



The Cwm Taf Joint Statement of Strategic Intent for Children, Young People and Adults with Learning Disabilities (including autism and complex needs) and their families

**Analysis of Stakeholder Engagement Report
September 2017**

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	Information and Questionnaire used  LD survey doc.pdf	

1. Introduction

The Cwm Taf Social Services and Wellbeing Partnership are working together to look at the way they provide health and social care services to people with a learning disability of all ages and those with complex needs and/or autism and their families.

Our joint vision is that people with a learning disability will be able to access modern services that promote their independence, reduce reliance on long term services and emphasize choice and control.

That children, young people and adults with a learning disability (that includes autism and complex needs) will be able to access efficient and effective services that enable person centred outcomes and minimise escalation of need and risk through the promotion of early intervention, prevention, greater independence and access to opportunities.

Our strategy for learning disability services is focused on the following key messages:

- Maximising the use of universal services
- Increased early intervention, prevention, information, advice and assistance
- Building community support and developing people's independence
- Sustaining people in their own homes
- Enabling people to live full lives and achieve their potential
- Keeping people safe
- Making best use of our resources

This work is set within the context of the Social Services and Wellbeing (Wales) Act 2014 and it outlines the strategic approach to the commissioning of learning disability services by partners across Cwm Taf.

The statement encompasses individuals with learning disabilities of all ages and those with complex needs and/or autism and their families. Individuals with learning disabilities are those who have:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning)
- Which started before adulthood with a lasting effect on development

2. What did we do?

- 2.1 The initial draft statement of strategic intent for Children, Young People and Adults with Learning Disabilities (including autism and complex needs) and their families (referred from now on as the Statement) was developed in response to what service users, carers and other stakeholders had told us previously and with reference to good practice and research from elsewhere.

The engagement activity we have undertaken during 2017 was intended to make sure that we have correctly addressed the things that you told us and that the Statement is focussed on what matters

- 2.1 Over a 16 week period, between the 11th of May and the 31st of August a number of staff briefings, stakeholder focus groups and service user conversations have been undertaken across the region.

The Focus groups

Focus Group	Participants
Parent Carers	8 participants
Council Staff outside Social Services	11 participants: libraries, leisure, adult education, customer services, community wellbeing, contact centre, youth engagement & participation, housing, integrated transport unit.
Adult Health	8 participants: therapies & health sciences, mental health, learning disability, primary care, OT, carers co-ordinator, nutrition & dietetics, substance misuse, patient care & safety, district nursing.
Children's Health	14 participants: OT, SALT, physio, dietician, neurodevelopment team, nursing, paediatrician, commissioning, psychiatrist, early years, planning, engagement & participation.
LD Community Groups	9 participants: Touch Trust, RCT, Mencap, Arts Factory, Autism for Children, Dewis, Viva
Wider Community Groups	7 participants

Each focus group lasted two hours and followed a similar procedure. Participants were asked to introduce themselves by stating who they were, what their role was and what that meant they were responsible for. The facilitator then spent ten minutes setting the context around the Social Services Well-being Act (SSWB Act) and the Cwm Taf Statement of Intent for Learning Disabilities. Each focus group was then asked the same set of questions:

- What impact has the SSWB Act had so far?

- Is there anything in the Statement of Intent that stands out to you?
- What things would you like to do differently?
- What impact would it have?
- What would it take to be able to do it differently?
- How would you like us to take the engagement forward?
- Who else could help us?
- Any other resources that could help us?

The discussions were allowed to flow naturally and the facilitator didn't move onto the next question until the discussion naturally paused. The focus groups were recorded, transcribed and the data analysed using Nvivo.

Stakeholder Briefing

At the start of the engagement process officers from across the Partnership created a comprehensive stakeholder map (available on request) to ensure that all briefing materials could be widely distributed and operational staff updated and involved

To support effective service user engagement a focus group was facilitated on the 19th of May. This session was arranged for staff (from across the service) and the self advocacy group (Peoples First) to consider how best they could engage with and gather the views of the wide range of people with learning disabilities with differing levels of need and communication skills. The outcome of this session was to ensure effective conversations with service users about the plan and its content

Meetings with service users (Peoples First)

People's first facilitated conversations with service users about the Statement of intent in a series of meetings during July

These sessions were very well attended and utilised the 'easy read' document produced to support the engagement process

Service user participation at these meetings were as follows

Merthyr	18
Rhondda	8
Taf Ely	10

Online suggestion box

To further capture people's views and reflections, an online suggestion box was created on the Cwm Taf Hub.

Officers from across the partnership publicised this online facility within their service areas, with stakeholders, service users and carers. This facility was also publicised through the stakeholder briefings and focus groups

Participants that recorded their views in the online suggestion box were as follows :

A person with a learning disability	1
A carer for someone with a learning disability	14
A professional working with people with learning disabilities	35
other	7
Total	57

ABMU Mental Health and Learning Disabilities Commissioning Board

Abertawe Bro Morgannwg UHB is the provider of specialist LD health services for our population in Cwm Taf

Officers presented the Statement of Intent to their Mental Health and Learning Disabilities Commissioning Board on the 10 August 2017 where it was agreed and given their support

3. Focus Group Findings

The findings are grouped under three themes (Universal, Universal Plus, and Early Intervention) that reflect the model for commissioning an ordinary life described in the statement of intent.

These findings are a summary of the key issues raised; a more detailed illustration of the discussion is available on request

Universal

- There is a direct correlation between families having a bad experience of universal services not coping with their family member with learning disabilities and the conclusion that the only solution therefore is a specialist service.
- There is a lack of community infrastructure
- There is a need for social prescribing
- There is a need to empower people with learning disabilities and their families
- There is a need to increase community presence and contribution so as to reduce stigma
- There is a need to support and empower staff working in universal services
- Community environments need to be more accessible.

Universal Plus

- Participants consistently stated that universal plus does not currently exist and is again the reason that people jump to the conclusion that the ONLY solution is a specialist service.

Early Intervention

- Issues around early intervention consistently centred around challenging behaviour and the lack of access families have to support that helps them to manage and reduce such behaviours.

Meetings with service users (Peoples First)

These findings are a summary of meetings with service users, facilitated by Peoples First. The findings below reflect the structure of each meeting and identify the key themes recorded in the minutes. A more detailed record of each meeting is available on request

When asked if the statement of intent addressed the important things for them they noted particularly that it did not address:

- Transport as they felt particularly that transport was key to supporting access to the things they want to do
- Access to places to support people with learning disabilities feel more part of the community and help them be more independent

The things they identified as 'what matters' to them were (in summary):

- Healthy eating,
- Keeping fit and able to exercise (walking, swimming, dancing, going to the Gym, shopping, football, badminton, bowling, Zumba),
- Access to IT and communicating online with friends
- Being with partners, friends and family and socialising, going places with them
- Living with family,
- Learning and maintaining new skills Gardening, Arts and Crafts
- Working /having a job
- Having access to good local doctors and being confident to tell the doctor how you feel and having them listen to you
- Being Active
- Being happy
- Health and well being of family
- Having a break and a holiday

It was noted in particular during these meetings that communication with service users needs to be prioritised with regards to any changes to services and that they are concerned to ensure that they are fully engaged in any change to service delivery in the future

Online suggestion Box findings

These findings are a summary of the responses recorded in the online questionnaire which was live from May to August 2017. A more detailed record of the online response is available on request

Of those who participated 90% recorded that they felt the statement of intent recorded the most important things for them

For those who didn't agree their comments referred primarily to the fact the document was written at a high level and lacked the detail of how it would be applied in practice

In addition there was specific reference to the fact the draft document does not refer to the Additional Learning Needs and Education Tribunal (Wales) Bill 2016 and its implications

When invited to provide further comment about the statement of intent and its content these included

- Support for the development of universal services
- Concern with regards to financial resources to manage both low level support and specialist care
- An emphasis on requests to improve communication both in terms of engagement and in relation to service delivery

When asked what they felt mattered the most to people with learning Disabilities the respondents identified the

- Having the right care and support when they need it
- Being independent
- Being with friends and family
- Being cared about
- Being able to take part in what's going on in the community
- Being active and involved in new things
- Having a safe and comfortable home
- Being able to learn new skills
- The health and wellbeing of their carer/parent
- Having good advice and support to keep themselves healthy
- Being treated as a respected individual

Feedback from Education

People working locally in our Education Services have noted that the figures quoted in table 1 of the Statement of Intent do not reflect their experience.

For example, the number of young people in RCT that have needed a statement saying that they have a Special Educational Need has grown by 46% since 2012 (from 564 to 823 pupils in 2016).

This discrepancy between actual growth in education and predicted growth in health and social care could be as a result of variations in reporting criteria but more work is required to examine the data to improve confidence in its reliability for future service planning across all services

The initial draft of the SOI did not refer to the Additional Learning Needs and Education Tribunal (Wales) Bill 2016. (Introduced in December 2016)

This significant piece of Welsh Legislation has currently progressed to Stage three of the Welsh Assembly process and is set to become Law early next year (with an implementation date to be determined). It is anticipated that the implications of the Bill will be significant for Local Authorities and joint planning between Health, Social Care and Education will be required to co-ordinate its implementation, the extent of this task will become clearer as the Bill progresses and its Regulations, Codes of Practice are formally agreed

Conclusion

Generally the Statement of Intent has received widespread support particularly the service model for commissioning an ordinary life.

We have heard that access to universal and community services and activities is currently a challenge for people with learning disabilities, and service users in particular identified the practical difficulties they face whilst trying to live an ordinary life in the community.

We have noted that we need to continue to look at what matters to people with learning disabilities and their families and to engage them effectively in the design of the service going forward. This is because our understanding of accessibility to both universal services and community services has to be informed by the experiences of those who are trying to access them to ensure the key challenges they face are addressed

The Statement of Intent is intended as a strategic statement for partners to use as a framework for further commissioning and development but the nature of this high level document was frustrating for some who are anxious to understand how planned change will affect them directly

A strong message from all participants was the need to communicate more effectively with people and to engage them in any change and development of the service

To that end the Regional Steering group that involves representation from both Merthyr and RCT Local Authorities, Cwm Taf University Health Board, People First and third sector community groups will be responsible to ensure effective engagement and communication activities with service users, carers parents, staff and other stakeholders during the next steps are prioritised

Prior to embarking on the more detailed work to implement the model and to conclude the work on the actual statement itself we will amend the draft document to incorporate the Additional Learning Needs and Education Tribunal (Wales) Bill 2016 and its implications. It is noted that as this Bill progresses its requirements will necessitate closer working between Health, Social Care and Education particularly with regards to planning transition

It is acknowledged that there is a discrepancy between the figures published in table 1 of this Statement of Intent and the experience of actual demand in Education Services. Further work has already been identified as required to establish a more robust register of people with a learning disability in Cwm Taf and it is noted that this planned work should include colleagues from Education so that projected data in the future can be reported with greater confidence and transparency

For further information and access to more detailed reports please contact

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