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Commentary on "Learning Disability Services: User Views on Transition Planning"

Commentary: Continuity of care for young people with intellectual / developmental disabilities during transition: The reality and challenges

Introduction

Transition to adulthood has long been identified as a potentially difficult time for young people with intellectual / developmental disabilities (IDD) and their families. For this population, transition represents not only a symbolic move from childhood to adulthood involving the challenges all young people face during this period, but often a transfer of their care and support from children's to adult's services. For many young people with IDD and their families this will be a complex process requiring them to navigate new services, build relationships with different professionals, and co-ordinate new packages of support. Historically, this process has been described as a 'cliff edge' by young people and their families in that existing levels of support may be reduced or withdrawn (King, 2017).

Despite the significance of this period in the lives of young people with IDD, it is a relatively under researched area. Hughes and colleagues' article on transition planning in this issue is therefore timely and significant and takes a unique approach to the topic by situating the findings within Freeman and colleagues' (2000) framework of continuity of care. This framework emphasises the importance of maintaining continuity of care during transition and describes six key elements including: experienced continuity (for the young person and their family); continuity of information (efficient and appropriate information sharing between professionals); cross boundary and team continuity (effective communication between all stakeholders); flexible continuity (ability to adapt to the young person's needs); longitudinal continuity (the involvement of as few professionals as needed); and relational or interpersonal continuity (having a named professional and building a relationship with this professional). Forbes and colleagues (2001) expanded this to consider three additional components that may be facilitative of continuity of care: the service structure and process, the young person's development, and the family's adjustment to their new role.

The concept of continuity of care is, I would argue, particularly relevant for transition from children's to adult's services for young people with IDD given that these young people may have multifaceted needs, requiring integrated services across education, health and social care. This commentary will therefore consider the concept of continuity of care at transition for young people with IDD in more depth. It will examine the policy context relevant to continuity of care for this group, as well as research evaluating whether continuity of care is evident in young peoples' and families' experiences. Finally, challenges to achieving continuity of care within the current service context will be highlighted.

Policy and research context

As Hughes and colleagues highlight, transition for young people with IDD has been a key policy focus since *Valuing People* (Department of Health, 2001), and a number of recent policy initiatives in England have further emphasised the importance of good transition outcomes for this population. While beyond the scope of this commentary to provide a comprehensive overview of legislation, key elements relevant to promoting continuity of care during transition will be highlighted. Both the Children and Families Act (2014) and the Care Act (2014) identify transition as a central concern for education, health and care services in England. Under the Children and Families Act, support for young people with an education, health and care plan (EHCP) can extend to age 25, therefore enabling an overlap with provisions in the Care Act (which begin at age 18) and potentially removing the historic cliff edge of service provision at age 18. Transition planning for young people with an EHCP should begin in year 9 and be focused on achieving key goals in relation to employment or education, independent living, community participation, and health (Department of Education and

Department of Health and Social Care, 2015). Furthermore, Local Authorities have a duty to conduct a Care Needs Assessment under the Care Act for any young people likely to have social care needs in adulthood in order to promote early planning and ensure continuity of support. Both Acts emphasise the importance of collaborative working across both children's and adult's services to further minimise fragmented support. Recent National Institute for Health and Care Excellence (NICE) guidelines on transition (NICE, 2016) and challenging behaviour (NICE, 2015; 2018) are consistent with this and emphasise the importance of continuity of care for this population, particularly where young people may have complex needs.

When asked directly, young people and their families often confirm the importance of continuity of care to their experiences of transition. For example, family carers consulted by Smart (2004) highlighted a number of indicators of poor continuity of care characterising their experience of transition, including poor collaboration between organisations and professionals, uncertain funding arrangements, and a lack of information or support for them or their relative during the process. Similarly Ward and colleagues (2003) found that although aspects of transition had been handled well for some young people, the transfer from children's to adult's services had not been planned adequately by the time they left school. Such experiences are likely to have detrimental impacts on all elements of Freeman and colleagues' (2000) framework of continuity of care for young people and suggest issues with the service structure and process element (Forbes et al., 2001) of transition support. Hughes and colleagues' findings support the notion that continuity of care is not commonly experienced by young people with IDD at the point of transition. Where positive experiences are reported these often refer to indications of good continuity of care such as being well connected with professionals, having a named professional, ensuring that there is adequate time to plan, and family involvement in transition (Heslop and Abbott, 2007; Ward *et al.,* 2003a; Ward *et al.,* 2003b).

Little research has examined the consequences of a lack of continuity of care for young people with IDD at transition. However, evidence of poor post-transition outcomes may be symptomatic of poor continuity of care during the transition process. In an ongoing research project at the Tizard Centre examining transition from residential educational settings, instances of rapid placement breakdown have been reported, and examples have arisen of young people remaining at the educational placement for longer than planned or returning after transition due to suitable placements not being identified in time. Anecdotal family reports also suggest a lack of well-planned transitions resulting in emergency placements or young people initially returning home. This may suggest issues with flexible continuity (Freeman *et al.*, 2000). This picture is also reflected in the literature, suggesting a high number of placement breakdowns (Abbott and Heslop, 2008; Smart, 2004), recognition of the role of transition in reducing inpatient admissions within the Transforming Care Agenda (NHS England, 2017), and other detrimental outcomes following transition such as poorer health and wellbeing (Young-Southward *et al.*, 2016), or an increase in restrictive behaviour management practices and a reduction in behavioural plans (Emerson *et al.*, 1996).

Challenges to continuity of care

Despite a clear policy impetus for promoting continuity of care during transition, the research evidence and message from young people and their families is that this is not currently being achieved. This may in part be due to a number of challenges in IDD support and services. For example, the current economic climate of austerity is likely to have a considerable impact on continuity of care. King (2017) highlighted that eligibility criteria, commissioning practices, and benefit entitlements may limit a young person's access to services when reaching adulthood, and it is likely that these areas will be impacted by austerity measures as services seek to streamline their use of resources. Families report that services are lacking or are no longer accepting referrals due to

funding cuts, and that professionals struggle to appropriately support transition due to turnover and low staff numbers (Martin *et al.*, 2011).

Furthermore, lack of information sharing between children's and adult's services is often highlighted (e.g., Department of Health, 2011; Emerson and Glover, 2012; Hudson, 2006; Martin *et al.*, 2011), contributing to difficulties at transition for young people with IDD and their families. Families report having to repeat information to multiple professionals, and organisations report being unaware of young people approaching transition if they have not been provided with or sought this information (Hudson, 2006; Martin *et al.*, 2011). Here again evidence from ongoing research supports this with some organisations unable to identify young people who have recently transitioned to adult services from residential education. Without appropriate and efficient information sharing, continuity of information will not be experienced and will likely result in delays and issues with continuity of care in other areas at transition. It will also prevent adult services from planning and organising support based on likely need, something which the Care Act has emphasised as important through the use of the Care Needs Assessment.

In addition, specific groups of young people with IDD may be at increased risk of experiencing poor continuity of care at transition such as those placed in residential educational settings. These placements are often not registered to support the young person's primary need (Tomlinson et al., 2017) and therefore may not be well placed to identify and support transition to appropriate placements for these needs. Furthermore, given that these placements are often located far from the young person's home area (McGill *et al.*, 2006) it may difficult for families to be regularly involved in the transition process and for professionals from the young person's home area to attend review meetings (Morris *et al.*, 2003). This is supported by evidence suggesting that both families and professionals felt the distance between the young person's educational placement and their home area exacerbated the transition process (Gore *et al.*, 2015; Heslop *et al.*, 2007). Emerging evidence from the aforementioned ongoing study also suggests that residential educational placements often develop links with specific adult placements or provide adult placements as part of the organisation, and tend to utilise these for a number of young people from the school/college; it is not known whether this is linked to a lack of flexible continuity of care if such placements are not tailored to the young person's needs. Many of these issues are likely to also be relevant to young people who are in care or who have complex needs such as an Autism Spectrum Condition, challenging behaviour, or additional mental or physical health conditions. For these young people, a high number of professionals will likely be involved in their transition, challenging the ability to achieve longitudinal and relational/interpersonal continuity. They may therefore need additional support to achieve positive transition outcomes.

Conclusion

Continuity of care is a key outcome for young people with IDD at the point of transition from children's to adult's services. This population often requires integrated services from education, health and social care, meaning that continuity of care is particularly important. Despite this and a clear legislative focus on continuity of care, evidence suggests that this is not currently being achieved for many young people with IDD. Economic austerity, geographic spread of services, use of residential education or care, and the involvement of a number of professionals where young people have complex needs challenges the ability of professionals to maintain continuity of care for young people. Despite this, positive transition outcomes have been reported (e.g., Smart, 2004) evidencing that it is possible to provide good support to young people with IDD at transition. Recent legislative changes will hopefully facilitate this. However, this commentary has highlighted that continuity of care should be a clearer focus for services who support young people with IDD at the point of transition, to ensure that they are able to fully achieve their goals for adulthood.

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