

WHAT MATTERS to ME

A Co-Productive Approach to
Shaping Service Priorities for
People with a Learning Disability
and their Parents and Carers
across Cwm Taf



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INTRODUCTION:

Voice, Choice and Control

Across Wales people with lived experiences have been provided with unique opportunities to have a say and be involved in the design, delivery, decisions and evaluation of the services they use and interact with, through the Social Services and Wellbeing (Wales) Act, 2014. The Act has developed a framework to safeguard and improve the wellbeing of people who need care and support, and their families and carers, through the positive transformation of Health and Social Care services. To do this, the Act imposes duties on local authorities, health boards and Welsh Ministers that requires them to work in such a way that people with lived experiences are given control over what support they need, and empowered to be part of the decision making processes relating to their care as equal partners.



The Social Services and Wellbeing (Wales) Act, 2014 is based on four fundamental principles:

Voice and Control – putting people with lived experiences and their individual needs at the centre of their care. Giving them a voice in and control over what services and support they need to help them have good wellbeing

Prevention and Early Intervention – to increase preventative services across Wales and reduce the number of people developing critical needs

Wellbeing – supporting people with lived experiences to achieve their own positive wellbeing and to be able to effectively measure the success of the care and support they receive

Co-production – creating opportunities for people with lived experiences to become actively involved in the design, delivery, decision-making and evaluation of Health and Social Care services, being recognised as 'experts by experience'

To oversee the implementation of these principles, Regional Partnership Boards have been set up across Wales comprised of members from the local Health Board, Local Authorities, NHS Trusts, Third/Voluntary sector and citizens themselves as both service users and carer representatives. As part of their mandate under the Social Services and Wellbeing (Wales) Act, 2014, Regional Partnership Boards have been asked to prioritise the integration of services in relation to:

- Older people with complex needs and long-term conditions, including dementia
- People with Learning Disabilities
- Carers, including Young Carers
- Integrated Family Support Services
- Children with complex needs due to disability or illness

The purposes of the What Matters To Me project are rooted in driving service transformation to better support the needs and wishes of People with a Learning Disability and their Parents, Carers and families, providing them with opportunities to have their voices heard through an intentional co-productive approach.

PROJECT BACKGROUND:

The meeting of minds to drive change

Co-production is a process that aims to re-balance power structures so that an equitable and safe working environment can be established that allows for the meeting of diverse, unique and interested minds to drive forward positive social and service based change through issue identification, effective conversations, the sharing of personal and professional experiences, and joint decision-making.

As a response to the Social Services and Wellbeing (Wales) Act, 2014, the What Matters To Me project developed its foundations in 2017 alongside wider work being conducted for the regional population needs assessment by the Cwm Taf Regional Partnership Board (later Cwm Taf Morgannwg Regional Partnership Board). The project aimed to engage people with a learning disability in conversations about what they felt were important factors to improving their lives. In 2018, these conversations widened to include parents and carers of people with a learning disability, and later Cwm Taf (RCT) People First supported a core group of these parents/carers to formalise as a parents and carers support network for the Rhondda Cynon Taf area named The Grapevine.

Following these conversations Cwm Taf (RCT) People First, The Grapevine, Rhondda Cynon Taf County Borough Council Learning Disability Services and Cwm Taf University Health Board (later Cwm Taf Morgannwg University Health Board) reviewed the findings and identified a number of common themes from which priorities for learning disability services were drawn and encompassed within the Cwm Taf Regional Plan (2018-2023) but more specifically within the Cwm Taf Learning Disability Statement of Strategic Intent (September, 2017).

To support the successful implementation of the Cwm Taf Learning Disability Statement of Strategic Intent, it was agreed that a Regional Learning Disability Steering Group would be established to oversee the work, bringing together representation from Merthyr Tydfil County Borough Council, Rhondda Cynon Taf County Borough Council, Cwm Taf University Health Board, Cwm Taf (RCT) People First, The Grapevine and other Third Sector community groups, as a meeting of minds and a step forward within an emerging co-productive model. Cwm Taf (RCT) People First alongside their Third Sector counterparts were then charged with the responsibility of the effective engagement and communication of activities with service users, carers, parents, staff and wider stakeholders to ensure that citizen voice and need were at the centre of the work being conducted. To further ensure success a number of provider led work streams were developed to assist and promote the joined up working of the identified priorities as shown.

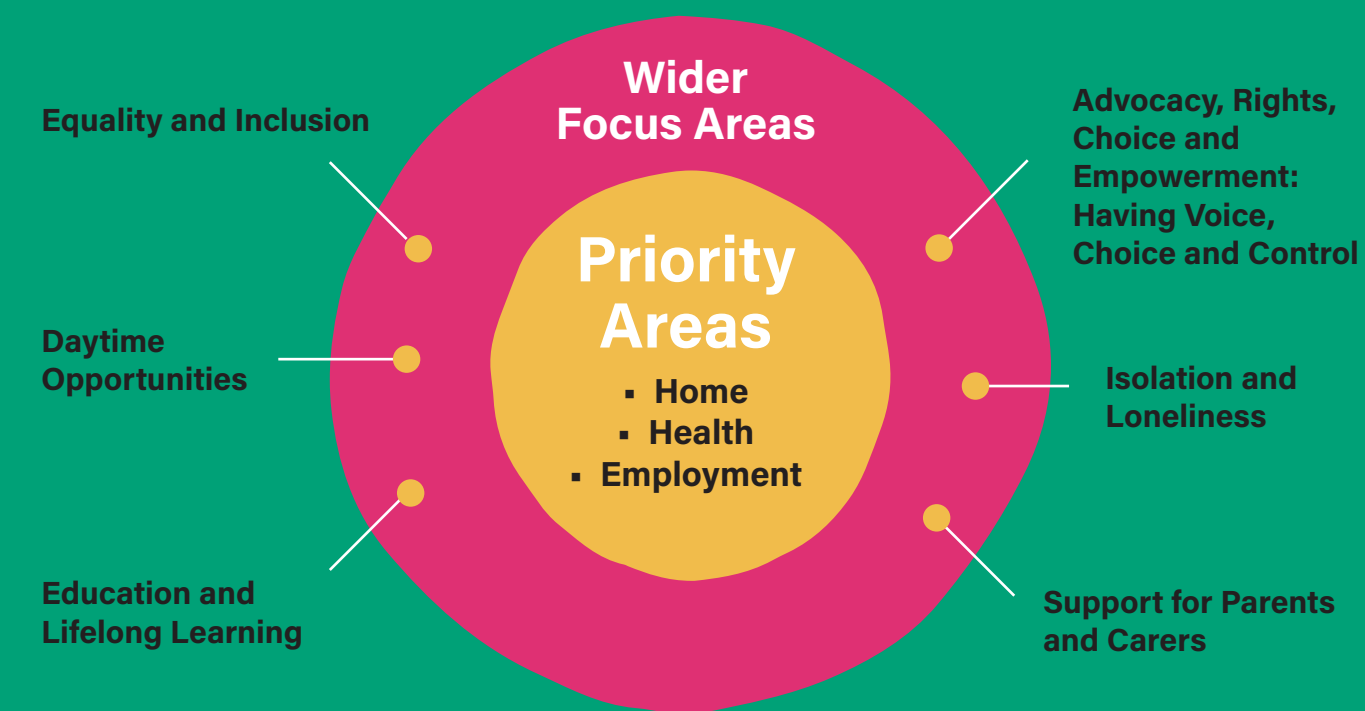
Theme	Priority outcome	Method	Purpose
My Community	Preventing loneliness & isolation by increasing community inclusion Lead: RCT	Community Asset Mapping	Better understand what is available & not being utilised; what can be built on & where the gaps are
	Reducing stigma Lead: People First	Raise awareness & positive images campaign	Develop a coordinated approach to raising awareness
My Home	Meet range of housing needs now & in the future Lead: RCT	Map current demand – review best practice – develop range of solutions	Agree a strategic vision for housing and set of priorities
My Education, Employment and Life Long Learning	Improve & increase the options for further education Lead: RCT	Develop a multi-agency protocol for transition collaboratively	Develop an agreed way of doing things that provides opportunities and choice
	Improve & increase the options for employment, training & lifelong learning Lead: RCT	Map current need and provision – build on current practice – areas for development	Develop understanding and agree a range of doing things that provides opportunity and choice
Communicating our Work	That people know and are engaged in our work	Supporting the effective delivery of a multi-strand communication strategy	Ensure people know and are engaged in our work

Following an initial period of positive activity, the work being delivered under the Statement of Strategic Intent hit a stumbling block once the initial action plans had been completed, and work seemed to grind to a halt. On reviewing the work that had been completed, people with a learning disability reported that they felt they were still not being listened to effectively throughout the decision-making process and called for their voices to be considered, valued and respected fully in future work. Still believing in the value and vision of the Statement of Strategic Intent and its potential to create a platform for citizen voice, Cwm Taf (RCT) People First led a piece of work in early 2019 to review all the information they had gathered from people with a learning disability and to re-engage its members, as well as wider citizens in What Matters To Me conversations.

HAVING OUR SAY: What Matters To Me Events 2019

In early 2019, Cwm Taf (RCT) People First undertook a detailed review of all the information that they had gathered from people with a learning disability about the things that were affecting people's lives and the things that they felt were important to consider moving forward. Once all of this information had been collated an event was held (February 2019) to relay the findings and establish what was missing or had changed, as well as identify the top priority areas for future focus. The event was attended by 130 people with a learning disability and their parents and carers from across the Cwm Taf area.

Following the event 9 areas of focus were identified by attendees. It was recognised that it would be difficult to set-up and develop meaningful, purposeful and fully co-produced work for all 9 focus areas at the same time, and therefore, attendees were asked to highlight which of the 9 were most important to them. As a result, 3 priority areas were identified, with the agreement that work efforts between all stakeholders would be concentrated on them as part of the development of a co-produced process upon which the wider focus areas can be replicated at a later date.



Following the agreement of these priority areas, 2 further events were held in July 2019, to once again bring together all interested stakeholders and develop the foundations of the Home, Health and Employment action plans for needs/experience led service transformation. Over 140 people attended each of these events, reinforcing the value people with a learning disability and their parents and carers placed on having the opportunity to have their voice heard and to be actively involved in the design and decisions of their care and support services. Details of what attendees said was important to them under each of the focus areas is captured within the following section of this report.

WHAT WE SAID:

The Themes of Our Shared Experiences and Priorities for Change



HOME

Barriers that we face about where we live:

- ➡ Limited spaces in supported living accommodation
- ➡ Staff shortages
- ➡ Being scared of not being compatible with other tenants
- ➡ Being scared of moving out incase I get lonely
- ➡ Being given strict timings of when I need to come home by – no freedom
- ➡ Having limited access to my own home – not having my own key



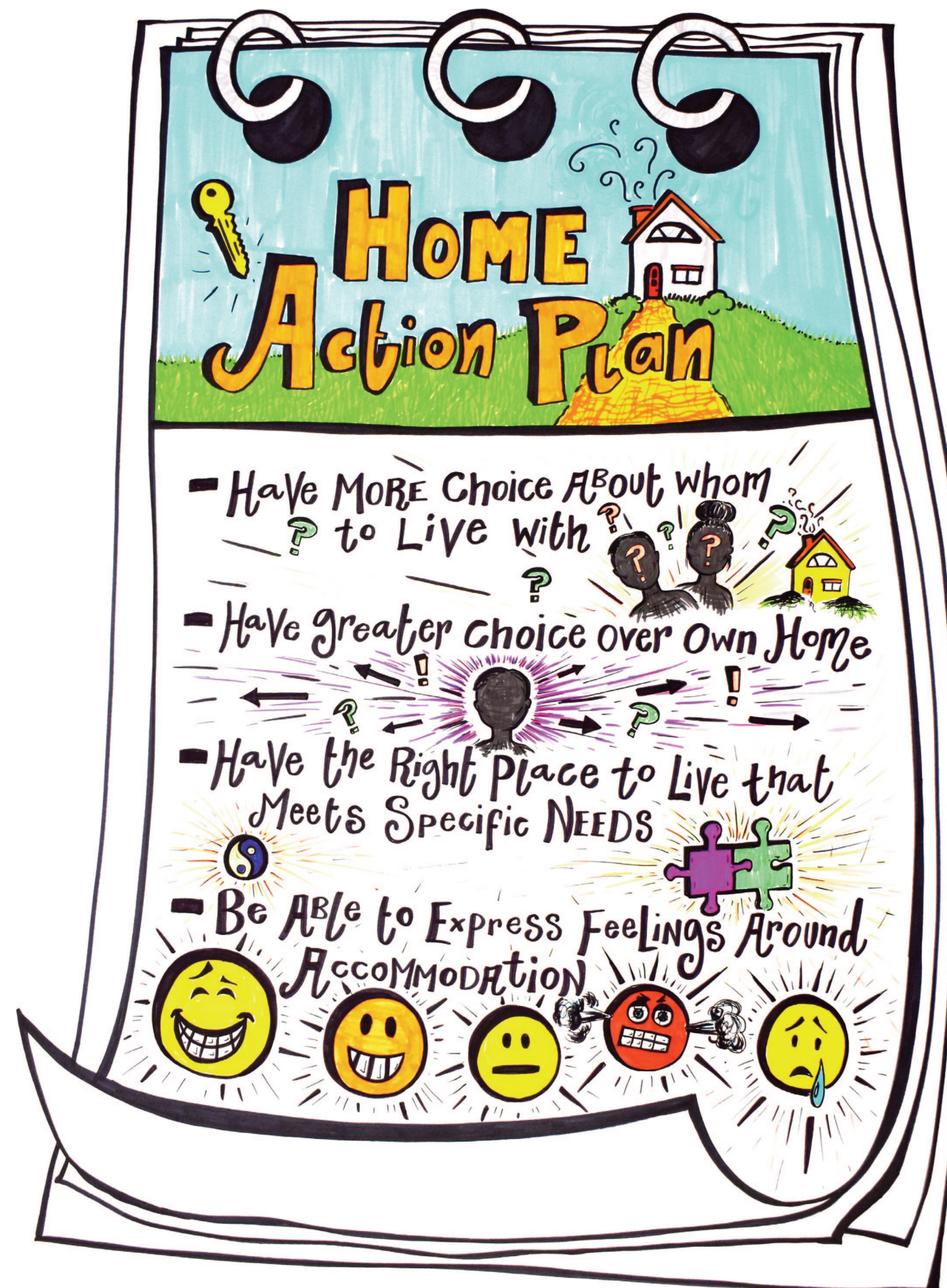
“

I feel like where I live is your place of work and not my home!

”

The things we want when it comes to our home:

- ➡ To be able to choose where I live and with who – it is important that I live with someone of a similar age and who has similar interests to me
- ➡ Being able to choose what I do and when I do it
- ➡ Being able to choose my own bedtime
- ➡ To be able to have a pet to keep me company
- ➡ To have my own key
- ➡ To decorate my room the way I want it
- ➡ Being included and informed about anything that is written about me
- ➡ Having quiet zones within supported living accommodation
- ➡ Having the right support when I am moving
- ➡ Being given financial advice
- ➡ Having opportunities to socialise
- ➡ Being able to stay with/visit my family when I choose
- ➡ Having access to warden-controlled housing at a younger age
- ➡ More House Staff to increase opportunities and quality of home life
- ➡ Having a garden
- ➡ To stay in Wales
- ➡ Support to live independently



HEALTH

Barriers we face when it comes to our Health Care:

- ➔ Healthcare professionals don't talk or listen to us: opticians, dentists, receptionists, doctors and nurses
- ➔ Healthcare professionals not knowing my background and not understanding my personal preferences or reasonable adjustments needed to make my appointment successful
- ➔ Training is often not enforced and so things never get better

The things we want when it comes to our Health Care:

- ➔ Healthcare professionals to have good communications training: communication aids, flash cards, sign along, photo symbols (Easy Read), keeping eye contact with me and speaking to me not just my parents or carers
- ➔ Longer appointment times so that I don't feel rushed and can communicate all of my needs to the healthcare professional, as well as making sure that I fully understand all the information they are giving to me
- ➔ Making sure that all the information I need is offered to me and if possible giving me Easy Read information to take home with me: information on my illness or condition, summary of what was discussed in the appointment, help that is available to me, when my next appointment will be and anything else I need to know

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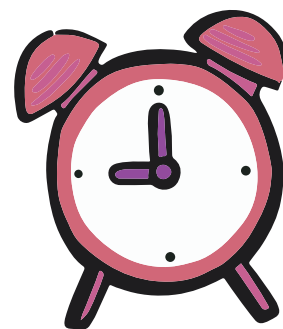
I often get anxious when I have to go to an appointment, and I don't know the person that I am going to see

”

- ➔ Make information and signs easier to understand so that I know where I am going. Having a hospital or GP surgery map could also help me find my way
- ➔ Home visits to talk about my health
- ➔ More advice on how to keep myself healthy: nutrition and exercise
- ➔ Having someone I know stay with me if I have to stay in hospital
- ➔ Having a personal health diary that will include my personal preference and any reasonable adjustments that might be needed: visual difficulties, hearing difficulties, level of understanding
- ➔ An agreed set of symbols to use in all healthcare services across Wales
- ➔ Follow-up telephone calls to make sure I am ok and to see if I have any questions or didn't understand something
- ➔ Making trusted relationships with my healthcare team, seeing the same doctors and nurses who know and understand my needs so that I don't have to relay the same information and story over and over again
- ➔ Having a waiting room number system so that I know where I am in the queue to reduce anxiety
- ➔ Spending more time with patients on a hospital ward to make sure they know what is going on
- ➔ Having a behaviour specialist available at doctors surgeries
- ➔ Being treated with respect



EMPLOYMENT



Barriers we face with Employment:

- ➔ Employment can affect my benefits
- ➔ Not a lot of paid opportunities on offer to people with a learning disability, mainly volunteering roles
- ➔ Being restricted to what jobs are available even if they don't meet my needs, skills or interests
- ➔ Low self-esteem, low confidence and anxiety
- ➔ Employers and other staff not understanding the individual needs of a person with a learning disability
- ➔ Not knowing who I can speak to so that I can get help and advice about employment
- ➔ Not knowing how to write a CV
- ➔ Accessibility issues, especially for those with a physical impairment
- ➔ People with a learning disability are not told that they are able to get paid employment and are not encouraged to do it
- ➔ Not enough qualified staff to help me and work alongside me
- ➔ People don't listen to what I want to do and instead they let my parents decide
- ➔ Using Health and Safety as an excuse

The things we want when it comes to Employment:

- ➔ More information about how my benefits might be affected so that I can make the best decision for me
- ➔ Increased support from the Department of Work and Pensions
- ➔ Having access to suitable transport so that people with a learning disability can get to work and home on time

“

I worked in a charity shop but couldn't stay because of insurance

”

- ➔ More careers advice for people with a learning disability
- ➔ Employability skills training for people with a learning disability: teamwork, money management, job responsibility, travel training
- ➔ Having dedicated times for people with a learning disability to attend the job centre
- ➔ Having dedicated job fayres for people with a learning disability
- ➔ Having access to a wide range of education and training opportunities so that I can do the job I want and linking college courses with potential careers
- ➔ Having clear advice for parents and carers about employment for people with a learning disability
- ➔ Easy Read information on what employment opportunities are available to me and what support can be given to help me succeed
- ➔ Careers talks and work experience opportunities for me at the end of school but before transition so I can make good decisions about my future
- ➔ Having local opportunities which don't require me to travel far
- ➔ Better and more frequent reviews with my Social Worker to express what I want to do
- ➔ More support to start my own business
- ➔ Linking day services to employment opportunities and work experience



EQUALITY AND INCLUSION

- ➡ Reducing stigma and challenging the stereotypes of people with a learning disability:
 - ➡ Disability and Equality Awareness
 - Training for professionals and people in the community
 - ➡ Changing attitudes at an early age/ educating children
- ➡ Identifying issues/barriers for people with a learning disability and working with professionals to find solutions
- ➡ Tackling Hate/Mate crime, and feeling safe and accepted in our communities
- ➡ More social activities that we can be part of
- ➡ Not having separate activities for people with a learning disability – seeing us as people not labels
- ➡ Having employment opportunities for people with a learning disability
- ➡ BEING INCLUDED!!!



DAYTIME OPPORTUNITIES

- ➡ Friendships
- ➡ Familiarity
- ➡ Investment in Day Centres with extreme concern over day centre closures
- ➡ Quality of buildings/facilities/amenities for day centre provisions with specific concern raised at Gadlys centre in Aberdare
- ➡ Having a continued and consistent service
- ➡ Increasing resources especially internet, computers and iPads
- ➡ Having more activities to do both in day centre and in the community: knitting, Horse Riding, Dancing, Cinema Trips, Swimming, Arts and Crafts, Football, Gardening, Making Cakes/Afternoon Tea, Storytelling, Coffee Mornings, performing arts and local theatre groups
- ➡ Getting involved and chairing charity events
- ➡ Employment and work experience opportunities in the community
- ➡ More options about what I do in the day and being able to change my mind and try something new



EDUCATION AND LIFELONG LEARNING

➡ People with a learning disability need to be given more education opportunities – this includes:

- ➡ A wider range of courses
 - ➡ Options to study in an education institution OR in the community
 - ➡ Not having to repeat the same course over and over again
 - ➡ Not being segregated from other students – promote inclusion!
 - ➡ Being given the option to choose what course I want to do, not being told what I must do
 - ➡ Making courses accessible and using reasonable adjustments to help someone do what they choose
 - ➡ More life skills courses
- ➡ Ensuring that people know all the options that are available to them so that they can make an informed choice
- ➡ Being supported to climb the education ladder as high as I can or want to go

“

I have been let down by the education system who didn't teach me to read or write

”

- ➡ Having access to suitable transport so that people with a learning disability can get to college or their class easily
- ➡ Better information and choice within transition to help people do what they want and can do in education



ADVOCACY, RIGHTS, CHOICE AND EMPOWERMENT: HAVING VOICE, CHOICE AND CONTROL

- ➡ Being treated like an adult and not like a child
- ➡ Having clear and accessible information
- ➡ Having as much consistency as possible
- ➡ To be fully informed
- ➡ Easy access to involvement and co-production
- ➡ Capacity building and training
- ➡ Being taught new things
- ➡ Feeling understood
- ➡ Being able to choose what I want
- ➡ Expressing my views
- ➡ Participating fully
- ➡ Identifying barriers and finding solutions to overcome them
- ➡ Knowing my rights
- ➡ Being listened to
- ➡ Having the right support
- ➡ Being able to speak for myself
- ➡ Being a person not a label
- ➡ Being treated as an equal
- ➡ Being respected
- ➡ Being given the opportunity to 'have a go'

ISOLATION AND LONELINESS

- ➡ More social activities in my area
- ➡ Something to do in the evenings
- ➡ Having someone who listens: Befriending Service
- ➡ Having hobbies to keep me busy
- ➡ Having/making friends
- ➡ Staying in touch with friends on the phone and through the internet
- ➡ Socialising
- ➡ Having pets to keep me company
- ➡ Being part of community groups
- ➡ Having the confidence to meet new people



SUPPORT FOR PARENTS AND CARERS

- ➡ More respite care options
- ➡ More consistency and better-quality respite care
- ➡ Planning for the future – what will happen after I am gone
- ➡ Better facilities in the community such as changing facilities at leisure centres
- ➡ Being able to and provided opportunities to advocate for our children when they are unable to advocate for themselves
- ➡ More support options for parents who work
- ➡ Group holidays and day trips
- ➡ Having Direct Payments/Personal Assistances to help provide care
- ➡ Being more involved in the design and decisions of, and having increased confidence in the care provision offered to our children



SUMMARY OF KEY OBSERVATIONS:

Reducing Stigma:

- Challenging stereotypes and changing attitudes through training and inclusion
- Increasing the presence of people with a learning disability in the community, employment and mainstream provisions

Advocacy:

- Capacity building and training for people with a learning disability
- Being listened to and feeling understood
- Knowing Your Rights!
- People with a learning disability being able to speak for themselves
- Being treated as an equal with respect
- Parents being able to advocate for their children

Education:

- Increased educational opportunities by reducing barriers such as segregation and introducing more individual targeted support and reasonable adjustments

Transport:

- Having access to suitable and regular transport options so that people with a learning disability can attend activities/employment of their choice
- Increase availability of travel training

Friendships:

- Helping people with a learning disability to have the confidence to meet new people
- Creating opportunities for people with a learning disability to make and maintain friendships

Respite:

- Increased options for respite care
- better quality and more consistent respite care
- Options for group holidays and daytrips as respite care

Transition:

- More support and information within transition to help people do what is right for them as an adult
- Careers advice and work experience opportunities to help young people going through transition make better informed choices about their future

Employment:

- Creating more employment opportunities for people with a learning disability
- Ensuring people with a learning disability and their parents and carers are provided with the right information about employment options
- Ensuring the right support is in place for people with a learning disability to undertake employment

Involvement:

- Being included/fully involved in an effective co-productive approach to design services and have control over decisions made about individual care – Person Centred models of working
- Barrier identification and joint solution creation

Leisure Activities:

- Creating more activities for people with a learning disability to get involved in, both specialist provision and community integration
- Opportunities for people with a learning disability to socialise with friends

Service Improvement:

- Investment into Learning Disability Services to increase the offer, quality and confidence in service
- Ensuring links are made between day centres, education and employment opportunities

Ownership:

- Providing ownership to people with a learning disability and their parents and carers to be able to make informed choices about their home, their healthcare and what they do during the daytime and evenings

THE WAY FORWARD: A New Era of Co-production

Following the success of the What Matters To Me events, and with reflection on the work completed under the Cwm Taf Statement of Strategic Intent, all partners agreed that it was time for a new era of co-production that would allow for a citizen led approach, providing people with a learning disability and their parents and carers the opportunity to lead and become the driving force behind service transformation.

Armed with the foundational action plans for the 3 identified priority areas, new workgroups designed and chaired by people with a learning disability were established. These workgroups called for service providers and partner organisations to collectively work with learning disability representatives to overcome barriers; find solutions to issues and problems; make decisions; and implement long-term sustainable needs led change. To remove previous barriers that had prevented full citizen involvement, these new workgroups were less formalised in their design in the hope to minimise talk and instead promote action. Therefore the action plans for each workgroup would be the central driving force for the activities undertaken by the workgroups, replacing the need for rigid meeting agendas and overly detailed meeting records.

The new workgroups for: Home, Health and Employment were launched in September 2019. As part of their phase 1 activities they were tasked with reviewing the foundational action plan that had been created by people with a learning disability and their parents and carers at the July meetings, and developing a comprehensive action plan for each priority area outlining intended sustainable and purposeful change through a range of short, medium and long-term goals. The workgroups were also given the responsibility to oversee and coordinate work undertaken as part of the action plan, as well as creating communication pathways to feedback updates, information and decisions to the wider groups of people with a learning disability and parents and carers who had been part of the What Matters to Me events, as well as feeding forward the same into regional decision making processes through the Regional Learning Disability Steering Group.

To ensure that the workgroups stayed relevant and appropriate to the emerging needs of people with a learning disability and their parents and carers, it was agreed that each workgroup would be reviewed on an annual basis. The next sections of this report outlines the progress made and barriers faced by the individual workgroups as they worked towards long-term sustainable service transformation.

END OF PHASE 1 REVIEW

Sept 2019 – March 2020

Through their initial six-month period, the new model of citizen led workgroups struggled to attract the relevant audience and influence to launch the envisioned changes anticipated. It appeared that service providers and professionals found it difficult to deviate from traditional meeting styles and truly embrace this new era of co-production and citizen led change. However, as people with a learning disability and their parents and carers, through the support of Cwm Taf (RCT) People First and The Grapevine, continued to advocate for the voices of their peers to be heard, listened to and respected, the financial year closed with a fresh commitment to this work, and meetings in early 2020 saw increased engagement. As a result, the What Matters to Me project was able to generate co-produced theme-based action plans for each of its priority areas to guide and underpin work across all stakeholders through the projects phase 2 activities (April 2020 – March 2021) and beyond. Within this section an overview of the action plan tasks has been highlighted to provide a baseline of information for future annual progress reviews.

HOME ACTION PLAN TASK OVERVIEW:

Improve Person Centred Approaches Planning by ensuring that the individuals housing needs and wants are included in their personal assessment and that accommodation is included within their transition care and support plans

Develop a regional housing plan to stimulate the sourcing of good quality accommodation from housing developers and providers and offer more housing choices that will help to meet housing needs now and in the future

Improve the provision of information, advice and support about housing to people with a learning disability and their parents and carers

Setup a Housing Forum to ensure the voices of people with a learning disability in supported living (and other housing options) can be heard and included in the work of the workgroup

Develop and improve community-based opportunities to increase independence and choice for people with a learning disability

HEALTH ACTION PLAN TASK OVERVIEW:

Develop an agreed set of symbols to be used in healthcare settings across Cwm Taf Morgannwg/ Wales/ Universal

Create and implement Easy Read templates for appointment letters and healthcare information, including how to take medications and aftercare

Develop and implement communication training for healthcare staff looking at the use of flash cards, communication aids, sign along and Easy Read

Explore issues relating to lengthy waiting times for dental treatment for people with a learning disability and identify solutions to reduce waiting times

Development of a Health diary for people with a learning disability to record all of their medical information and personal preferences so that health care professionals can easily understand the best ways to treat them

Develop and implement learning disability awareness training for all healthcare staff, including receptionists

Ensure all people with a learning disability are being offered an annual health check and that this information is being used effectively to inform their health care

EMPLOYMENT ACTION PLAN TASK OVERVIEW:

Establish a regional learning disability employment forum to discuss the employment issues affecting the lives of people with learning disabilities

Develop a focussed campaign across the region about the benefits of working, whether paid or unpaid, and about how this may impact on benefit entitlements and how it can help people have a regular job etc.

Ensure that people with a learning disability have access to appropriate education, employability learning programmes and training opportunities to learn the skills they need to have a job

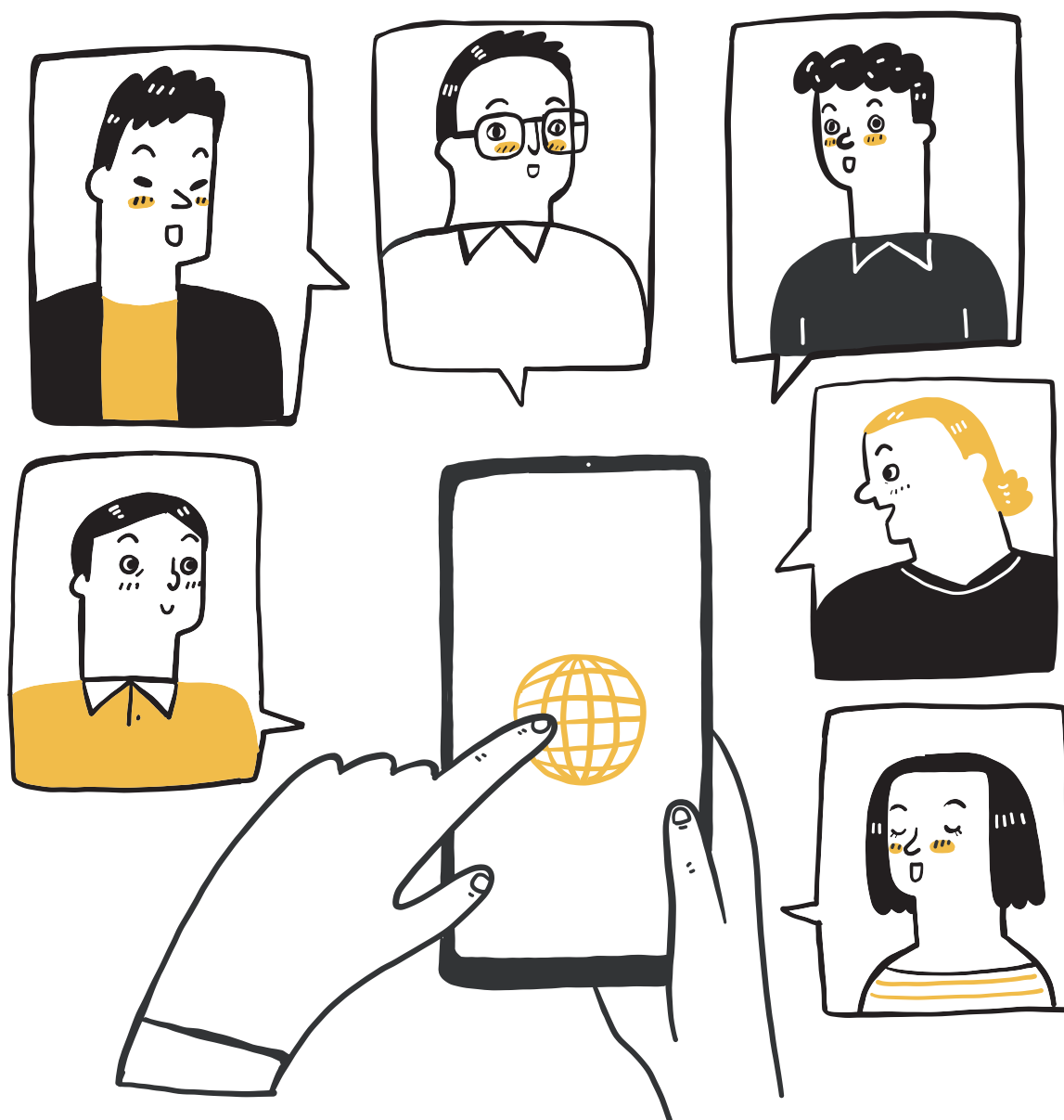
Enhance work support mechanisms available to promote sustainable employment and enable career development

Establish a regional Transition Group

END OF PHASE 2 REVIEW

April 2020 – March 2021

Activities undertaken by the workgroups for Home, Health and Employment were largely suspended through this phase 2 reporting period due to the Covid-19 pandemic and subsequent lockdown restrictions. During this period many statutory partners have had to shift their focus to working towards Covid-19 recovery models and ensuring the prevention of infection spread through Test, Track and Protect measures. This has meant that the workgroups have not made as much progress as originally anticipated for this reporting period. However, in some areas work has been able to continue and through the collective embracing of a shift to virtual/remote working models some of the workgroups' tasks have flourished, whilst others have identified pitfalls and shifting of priorities.



One of the most significant developments of the What Matters to Me project during this period has been the increased priority of many people with a learning disability and parents and carers around daytime opportunities. In light of the covid-19 restrictions, many daytime opportunities have had to close, leaving many people with a learning disability and parents and carers lost and isolated. Digital connectivity projects have helped to overcome some of these issues, but an overwhelming 77% of people with a learning disability have reported their desperation to engage in face-to-face activities and provisions. This call from people with a learning disability and their parents and carers, has promoted the What Matters to Me project team to develop the foundations of workgroup priority expansion, so that a dedicated workgroup to oversee the return of daytime in a

post covid-19 world is established. At a local level this is being driven by Cwm Taf (RCT) People First's work on its My Day My Way project. The creation of this workgroup aims to ensure that citizen voice is a critical part of any recovery plans and service development moving forward.

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HOME ACTION PLAN REVISIONS AND PROGRESS UPDATES

TASK	UPDATE
Develop a regional housing plan to stimulate the sourcing of good quality accommodation from housing developers and providers and offer more housing choices that will help to meet housing needs now and in the future.	Drive indicated that they had implemented a housing plan across their accommodation services to help identify and facilitate moves to Penllew Court. Information sharing consultation events were held to establish what people wanted from the accommodation in terms of facilities, opportunities and outcomes. However, no update was offered by other members of the housing workgroup indicating that there is still work to be done to achieve a consistent and coordinated housing plan regionally.
Review existing supported living and other housing options to make sure it meets the needs of people with a learning disability, now and in the future.	Housing providers Drive and Catrefi Cymru indicated that they had begun such a review and as a result had been implementing person centred support especially in terms of step up/down accommodation options for people. Catrefi Cymru are currently working on a development at Crown Avenue with RCTCBC to provide an additional housing option for people with a learning disability.
Develop a housing pathway for people with a learning disability (preparing for adulthood or moving from their family home/other accommodation) to include the introduction of 'taster' / respite options within supported living settings.	No update

TASK	UPDATE
Collate a single accommodation and housing needs list across the region for people with a learning disability accessing social care, including people who need new or different accommodation, and use this information to inform the regional housing plan, making better use of existing options and new developments as opportunities arise.	No update
Ensure that the person's housing needs and wants are included in their personal assessment and accommodation is included within their transition and care and support plans.	Housing providers Drive and Cartrefi Cymru have indicated that they are currently using individual support plans for tenants and engaging them in 'What Matters' conversations to identify short and longer-term goals and outcomes.
Improve the provision of information, advice and support about housing to people with a learning disability and their families/carers	Housing providers Drive and Cartrefi Cymru are working to ensure accessible information is readily available to their tenants. In addition, and as a response to questions and concerns being raised by people with a learning disability in relation to supported living through the covid-19 pandemic, Cwm Taf People First facilitated a number of 'Hear Our Voice in Lockdown' online events to bring service providers, people with a learning disability and their parents and carers together to discuss emerging issues and ensure that relevant information was shared and understood
Improve the process and policy for matching nominated tenants and improve engagement with new and existing tenants and their families/carers when filling accommodation voids in order to offer choice.	Cartrefi Cymru have offered a number of resources/strategies they are implementing to meet this task, they include: vacancy profiles; scheme profiles; compatibility meetings; visits; and virtual tours.
Review the approach to engagement and participation of people in supported living (and other housing options) to include the setup of a Housing Forum and consistent use of "Good Service Checker" type visits to ensure people with a learning disability are receiving a good service that meets their needs and what matters to them.	Housing providers Drive and Cartfrei Cymru offered updates and provided examples of work being undertaken to meet this task, they include: Good Service Checkers implementing Good Service Questionnaires with peers across different accommodations and holding regular house meetings to discuss issues and wants.

TASK	UPDATE
<p>Develop and improve community based opportunities (for example community support networks community connection and day and night opportunities) to increase independence and choice for people living with a learning disability.</p>	<p>This has been difficult to achieve through the covid-19 pandemic and lockdown restrictions, however, housing providers Drive, Cartrefi Cymru and Innovate Trust have been hosting social events and activities for their tenants and other people with a learning disability to get involved in virtually. Innovate Trust have developed the Insight App to host/advertise a range of activities people can get involved in across Wales.</p>
<p>Develop a regional approach to initiatives such as "Stay up Late Campaign" to make sure people with a learning disability are able to lead active and fun social lives and the kind of lives they want to live.</p>	<p>This has been difficult to achieve through the covid-19 pandemic and lockdown restrictions, however, housing providers Drive, Cartrefi Cymru and Innovate Trust have been hosting social events and activities for their tenants and other people with a learning disability to get involved in virtually. Innovate Trust have developed the Insight App to host/advertise the range of activities people can get involved in across Wales.</p>
<p>Explore opportunities to use resources (commissioned hours) more flexibly and review current staff rota's and working patterns to provide more opportunities for activities that people want.</p>	<p>Housing providers Drive and Cartrefi Cymru have indicated that they have undertaken reviews of staff rota's and are looking to ensure as much flexibility as possible to meet people's needs.</p>
<p>Review current arrangements in place across supported living to improve the process and policy (and ensure consistent use) in relation to:</p> <ul style="list-style-type: none"> ▪ People having their own key to their own home ▪ People accessing what's written about them in their daily records; including contribution to what is written ▪ Office space and activities within supported living ▪ Assistive technology within supported living 	<p>Housing providers Drive and Cartrefi Cymru have indicated that they are using a co-productive approach with their members to ensure that these issues are addressed. Both indicated that all tenants now have a key and that staff support them to keep it safe (relevant risk assessments are in place).</p>

HEALTH ACTION PLAN REVISIONS AND PROGRESS UPDATES

TASK	UPDATE
Develop an agreed set of symbols to be used in healthcare settings across Cwm Taf Morgannwg/Wales/Universal.	People First groups across Wales have been working with the University of South Wales, commissioned by Welsh Government, to develop and launch a Wales-wide Health Passport for people with a learning disability to inform their healthcare team of their medical history and personal preferences. Whilst this hasn't developed an agreed set of symbols it is a start to push toward a consistent approach across Health Boards in Wales.
Create and implement Easy Read templates for appointment letters and healthcare information.	Work is currently being undertaken by Public Health Wales to increase the amount of information being produced in Easy Read. This has been critical throughout the covid-19 pandemic, and is something that the workgroup will continue to pursue in liaison with Public Health Wales to ensure that it is implemented effectively and that this information also covers appointment and health related letters.
Develop and implement communication training for healthcare staff looking at the use of flash cards, communication aids, sing along and Easy Read.	At the end of the projects phase 1 activities, and prior to the covid-19 pandemic, discussions within the workgroup had started in relation to Primary Care Training opportunities. However, during the past 12months these conversations have not progressed in light of the covid-19 response. This is something the workgroup is keen to discuss moving forward as part of the projects phase 3 activities (April 2021-March 2022).

TASK	UPDATE
Explore issues relating to lengthy waiting times for dental treatment for people with a learning disability and identify solutions to reduce those waiting times.	It was agreed by the workgroup at the end of its phase 1 activities that membership of the group should be extended to dental practitioners working within the region. To date this has not happened due to the covid-19 pandemic.
Development of a Health diary for people with a learning disability to record all of their medical information and personal preferences so that health care professionals can easily understand the best ways to treat them.	People First groups across Wales have been working with the University of South Wales, commissioned by Welsh Government, to develop and launch a Wales-wide Health Passport for people with a learning disability to inform their healthcare team of their medical history and personal preferences.
Develop and implement Learning Disability Awareness Training for all healthcare staff, including receptionists.	<p>Cwm Taf People First continue to work with the University of South Wales to deliver training to student nurses, and with Cardiff University to deliver training to student doctors. This training has been facilitated online over the past 12months due to the covid-19 pandemic.</p> <p>The workgroup would also like this training to be delivered to qualified healthcare staff and will look to develop this within Primary Health Care settings alongside the communication training task.</p>
Ensure all people with a learning disability are being offered an annual health check and that this information is being used effectively to inform their health care.	Prior to the covid-19 pandemic, Public Health Wales had begun some work around the take up of annual health checks. In early 2021, Cwm Taf People First were involved in the creation of a Health Champions group facilitated by Cwm Taf Morgannwg University Health Board to explore, among other things, the effectiveness of the annual health check and to gain the insight of people with a learning disability to improve the process/experience.

The challenges endured by the covid-19 pandemic has also led to a number of people with a learning disability raising concerns and questions for the Health Board as information being relayed to them has been largely confusing and inaccessible. The questions that had been asked were circulated to the workgroup, and the Cwm Taf Morgannwg Research, Innovation and Improvement Co-ordination Hub provided information they had at the time. This was then complimented by information being released by Public Health Wales in an Easy Read format.

As the pandemic continued, Learning Disability Today released an article outlining details of the inappropriate use of Do Not Resuscitate orders

for people with a learning disability, which again raised a high level of concern for people with a learning disability across the Cwm Taf Morgannwg region. As a result, it has been requested that the following task be added to the workgroups Health Action Plan to investigate if Do Not Resuscitate orders have been used inappropriately within the region and what measures are being/can be taken to ensure this is rectified and safeguarded in the future:

- Investigation into the potential inappropriate use of Do Not Resuscitate orders for people with a learning disability, and the creation and implementation of reasonable safeguards to ensure that this issue is rectified/does not happen in the future.

How are people with a learning disability who have covid-19 being treated?
Alex

When is lockdown going to be over?
Darren

When are things going to be back to normal?
Sam

When will it end?
Janis

What reassurances are there that people with a learning disability who have symptoms of covid-19 are going to be tested and how do they get a test?
Lynne

What are the distancing rules for workers entering the homes of people with a learning disability and what PPE should they be wearing?
Tom

How are they supporting people with a learning disability who have epilepsy at this time?
Bradley

When will I be able to see my family again?
Victoria

How many people can have a flu jab whilst this is going on?
Carl

How do we know if ambulance staff/ doctors/nurses are not carrying the virus?
Alex

How are they keeping people with a learning disability informed about Covid-19?
Lynne

If I go to the hospital/doctors how do I know it is safe and I won't catch the virus?
Chloe

Is there an ID card that NHS staff could carry to show that they have been tested and are negative for Covid-19 to reassure us that it is safe to see them?
Sammy

EMPLOYMENT ACTION PLAN REVISIONS AND PROGRESS UPDATES

TASK	UPDATE
Establish a regional learning disability employment forum to discuss the employment issues affecting the lives of people with a learning disability.	To date no such regional forum has been established. RCTCBC stated that due to Covid-19 the Council suspended many of its services in line with WG requirements in March 2020 and transferred staff over to focus on supporting residents on the Shielded Patients List and NSV people so they have not been involved in a regional forum.
Identify the known barriers to employment and work to develop an employment action plan to overcome these barriers.	RCTCBC indicated that a plan is currently in place under the Communities 4 Work+ scheme that aims to address the barriers that were identified within the What Matters To Me events, and that a named officer has been identified to lead on disability/learning disability employment.
Improve the provision of information, advice and support about employment opportunities for people with a learning disability, and their parents and carers.	No update to date – RCTCBC have identified a named officer to lead on this action over the next reporting period.
Explore opportunities/projects to: <ul style="list-style-type: none"> Create more supported employment/employment opportunities across the region Create more opportunities to maximise the support for someone with a learning disability to access apprenticeships, internships, work placements and volunteering 	Gateway to Employment Supported Internship programme launched September 2019 in partnerships between RCTCBC, Coleg y Cymoedd, Learning Disability Wales Engage to Change project, and Elite Supported Employment to provide opportunities to students with a learning disability. September 2020 cohort of Interns has been delayed as a result of Covid-19, however virtual employability skills are being delivered to interns. Cwm Taf (RCT) People First have also expanded their employment opportunities for people with a learning disability to include 2x Project Explorers.

TASK	UPDATE
Develop a focussed campaign across the region about the benefits of working, whether paid or unpaid, and how this may impact on benefit entitlements and how it can help people have a regular job etc.	Cwm Taf (RCT) People First have planned to incorporate this into their ongoing work within the next reporting period (phase 3). This will include having a dedicated Employment workstream and running a series of events to increase the skills and knowledge of people with a learning disability across the Cwm Taf area.
Organise a learning disability work event/ jobs fayre that provides opportunities for people to engage with a range of prospective employers looking to recruit.	A joint partnerships jobs fayre was held in March 2020 and was attended by 200 people. It was hoped that this would be repeated in March 2021 but due to Covid-19 restrictions this was not viable. Instead Cwm Taf (RCT) People First held a mini employment event virtually.
Promote the value that people with a learning disability can bring to businesses and the local community.	Cwm Taf (RCT) People First have commissioned a short film to be produced in the next reporting period (phase 3) as part of its activities under the focussed Employment Campaign.
Increase the number of Disability Confident Employers across the region.	Communities 4 Work+ and Staywell@work programmes provide support for people to sustain employment and progress at work. Due to Covid-19 restrictions, this support is currently being delivered virtually. Cwm Taf (RCT) People First indicated that they have support mechanisms in place to help their employees maintain their employment.
Create a structured program of support for the workforce to engage with those accessing daytime opportunities workgroups.	No Update
Ensure the care and support that people receive will be focussed on supporting them to learn the skills they need to have a job, where appropriate.	No Update
Review and improve the support to Care managers in promoting work and volunteering during the transition process.	No Update

TASK	UPDATE
Increase the intensive pre-employability support available for those accessing employability programmes, with an increase in job clubs available to participants.	RCTCBC had aimed to run work club sessions this year specifically for people with autism or low-level disabilities, however, due to covid-19 this has not been possible. Virtual delivery is now being explored as an alternative if normal delivery is unable to return soon.
Ensure that people with a learning disability have access to appropriate education, employability learning programmes and training opportunities to learn the skills they need to have a job.	Cwm Taf (RCT) People First have successfully increased the IT skills of over 70 people with a learning disability across the region by supplying iPads and engaging them in themed workshops and events online. As a result of Covid-19 adult community learning provisions across RCTCBC have suspended their face-to-face delivery and have been running a limited online service, however engagement on this has been low.
Review current arrangements in place to improve the processes and policies in place in relation to Travel Training.	No Update
Establish a Regional Transition Group.	No Update
Review current arrangements to improve the processes and policies (and ensure consistent use) in relation to transition from school to college and into adulthood.	No Update

PROPOSED CITIZEN VOICE STRUCTURE

After careful review of need, demand and progress to date, Cwm Taf (RCT) People First have developed a citizen voice structure to further support the activities of each of the workgroups for Home, Health and Employment, as well as creating opportunities for people with a learning disability to start to co-create and co-design future work around the wider focus areas. This citizen voice structure will be made up of a number of thematic focus groups of people with a learning disability from across the Cwm Taf Morgannwg region, coming together to discuss their experiences, identify common themes and possible solutions for service change.

Where in existence the work of the relevant focus group will be fed into the regional workgroup for that theme as well as acting as a consultation body for the workgroups to sense check their ideas and engage a wealth of interested experts by experience in any ongoing processes of co-creating, co-designing, co-decision making, co-delivering and co-evaluating. For those focus groups where a workgroup does not currently exist, work will be offered and/or assigned to the most appropriate partner organisation or consortium of organisations to begin to drive change, especially at lower levels. It is hoped that through this process future regional workgroups will emerge organically.



Regional Learning Disability
Steering Group



Regional
Home Workgroup



Regional
Health Workgroup



Regional
Employment
Workgroup



Regional
Daytime
Opportunities
Workgroup



My Home
Focus Group



Health and Wellbeing
Focus Group
(Health Champions)



Friendships/
Relationships and
Leisure
Focus Group



My Day My Way
Focus Group



Education & Lifelong
Learning
Focus Group



Accessible
Communities
Focus Group

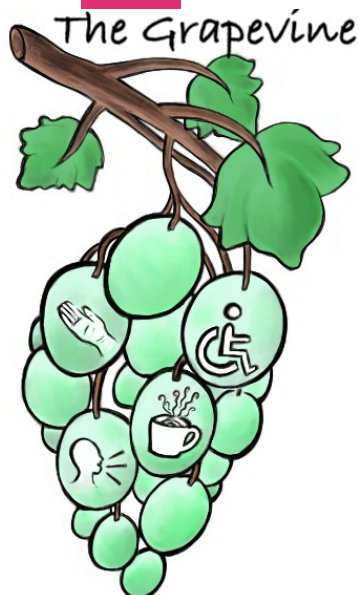


Cwm Taf People First



Rhondda Cynon Taf

PEOPLE FIRST LIMITED



Cyngor Bwrdeistref Sirol
MERTHYR TUDFUL
MERTHYR TYDFIL
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