

8th May 2015

Draft Equality Impact Assessment on Self Directed Support

Barnardo's NI is writing in response to the Health and Social Care Board's consultation on the Draft Equality Impact Assessment on Self Directed Support (SDS). Following consultation with several of our senior practitioners we would like to highlight the following key points:

1. Targeted engagement / point of clarification

For the purposes of meeting Section 75 equality duties, we note the draft EQIA refers to 'targeted engagement' with Barnardo's NI as representing the younger age group. Barnardo's NI is the largest children's charity working in NI and as such would be regarded as a key Section 75 organisation in terms of age. However, we are concerned that our role and remit is not accurately reflected in the document; nor is the fact that we were consulted only in relation to one specific service / older age group. In the absence of wider consultation with Barnardo's NI or other children's organisations regarding the potential impact of SDS across the age range, we believe the HSCB has not fully met the EQIA requirements in respect of age and should review this.

With regards Barnardo's NI representation in the draft EQIA we would also request the following clarifications are made:

- The document incorrectly states that Barnardo's NI works with an age range of young people between 11 and 25 years and should be amended. This statement applies to only one of our many services, the Disabled Children and Young Peoples' Participation Project (DCYPPP), which was the specific service HSCB consulted with as part of the 'targeted engagement.'
- Barnardo's NI works with up to 10,000 children and young people aged 0-21 years and their families. We also work with some young people aged over 21 who are disabled and/or care leavers. Our service delivery is NI-wide via 40 services and specialist programmes and we work in more than 200 schools. We are working with BME and looked after children, young

people at risk and disabled children across the age range and within many of our different services. Our specialist services include child sexual exploitation, young carers, parental substance misuse, supporting pre-school children with autism and a disability participation project (DCYPPP).

- The correct use / spelling of our organisation's name throughout the document should be Barnardo's NI.

We would request that consultation with our organisation is made clear in the document as being with the Barnardo's NI Disabled Children and Young People's Participation Project (DCYPPP) and therefore one specific age group. Barnardo's NI would also suggest that for future Equality Impact Assessments on policy which will impact on children of all ages / different needs that the HSCB engages with a broader spectrum of our services. We know from our DCYPPP service and their active and positive engagement with the HSCB how important it is that young people are given meaningful opportunities to input into the development of policy and practice. This is valuable for the young people themselves and also those responsible for the design and delivery of policy and services affecting children's lives.

Building on the existing good participation practice embedded within our DCYPPP service, Barnardo's NI would therefore be very happy to facilitate wider access to our services and would welcome further discussion on how to progress this.

2. Age

Barnardo's NI generally welcomes the underpinning principles of Self Directed Support (SDS) as aiming to promote peoples' autonomy and independence. However, in order to fulfil its potential to transform care for children and young people, it must be delivered appropriately and supported by adequate levels of funding. This is essential to support its implementation and reduce infrastructure costs and the risk of increased bureaucracy.

While the draft EQIA states the analysis of the data gathered suggest there were no differential impacts or needs in relation to age, we believe this needs further consideration. We would refer you to our previous comments at Point 1, notably that consultation across the full younger age range is incomplete and needs reviewed.

We know from consultation with older young people in the DCYPPP service that SDS will likely have many benefits, especially for

enhancing quality of life and well-being. Some young people did express concerns about the age of consent and important decisions being made without their voice being heard, particularly where they do not agree with a parental decision and there is no alternative advocate. It is therefore essential that clear mechanisms are built in to SDS to ensure advocacy support and consultation with young people throughout.

It is generally unclear how the complexities around purchasing services will be managed. Barnardo's NI would be concerned that some vulnerable children will lose out on services, particularly vital continuity of care, when financial and commissioning responsibility is no longer the responsibility of Health and Social Care Trusts. Given how poorly service integration has been to date, as well as issues with waiting lists, it is difficult to see how some parents who are already dealing with multiple pressures / adversities can effectively navigate and coordinate that. Furthermore, it is unclear to what extent parents would be able to afford to purchase the current services on offer via Trusts which could lead to a reliance on lesser quality provision. Access to advice, information and support to ensure parents are confident about using SDS to employ and manage their own staff will be essential.

Direct Payments have long been in place for adult physical and learning disability however in our experience the situation is often more complex with younger children and this will need consideration. Indeed many of the parents we work with do not take up Direct Payments as they view it as an additional pressure. While we are aware that the opportunity to purchase services is one of choice, we are concerned that this concept will be reduced over time if more funding is channelled towards SDS.

While we believe it is a positive development for individuals to have greater autonomy and independence within SDS, there needs to be strong, in-built assessment and safeguarding processes in respect of disabled children and their rights. The protection of children from abuse, neglect and or exploitation is paramount and unfortunately in our experience, failure to do so can sometimes involve a parent or carer. Equally important should be the standard of care afforded to disabled children and it needs to be clear there will be no reduction in the quality of service currently provided through the statutory and voluntary sectors. Barnardo's NI would welcome clarification about the mechanisms which will be put in place to ensure this.

Finally, we would welcome some information on how the Health and Social Care Trusts will ensure that appropriate monitoring, recording

and evaluation practices are in place in relation to the implementation of Self Directed Support.

3. Supporting information / evidence

In the document there is a general lack of statistical and other contextual information, or a clear evidence base. This would include, for example, an absence of any reference to the UNCRC, as well as evidence of learning from other countries. It would also include information about the increased vulnerabilities to abuse for disabled childrenⁱ; and evidence about the impact of Direct Payments which have been used with adults for many years now, particularly with regards physical disability. The draft EQIA should clarify why the uptake of Direct Payments is lower by parents with young children compared with adults; this would be an important factor for consideration in respect of introducing SDS.

Moving forward Barnardo's NI would also like to see clear evidence of how information gathered through the pre and current consultation exercise will inform the actions arising from this EQIA.

For further information about any of the points raised in this response, please contact:

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ⁱ For example: a) [Safeguarding Board for NI - Strategic Plan 2013-17](#) (p20-21). b) Jones, L; Bellis, M; Wood, S; Hughes, K; McCoy, E; Eckley, L; Bates, G; Mikton, C; Shakespeare, T; Officer, A (2012) Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet*. Sep 8;380(9845):899-907. Epub 2012 Jul 12. c) Stalker, K & McArthur, K (2012) Child abuse, child protection and disabled children: a review of recent research. *Child Abuse Review*. 21(1) 24-40. d) Disabled Children and Child Protection in Scotland: An investigation into the relationship between professional practice, child protection and disability <http://www.gov.scot/Resource/0044/00447850.pdf>