



## **Response to Health and Social Care Board draft Equality Impact Assessment on Self Directed Support Consultation**

**Association for Real Change (NI)**

**Association for Real Change (NI)**  
Wildflower Way,  
Boucher Road  
Belfast  
BT12 6TA

## BACKGROUND

ARC (NI) welcomes the opportunity to respond to the consultation on the Health and Social Care Board draft Equality Impact Assessment on Self Directed Support.

ARC (NI) is a membership umbrella body, supporting over 35 learning disability providers to put real change into action by providing high quality information, accredited and non-accredited training, conferences, networking opportunities and good practice guidance to promote new ways of working.

ARC (NI) gained feedback on Self Direct Support from members from its TILII project. Telling It Like It Is (TILII) groups are advocacy groups of men and women with a Learning Disability who come together to speak out about what matters to them. TILII groups are part funded by Belfast and South Eastern Health and Social Care Trust and facilitated by ARC NI. The TILII groups currently work in Belfast, Lisburn, Bangor, Downpatrick and in Muckamore Abbey Hospital.

TILII members receive a diverse range and quantity of support, currently no TILII member receives support through Self Directed Support. TILII responded to the Easy read version of the report.

TILII members expressed their concern at not having information and knowledge on what Self Directed Support is, many were unaware of Self Directed Support and therefore feel more engagement and information needs to be given to service users, families and carers. Self Directed Support was explained to TILII members as outlined in the requested Easy Read Version of the report.

Thoughts on Self Directed Support (direct quotes from people with a learning disability)

- *It would be nice to have support when I need it, not what suits other people*
- *If I could have control and choice all the time I will be happy all the time*
- *It is our human right to have a say in what we do*
- *It is my life I should be at the centre*
- *I think it sounds good*
- *I would like to be in charge but with help- but not over bearing help*
- *In theory sounds pretty good but in reality will it work because of the choice thing?*
- *I should have a choice instead of people telling me what to do*
- *It is our life, we should have control and choice, our carers and family should work with us to help make our lives better.*

TILII members would like to response to report with the below points and recommendations.

### **Page 4**

**‘Staff will be given training and the Self Directed Support people receive will be checked to make sure it is doing what it is supposed to be doing.’**

TILII feel that staff receiving training is very important and are happy that this is included; they also agreed that it is important that support is checked. TILII would like to know what the training includes and recommends that people with a learning disability should be involved in the designing and delivering of this training as Self-Directed Support is to make sure people are at the centre of

their care. TILII would also like to know how the support that people received will be checked? Will people receiving the support be included in the 'check' or will it be just staff?

### **Recommendation**

Training is essential for staff members but also for service users, their families and carers. TILII would like to recommend that training is not only offered to staff but to Service Users, families and carers. TILII would like to stress the importance of people with a learning disability and others that will receive Self Directed Support to be involved in the designing and delivery of Training to make sure that 'people are at the centre of their care' .

### **Page 5**

#### **'We gathered information on self-directed support by: Talking to people with a disability, older people and carers.'**

TILII are pleased that people with a disability were involved, as it is extremely important that people with a disability have their say from the start on issues that affect their lives. The majority of TILII members were unaware of Self Directed Support and they would like to know how many people with a learning disability were talked to about Self Directed Support and how?

TILII members would like to highlight the importance of consulting and engaging with people with a learning disability, older people and carers. *The aim of self-directed support is to make sure people are at the centre of the care they receive. This means that they are in charge*<sup>1</sup>. This cannot happen if the people who 'will be in charge' are not properly involved, consulted with or included from the start. Service users need to be consulted with just as much as Statutory and Voluntary organisations. *"To me not asking people with a learning disability what we think shows that we don't have control and choice over our lives and it (self-directed support) is not person centred, we aren't even asked"*<sup>2</sup>

### **Recommendation**

TILII would like more involvement and engagement for Service Users and anyone who will receive Self Directed Support. TILII would like to highlight the importance and need to include service users from the start if Self Directed Support is going to work and be person centred.

#### **TILII considered the 3 key groups, Age, Disability and Carers as outlined in the report:**

##### **Age**

TILII felt older people could be affected if information and access to services, support staff, help and advice is not tailored to their needs or actively promoted. It was explained to the members that Self Directed Support is a choice and only people that wish to have it will access it. TILII members, who considered themselves to be older, expressed strong concern over the concept of 'change' and the idea of something new. Some members stated that they did not want things to change in their life;

---

<sup>1</sup> Easy Read Version page 4

<sup>2</sup> Quote from TILII Member

they wanted to stay the same and not have more choice or control regardless of the potential benefits. They value and need routine.

TILII members who had elderly parents as their careers, stated how they don't want to have to change things, they like things how they are and are fearful that day centres will close down.

This group will be affected in a negative way if sufficient training, help and support is not offered. There is a perception that with any change to services or support, families are left out of the decision making, they are not given support and as such have developed a resistance to any change (positive or negative) if they 'stick to what they know' their son/ daughter will be 'okay'. This perception and knowledge of potential barriers to ensuring everyone has equal opportunity and to access Self Directed Support including older people, needs to be addressed and included in the strategy for offering advice and support. If the needs and concerns of older people are not seriously acknowledged then they will be disadvantaged and negatively impacted.

TILII agree that older people who may want to become employers need help and advice and welcome this, however it is not just older people that need help to become an employer-**everyone does.**

TILII raised concerns for young school leavers with a disability accessing Self Directed Support. Will they get information and guidance about Self Directed Support when they are leaving school? Some TILII members felt that the benefits of Self Directed Support would help people with a disability when they leave school, they could have more support and options for employment and attending college. TILII thought that training and support should be available to include people attending schools, teachers, career advisors and employment officers. This would ensure that young people with a disability could access Self Directed Support and not be excluded.

### **Disability**

TILII agree with the importance of Self Directed Support being available to everyone regardless of their disability. They also agree that some people with a learning disability and their family may find managing personal budgets difficult.

*'The Trust will help anyone who needs advice and support in managing a personal budget'<sup>3</sup>*. TILII would like to know what this would be and how the Trust is planning to ensure that the support needs of people with a disability are met. Advice and support offered by the Trust must suit the needs of all disabilities; TILII expressed the need for people with learning disabilities and communication difficulties to be given the right amount of support to manage a budget. TILII members feel if individual needs due to a disability are not met in the support and guidance of personal budgets many people with a disability could end up being left out.

*'If someone is said to be "without capacity" they may have a legally appointed representative who can make decisions on the individual's behalf'<sup>4</sup>*. TILII would like to know if the Trust will be checking and monitoring this person (appointed representative)? This is a concern for some TILII members, as

---

<sup>3</sup> Easy read version page 9

<sup>4</sup> Easy read version page 10

some have experienced first-hand and from close friends or family members, abusing this responsibility and spending their money or not allowing them to buy or do things that they want to.

TILII feel that Self Directed Support could be a positive thing for people with a learning disability if they get the correct support to have control over their lives, the opportunity for people with a learning disability to have choice and a say in their care and support would be *“life changing”*. *“If I could have control and choice all the time I will be happy all the time”*<sup>5</sup>

## **Carers**

TILII members who use carers felt that carers could be concerned about Self Directed Support if they don't understand it correctly. As with all keys groups TILII highlight the lack and need for more engagement and information on Self Directed Support.

Some TILII members felt that carers would be concerned about losing their caring role or that the person they care for will receive an inadequate service. This concern came from one TILII member asking *‘if someone had full control over their carer and support, could they refuse things like some personal care or help?’* This TILII member went on to explain *“One of my carers is a family member and I hate getting ..... (personal care) as my family member, they tell me I have to have it done but if I could pick someone else, my family member would be worried that I wouldn't be looked after as I would probably refuse certain parts of my personal care. How much control will people have?”* This TILII member added that they had capacity to consent for themselves and asked how the *Trust will support carers to have a say in the decisions being made in the care and support service provided through Self Directed Support*<sup>6</sup>. TILII asked in relation to this again how support and services would be monitored to ensure carers are supported.

TILII had some additional concerns and questions they felt needed to be addressed.

## **Employing Personal Assistants**

TILII members liked the case studies; they found these helpful and inspiring. Many TILII members would like to employ a Personal Assistant but feel that there is not enough information or guidance on how they would do this. They have some concerns and would be worried about employing someone. TILII feel that people's fears and concerns to employ a Personal Assistant needs to be a key focus and addressed if people are to successfully benefit from Self Directed Support.

TILII members have some questions that they feel should be answered and given to service users

1. How would I hire someone, do I need a contract, police checks? If I do how do I do that?
2. How do I pay someone? Is it in cash or bank account?
3. Can I decide when I need someone to help me and for how long?

---

<sup>5</sup> Quote from TILII Member

<sup>6</sup> Easy Read Version page 11

4. I want to do my own job description for my Personal Assistant; will there be training and support for people with a learning disability to do this?
5. Do I need a recruitment agency, how do I find people (to employ)?
6. I want to interview the people that will be supporting me- is there help or training to support me to interview on my own?
7. What if I don't like my Personal Assistant?
8. Can I get a Personal Assistant on my own or do I need help, like with Cedar or Positive Futures (organisations)?
9. What if my Personal Assistant phones in sick, what do I do, can I get help from the Trust?
10. Can I employ my family? They know me and have more experience of supporting me than another staff member.

### **Choice**

TILII would like to know is there a plan for ensuring people with a learning disability are involved and included so that Service Users are enabled to make informed choices and access information to make a decision.

Many TILII members welcome and agree that they should have control over their support. Some TILII members thought it would be good if they had the choice to go to a day centre or not (others strongly felt they didn't want to leave the day centre) those TILII members were unsure as to what they could do if they had choice and control over their day.

TILII members liked the idea of going to clubs, learning something new and doing sports but couldn't think of any in their community that they could access, even if they had the support to get there and take part. TILII members would like to know if the Trust will be organising groups and activities or letting people know what is on and where, so they can make an informed choice on what they can do with their lives?

*'What's the point in having control over my life if I have no idea what my choices are and what I can do, will someone tell me what choices I have?'*<sup>7</sup>

*"How can I make choices if I don't know what my choices are?"*<sup>8</sup>

TILII asked in addition to the case studies provided could there a 'Pros and Cons' list to help service users, families and carers make an informed decision about Self Directed Support.

---

<sup>7</sup> Quote from TILII Member

<sup>8</sup> Quote from TILII Member