

Appendix 2

Carer Input into the Report for the Health and Wellbeing Board

Draft LD Strategy 2015-18 Better Outcomes for People with LD and their families

Co-Production and Partnership Working

Carers are pleased that in developing the draft LD Strategy, Officers have made genuine efforts to work with them as true partners and that this has resulted in a strategy that carers feel reflects their views and opinions.

Other excellent examples of joint and partnership working are provided by the work of the Young Adult's Team and its steering group. Carers feel truly engaged and involved and have an excellent relationship with their co-stakeholders including Young Consultants.

Carers are happy and eager to co-produce in 'real' ways in the knowledge that this can help them to co-own decisions.

Carers realise that a healthy partnership and engagement process means that not all discussions or decisions are able to be resolved in a way that ensures all parties are satisfied. They believe that challenge and scrutiny should not be regarded in a negative way but is seen as part of a constructive process.

Carers hope that these good practices can become a template for all activities relating to LD services and carer issues; in order to ensure there are fewer examples of poor partnership working and working with carers too late, once decisions have been made or inconsistently in the future

In the future carers would like to see Strategies, Action Plans and Outcomes which are 'person centred and integrated' both for them and their family members developed in partnership and with a whole family approach.

LD Partnership Board Governance

Carer Representatives are pleased that the Governance arrangements for the LDPB and sub groups still includes carer members and independent support for them to engage in discussions in a meaningful and well informed way and to facilitate engagement with the wider LD carer population.

The draft Learning Disability Strategy

Carers understand the financial issues faced by the Local Authority and NHS but also require that these partners also recognise the financial contribution they make.

Carers are optimistic that the draft 3 year learning disability strategy is setting the right general direction of travel. They are pleased that the commissioning manager tasked to do this piece of work, has worked in such a positive and co-productive way.

However they recognise that the success or otherwise of this strategy and its guiding principles is reliant on comprehensive, quantifiable and qualitative outcomes for all partners

Carers believe that, to ensure that the LD strategy is effective and services and the lives of people with learning disabilities are improved, it is essential that there is :-

- **An effective mechanism for quality assurance of services** provided by Local Authority, NHS and private providers. Including mechanisms to ensure safe guarding irrespective of who purchases the service.
- **Full Support from leadership** to ensure the Strategy is successful in meeting its targets
- **Comprehensive and quantifiable outcomes for all partners**
- **A market place** that is providing services and options that are safe and sustainable both for the service user, carer and provider
- **An understanding and mechanism to adjust Direct Payments to reflect changes in the CPI or average earning**, as is done with the State Pension. Without this there is a real threat to the viability of the market place which will see real increases to input cost. It is already a threat to the well-being of service users as the services reduce in quality/safety/duration.
- **Services that are person and family centred** understanding the impacts on the whole family. Ensuring that all strategies likely to impact on the lives of people with LD and their family carers interconnect, and are not seen in silos
- **A system that allows real choice and support** that is available to exercise choice in a realistic way with a proper understanding of the consequences of choices
- **Education, awareness raising and training** to ensure people with learning disabilities and their carers are understood and accepted.
- **Integration of social care and health systems** so that people only have to tell their stories once and systems talk to each other.
- **Services that do not operate in isolation and in 'silos'**
- **Effective and good partnership working** with all key stakeholders including people with LD and family carers, and led by people with learning disabilities and their carers
- **Decisions based on the evidence** provided by and from those using services and their families
- **Real understanding of impacts of changes** and the 'hidden' effects and having mechanisms to listen

- **A way of listening and learning from 'experts by experience'** avoiding making decisions that increase costs in the long term e.g. Housing matching, inability to continue caring etc.
- **Better connections between providers of service and commissioners** and learning from best practice

Evaluating the outcomes

Carers suggest there has to be a **comprehensive means of evaluating and measuring the outcomes of the strategy both qualitatively and quantifiably.**

Carers

- Carers expect that definitions and underpinning values and commitments to carers in Worcestershire Carers Strategy 2015-18 will be applied to LD carers
- There is clear guidance in the Care Act with regard to carers and LD carers will expect LD services to comply with this guidance including their rights in regard to:
 - Well-being
 - Information and advice:
 - Prevention
 - Assessments
 - Meeting support and care needs
- Carers will expect all services to 'Think Carer' and to respect their unique knowledge and expertise. Carer Aware – we would like commissioners to embed this requirement into social care related contracts (not just for carer services)
- Carers of people with LD often provide a 'lifetime of care', this should be acknowledged
- It is essential to understand the need to engage and support parent carers, carers at transitions and carers of adults in ways that meet their needs and support them in their caring roles which will change over time
- Support for carers needs to extend to advocacy and support to help them engage in strategic decision making, partnership working, co-production and service development.
- For some people with LD their carers are their advocates and carers hope that this role will be recognised, understood and valued.
- Caring for someone with LD for a lifetime means that the impact and burden of care affects the whole family, carers would like to see this recognised and assessments and services that are 'family' focussed.

Ray Eades: LD Carers Reference Group Chair on behalf of members of LD Carers Reference Group and LD Carers Consultative Group

15.1.15