



Transition and integration – changing our starting point

Simon John Duffy

The Centre for Welfare Reform, Sheffield, UK, and

Pippa Murray

IBK Initiatives, Sheffield, UK

Abstract

Purpose – The purpose of this paper is to offer a hypothesis about the core elements of an effective transition process in a system of self-directed support and to suggest that the approach to integration in public services may need to radically change.

Design/methodology/approach – This is a reflective piece, drawing on decades of practical work by the authors, combined with an understanding of the literature and the social policy context.

Findings – Typical solutions to the problem of transition focus on system change instead of ensuring that power and control shifts to families and young people. A change in starting point opens up more empowering and practical solutions for the real world.

Originality/value – This paper goes deeper than others on the same subject by moving beyond the outcomes and issues, to suggest some lessons for social policy makers, professionals and citizens.

Keywords Integration, Integrated health and social care, Community empowerment, Care and support, Holistic approaches to care, Personal budgets

Paper type Conceptual paper

Introduction

The transition of disabled children into adulthood and the complexities of bridging adult and children services, while also connecting social care, healthcare and education, has been a topic of several previous articles within the *Journal of Integrated Care*. In particular recent articles have explored some of the thinking and practice that is changing with the introduction of self-directed support (Cowen *et al.*, 2011; Mitchell 2012a, b).

The main focus of this paper is to draw on the practical experience of the authors in developing, testing and sustaining a radical model of integrated self-directed support, called personalised transition. We will argue that many initiatives to improve the transition process are fundamentally flawed because they fail to respect the basic rights of young people and families (Duffy, 2010). Only if we begin to look at things from this perspective will we develop respectful and effective social systems. In addition we will suggest that this approach, is not hostile to integration, but may require a fundamental re-think of what integration means as self-directed support begins to be effective.

The transition problem

To achieve a good adult life for themselves disabled children face all the normal challenges: emotional maturity, changing family dynamics, self-awareness and the desire for independence. In addition they will also have to confront the additional problems that exist because of society's ongoing failure to welcome disabled people as full citizens: lower expectations, prejudice, lack of assistance and limited accessibility (Mansell, 2010).



But, in addition to all these problems, disabled young people and their families also have to overcome a problem that is the making of the welfare system itself: the gap between children's services and adult services and a paternalistic system that provides limited and obscure entitlements (Morris, 1999).

The gap between children's services and adult services can feel enormous, and this gap is experienced in almost every aspect of the welfare state: social care, healthcare, education and benefits. The differences are legal, normative and practical and, at the point of transition, a series of relative certainties and securities suddenly seem undermined:

- Entitlements suddenly change, new assessments take place, and many young people find themselves "no longer eligible" for support.
- Families, who have acted as representatives for their children's interests can find that they no longer have any involvement in key decisions (Duffy, 2013a).
- Schools, respite services, medical services, social workers, which, whatever their strengths or weaknesses, have been fixed points of support, are all changed.

Unsurprisingly the end of one regime and the start of a new one is rife with potential problems of expectation. Families and those on the children's side of the gap will often blame adult services for acting too slowly, providing inadequate care and for not listening to their wishes. On the other side of the gap adult services will often blame families, schools and children's services for their low expectations and for their resistance to the norms and services promoted by adult services. Given this difference in expectations it is not surprising that the transition period is often associated with complaint, conflict, anger and poor decision-making.

One extreme symptom of this is the high number of children who are sent away to residential college, placed in some other residential service or spend their entire adult life attending a day centre. In the two years preceding the changes we will describe, eight out of 24 children who went through transition ended up in a residential service (Cowen, 2010).

Finding an ethical solution

Both of us were governors at Talbot Special School in Sheffield and this gave us a particular perspective on the transition process:

My first Governor's meeting was at the beginning of first term. I was surprised that there was no report or discussion about what had happened to the young people who had just left the school: what jobs they had, what courses they were doing, where they were going in life. There was just silence; and when I asked a question there was no information. I am sorry to say that I mistook this silence for not caring. The truth – I was to find out later – was that they were just too saddened by what had happened after school to want to know too much, or to be reminded about it. Instead they focused on protecting and supporting children within the bubble that they had created around them (personal recollection).

We discovered that hope was the key to high expectations. It is only when professionals and families have some reason to believe that good outcomes in adulthood are possible that it is possible to change the expectations fostered in childhood.

We decided to work from within the school to see if we could bring about positive changes within the transition process in 2006 (Cowen, 2010). We began by talking to

children, families and teachers. What we found from their perspective was that much of the talk about planning for adulthood seemed to be bogus. In brief, many felt:

- there was no real planning, instead the actual decisions were made in a mad scramble in the summer when school was already at an end;
- there was no point thinking about jobs, homes or leisure, for only inflexible services were really available: placements in college, day services or places in residential college; and
- the system was confused and confusing: there many professionals, but nobody was clearly accountable and the school had no influence on the final decisions.

Unsurprisingly cynicism was high and expectations were very low. Fortunately we were able to call upon a range of families and professionals to begin crafting a very different kind of solution.

This solution – which we called personalised transition – was based upon a different approach to the transition problem (Cowen, 2010). Instead of treating transition as a technical problem that required a systemic professional solution we treated transition as a problem of citizenship, one that required a new understanding of rights and responsibilities (Duffy, 1996).

The personalised transition model has four main elements (see also Figure 1):

- (1) family leadership – begin by putting families and young people in charge; it is their life and they need to make the critical choices;
- (2) clear entitlements – tell people, as soon as feasible, how much money they have to develop any support they need – this was to include funding from social care, the NHS and the education system;
- (3) human support – support people with a real human relationship, not multiple professionals, rooted in peer support and support in the school; and
- (4) citizen-focused curriculum – refocus the whole curriculum on citizenship; begin planning for work, home and a real life in school from the very beginning.

Of course, putting this model into practice has been difficult and only some aspects of the model have been effectively achieved. Nevertheless it remains one of the most far-reaching and radical applications of “personalisation” so far, and more importantly, it has had some very positive outcomes (Duffy, 2012a).

Outcomes

In 2010 a researcher interviewed young people, families, teachers and other professionals and it was also possible to identify some of the key outcomes from multiple-perspectives. She concluded:

The outcomes have made a significant difference to the lives of these young people and their families. Young people with severe impairments are finding work, getting more involved in community life and having better lives (Cowen *et al.*, 2011, p. 33)

The financial outcomes were also positive, most encouragingly of all, this system seemed to end the pressure to send young people away from the city to residential colleges many miles outside Sheffield. Many individuals have continued to rely significantly on local services that have been commissioned by the local authority; however, some have started to develop radically different and more inspiring support solutions.

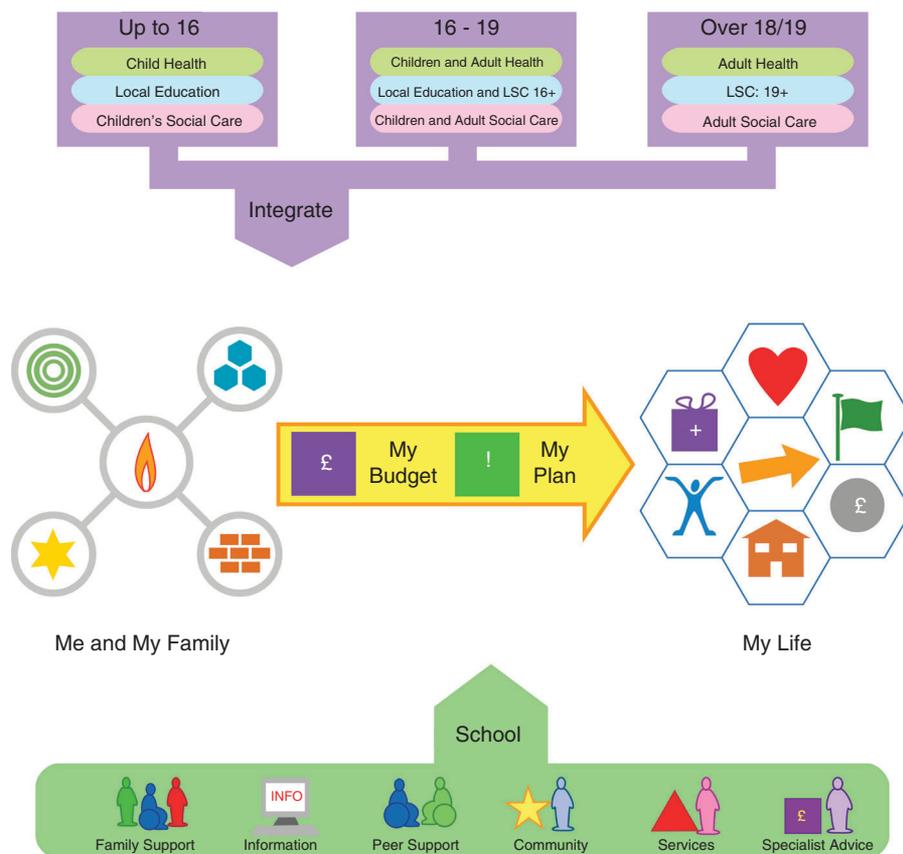


Figure 1.
Personalised transition

Jonathan provides one example of the more radical change that is possible (Alakeson and Duffy, 2011). Jonathan has very complex health needs and his support was funded by the NHS and the Learning and Skills Council (LSC). Together with his mother, Jonathan has developed a personalised package of support which gives him much more flexibility. Instead of attending college or going into residential care (the most likely outcomes in the old model) Jonathan has a job in the building trade. Jonathan has acquired two City & Guilds Qualifications and has learnt many new independent living skills. Better management of his health condition has led to savings of over £100,000 to the NHS in reduced hospital admissions (Alakeson and Duffy, 2011).

Three years into the programme of personalised transition, as understanding and confidence grew, two students with high support needs moved into their own homes within months of leaving school. Moving into their own home was a first for students at Talbot and sets a standard. Both these initiatives were the result of parents' raised expectations and aspirations for their sons.

The programme of work experience has radically changed since we first started working on personalised transition at Talbot. At that time very few students went out on work experience placements and those who did, tended to go out to tried and tested employers from around the city. The school now has a new approach. They work with

the students to find out what they are interested in trying out, and then work with small local businesses to provide opportunities for the students. Students are encouraged to try out a range of work experience placements rather than just trying out one.

This year, staff and governors at Talbot School have worked closely with Sheffield City Council to enable six young people who were unable to access a course at Sheffield College, to pull down education funding that allows them to access further education in a variety of community settings.

Lessons

On the face of it personalised transition provides an interesting case study of the kind of positive changes that can flow from the application of self-directed beyond adult social care and into services for children, the NHS and education. However, it is important to recognise that these changes were hard-won and that they depend less upon new processes and more upon a deeper understanding of how positive change and improved expectations are actually generated.

To end this brief paper we want to offer four lessons that we draw from our experience in developing and supporting the implementation of personalised transition. Each of these lessons has significant implications for how we think about integration in the context of self-directed support:

- (1) change begins within; much of what we need is around us;
- (2) we need inspiration to change; and
- (3) progress is not inevitable.

1. Change begins within

The critical assumption of the personalised transition model is that the life a disabled person is their own life. It is beyond the proper responsibility and competence of services to shape and determine how people choose to live. In situations where services have traditionally exercised a great deal of power (however inappropriately) the first challenge will be to help create the space and opportunity that people need to start to consider what they will do themselves.

To an extent this means that any new system – whether relatively helpful or unhelpful – will not determine the final outcomes, only the people who use that system determine what is achieved. This observation may be similar to the point that Mitchell makes, and which suggests that a focus on any system, as if it can straightforwardly be determinant of the outcomes, can be misleading (Mitchell, 2012a).

If we are thinking about integration and self-directed support it is important to consider what messages, spaces or supports, for any given process, reinforce the individual's sense of control and ability to reflect positively on their options. Improved system integration does not necessarily help people themselves reflect on themselves, their circumstances and what they want to change.

2. Much of what we need is around us

One of the consequences of the dominance of services in disabled people's lives is not only a weakened sense of person autonomy but also a failure to identify the individual's true assets (Rhodes, 2010). The centre piece of conflict, negotiation and planning are the service solutions that everyone is familiar with. We tend to think that "what we see is all there is" (Kahneman, 2012). This means that the institutionalisation and exclusion of disabled people is fed by our limited imagination rather than by reality.

One technique for challenging this distorted vision is to remind people that real life is built upon our real wealth which, as Murray describes is made up of (Murray, 2010):

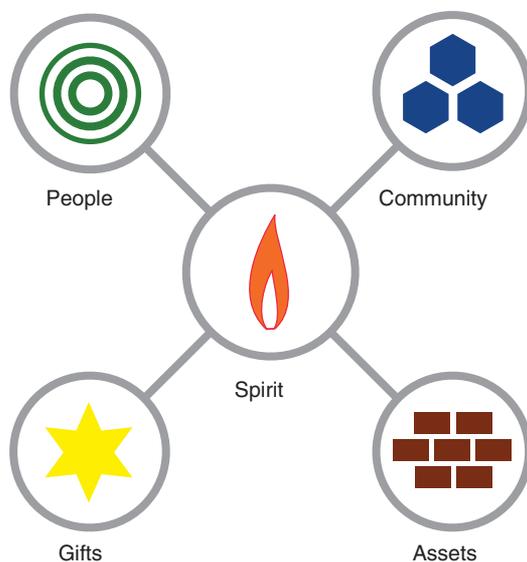
- (1) gifts – our unique mixture of needs and capacities which we must meet and exercise; people – the people we know who care about us and can help us;
- (2) community – all the opportunities for contribution and involvement that are accessible to us;
- (3) assets – our time, money, energy and the other resources we can use and exchange; and
- (4) spirit – the sense of hope and creativity which enables us to connect and use the different dimensions of our real wealth.

Thinking about decision making in this way is important because it moves away from the risky notion that budgets for care and support (however generous or inadequate) are the central resource in someone's life. A good life is not created by a budget, the budget simply enables the other elements of our real wealth to come into use (Figure 2).

Thinking about integration in this context could have some radical consequences. On this model it is the person or family who integrates, not necessarily the system (Duffy, 2004). In fact whether resources should be integrated before they are turned into individual entitlements is an interesting question. If people can genuinely integrate educational, health or social care resources into solutions that meet needs and achieve good personal outcomes it is questionable whether system integration is helpful or a hindrance. The more integrated the system, the fewer flexibilities for the person.

3. *We need inspiration to change*

When expectations have been dampened or distorted by society or by the services you experience then change is hard. Even if you know you have a right to make a decision,



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Figure 2.
Real wealth

even if you have identified your real wealth, you may still not feel inspired to make the necessary changes (Murray, 2011).

Certainly many families did not feel ready to make the move to more inclusive and person-centred solutions. They continued to rely on day services commissioned by the local authority or on traditional college placements. However, in our experience, what seems to help people gain confidence and make more significant changes is:

- peer support – it is hearing from others who feel share our experiences that we are most likely to take a risk;
- trusting relationships – it is where others are able to offer genuine, personal and long-standing support that they are best able to help lift expectations; and
- experienced reality – it is when we see that others are doing things differently, that what is normal is now different, that change becomes easier.

Quite an interesting example of this shift was provided by the school itself. Initially enthusiasm for the personalised transition project was not high. The project was led by governors and outside professionals. However, after the first year, there was a positive and significant change in culture and in thinking. The school itself, without any external stimulus, began to develop its curriculum for citizenship as it began to realise that adult services could now work with families and young people to offer better options.

Again, in the debates about integration, it may be time to think about the temporal and social aspects of change and to start seeing not professionals and multi-disciplinary teams as the focus of change, but people and families. This does not mean burdening people with the challenge of integrating systems, but rather strengthening the rights of citizens to negotiate the right kind of support, sometimes from different systems. Specialist supports are useful, but not when they are in control of the process, it is our ability to access those supports and weave them into our lives which ensures their effectiveness.

4. Progress is not inevitable

None of this is inevitable. Without the right leadership, support and some luck, it is difficult to bring about any of the changes described above. Personalised transition effectively threatens every vested interest in the current system, demanding changes in professional practice, thinking and local systems.

For example, while families are still told their budgets much earlier than they were, there are still significant delays in setting budgets, agreeing plans and being able to use funding flexibly. Often people's plans are now being scrutinised by panels and other professionals so that real freedom and control is eroded. The innovations that are described as examples of personalisation do not seem to be rooted in any real or substantive rights. Rather they are "rights on loan" from the service system itself (Duffy, 2012b).

Also, Sheffield continues to be one of very few local areas that has been able to individualise health and education funding. And while national policy continues to express enthusiasm for this approach, the reality on the ground is that there are many obstacles to progress (Department for Education, 2012). Matters have been made even worse by the structural confusion in the NHS, which has now led to hiatus in leadership in this important area.

Moreover, while funding for adult social care, NHS "continuing care" and adult education was successfully individualised and often families were told their budget

many months before school ended. However, seven years later, children's services are still not able to find the will to work to the same model. It is a shame that an approach which provides such a positive role for schools and children's services has not been adopted and integrated across the local authority.

As the current financial crisis hits local government many places are returning to an integrated social care system – putting adults and children back together again (Duffy, 2013b). It will be interesting to see if this helps further break down some of the barriers to good transitions.

Conclusion

It is perfectly reasonable for professionals at every point in the system to measure their success by the degree to which young disabled people have strong, positive and community-focused goals. However the lesson of our work in Sheffield, is that this should not be the primary goal of professional services. For at the heart of those expectation is the will of the individual and the love and support of family and friends. This is a far more appropriate and powerful force than a professional intervention.

There is a danger that the professional will, inappropriately, start to act as if it is the young disabled person or their family who are the problem. Ignoring the systemic barriers that are created by the system itself, professionals can be tempted to think that their job is to lift expectations by training, planning and inspiring. Some individuals may need this kind of help, but as a rule, it is an unwarranted interference that can easily become distracting and patronising.

The real focus for professional action and the fundamental locus of their responsibility, is to ensure that young disabled people have the means to exercise their rights. This is not just a matter of budgets, although budgets can be important. It is also about ensuring people have the independence, information, skills, experiences and relationships that enable the active exercise of those rights.

It is often “the system” within which professionals work which erode these rights; but it cannot be appropriate to treat these systemic failures as external constraints. These systems are designed and delivered by professionals themselves. We must have higher expectations of ourselves and of our public institutions. We must measure our systems by their capacity to liberate and support the active citizenship of our young people.

This is the paradox: the best approach for raising the expectations of disabled people is for professionals to have higher expectations of themselves and the systems they administer. System integration and team integration may not be essential requirements for any of this and may in fact distract us from important work.

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Corresponding author

Dr Simon John Duffy can be contacted at: simonduffy@mac.com