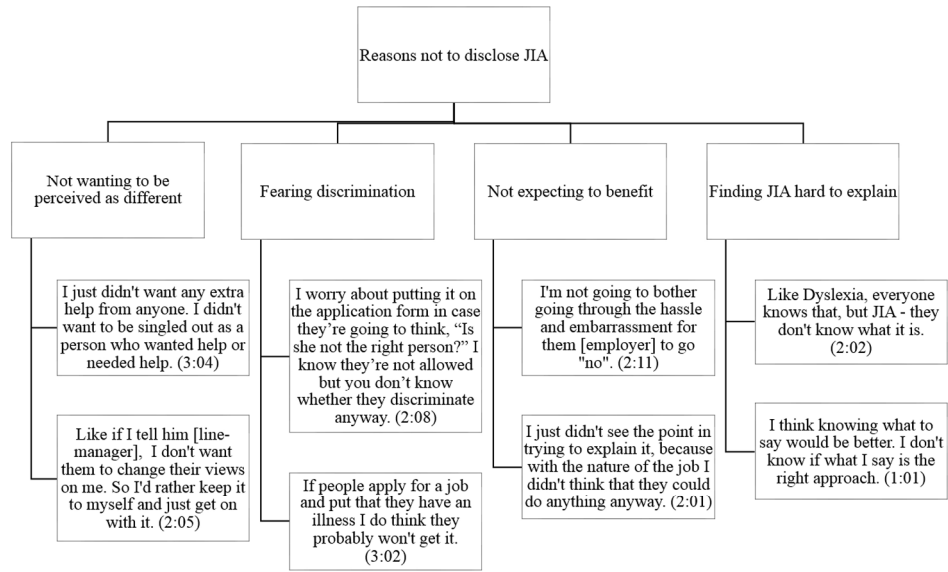


Figure 1 How young people account for selective and limited disclosure of JIA. † (Participant number from table 1 in brackets.)

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Review

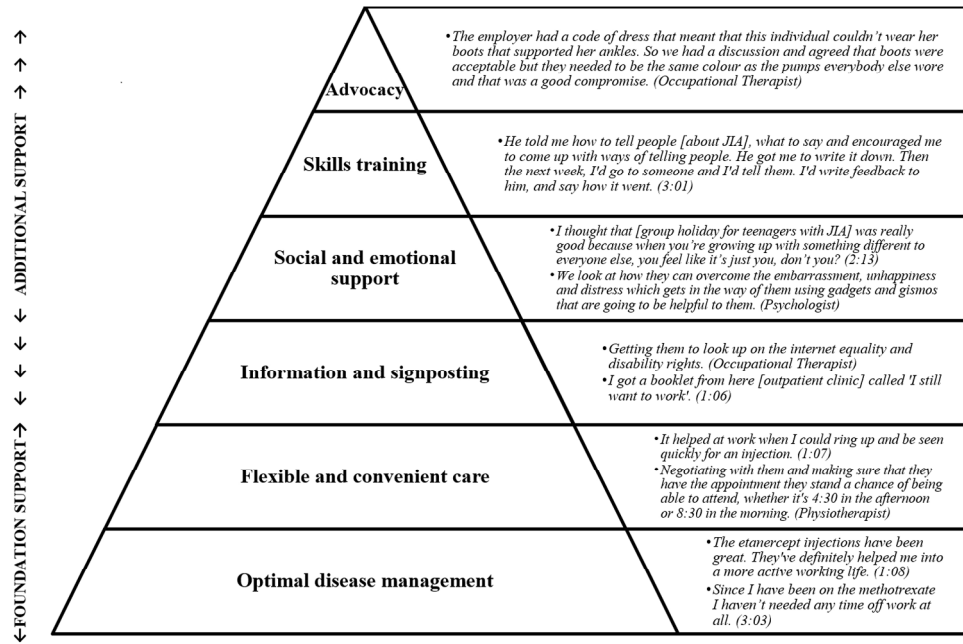


Figure 2 Types of support from health professionals benefitting some young people!! + !! + .  
(Participant number from table 1 in brackets.)

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4 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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## Supplementary Figure S1

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