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# The path to fairness

**Pippa Murray** calls for radical change to welfare and support services for families of children with disabilities and SEN

In spite of the plethora of policy and legislation attempting to improve the life chances of disabled children and adults over the past decade or so, and the many different models of support available, disabled children with SEN and their families continue to report poverty, exclusion and having to struggle for the education and support they need (DCSF, 2009). Disabled teenagers also report an over reliance on their parents as they depend on them for their basic support needs as they grow into adulthood (Murray, 2002).

If we examine the current systems of welfare for children with SEN and disabilities, we see that the good intentions of all are thwarted by the incoherence, opacity, rigidity and complexity of the current system. Families currently access support from

a wide range of services including the NHS, social care, education and the tax and benefit system. The lack of join up between these systems means that most families are confused about what they are entitled to, and professionals struggle to provide accurate and timely information about entitlement and support.

The inability of current services – health, education and support – to make a sustained difference to the lives of disabled children and their families results in distress and inequality.

Parents are looking for straightforward solutions to the pressures they face: an extra pair of hands, a night's sleep or the flexibility to use support when they need it most. Disabled children want opportunities for friendship and fun; their brothers

*The good intentions of all are thwarted by the incoherence, opacity, rigidity and complexity of the current system*

and sisters want to hang out with their friends and have quality family time. The personalised pathway outlined below offers the opportunity for these things to happen in a way that transforms family life, provides greater equity and allows scarce resources to go further.

### The personalised pathway

A range of exciting and innovative reforms promoting personalisation in education, health, social care, housing, transport and other services is taking place in pockets across the country. However, progress is slow and patchy and has become unduly tied to different departmental priorities and perspectives. There is a danger of personalisation driving up bureaucracy and complexity. What families really need is a unified and coherent pathway giving them the help they need.

The key elements of the personalised pathway, extrapolated from the successful model from Sheffield and described in *Personalised Transition* (Cowen, 2010), are:

- family leadership – systems need to respect and support the leadership of families at every stage
- curriculum for citizenship – people do need support and

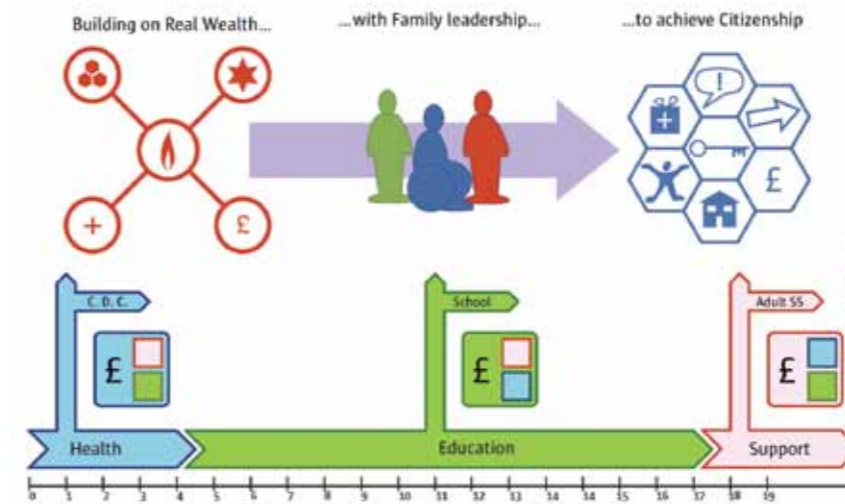


Figure 2. Personalised pathway.

additional expertise, but this support should be focused on the young person achieving citizenship

- coordinated expert support – people do need a partnership with the state and this is usually best managed through one clearly identified individual within an appropriate organization
- integrated individual budgets – most additional support and funding could be integrated in one individual budget that can be managed by the family

or a trusted professional or representative.

As the diagram above demonstrates, if we extend these principles we have a personalised pathway from birth to death. Our policy proposal is that all children entitled to a statement of SEN will be supported on this pathway.

### Family leadership

All families should have the authority to plan and lead their own support and shape the way things work locally. This capacity should be assumed and supported. At the initial point of contact

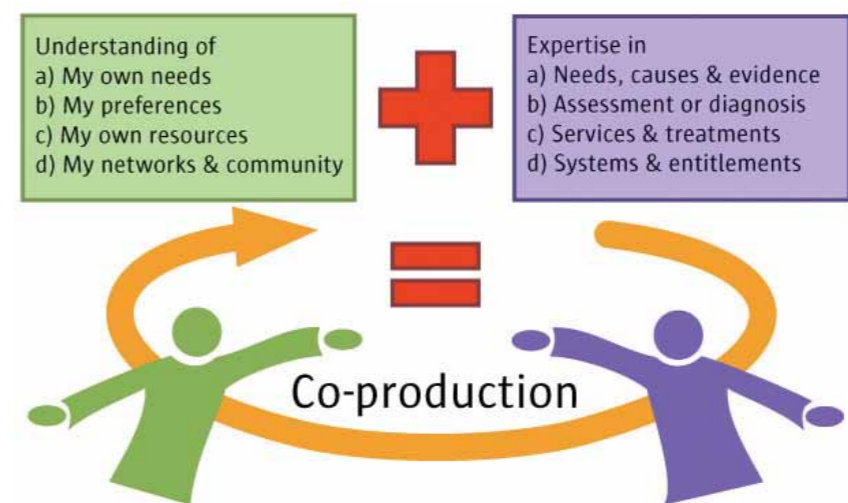


Figure 3. Co-production.

with a child development centre parents should be:

- put in touch with other families
- given information about systems and the range of available support and services. Once parents have enough information to understand the world they are entering into, they can influence, demand and offer constructive criticism with confidence. They will be empowered to put their own views forward, regardless of the availability of activities, support or services. These views will be taken into account as plans are made for their child.

### Curriculum for citizenship

When children reach school age, the school should become the natural hub for providing support and education to the child and their family. The school will take over from the development centre the role of coordinating any additional external expertise. Developing a curriculum for citizenship helps the school realise its role as a valuable resource to support the student's preparation for life as a citizen.

In addition, personalised learning programmes in schools should:

- enable all children and young people to communicate what is important to them. This fulfils the fundamental human right of having a voice, and allows students to focus on the voice of each student, whatever their means of communication. This careful listening provides the starting point for developing a wide, creative curriculum based on communication and skills
- develop person centred approaches throughout the school. This will include person centred reviews for all students (ensuring health issues



Figure 1. Complex service array for disabled children and families.

are included), personalised home school agreements and communication charts

- provide a skills based curriculum giving students opportunities to make choices and, where appropriate, decisions. All students with a statement of need should have an identified budget with which to buy the education and resources that best suits their needs.

### Coordinated expert support

Families should get the right support at the right time, and professional leadership and coordination should be provided by one lead agency at any one time. Children's development centres and schools should become vital points of focus for professional support.

The initial multi-agency assessment would act as a critical point for:

- informing parents about their entitlements – working out any individual budget through health and preparing the way for an identified budget connected to the eventual statement of educational needs
- completing the common assessment framework. This will be linked to a modest budget held by community lead professionals or key workers. Families will be signposted,

as appropriate, to specialist services and resources in their local communities

- giving parents information about community resources and relevant voluntary agencies.

### Integrated individual budgets

All families should have a clear entitlement to an individual budget which combines funding for support, education and the management of long term health conditions. The pathway should ensure that:

- entitlements are transparent with clear eligibility and resource allocation systems for the different funding streams. Eventually these streams will marry, with families having one assessment form that covers education, health and support
- families are informed of their budget at an early stage in the process so that they can take time and care with planning
- professionals supporting individual families will take the lead on streamlining particular areas of support needed from other agencies, such as housing or transport.

### Conclusion

With these four elements in place, the pathway would lead to:

- improved outcomes for children and families
- a stronger voice for parents
- a greater focus on children's needs
- simpler, more accountable systems
- a more strategic local approach.

The most effective way to develop this pathway is for government departments to work with communities and families to develop an integrated pathway for the care, support and education of disabled children. However, to drive this policy forward we will need to see local and national leaders move on from narrow, departmental perspectives. We will need to see leaders emerge who are willing to champion the family and the young person and understand that the needs of the family come before the needs of the system. **SEN**

### References

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### Further information

Dr Pippa Murray is the author of several books which document the lives of disabled families, including *Let Our Children Be: a collection of stories* and *Hello! Are you listening?* She has founded several parent-led organisations and is a long-standing campaigner for reform of the SEN and welfare systems.

The full text of *A Fair Start: A Personalised Pathway for Disabled Children and their Families* by Pippa Murray is published by The Centre for Welfare Reform in association with The University of Birmingham. It is available for download at:

[www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

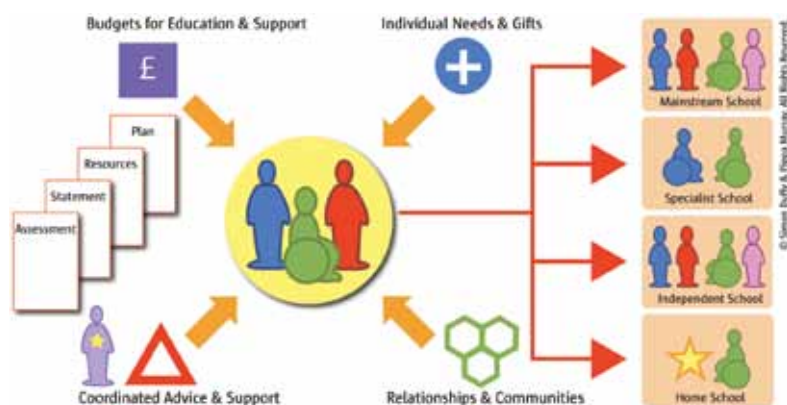


Figure 4. Individual education budget.