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LEARNING DISABILITY SERVICES: USER VIEWS ON TRANSITION PLANNING

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LEARNING DISABILITY SERVICES: USER VIEWS ON TRANSITION PLANNING

Abstract

Purpose

This paper explores the views of service users with learning disabilities on issues associated with continuity of care in the transition from full-time education to adult care and support.

Design/methodology/approach

Data collection was undertaken with service users with learning disabilities and staff in two advocacy organisations in one area of England. Nineteen participants attended three focus groups. Analysis focussed on continuity of care and was guided by the framework approach to qualitative analysis.

Findings

Staff in three organisations were identified as contributing to continuity of care within the transition process: the government information, advice, guidance and support service for young people (personal adviser / careers officer); the local education service (college access officer); and voluntary sector organisations (paid staff leader). Information relating to learning and social development, and, to a lesser

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3 extent, health, communication skills and potential for self-care and independence,
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5 were identified as salient to transition planning on leaving full-time education.
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10 **Research implications**

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13 They provide insights into the challenge of achieving horizontal service integration
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15 and thereby enhance the service user experience findings could be used to inform
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17 strategic planning locally.
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23 **Originality/value**

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27 Continuity of care in the transition planning process is highlighted in policy guidance
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29 with recognition that practice and procedures require improvement. This research
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31 explores areas for development from a service user perspective.
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36 **Key words:** continuity of care; learning disabilities; focus groups; transition planning;
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38 integrated services; user involvement in research;
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Introduction/Background and aims

Transition planning for young people as they leave school is a longstanding concern for policymakers (The Scottish Government, 2010; Conlon, 2014; Department of Health, 2017). It includes the transfer of responsibility from children's to adults' services in respect of social care and the end of full-time schooling and the possibility of further education before there is a sole focus on work and other daytime occupation. In England, local authorities must carry out a transition assessment for children and young persons if they are likely to have needs for care or support in adulthood (18 years of age or above) (Department of Health, 2017). More generally, the 21st century has emphasised the importance of providing support to adults with learning disabilities to build capacity to manage their own lives (Malin and Race, 2010).

Policy guidance continues to emphasise continuity of care for learning disabled young people and their families within the transition process and there has been considerable interest in the concept itself (Department of Health 2001; 2017; Parker *et al.*, 2011; Haggerty *et al.*, 2013). Freeman and colleagues (2001 p7) proposed a multi-aspect definition of continuity of care with the overarching aim being to achieve the experience of 'a co-ordinated and smooth progression of care from the patients' point of view', summarised as *experienced continuity*. Within this six components were identified (Freeman *et al.*, 2001; Forbes *et al.*, 2002).

1. *continuity of information and coherence of the user record* - efficient transfer of information between professionals in touch with the service recipient.
2. *cross-boundary and team continuity* - effective communication between professionals, services and recipients.
3. *flexible continuity* - recognition that individual needs changed over time and took account of this.
4. *longitudinal continuity* - care delivered by as few people as is consistent with the service recipient's circumstances.
5. *relational or interpersonal continuity* - service recipient access to a named professional with whom they could establish and maintain over time a therapeutic relationship.
6. *developmental continuity* – service facilitates (rather than respond to) change, offering opportunities for personal development.

Located within the overarching goal of integrated service provision this provided the conceptual framework for the research. The aim was to elicit the views of service users regarding issues associated with continuity of care within the transition from full-time education to adult care and support.

Method

Setting

The research was undertaken in one area of England between 2011 and 2012. In it the local authority, a unit of local government, was responsible for the provision, via three separate directorates, of education and social care services for both children and adults. General practitioners and primary and secondary health care services were provided by the National Health Service. Exploration of employment options was available through the local office of the national United Kingdom government information, advice, guidance and support service for young people.

Data collection

The design and conduct of the study was developed by the research team in partnership with service users and staff in two local advocacy organisations.

Schedule development

- *Visual analogue tools:* were employed to gain information about age and gender. A traffic light model previously used by the advocacy organisations which incorporated Makaton hand signals was used.
- *Discussion guides:* were informed by policy guidance and local documentation specific to the transition planning process. These comprised (1) a list of organisations and personnel providing assistance in the planning and provision of support and care for young people when they leave school and (2) information collected within the transition planning process. Material was formulated using symbols and pictures as appropriate to facilitate discussion. These are summarised in Table 1.

(Table 1)

Focus groups

Three focus groups were specially convened for this research and provided a diverse collection of views (Morgan, 1996). Recruitment was undertaken by the advocacy organisations. Group sizes were intentionally small (not more than 10 participants) (Cambridge and McCarthy, 2001). Guidelines recommend 'segmentation' of participants so that each group comprises people with broadly similar characteristics of interest to capitalise on shared experiences (Morgan, 1996). Therefore, participants in the first group were selected to represent young people with recent experience of leaving full-time education. A second group comprised an older cohort able to reflect on their personal experience to identify good practice. The third group was selected from recent recruits to local authority day services. Members of the first two groups had experience of contributing to service development. Inevitably there was variation in attendance on the day of the focus group, reflecting personal circumstances at the time.

Groups were designed to be flexible and responsive to the needs of the participants allowing them sufficient time or assistance to fully contribute. To promote equality all participants and facilitators had name badges (Boyden *et al.*, 2009). Each group was limited to two hours and divided into two parts with a comfort and refreshment break at the midpoint to minimise the risk of impromptu breaks and other distracting activities (Cambridge and McCarthy, 2001; Boyden *et al.*, 2009). Refreshment breaks also provided an opportunity for informal contact between participants. This was identified as a recruitment incentive by the advocacy organisations because it provided the opportunity to socialise with friends. Participants received a certificate

acknowledging their contribution and both attendees and their carers were reimbursed their travel expenses.

The settings in which the focus groups were conducted required a flexible approach to data collection with multiple methods designed to maintain interest and help participants express their opinions (Gates and Waight, 2007). Each group was facilitated by members of the advocacy organisations and divided into two parts supported by an easy-read agenda.

- *Part one:* collected demographic data and obtained participant consent. Large response boards were employed and each participant was asked in turn to place a colour coded 'tick' to indicate their response. Consent was requested from service users participate and to permit their personal information to be used within the research using a similar process. Confidentiality and anonymity were assured at each time.
- *Part two:* explored perceptions of the organisations, personnel and information associated with transition planning. Discussion was free flowing; with each group having the opportunity to discuss all the items listed.

Three types of data were collected from the focus group sessions.

- *Electronic notes made on screen* during the discussion by the facilitator to guide and record the discussion.
- *Notes completed by a 'live scribe'* who pictorially represented the on-going discussion.

- *Detailed written notes taken by two researchers* which were later collated and reviewed against each other to ensure reliability.

Data analysis

These data were then interrogated in two ways. First, the views of participants about people and organisations involved in the transition planning and the information requirements of the process were extracted. Second, the framework of continuity of experienced care was used to systematically categorise the comments of participants (Freeman *et al.*, 2001; Forbes *et al.*, 2002). This is akin to a framework approach to analysis whereby material is organised according to key issues and themes employing a deductive paradigm (Richie and Spencer, 1994). It incorporated a pragmatic rating of value and evidence to estimate its evidence in practice and value to the service user.

The research received ethical approval from the NHS National Research Ethics Committee (South West, Bristol) on 23rd November 2010 (reference: 10/H0107/60).

Results

Focus groups and participant characteristics

Focus group one comprised six young people with recent experience of leaving full-time education; focus group two, representing an older cohort, had ten participants; and focus group three was smaller than planned and comprised two young people who had recently made the transition from full-time education to local authority day services. Overall, most participants were male and over the age of 25 years. In

group 1 and 3 most were under 45 years of age but in group 2 the majority were over 45 years of age. Most participants in group 1 were male. There were equal numbers of males and females in groups 2 and 3.

Participant views

Discussion was based on the list of organisations in Table 1 and those organisations and personnel identified as important by focus group participants are highlighted within it. In terms of information to inform the transition process, the *education service* was identified as the prime source. Class teachers and college access officers were identified as the main contributors. Their contribution was acknowledged and valued particularly by the younger participants. Local authority *social care* services were only recognised as the gatekeeper for day services and social workers a means to achieving this. In terms of *other local authority services*, four members of one focus group identified youth workers as useful contributors to the transition planning process. This was based on their experience of attending youth clubs and similar activities as they grew older. All the groups were aware of the existence of the UK governmental information, advice, guidance and support service for young people (known locally at the time as Connexions). However, the role of the personal advisor, and prior to that the careers officer, was not recognised as important in planning for their futures. No *health care* professionals were identified as significant contributors to transition planning by any of the focus groups.

Two roles were identified for the *voluntary sector* by virtue of the assistance it provided young people during the transition planning process and beyond. First,

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3 focus group participants were aware of the advocacy role of local voluntary
4 organisations. Second, they identified the opportunities afforded by these
5 organisations for personal development through structured activities. Additionally,
6 focus group participants who were supported by family members, particularly
7 parents, rated their contribution to the transition planning process as being more
8 important than that of professionals within any of the organisations identified above.
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19 Seven items identified as important by focus group participants are highlighted in
20 Table 1. Three related to *learning and social development*. All focus groups thought
21 it important that activities that service users participated in and enjoyed were
22 included in documentation relating to transition planning. Performance in full-time
23 education or a work setting and service users' perceptions of self were also identified
24 as relevant information for the transition planning process. With regard to *health*,
25 two items were identified as important: physical needs and those arising from a
26 disability; and history of physical development including mobility needs. In terms of
27 transition planning, knowledge of *communication* problems arising from specific
28 speech and language difficulties were viewed as essential. With regard to *self-care*
29 and *independence*, focus group participants focused not on the level of help they
30 needed but that those involved in transition planning were aware of the contact
31 details of all the people providing care and support. Whilst this list included family
32 members, focus group participants did not identify information about *family*
33 *circumstances* for inclusion in transition planning documentation.
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Continuity of experience

Table 2 summarises the discussion of continuity of experienced care using the conceptual framework described in the introduction. Participants identified three aspects (3, 5, 6) that had been experienced and valued. It was suggested that two of these – *flexible* (3) and relational or *interpersonal continuity* (5) – were not the sole preserve of statutory agencies and examples were given of this experience being provided by advocacy groups within the voluntary sector through opportunities for personal development and support and encouragement over time. Family members were also identified as important with regard to the latter. Discussion relating to the other - *developmental continuity* (6) - revealed that this concept had relevance for service users which extended beyond the process of transition planning. This included a notion of ‘measured change’ in the sense that service users were involved in preparations for events which it was envisaged would have a significant impact on their life which often reflected their own changed circumstances. Focus group participants provided little evidence of the remaining three aspects. However, two of these – *continuity of information and coherence of user record* (1) and *cross-boundary and team continuity* (2) – which related to the content and process of information sharing between professionals and with the service users were highly valued. Focus group discussion provided few examples of the remaining aspect, *longitudinal continuity* (4). With little experience of continuity of care through important transitions in their lives it was unsurprising that the prospect of a disproportionate number of people being involved in their care was largely beyond their experience.

Discussion

This paper provides new information from service users about issues associated with continuity of care within the transition from full-time education to support funded through adult social care services, recognised as a difficult process for both disabled young people and their parents or carers. It presents the views of service users on aspects of policy guidance using a methodology which included local advocacy organisations in the design of research tools and data collection. However there are a number of study limitations in relation to this small scale research study which employed a focus group methodology. First, the experience of participants was mainly derived from services in a single locality. There was no opportunity to replicate this study in other areas. Second, the selection of participants used a convenience sample. This took no account of their age, experience of transition, educational opportunities and communication skills. Third, the focus group methodology required sufficient language and communication skills to participate in discussion.

The implications of three aspects of continuity of care which emerged from the focus groups are discussed below.

- At the point of transition personal budgets permit young people and their carers the opportunity to purchase individual forms of support beyond those specified in the statutory guidance (Department of Health, 2017). Thus they offer the possibility, but no guarantee of, greater continuity of care. In particular, they provide the opportunity to promote *flexible continuity* with the capacity to adjust to the needs of service users (Jeeman et al., 2001).

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- The potential for existing services to provide opportunities for personal development and promote *developmental continuity* within and beyond the transition process was highlighted in this study. Developmental continuity, as noted previously, was not just about responding to change but its active facilitation, encouragement and management, taking account of the unique needs of young people within the context of their psychosocial development (Forbes et al., 2002). Small and colleagues (2013) developed this theme further by suggesting that transition planning should mobilise the meso system (workplace, leisure facilities and neighbourhood) to accommodate the individual needs and ability of a young adult with a learning disability.
- An opportunity for the voluntary sector to support service users, both through and beyond the transition planning process, was highlighted in this study. In this role staff in these organisations might provide a therapeutic relationship over time thereby promoting *relational or interpersonal continuity* of care (Freeman et al., 2001). This assumes the sustainability over time of example local advocacy groups. However there are often uncertainties regarding the level, length, and nature of contracts which militates against the development of stable high-quality services in the non-statutory sector (). Notwithstanding these caveats local advocacy groups could offer a means of promoting the well-being of service users with an entitlement for care and support, possibly in partnership with other providers (Department of Health, 2017).

Continuity of care is conceived of as a global outcome of integrated service provision. In this study the relationship is more nuanced and there are four reasons for this. First, initiatives to promote integration generally span local government and the NHS (Wistow, 2012). In this instance continuity of care requires the broader integration of services: within local government (adult services, children's services and the education service); within the NHS (primary care, secondary care and GP services); and other agencies (the voluntary sector and the employment agency). Second, the concept of integrated services is multifaceted [REDACTED]. In contrast, this study focuses on a single aspect, the transfer of information between organisations, particularly the personnel involved and the information which might usefully be addressed within transition planning. Third, integrated services promoting continuity of care are often a strategic policy objective (Department of Health, 2017). On the other hand the data in this study draws on the views service users derived from their experience. Fourth, most services within transition planning are located within a single geographical area and to promote continuity of care they are required to be complementary and work in partnership. This suggests that pursuit of the goal of horizontal integration, defined as the integration of activities which occur at the same level in the production process, should characterise transition planning within localities (Rumbold and Shaw, 2010).

Conclusions

Overall, the use of a multi-aspect definition of continuity of care as an analytic framework has provided the opportunity to benchmark current practice and highlight areas for development in transition planning. It permitted data collected in one

locality at a point in time to be placed in a wider context. Furthermore this study has provided a service user perspective about the organisations and information central to the transition from full-time education to adult care and support. As such it contributes to the debate about the constituents of integration in respect of coordinated care experienced by service users. The findings should not be viewed in isolation but together with the views of other stakeholders taking account of resources available locally to facilitate transition planning. Nevertheless within these parameters these data suggest service users would value greater involvement of the voluntary sector, possibly promoting continuity of care over time and facilitating links between services, together with a realistic appraisal of data requisite to the transition planning process.

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Tizard Learning Disability Review

Table 1: Organisations, personnel and information

<i>Organisation</i>	<i>Person</i>
Connexions	Personal adviser (careers officer)
Education service	Class teacher*
	College access officer*
	Educational psychologist
Social care	Social worker (Children's Services)*
	Transition worker
	Social worker (Adult Services)
Other local authority services	Youth worker*
	Housing officer
	Work placement co-ordinator
Health care	GP or paediatrician
	Occupational therapist or speech and language therapist
	School nurse
Voluntary sector	Paid staff leaders of local advocacy groups*
<i>Information</i>	<i>Specific item</i>
Health	General health needs and do you have a disability*
	Mobility needs and physical development history*
	Medical history and past behavioural issues
Communication	Ability to understand
	Speech and language difficulties*
	Ability to express ideas
Learning and social development	How well you do at school or in your job*
	Activities you take part in or services you receive /
	Activities you enjoy*
	Understanding, reasoning and problems solving issues and abilities
	Your views on how you see yourself – identify, self-image, self-esteem and social presentation*
Family circumstances	The support you get from your parent and / or carer (e.g. safety, warmth, stability, guidance and stimulation)
	Relations between you and your family and you and your wider family
	Any family housing, employment or financial problems /
	Do your parents or brothers and sisters have problems
Self-care and independence	Overall level of need
	What do you need help with / Your views
	Names and details of all the people that will help you*

Notes: *Identified as important by focus group participants

Table 2: Continuity of care

Component of continuity	Examples from focus group participants	Rating	
		Evidence in practice	Value to service users
1. Continuity of information and coherence of the user record	<p>Information should focus on ability in a positive sense, for example where significant improvements in behaviour had been made there was no need to detail earlier behaviour.</p> <p>Saying 'difficult' things just once is important in the knowledge that the written record can be shared between professions, for example a preference for continuing to live in the family home.</p> <p>The level of detail about life experience to date and current circumstances needs to be appropriate and determined by 'what you need to have to help me', for example not specifying why medication is required but the consequences of not having it.</p>	Little evidence	High value
2. Cross-boundary and team continuity	<p>Service users want to be at the centre of communication and involved in determining the information that is transferred between services. However written information should be supplemented by speaking to the service user. A number of examples of a lack of information sharing between professionals were given:</p> <ul style="list-style-type: none">• service user being reassessed on transfer from school to work environment• dentist needing to know current medication• day centre having little or no information on service users transferring from full-time education. <p>One positive example was given:</p> <ul style="list-style-type: none">• day centre staff visiting a highly dependent service user in school before their transfer. <p>Service users should appreciate the benefits of sharing information between organisations, despite little experience of it.</p>	Little evidence	High value

3. <i>Flexible continuity</i>	There was evidence of voluntary sector advocacy groups providing service users with the opportunity to achieve positions of responsibility and respect within them, evidenced for example by members acting as facilitators to the focus groups.	Evidence	High value
4. <i>Longitudinal continuity</i>	Nobody said that too many people were involved in their care and the example given of continuity of care over time related to general practitioner services.	Little evidence	Low value
5. <i>Relational or interpersonal continuity</i>	An example was given of a teacher in a school or further education setting acting as a champion, promoting the potential of the service user and also encouraging them to act as their own champion. When a professional did not provide this aspect of continuity the vacuum would typically be filled by family (parents mainly) or the voluntary sector. Family support was identified as very important in this context.	Evidence	High value
6. <i>Developmental continuity</i>	Service users had an expectation that their wishes would be paramount in the timing of changes to promote their personal development: <ul style="list-style-type: none"> • training available to service users to help them to use public transport to promote greater independence when requested • proposals to change living arrangements to reflect service user views rather than those of professionals. Developmental continuity extends beyond transition planning: <ul style="list-style-type: none"> • users in the over 45 age range had training involving using a computer • help with improving reading and writing skills. 	Evidence	High value