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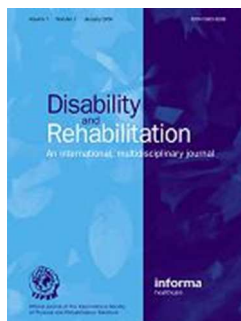
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Experiences of employment amongst young people with juvenile idiopathic arthritis: a qualitative study.

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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.
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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.
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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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50 Conclusions: Low expectations of employers may affect young people's decisions about
51
52 disclosure and seeking appropriate support in the work place. Health professionals can equip
53
54 young people with knowledge and skills to negotiate appropriate support, through signposting to
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1 Young people, employment and arthritis. 2

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 adulthood¹⁻⁴. This link between poor health in
14 adolescence and lower employment rates in adulthood, has been recorded in both physical¹⁻⁴ and
15 mental health conditions⁴. JIA is the most common inflammatory joint disease in childhood and
16 persists into adulthood in at least a third of young people⁵. 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 time⁵. The management of JIA has improved rapidly in
19 recent decades, with effective new drugs and multi-disciplinary care⁶. This has led to an
20 improvement in clinical outcomes for many patients⁷, which ~~may facilitate~~ ~~should enable~~ more
21 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 controls⁸ and
41 significant adult rheumatology literature is devoted to understanding employment experiences⁹
42 and evaluating interventions towards maintaining or resuming work¹⁰⁻¹². 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 JIA¹³ found only one study focussing on employment¹⁴. 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
5 about disclosing their condition to potential employers ¹⁴. Canadian surveys of work experiences
6
7 amongst young adults with rheumatic disease (including JIA) reported significant disease related
8
9 absenteeism, job disruptions and productivity loss ¹⁵. Entering the workplace with a long-term
10
11 health condition and no prior work experience is likely to present different or additional
12
13 challenges, compared to developing a long-term health condition as an adult during a career of
14
15 work. This may explain why adults with childhood-onset systemic lupus erythematosus (jSLE)
16
17 were less likely to be employed than those with adult-onset SLE, independent of demographic
18
19 and disease characteristics ¹⁶.

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26 Professionals caring for young people with JIA appear uncertain how best to support this group
27
28 into employment ¹⁷⁻¹⁹. A key component of the care of young people is their transition to adult-
29
30 centred services ²⁰. Addressing vocational issues during this time is integral to transitional care
31
32 programmes, for example by asking about career plans, work experience and participation in
33
34 household chores to promote vocational readiness ²⁰⁻²³. However, a study exploring adolescents'
35
36 perspectives of their pre-vocational and early employment needs reported limited, uncoordinated
37
38 services ¹⁴ and several studies have reported unmet training needs amongst paediatric and adult
39
40 health professionals with respect to vocational issues ¹⁷⁻¹⁹. The objectives of this study were to
41
42 explore the expectations and experiences of employment amongst young people with JIA, and
43
44 the actual and potential role of the multi-disciplinary team in promoting positive employment
45
46 outcomes. This study focuses primarily on young people aged between 16 and 25 years, when a
47
48 majority of young people in the UK complete full time education and many enter employment ²⁴.

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2 3 4 5 **Methods**

6
7 The methodological approach taken was *qualitative description*, as described by Sandelowski
8
9 ^{25,26}. 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 ²⁷. 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
51
52 young people. Adults aged 26 to 31 years were included to take into account trends towards
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2
3 longer periods in education and training²⁴. 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 sampling²⁸ was undertaken, seeking cases~~were~~
14
15 sought to revise, challenge or add to the analysis.
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20
21 The initial interview schedule was developed using a review of relevant literature and unreported
22
23 data from a previous questionnaire²⁹. 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 interviews³⁰. 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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1 Young people, employment and arthritis. 6

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3 the text) was applied to the transcripts from the first data collection phase²⁸. 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 data²⁸. Mapping (creating visual representations of
8
9 relationships among codes and themes) was used to assist the grouping of codes into themes²⁸.

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:
32
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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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1 Young people, employment and arthritis. 8

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3 amount of schooling was another reason some young people changed their aspirations. Those
4
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)*
5
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 2010³¹) 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 legislation³¹ 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 ³¹, 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
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*
43
44 *knees and my back. So I'd come home from a shift and just crash (participant 2:01)*
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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

2
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.
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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 ³² 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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50
51 The foundation levels of support (figure 2) can only be provided by health professionals. The
52
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
5 levels of support with some lacking support. For example, all of the interviewees not in EET had
6
7 also previously failed to complete a course or training programme. Their narratives indicated a
8
9 lack of guidance to make sensible choices or assistance to negotiate appropriate support to
10
11 succeed.
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19 Discussion

20
21 Despite widespread agreement on the social and economic value of employment for individuals
22
23 ³³, to date little attention has been given to the employment related experiences and needs of
24
25 young people with JIA. Shaw ¹⁴ 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 ¹⁴. 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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1 Young people, employment and arthritis. 14

2
3 expected, given the lower reported employment rates for young people with JIA and other
4
5 childhood-onset conditions ¹⁻⁴. 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 ¹⁴
18
19 and cancer ³⁴, as well as for adults with rheumatoid arthritis ³⁵. 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
26
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 ³⁵, 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 ²⁴ and may consequently have less autonomy. This
42
43 potentially disadvantaged position in the workforce, may increase the need for support among
44
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 services³⁶.

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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 planning²³. The HEEADDSSS framework³⁷ 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 conditions³⁴. Thus, there may be scope to develop and test
37 generic interventions jointly across specialties with occupational therapists likely to play a key
38 role¹⁹, though unmet training needs of health professionals remain a barrier¹⁷⁻¹⁹. Positively

1 Young people, employment and arthritis. 16
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3 evaluated examples from other specialties of such interventions include role play³⁸, hospital-
4 based vocational readiness counselling and group programmes both for young people themselves
5 and for parents or carers³⁹.
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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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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
8 cared for in other settings and without age appropriate clinics are not known. In spite of
9
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
13
14 time of economic recession and high youth unemployment in the UK ²⁴ which may have affected
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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
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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
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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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57
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- 1 Young people, employment and arthritis. 21
- 2
- 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.
- 32
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1 Young people, employment and arthritis.

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3 **Table 1 Characteristics and circumstances of patient participants**

4 (separate document)

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

10 **Definitions**

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

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

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

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

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

19 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**

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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**

12
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
<u>Young people</u>	<u>Mean 21.1</u>					<u>Mean 12.4</u>	
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
<u>Adults</u>	<u>Mean 29.7</u>					<u>Mean 20</u>	

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

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

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.

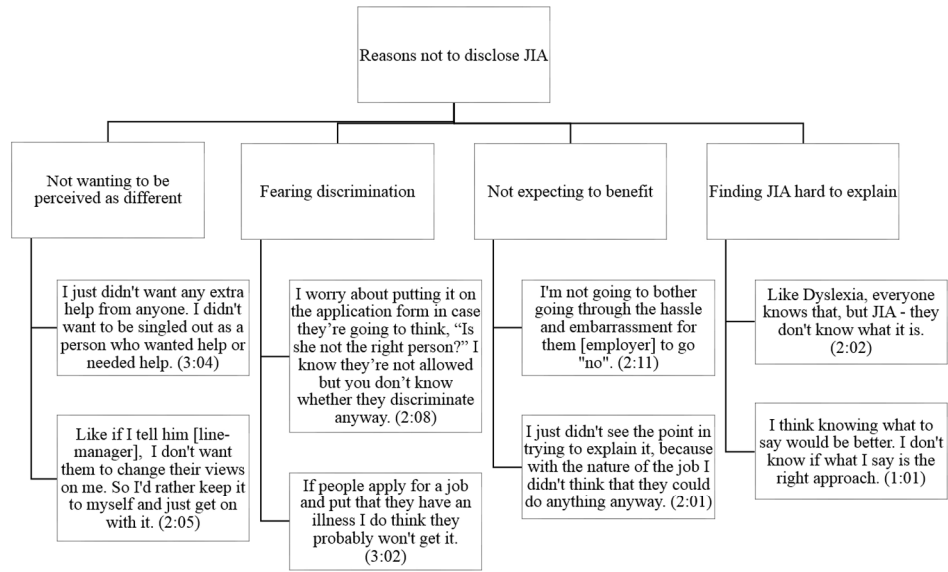


Figure 1 How young people account for selective and limited disclosure of JIA. † (Participant number from table 1 in brackets.)

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Review

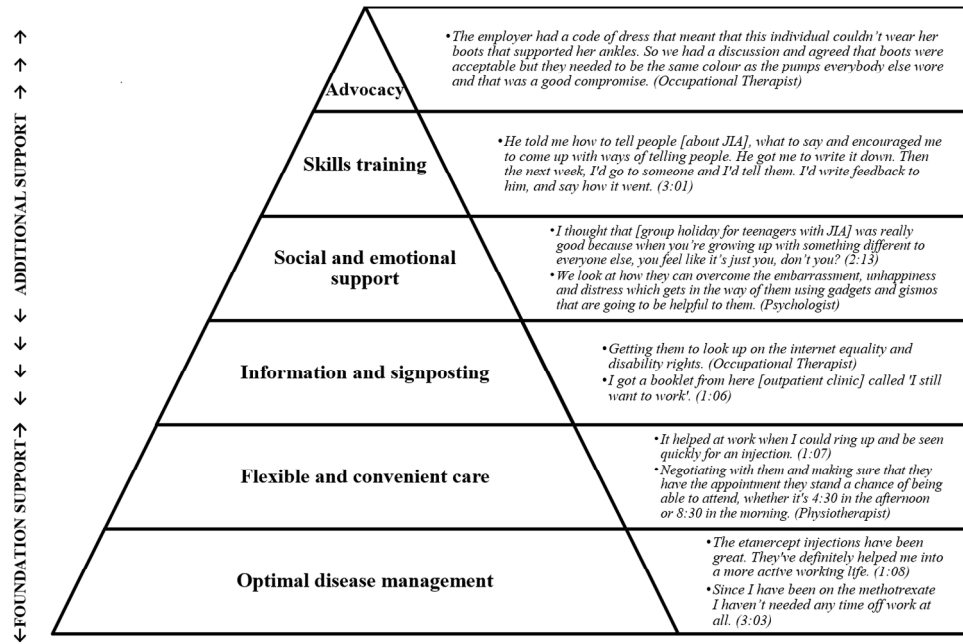


Figure 2 Types of support from health professionals benefitting some young people!! + !! + .
(Participant number from table 1 in brackets.)

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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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32 Flexible working hours
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Supplementary Figure S1

Hidden impacts of JIA in education, employment or training.