WALK IN OUR SHOES

Listening to adults with a learning disability and their families

A report for Croydon Council to inform the future of system and service design

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ThePublicOffice

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gym on Monday

Foreword

What does living a ‘good life’ mean for people? And how easy or difficult is it to live well and thrive, with a learning disability, in Croydon? How do we want the future to be?

The system of support in Croydon for people with learning disabilities and those who care for them was probably never actively designed as a whole. A patchwork of services has evolved over decades, responding to different requirements and as national policy has changed. It doesn’t fit together very well. We know it doesn’t meet people’s needs very well.

If we understood fully what life looks and feels like, what people’s dreams and aspirations are, what would we design - especially if the community and the Council were working together? And given budgets are so tight, how might we use the resources we have differently to get the best possible results?

We want Croydon to be a great place to live, for everyone. To ensure that this can be true for people with learning disabilities and the parents and family members who care for them, we know that we need to start by listening. One participant in this enquiry offered the Council the challenge, ‘They need to walk in our shoes!’ They are right.

This rich and detailed enquiry by ThePublicOffice is the first step in Croydon Council doing just that. I am so pleased that the results of this listening exercise are presented in this report using so many first person quotations. Deep listening has been done on our behalf; now it is the Council’s job to show that it has been hearing. The messages in this report are tough and the challenge will not be a quick-fix, but there is also much to be positive about: great ideas, energy and enthusiasm, and so much potential for growing something better and new for Croydon.

We are committed to working with people with learning disabilities, with parents and carers, and with colleagues from across the system to respond: to turn courageous listening into bold and radical action. We all know there is less money available, but I am confident that working together we can spend it well.

I look forward to continuing this learning journey. Will you join us in the movement for change?

BARBARA PEACOCK
Executive Director People, Croydon Council

Overview

In mid October 2016, Croydon Council commissioned ThePublicOffice to lead a rapid enquiry into the system of support for people with learning disabilities in Croydon. This was to involve a substantial exercise of listening and engagement across a wide range of people with a learning disability and their families, from which key insights could be drawn.

The Council wanted to learn more about the realities of people's lives. It wanted to understand people's experiences of the full range of services and support that it provides or commissions, but it also wanted to understand people's needs and aspirations more broadly.

With high ambitions and a very tight timeframe, ThePublicOffice team worked for an intensive 3-month period to develop the findings presented in this report. Our researchers ran enquiry and engagement activities with key groups in Croydon (people with a learning disability, family or carers of people with a learning disability, providers of services and frontline workers). We designed a specific methodology and bespoke engagement activities for this project, so that people with a wide range of support and communication needs could participate fully. The research has involved small and large scale enquiry and engagement events, observations and visits to key services, semi-structured interviews in person and by telephone, home visits with groups of people and families, and more.

We have tried to model openness, inclusiveness and collaboration throughout this enquiry. Given the complexity of the issues involved, and the requirement rapidly to identify clear themes from a huge number of complex stories, we took time in the final stage of insight development to return to the community: at large scale events we played back our emerging analysis, to ensure that people with learning disabilities and their families were confident that we had accurately synthesised and summarised what they had told us. These 'second round' conversations further enriched the nuanced insights that we had gathered, and enabled us to involve people in early discussions about what it would take to get to a different future.

There are some challenging messages in this report about the reality of people's lives, what people want for their future, and how the system might need to shift to enable people to live less stressful, more manageable and more enriching lives. There are also difficult messages about how the Council might need to work differently to listen to and work with people, and lead and influence change across Croydon.

There is also much to be positive about: great ideas, energy and enthusiasm, and so much potential for growing something better and new for Croydon. We hope that this report inspires thinking and reflection, further research and engagement, and a positive movement for change.

Context for this enquiry

There are a number of significant and connected drivers for this work.

1. Like many other local authorities, the Council is reviewing and re-thinking support for adults with a disability and their families at a systemic level. It recognises that:

- there needs to be a much greater focus on outcomes - on supporting people to lead rich and fulfilling lives - rather than merely providing 'services';
- one-size-fits-all solutions are not helping people to live great lives of real independence;
- if there is to be flexibility and choice for citizens, especially as micro-commissioning grows, it will need actively to shape up a more mature and responsive market.

At the heart of the Council's ambitions lie a range of assumptions: that it is possible for more people to live happy, healthy and more fulfilling lives in their own homes; that fewer people should need to be admitted to residential care; and that more people can be supported to access safely exactly what they want and need within or closer to their communities. Credible plans to deliver on these ambitions must be based on a deep and rich understanding of what people's whole lives are like - both people with learning disabilities and the lives of those who care for them, what people's ambitions are, and how they want to be supported.

2. Council budgets are under unprecedented pressure. In the context of needing to find savings, a difficult decision to close a respite home had been announced in summer 2016, but without warning, causing significant anxiety for many families who used the service. The Council realised quickly that this had not been well-handled and that deep listening was needed to understand people's needs and lives before decisions could be taken. The Council also realised that it would be better to think about the future provision of respite within a broader understanding of how well the whole system of support in Croydon operates.

3. The Council recognises that there is the opportunity for better decision making and the emergence of new ideas and solutions if the authority can work in much deeper partnership with citizens. Such a relationship of co-production would be quite a change from how things have been done historically, and will require a shared journey of honest learning. In order to establish solid foundations for such a shift in the relationship, Croydon Council wants to understand what life looks like from the perspective of people with learning disabilities and their families and carers, and what the relationship with the Council currently feels like.

In responding to this brief, we aimed to build a picture of what's going on for people in Croydon, and what they want and need.

We also aimed to develop new relationships with people across the system that would build trust, aide co-operation and unlock energy and enthusiasm.

Our methods and approach

We set out to involve key groups in Croydon (people with a learning disability, family or carers of people with a learning disability, providers of services and frontline workers) in an exploratory and wide-ranging conversation.

Phase 1: Scoping and Set-up (October 2016)

During this phase, we worked intensively with colleagues at the Council and a wider group of stakeholders to understand the aims, the context and the drivers for this project. We quickly developed an enquiry framework and a focus for our activities. The enquiry framework was an important anchor for the research, helping our team to move far and wide across Croydon and flex our method and approach depending on the people we were with to maximise participation. Using this framework, we created a range of research and engagement activities that could be run in different ways to explore questions and themes.

AREAS OF ENQUIRY

1 Understanding people's aspirations and needs (people with a learning disability)

What is life like for people with a learning disability in Croydon? What constitutes a 'good life' (now and in the future)? What kinds of things enable people to live a good life (what relationships/activities/occupations/services/support)? What specific services and support are people currently using? How are they using these things and what is their experience?

2 Understanding people's aspirations and needs (family/carers)

What is life like for family and carers of someone with a learning disability in Croydon? What constitutes a 'good life' (now and in the future)? What kinds of things enable people to live a good life (what relationships/services/support)? What specific services and support are people currently using? How are they using these things and what is their experience?

3 Spotting enthusiasm for and exemplars of change

Where does enthusiasm and interest lie for the kinds of changes that are proposed by this agenda? Where are the people who are impatient for change and/or already working and living differently (for example, where people are successfully using personal budgets to meet needs in the community; or successfully moving out of residential care and into independent living)? Are there people who are now working, earning a living, building their skills or participating in a markedly new and ambitious way? Have people with learning disabilities (or families) wanted to make change, or be more ambitious in some way, and what has the experience been like? What gets in the way?

4 Exploring resistance to change

Where does resistance lie in the system and what are people most concerned about (including people with a learning disability currently using threatened services; their families; providers of and practitioners working within these same services)? What would enable people to feel more empowered to shape and influence change?

5 Mapping Croydon's community assets

What is it like for people with a learning disability to live in Croydon? What do people like about living in Croydon, and what do they not like? What specific activities and services (either run by the Council or in the community) do people value and participate in regularly? How easy is it to access what you need? How much choice and variety do people think there is? What is missing? What would make the borough a better place to live for people with a learning disability?

Phase 2: Rapid Research (November - December 2016)

During this phase, we continued to engage key stakeholders and recruited a wide range of people to our enquiry. We ran interactive events for small and large groups, undertook observations and visits to key locations and services, conducted semi-structured interviews in person and by phone, made home visits with groups of people and families, and more. We also developed a preliminary set of findings to share with the Council and our research participants.

6 Exploring opportunities for better engagement and strengthening relationships

For people with learning disabilities, and their families: How well do people currently feel their views are heard and understood? What are people's experiences of expressing their needs and preferences (to health and social care, schools and colleges, other support services)? Who represents people's interests (family, personal advocate, advocacy group, Learning Disability Partnership Board, other)? Do people feel responded to and able to influence things?

What do people think the Council (and others) could do to understand their life, preferences and needs better? How would people most like to share their views and have an influence? Can people point to particular providers (or similar) who do this well? What does it look like? If people could say anything to the Council what would it be?

For frontline practitioners and providers of services: How well do people currently feel the views of people with learning disabilities and their families are heard and understood? How would people characterise the way that the Council currently works with people with learning disabilities and their families?

Phase 3: Developing insights & findings (January - February 2017)

This crucial stage of research has involved further large scale events to test key findings and thinking with people with a learning disability and their families. We ran interactive exhibitions that enabled people to see and respond to key messages. We captured all feedback, then undertook a final iteration of the findings and began to develop a written report and a film (to make the main findings of the report as accessible as possible).

DESIGNING ENQUIRY AND ENGAGEMENT ACTIVITIES FOR PARTICIPANTS WITH A LEARNING DISABILITY

People with learning disabilities have a wide range of communication needs and preferences. Existing models of government consultation mostly do not meet these needs, often relying on very focussed, closed questions that require a verbal or written response.

We design things differently. Our experience has shown us that the following things really matter to developing genuine insight through research.

1 Have open, exploratory conversations. Don't use direct questions

We know that direct questions can be difficult for people with learning disabilities, making them feel under pressure to give an answer (often the answer they believe the person asking the question wants to hear). There is also a tendency among people with learning disabilities to perceive a series of questions asked by professionals or in a formal setting as a test (Redley and Weinberg, 2007). The need for a written or verbal response also excludes those who cannot read and write and/or are non-verbal.

We ask 'why?' a lot in order better to understand, and seek to listen to and capture people's stories, chewing over them in analysis and sense-making sessions: what have they said? what did they convey? what does this mean?

2 Meet people on their own turf. Don't make them come to your meeting

Government consultations often require participants to attend a meeting, often during the day and at a council office, which can be difficult for people with learning disabilities who may have mobility issues, financial constraints or limited choice and control over where they go. We arrange to go where people are - at home, a social club, a day service - and have our conversations at their convenience, and where people feel comfortable.

3 Help people to express themselves in a way that suits them. Don't try to make them fill out your questionnaire

Questionnaires are often available online in a written format that poses accessibility issues for people with learning disabilities, many of whom do not have access to the internet. We avoid asking people for a written or verbal response. Instead, we are there in person and offer a range of prompts that help people to express themselves in the way that suits them best (including through making, drawing, signing, using symbols, etc).

4 Be a human being. Don't be afraid to show empathy as you talk to people - or to have fun

Council-led research or consultation can have such an aura of formality around it that makes people tense up before you've begun. This doesn't encourage trust, honesty or deep story-telling, and the quality of insights suffers as a result. We make sure we are clear and organised - make sure everyone knows what's happening, where and why - but we aren't formal. By putting people at ease, making it fun, and showing that we are listening and caring the quality of conversation and insights is radically enhanced.

We developed an inclusive engagement approach, designed to ensure we reached a wide range of participants.

We developed a varied set of engagement methods that shifted the emphasis towards observation and open, exploratory conversations. Using highly visual and creative activities, we gave people the freedom to express things about their life experiences in the way that suited them best. Each session was designed around the communication needs and preferences of the group we were visiting in order to enable everyone to participate, including people with profound and multiple learning disabilities. Moreover we aimed to make all of our sessions fun, engaging and empowering for participants.

Some of the methods we used were:

- Immersive observation and shadowing (spending time at places where people with learning disabilities already go - for example going to Club Soda, visiting people at work at Nickel Support and joining a tour of Croydon run by Making it Happen)
- Guided tours of services by people with learning disabilities and staff
- Open conversations using visual and physical prompts such as photos, symbols and 'the glittery cube of questions'
- Supporting people to create visual stories about their lives using people figures, collage, drawing and painting
- Live sketching of people's comments and ideas
- Use of chalk boards

Key dates and activities

OCT

Phase 1

Scoping and set up

Developing enquiry framework and project plan

Research recruitment

NOV

DEC

Phase 2

Rapid research

Interviews

Visits and observations

Engagement sessions

JAN

Phase 3

Developing insights & findings

Playback to Council

Playback to groups of people with a learning disability (hosted by Whitehorse Road; also included users of Peter Sylvester and Cherry Orchard Garden Centre)

Playback to carers (Croydon Council Community Space)

FEB

Phase 4

Sharing findings

Publishing report

Creating film version of the report

Where did we go?
Who did we meet?

We actively engaged and worked closely with:

189

People with a learning disability

(through visits to formal settings and informal social places)

47

Family carers

(through groups hosted by formal settings, a workshop in the Community Space, through phone interviews and home visits)

We visited:

5

Day services

Nickel Support
(and Interestingly Different)

Day Space

Whitehorse Road (3 visits - including engagement with people from Garden Centre and Peter Sylvester Centre)

Lesley Park Road (2 visits)

Addington Heights

2

Schools

Priory School

St Giles School

1

Residential home

Russell Villa

3

Social groups

Theatre Group

Club Soda

Box Park Shopping Trip

4

Voice and influence groups

Croydon People First

Croydon People First Community Hub

Making a Difference group

CALAT Adult Learner Representatives

3

Home visits

To discuss direct payments and Heatherway; construction of user journey maps

2

Organisations offering support for carers

Parents in Partnership

Mencap

Section A
Listing to people with a learning disability

What do people want for their lives?

People with a learning disability want the same things as everyone else. They have basic human requirements for health and happiness.

> I will buy a flat. I will live there with my friends. I will need to do the washing and the dinner.

> “My girlfriend will come to visit. I will cook dinner for them. You can come. And you, (proceeds to invite whole room to dinner).”

A home

A nice place to live that is stable, personal and makes us happy. Choice about where we live and who we live with.

> My mum supports me every morning to get ready. Makes my breakfast.

> I'm engaged to my boyfriend. We met in college and did the same classes together. He's not here tonight because he's working. I can't wait to get married! I don't have a job at the moment but I'm getting one. I live with 4 flat-mates just now but I'm looking for a flat with my fiancee.

> I like going out with my mum at the weekends. In the car.

> Jo and Daniel are an item. It's old news now, they've been together for ages!

Family

A loving and supportive family. A break from our family when we need it. A family of our own if we choose, with a partner and/or children.

> When we speak on the telephone sometimes we talk for a long time.

> Yes! Yes! Friends are really important.

> Sometimes I see people at home. Or I see friends in town, like at the library. I see my friends at my church.

> My two special friends were from school. They are called Jane and Andrea. They don't come to the day centre. I get to see them if they ring me up. I go to the pictures with Andrea.

Relationships

Meaningful relationships with the people in our lives. Friends around our own age with whom we have things in common. Friends who we can meet, do things with and talk to regularly.

> I've being DJing since I was 12, I'm 55 now. I've always loved it. I'd like to become a professional DJ. I MC as well, I'm better at MCing, actually. I work in a garden centre 5 days a week, I'm a volunteer and don't get paid. I'd rather be a DJ.

> I used to work in a nursing home helping old people. I would play board games with them. They are stuck indoors playing board games all day, it must be so boring. I would tell jokes to them to make them laugh. My grandad used to be in a nursing home so that's why I wanted to help people.

> We've learnt skills at the Garden Centre. Mowing. Looking after the plants. We don't get paid. No money. I don't think that's fair.

> I worked in the mail room at the council… I enjoyed it. I met new people.

Sense of Purpose

A reason to get up in the morning. To feel like we make a contribution or a difference somehow to the world or others. For example we may work, study, volunteer or care for others.

“ I’d like to learn how to use buses. If I go with my friends they help me. You are not allowed to go on your own.

“ I love travelling on buses and trams. I know lots of people who travel on the buses. I say ‘hello’ to them.

“ Monday nights? That would be good. I can make my own way there.

“ I’m going to Jamaica this year. We are going together. Our carer is Jamaican. She’s taking us.

“ We like getting out and about in Croydon. We love going out at the weekends and we want to do this more.

“ If the weather is nice we go to Brighton for the day.

“ I like outings!

Mobility

To be able to move around freely and independently. To be able to go where we want, when we want.

“ Some people are not nice and will call you nasty names. It’s unacceptable.

“ If you are out and about…People are not always nice. They say ‘get out of my shop’.

“ I like it when the staff hear us.

“ Some people are friendly. Some not so friendly. Some push and shove and this makes me feel uncared for.

Respect & Equality

To be treated well by others. To be treated equally. To be listened to and considered an important voice in the world.

“ The next step for me is that I want to become an ambassador for CALAT. I want to go to companies and to places like Croydon People First to talk to them about CALAT, because I’ve got the confidence now.

“ I want to go to college soon. I want to go to college far away.

“ I work one day a week with a mental health charity teaching people how to use computers. I would have never thought I could do that.

Growth

To learn new things and develop our skills. To be able to use our skills in a way that allows us to grow and achieve results. To change what we do as our interests and lives evolve.

“ I don’t want them to make the decision for me. I’d like to have a choice. If they give me a choice at least I get to say what I want.

“ People should listen to us more.

“ I like it here. It would make me very sad [if something changed].

“ “Tell the Council that – I miss my friends. They were in Cherry Orchard.”

“ If something’s going to happen I want to know in advance. Why didn’t you tell me?!

“I miss my friends, we used to be together but now we are in three different places. Don't see much of our friends unless it is at events like the awards ceremony.”

Stability

A sense of security that things are not just going to be taken away or change suddenly. Feeling like we are in control of what happens to us.

9 Key Insights

Talking to people in Croydon about their experiences and the things that matter in their lives, we noticed the critical importance of the following things:

1

People need opportunities to develop and maintain a healthy social network

Relationships – with family and friends, and a wider network of people in the community – are one of the things people value most in life. Important in themselves, relationships also support people's health and well-being.

Opportunities to develop and maintain a healthy social network are critically important for people with a learning disability. We heard that it is sometimes not easy for people to develop or maintain relationships. Leaving school, stopping an activity, being forced to move to a new residential home or day service: these are all changing moments when meaningful relationships can be lost or threatened.

> “
> Relationships are very important ... If she doesn't get out she gets very depressed - she misses her friends. We have 4 or 5 people come to the house every week for tea.

> “
> Research suggests that many people with a learning Disability spend less than one hour a day outside their homes. Social isolation is a huge challenge.

We must ensure that the importance of relationships is considered through any changes to a person's current arrangements. Opportunities for people to develop and maintain friendships and a healthy social network must be a central and explicit aim of Croydon's system of support.

2

People need opportunities to try new and different things, with the right support

People need opportunities to grow and develop through their lives. It appears as though people are not getting enough opportunities to try new and different things.

We heard that doing something 'new' or 'different' can sometimes lack initial appeal. But often people like new things once they've tried them.

We observed interactions between excellent staff and people with a learning disability that modelled for us how people can be supported and encouraged to try new things that might at first seem scary or out-of-reach. We saw staff extremely skilfully providing 'just enough support': holding back from doing too much, and being patient through the process of learning, so that people felt empowered to do new things at their own pace.

> “
> I want to do horse riding. I know I'd be in safe hands. Know how to do it!

> “
> There have been a couple of occasions when I thought 'am I really going to do this?'. Look where I am today. I wouldn't have been able to do this without Club Soda's DJ class.

We must help people to do new and different things through their lives, encourage them and actively provide 'just enough' support, knowing how beneficial this will be.

3

People see themselves as contributors, not as people ‘in need’

Every person wants to contribute to the world and be recognised as having something to offer, something to give. This is utterly true for the people we met. They want to be known and recognised for their individual talents, capability and potential.

The people we met talked about the importance of looking out for friends and helping others. They showed us how much they care about what happens in their own lives, the lives of their friends and the wider world. They expressed dream jobs that involve making a difference for others (for example, teachers, nurses and Makaton signers). They shared concerns about injustices in their own lives, and the lives of others.

People also alluded to the sometimes unattractive and disempowering attitudes they came across in services and support designed for them, and in the wider world.

> “We come because we are treated like grown-ups here. We used to go to another group but they didn’t treat us like grown-ups.

> “All it is tapping into people’s gifts. I believe that everyone has a gift.

We must see all people as contributors to the world, and nurture individual capability and potential.

4

People need opportunities to pursue their passions and apply their skills

People want to pursue their passions and apply their skills, in a way that allows them to grow and achieve results that matter to them.

Many people told us they wanted opportunities to go to college, study and learn. They also told us that this was difficult to do in Croydon.

Many people told us they wanted jobs and more stimulating and purposeful things to do with their days. They also told us that there was insufficient support for this.

Pursuing passions and applying skills is really important for people. Everyone needs opportunities to grow and develop, regardless of their ambitions or capabilities. Whether it’s getting a job or setting the table, people want to be encouraged to learn new things, and experience the sense of achievement and reward that comes with this.

> “I get paid and love my job. Monday morning is my favourite time of the week! I love waking up and going to work.

> “I studied performance arts at college and I continue here [at the theatre group].

> “Making a cup of tea meant the world to the young man who did this for us. He had never attended a service or lived in a house where he could make the tea before, because the kitchens have not been accessible.

We must ensure that everyone can pursue their passions and apply their skills, in ways that are meaningful for them. Opportunities for this to happen can either be created or denied in every setting and on every day. This has to be a priority for design of services and training and support for staff.

5

People want to be treated as individuals

Many people told us how important it was that the people around them understood and respected their individuality. People told us this distinguished great quality interactions and relationships and enhanced people's lives, making so much else possible.

“

Priory school was really nice. All the staff. They all know me really well.

“

People need to know things. Like, if you call her Margaret she gets upset. She wants to be called Peggy. I have to tell everyone.

“

We are here to make people happy. When we see that we know we're doing a good job.

“

You have to be very observant. They may not be able to speak but there are so many ways they might be trying to tell you things. You have to follow people's lead, that's how you will learn more about them.

We must treat people as individuals, and ensure that the way they are cared for honours their individuality and uniqueness.

6

People want their views to be listened to and respected

People want to be listened to and heard, and for their wishes to influence and direct what happens in their lives. This doesn't happen enough. Many people currently feel especially left out of critical decisions that affect their lives.

“

I like it when the staff hear us.

“

[Those who make decisions that affect us] should go by what we say.

“

People don't ask us what we want at the moment.

“

People should listen to us more.

“

I don't think it's wrong that [the Council] make decisions but I think they should sit down and ask us.

We must respect people's right to be an active participant in decision-making. This must mean making meaningful efforts to enable those without a voice to speak up and be heard - both in decisions about their own lives, and in decisions that shape the future system - even when this slows things down or requires additional or different resources.

7

People want to be recognised and acknowledged

Being seen and recognised amongst peers and in the community is important to people. People's confidence and levels of ambition grow through a recognition of achievements. We observed many of examples of this – whether the rewards were prizes, a pay packet or just an acknowledgement from someone that they see you and like what you do.

People also clearly enjoy celebrating the achievements of others, and seeing people with a learning disability doing very normal (or very fabulous) things in Croydon.

“

It would help if I got paid for working at the Garden Centre. I have a house and decks to pay for.

“

We should play at BoxPark – loads of people would see us.

“

I want to see more people with learning disabilities working in offices and other places, not just in shops.

“

[I want to] use the skills I have got. I want certificates and pay.

We must encourage and reward people's talents, contributions and achievements, and increase their visibility and participation in public and community life.

8

If things need to change, people can adapt and accept things but the process needs to be handled respectfully and to involve them

Managing change is currently a big and controversial theme in people's lives.

We heard examples of people coping well with change, enjoying doing new things and being in new places – if they are well-prepared and supported. But sudden and unanticipated change is very traumatic and unsettling, putting a very high and very unnecessary stress on the individual, their family and on frontline staff. We heard lots of lots of distressing experiences.

Our conversations demonstrated that people are resilient and adaptable. Ultimately, it is the people that they are with (both staff and friends) that matter most to them, and they can get used to being in a new place, if the people around them are respectful and supportive.

But change must be planned for and managed so much better in future.

> “Even if you were evicted you'd get some notice.
>
> **Staff member at Addington Heights**

> “Here is better than the old building
>
> **Addington Heights service user who has moved from the Cherry Orchard service**

> “When we moved [my son] hated it. The community nurse came, we worked it through, and we sorted it out together.

We must involve people meaningfully in discussion and planning for the future, and support them as individuals through any change that directly affects their lives.

9

People want full access to the community

People want to be out and about in Croydon, moving through the days and the evenings, knowing that they are safe, welcomed and that their personal needs are met.

Being able to access the community – shops, restaurants, pubs, nightclubs, cinema, sports facilities, arts and culture – is critical for people. Many feel blocked from enjoying very normal things that most of us take for granted. This makes them very angry and frustrated.

Key issues for people include the dearth of accessible toilets (especially with hoists); not feeling safe, especially on transport; and the cost of some activities.

> “People with disabilities have problems at night. The streets are not lit and we can't see where we are going.

> “A lot of people with physical disabilities go shopping [in Croydon] on a Saturday morning but they can't stay out as there are no accessible toilets.

> “There is nowhere in Croydon they can be hoisted and changed. It's not a want, it's a need.

> “Shopkeepers in Croydon should be trained to work with people with a learning disability – how to treat disabled people.

We must strive to make Croydon fully accessible and welcoming for people with a disability. This means addressing design of the built environment and changing the attitudes of the community.

SECTION B

Listening to parents, carers and family members

Parents, carers, siblings and other family members play an absolutely crucial role in supporting people with learning disabilities. The things they do on a daily basis, often alongside working, running families and looking after their own health and well-being, help their loved ones to lead rich, happy and fulfilling lives. Their perspective on the system and on services for people with a learning disability, and on the support they are entitled to themselves as carers, is very important. It needs to be heard and understood separately from what we hear from people with a learning disability themselves.

Besides wanting good lives, good support and good opportunities for their loved ones, parents, carers and family members want:

Reliable, timely and dependable (day and respite) services, of a reasonable quality

> “ They want something familiar and safe. They like places like Heatherway, where they have known the place and the staff for years. Routine is important for them, and for their sons and daughters. Often their loved ones really don’t like going somewhere new. (Staff member)

> “ I don't need very much...Her day centre and her respite are the key things.

> “ All carers, but especially older carers, rely on stuff being there and being reliable. (Staff member)

> “ If only I knew there was someplace my son could go where he is safe and looked after.

Information about what is available and how to access it

> “ As long as I have a go-to point I don’t need very much. It’s made more complicated by fact that there isn’t a go-to point.

> “ I’ve absolutely no idea how people find out what is going on.

> “ No-one knows what number to call. This needs to change - and we need to be able to speak to the same person.

Advocacy and support

> “ There used to be a super manager. She even wheeled him over to the hospital to see me. She was on the ball for everything. We need advocacy.

> “ Get inside our shoes. It would be nice to have someone to stick up for us on that committee.

> “ [Health] isn’t looked after properly. She’s scared of needles for blood tests. I’ve tried so hard for so long to get someone to help me so she can get all her tests done. But no-one is listening.

To be listened to and treated as experts in our loved one’s needs

> “ We’ve done this [caring] all of our lives.

> “ They think everyone is the same. Not all Learning Disabilities are the same. We may have similar complaint but we are all different.

> “ Really proper listening should happen all the time. Most of them don’t understand what is is to care.

A range of issues that carers and family members raised with us relate to the way the system works and provision within it. We deal with these within Section C - Key Issues and Challenges.

We must recognise the essential (and difficult) role that family carers play in helping their loved ones with a learning disability to lead good lives.

We must listen to them, better understand their lives and work much more collaboratively to address problems and design solutions.

We must take seriously and respond to the specific ways in which they need support to do what they do. This includes helping to create in Croydon:

- Reliable, timely and dependable (day and respite) services, that are good quality
- Easy access to information about what's available
- Better advocacy and support, and help to navigate the system
- More opportunities for emotional support, perhaps through peer support
- Support to help think about and plan for the future
- Open dialogue around the future of services to which carers and people with a learning disability can make a genuine contribution.

Help to think about and plan for the future

> "In any other situation - if you were supplying a service you'd have an account manager or somebody - you'd only need them once or twice a year. But they might drop me an email once or twice a year - then you'd feel supported - there's your go-to point. It needs to be relational.

> "Vulnerable people are looking after vulnerable people. Where is the support for the supporter?

> "I'd like some support for me. No-one has ever spoken to me about how I feel about his condition. I'd like to speak with some other parents about what their lives are like.

Help to think about and plan for the future

> "We are all ageing carers. None of us are getting any younger.

> "As you get older, you don't know what's in front.

To be involved, and to get advanced notice if there is to be change

> "We need a lot of notice if something is going to close. We want to know what might happen before it happens. Before they make decisions.

> "Can the Council please give a lot more notice. We need to prepare people with a learning disability to understand the consequences of change - this isn't quick or easy. And we might want to appeal.

5 Key insights

Talking to carers in Croydon about their experiences and the things that matter in their lives, we noticed a number of critical issues that impact on how people feel about change:

1. Relationships are really important, and families want to work with people who they know, and who make the effort to know them. Frequent staff changes undermines trust.

“Social Workers know nothing. They don’t know people. Just take notes. Never at same place for very long.”

“The only contact I seem to have from the Council is every time there’s change.”

“I had to explain everything to so many different people…”

“They have no knowledge of the people. They come into your home and lay down the law, and then say ‘you have to have this and that’. Then three months later they’re gone. And everything goes with them.”

“Without exception I never see the same person each time, so conversation has to start over and over again.”

“We need continuity. The staff are moving so fast we can’t keep up.”

2. Older carers especially have noticed that there used to be more support available for people with a learning disability.

“In the past they had so much more. At Cherry Orchard they used to work. Putting things in plastic. On a Friday they used to queue for their wages. A sense of achievement and purpose. It was great. All gone now. Nothing left.”

“There used to be everything in one place at Geoffrey Harris House - art therapy, speech therapy, psychiatry, hydropool etc. Now I have to go to Kings for her teeth, and to Mayday for her boots. When I have to take her to Royal Beckenham it takes me 3 buses plus a 20 minute walk.”

“Groups just wander around, have a coffee and wander. They used to have jobs and be with their peers. A picture of failure. Everyone needs occupying and purpose – now it is aimless. I think a lot of parents and carers are disillusioned.”

3. Some families have had bad experiences in the past. This makes them wary about changes to services that they currently trust.

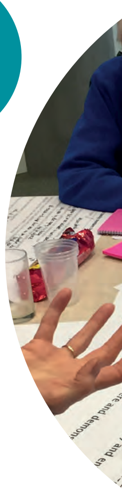
“The person who recommended the place [out of borough, bad experience] hadn’t even visited it.”

“We have lost a lot of trust. A few years ago we took him home and he was drugged up to the eyeballs.”

“When he came home he didn’t even have any of his clothes - they were all missing.”

“To put your most precious person into the hands of someone you don’t know and don’t trust is the worst thing imaginable.”

“They shut Craignish and then [name] didn’t see her friends again. She’d known them since school. Now she never sees them. It’s so sad.”



4. Some families say that they have found the Council unresponsive in the past. They feel that they have had to fight to get what they need.

"I came today [carers' engagement event] because I know it was the right thing to do. But lots of others [carers/ parents] have just given up. They just don't think it is worth it any more. So they didn't come."

"To get help you have to lose your rag! You have to threaten to do things you would never, ever do. Otherwise no-one listens. Ah, but then they listen."

"When you complain you get a labelled as a difficult parent, but you're just trying to care for your loved one."

"You have to constantly explain and fight. You get quite tired."

"Everything's a battle with the Council, it's one thing after another."

5. Many families recognise that there does need to be change. Change can be made manageable if approached in the right way.

"Families need to be supported and support others into independence. I learnt important and hard things around supporting my own son's independence. You always think, 'Nobody will love him like I will.' But you have a duty to step back - hard as it is - and let them be independent. When I die, I don't want him to say, 'All I've ever known is my Mum.' You're not doing them or yourself any favours."

"The vision should talk about things that mean something to people, paint a picture that means something to people. It could talk about empowering families, empowering communities to help themselves."

"People with a learning disability should be in a position to help the council to make decisions. You should nominate someone to ensure Croydon Council reads your report."

"I want to know what's going to happen before the decisions are made. We want to help you make the right decision."

Section C

Key Issues & Challenges

From the breadth of the research a number of significant systemic challenges emerged:

1. Adult services do not support ambition or progression, and there remains an enormous cliff-edge between child and adult services

Young people with a learning disability – just like all young people – have lots of ideas for their futures. Their aspirations are built and nurtured through school, but what's on offer beyond school does not encourage or support most people to realise their ambitions.

In the adult system, people's confidence to follow their interests or to try new things can be quickly eroded. For many years, people have talked about a 'cliff edge' between child and adult social services – not just an abrupt change in all forms of support, but also a feeling that good support and good services disappear when you reach a certain age.

Though the point of transition has stretched further into adulthood over the years, the lack of good services – sometimes of any services – continues to feel calamitous for many people.

"We show them the world then there is nothing for them, it's heartbreaking."

"Why is it that up to 18 you get everything, and then it gets worse until 25. And then it's nothing. They are so much more isolated as adults."

"Lifelong learning? But if you have a learning disability you just stop at 19. There used to be so much more. Nothing now."

"Spent 19 years building up skills. When she became an adult just dumped out there. No support."

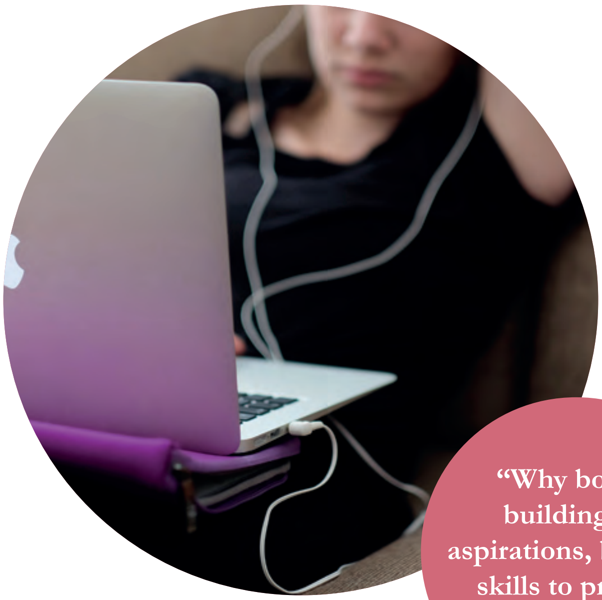
"You have to go out of county to go to college."

"What would you like to do this afternoon?"

"Dunno."

"Do you feel you have a choice in what you do?"

"No."



"Why bother building up aspirations, building skills to prepare adults for this?"

"They come back [to the school] and it's quite sad. We try to give them choice and control. We see them as adults and they are doing an activity a couple of times a week then are just at home."

2. Reliable support for adults during the day is critical, and the current approach is not helping people to lead great lives

The current system in Croydon, as in many localities, is dominated by rather traditional, building-based day services. There is not much support for people to do other, more ambitious things with their days and their lives (for example, continued study or skill-building, getting a job, or setting up a venture).

People want opportunities to do more with their day and their lives. They want a sense of purpose and to grow and develop through their entire lives.

Making this a reality for people with a learning disability requires consistent, reliable, personalised and appropriate support. For example, we heard that people with a learning disability using work-based day services often experience problems when they move on to other forms of employment. This is because there is insufficient support and advocacy for people with a disability in most workplaces, and that kind of support doesn't follow people for long. We heard that, because of this, many people who start mainstream jobs get bounced back to the day service. This leaves them feeling demoralised and makes it even harder for them to have confidence to try new things in the future.

We did not see many examples of people being supported to do more ambitious things across day services in Croydon. Many people we spoke to were very clear that current forms of support did not enable people to do something more purposeful and rewarding with their lives.

People really value some aspects of current day services. We heard that these are often places that help people to develop and maintain friendships and healthy social networks, and give people a sense of belonging and community. We heard a strong messages about the quality of individual support staff, from both people using services and their carers.

Despite parallel concerns about the quality of what is on offer in the day centres, there are also genuine concerns about what might happen if much-relied-upon day services were to be withdrawn without a clear vision and plan for creating promising alternatives.

"You have to be careful because society is not always caring. Most people are nice, but you only need one who isn't, and then you're destroyed. People need to be supported well if they're working in mainstream settings."

"Here they have great support and advocacy, but no one looks out for them when they leave. In a new job, they might get asked to do something dangerous, or to work longer hours and they may not feel able to say no. It doesn't end well. If we want people to have jobs, we have to think about what goes on in the other parts of the system."

"I don't want to sound like the old guy who thinks everything was better in the past, but at least [in the sheltered workshops] people had a purpose. My son occupied and cared for, and he brought home a little pay packet that made him feel good."

"People are wandering about town, trying to find things to do."

"His world revolves around the day centre. We shouldn't be doing away with them; we should be putting them back and making them much better than they are today."

"All the staff were dancing."

"Day Services have no structure anymore. Nothing to do."

"All the staff we've ever met have been amazing. They really do care."

"The staff here listen to us."

3. There are some good things going on, but mainly for a small group of people

There are some great opportunities and activities for people with a learning disability living in Croydon, but it seems apparent that these may be accessed only by a relatively small group of people. Visiting what's on offer across the locality, we met the same people again and again.

We are concerned about the lives of the people we didn't see and who are not accessing the best of what's on offer in Croydon.

> "I don't think there is a lot happening in Croydon for Craig. He's 27. I want him to be able to go to places with other people his age. I don't know about anything. Also he's in a wheelchair. He goes to Edmunds for respite. Its fine but there aren't many people his age. I'd like to know what the other options are."

> "Calum does lots of different things. Monday he goes to Mencap, because on Monday they take him to the Phoenix Centre for dancing. Tuesday he volunteers at City Farm (it's brilliant, he loves it). Wednesday he goes to Nickel Support – he works in the training centre. Thursday he goes to Orchard Hill College. He does the 'intro to work' course. He volunteers at two libraries for work experience. Friday he stays at home and goes out with his family. Every year I have to sort out Calum's activities myself. It's always a fight and a challenge to find him interesting stuff to do. I don't want him sat in a day centre every day."

4. Direct payments are not helping people to do great things

Direct payments are not living up to their promise of choice and control. People using these are paying for the same kinds of services that the Council has always commissioned. They are not finding or designing more creative forms of support that better meet individual needs, and empower people to do more ambitious things with their lives.

Issues that are stopping people make better use of direct payments include a lack of clarity around how money can be spent. People report that they feel constrained in their thinking by the recommendations made by social workers or care managers. They feel unable to push back on suggestions or make their own suggestions that might be more suitable. Some people report being given conflicting advice from different staff around what is possible and permissible.

Many people said they are fearful of using direct payments or feel forced into them. They are perceived to make a lot of work for people, rather than helping to make their lives easier.

Some people are interested in exploring direct payments, but have no idea who to talk to and where to start. They say that information is hard to find.

On the positive side, some people really do see the potential of direct payments to provide more opportunity and flexibility. They would like to have genuine choice in care and support, with inspiration, encouragement and support to design personalised solutions that make for more interesting and rewarding lives.

“It’s not direct payments that are the problem it’s the care managers: one says you can do one thing, another says you can’t.”

“Not all Social Workers know about them. Some just send you to allocated things, like day centres, anyway.”

“I wasn’t told I’d be responsible for the public money burden.”

“There’s enough to worry about without running a direct payment as well”

“When I started on Direct Payments, I was scared because I had a lack of knowledge. It’s a lot of money and it’s not my money. If you stray away from the agreed Care Plan you can be in a serious amount of trouble.”

“I’m too scared to use Direct Payments. It’s basically running your own business.”

“I can’t go out, I’m stuck here. No one has told me if I can buy extra care if I have money left in the account.”

“It was never part of our agreement with the council for the money to be used for anything other than to pay a carer. I’d be scared to use it for anything else. It would be nice for there to be more flexibility, for us or the carer to use it to take my son out. But I’ve stuck strictly to paying carers with it. I’d have to go back to the council and get him reassessed, go back and get a social worker. We haven’t had one for 2 years. Any changes you have to get a referral back to the system.”

5. Respite options do not feel clear or appropriate

Respite is critically important to carers. Short breaks help them to maintain their lives, jobs and families, and look after their own health and wellbeing, while continuing to support and provide care for a loved one with a disability for the rest of the time. Respite also allows people with disability a break, time with peers away from those from those with whom they live.

We heard that carers want greater flexibility when it comes to respite. The current model imagines that people are full-time carers who need a 'holiday' a few times a year, when the reality is that many carers hold down jobs and have wider family commitments. Sometime respite is needed to help people to travel for work, or take care of other personal commitments. For respite to be useful to carers, it must be more flexible and responsive and help people to have a break when they need a break.

People also want greater assurance of the quality of any respite services. The person's familiarity and comfort with any respite arrangement is a real a concern. Some people also have acute fears around quality because of a history of bad experiences.

"Being a carer is an incredibly tiring thing when you're healthy. If you're caring for someone with a learning disability they don't understand you're ill or getting older. It's important to recognise how vitally important some sort of respite is - regular activity that takes them out of the house - even NOT at times when either of you are ill and things are difficult."

"Taking them out for a bit is NOT respite."

"I don't need very much. I just need respite that's more flexible."

"Respite can't happen in our homes. It just doesn't work. No respite for them or for you if they are seeing you."

"Key thing right now would be to have more accessible respite – my commitment to make my life function as her primary carer. I have a trip in late February and there's nothing available. I'm working to pay tax into the system - but I feel I am penalised for that."

"It used to be that respite centre might be open 48 weeks a year, but now it seems like its 50/50 based on the weeks, and it doesn't marry up about the schedule and the family life. I've learnt to work around it. Most of the time the respite is useless. It definitely doesn't give me a break."

"Please get rid of this idea that having someone coming into the house is respite. They [the other children] won't defer to them."

6. There is no long-term planning of support for individuals and families, and crisis support feels insufficient

Carers report that they are currently offered no support and guidance to prepare for a future in which they will be no longer be around.

As carers get older and less able (and we spoke to many people who are caring for adults and in their eighties), they are under increasing stress. Many older carers find it very distressing to think about the future, and to imagine alternative arrangements that would see their loved ones living independently of them. It is very hard for them to start the conversation about 'what happens next' and to take the initiative to explore options, even though they know their personal situation is a looming crisis.

Carers also report unhelpfully slow response times in crises, when accommodation was required. Clear questions were posed to the Council about why there are no longer term plans and crisis plans for families.

"They wait for you to drop dead, and won't do any planning for the future until then."

"I'm not getting any younger. Give it 10 or 20 years I'm not sure how I'll manage."

"There is a great unknown around, who to turn to in an emergency. Respite can't keep rooms open, so the place that people go to could be completely new. It can be really distressing."

"It does have an effect on your health. When I had an operation, I couldn't lift, but she wasn't supposed to stay in respite. It was crazy. When you're ill there Needs To Be A Plan."

"I haven't got a clue what the options are for my sister and I should be much more aware. It's better for me to look at those options now when everything's ok, rather than if an emergency happened. I have no idea who I would ask. You need to have that detail to hand. I never had any regular contact from the Council. They say 'It's our duty to make sure people with a leanring difficulty are adequately provided for' but they don't care most of the time."

"We do carers assessments and help carers to do contingency plans for the future. Where could my son or daughter go? The Council say they can't tell people where their loved ones will go. But when a carer is in the 90s, you think – can't you just find someone a place? You just want reassurance and continuity, for both parties, so there can be less stress."

"Why is there no long term plan? Born like this, die like this. They are never going to get better. Why do you get everything up until 18 and then after 25, nothing?"

"Four years ago I was rushed into hospital. It took Croydon three weeks to find out where he could go - that three weeks was an 'emergency'."

SECTION D

Recommendations and inspiration

...to be contributors

...to be recognised and treated as individuals

...to have good relationships and a healthy social network

...to pursue passions and apply skills

...to grow and develop through adulthood

...to participate actively in community and public life

It is easy to look at the things that people want and need and assume that these things are already happening. They are probably already at the core our strategic visions, written into commissioning plans, and referred to into service specifications. But the reality is that these basic human rights are simply not evident in many people's lives.

Croydon, like many local authorities in the UK, is trying to break out of old-fashioned service models for people with a learning disability, and the deeply entrenched attitudes and behaviours that accompany them. The old models and ways of working simply don't deliver on the things that people want and need. They don't work for this generation, and they certainly won't work for the next.

The Council is doing well to explore how more personalised care and support could work, enabled by direct payments and a more diverse market of providers and stronger forms of community support. But to be successful, the new approach needs more thought and possibly some inspiration.

New solutions need to be underpinned by an ambitious and inspiring vision, brilliant by design, and openly and collaboratively developed and delivered.

Design Principles

Successfully delivering real transformation in complex living systems is very hard; the tendency to go back to tried and tested ways of thinking and working is common, and there will be pressure to compromise on ambition when the going gets tough and resistance to change kicks in. The adoption of design principles that detail HOW we are going to work can provide a very helpful scaffold: both a guide for planning and a checklist against which activity and results can be tested. Are we actually doing this? Where is the evidence?

Good design principles are grounded in the citizen or user's needs, are practical and actionable, and help you to make decisions. Based on what has emerged in this work, the following might be a useful set to start with:

1. Start with people's capabilities and their needs

Whole system and service design must start with identifying people's capabilities and needs. If we don't know what these are, we won't build the right thing. Do research, look at data, listen to users (both people with learning disabilities, and those who care for them), make time for collaborative sensemaking. Don't make assumptions. We must have empathy for people, and remember that what they ask for isn't always what they need.

2. Design with real-world intelligence

Look at how existing services are used and explore how well they really meet needs and deliver outcomes. Let real intelligence drive decision-making, not hunches or guesswork. Let service users tell us whether something works or not. Keep on doing this: test new ideas with people with learning disabilities, and with families, and keep on listening; prototype, learn and iterate in response. If something isn't working we will not be afraid to scrap it and start again.

3. Intentionally build trust

Prioritise relationships and continuity in support. Enable those that are trusted by people to do more for them, rather than handing-on. Design-in contact points that do not change, even if the personnel move on. Facilitate easy navigation around the system, and think imaginatively about who could make this happen (service users? staff in mainstream services?), and incentivise it.

4. Design for everyone

A brilliantly designed system will attune to the diversity of capabilities and needs (both of people with learning disabilities, and of the parents and carers who support them). Think about the people who will find things harder or hardest from the start. Ensure services are incentivised to provide great impact for everyone, not just for those easiest to serve. But don't design everything around the edge cases.

5. Understand and respond to context

We're not designing discrete services, we're designing for people and for great lives. Think hard about the context in which people are using our services. What else is going on in their lives? How does what we offer need to fit with or flex appropriately to work better? Build a whole system.

6. Unlock the capacity of the wider system

The resources that sit in our budgets are not the totality of resources that can help. Where else is there energy, capacity and capability? How can we support great outcomes by much greater collaboration with other resources? Where else are people having to go? Where do they feel comfortable going? Whom do they trust? What technology do they use - phone? Facebook? Deliberately create a shared vision and mobilise in pursuit of it.

7. Start small and grow from there

This is a huge ambition. Do not try to change everything all at once. Begin somewhere really focused; learn, grow capability, and build confidence.

8. Be clear

We will not let anything be said, written or communicated that is not simple, consistent and clear. Seek feedback so that we know we are doing this.

9. Pursue coherence

We recognise that to achieve our vision everyone in the system - from organisational leaders to frontline staff - will need to understand what's needed and play their part. People's beliefs and practice will need to change. We will need to develop a common narrative that everyone sees themselves in. The task is huge; we will start somewhere and relentlessly follow it everywhere.

10. Be courageous

We are seeking to understand difficult problems and unearth great possibilities. This will challenge received wisdoms and the status quo. We will make every effort to maintain the courage of our convictions. Reward tenacity.

How might people with a learning disability be supported to lead great lives?

Whilst everyone says this is what they are aiming to do, this is a question that few have demonstrably cracked at the level of whole system and service design. There are some inspiring examples, however, that offer shape and clarity to a vision for how things could be. We believe that getting under the bonnet of such exemplars can help us to see two critical things: just how much better things can be, and what some of the important components are of the approaches that seem to be getting there.

We think the following three examples of disability services and system approaches will be helpful for Croydon to consider. None of these initiatives does everything or solves every problem, but each shows us how differently we might need to think and work if we are to make services and support radically better for the next generation.

EXEMPLAR 1: The Vermont Model (Vermont, USA)

The State of Vermont encourages all adults with a disability to aim for meaningful, sustainable employment, offering direct financial payments and tailored support to enable participation in the workforce.

In 2002, Vermont became the first US state to stop funding sheltered workshops. The State was already in the midst of a system transformation that aimed to raise radically the level of ambition people with disabilities, and support full inclusion in community life.

In the 1980s, the University of Vermont received a grant to build programmes for integrated employment in partnership with state disability agencies. The movement grew and policymakers eventually decided sheltered workshops no longer fit the state’s values.

The Vermont Developmental Disabilities Services Division started by not allowing new people to go to sheltered workshops. The next step was to cut funding to these places over time. They worked in close partnership with providers through this process, and with individuals and families, to design and manage the shift.

Key aspects of the system transformation:

- Setting up supported employment programmes in each of the 14 counties to help people with disabilities find and apply for jobs, as well as learn and develop on the job (unlike many states, the support of a job coach does not fade over time, which helps to improve retention)
- Helping parents and carers to understand how their loved ones might be supported to be safe and to thrive in employment and self-employment
- Forming partnership with employers to educate them on how to hire and retain people with disabilities
- Creating new post-secondary education programs for people with disabilities that support them into employment.

Vermont leads against US states in almost every measure of workplace inclusion. Every adult with a disability is expected to work and given direct financial payments to enable their participation in the workforce. Vermonters with learning disabilities are twice as likely to find jobs in the community as their counterparts in other states. Nearly 40 percent work in the community alongside people without disabilities.

“I told my mom, ‘I am absolutely not going to spend my entire life bagging groceries.’ Now, I have my dream job.”

“We focus on individual directed services and an individual budgets approach to delivering services. Vermont asks ‘what do you want your life to be?’ and then builds services out of the budget that has been allocated. We have a mantra in Vermont – we don’t use state funding to fund programmes, we fund people. We fund people to access their communities.”

EXEMPLAR 2: Halton Day Services (Halton, UK)

Halton Borough Council runs a series of social enterprises in the locality that offer work placements to adults with physical or learning disability.

Taking a different approach to traditional day services, this award-winning initiative offers people a wide range of stimulating, work-based experiences, where they can learn pre-employment skills and access the workplace through business and entrepreneurship.

The service operates in around 25 venues across the borough and offers several different types of activities, including a hair and beauty salon, a microbrewery, catering company, ice-cream making business, arts and crafts and conservation ventures, a gardening business and their flagship service, a café at Norton Priory. Adults with learning and physical disabilities also work in the two shopmobility shops in the area as part of the service.

Halton works closely with the local Further Education college for students with disabilities. Students can come and visit and try out different aspects of the service whilst still at college, with a view to being placed in one of them once they have completed their course. Many work with social workers and others who know them to determine which roles and enterprise would best suits their skills and interests.

The Council's strategy was simple: divert resources from traditional 'bricks and mortar' based day services, and create opportunities structured for business and linked to the commercial world. Users of the service now have the opportunity to contribute to the running of a business and doing varied and rewarding new things.

People who use the service report that it increases confidence and gives them an immense sense of self-worth. 145 adults with a learning disability are currently working through this programme, which ultimately aims to support people to find mainstream employment.

"There is a real buzz in the shop [a pop-up craft shop that's currently part of the service]. Meeting customers and selling things is providing great experience. Everyone is very excited. We are putting ourselves in a shopping centre for the world to see."

"People need something after school or college to prevent them from ending up wandering the streets, never leaving their houses or sat in a day centre making the same things day in and day out. We are THAT something."

EXEMPLAR 3: Nickel Support (Sutton, UK)

Nickel Support runs a range of 'day services' in Sutton, but their approach to supporting people is anything but traditional – they prefer to describe themselves as 'Leading a Learning Disability Revolution.'

Nickel Support base everything they do on a strong set of principles and values, co-devised with people with a learning disability. Their vision is to have people with a learning disability standing side by side with peers and valued as equals in society. The activities and opportunities that they offer aim to empower people and develop their skills and confidence, with a view to encouraging proper participation in the community, and in work.

Nickel Support runs a community café and vintage furniture shop, Interestingly Different. Alongside these ventures, they run a variety of sessions for trainees that enable people to learn, develop and practice work-relevant skills. These include serving and food preparation, up-cycling, social media training and online sales (this includes photographing goods and then uploading pictures and content to sell on ebay).

Trainees interact with customers, develop computer skills, learn about pricing and numeracy, develop writing skills, undertake physical exercise, understand the values of team working and above all have fun.

Trainees attend up to ten sessions per week, using personal budgets to pay for sessions. Each session has relatively small numbers of trainees in attendance, as Nickel Support believe quality suffers when staff have too many people to support.

The sessions aim to teach the trainees the basics of business to enable them to then go on to develop and run their own social enterprises.

"I love coming here, it's full of laughter, we get stuff done"

"We set it up because we felt that there were no opportunities that gave people actual tradeable skills"

What distinctive features do these exemplars share?

These three examples share some common features that are worth noticing. Reflecting on these features, what does this mean for how we need to work to move forward in Croydon?

1. THEY START A REVOLUTION

These initiatives know that helping people with a learning disability to lead more ambitious and rewarding lives is a revolutionary project.

They acknowledge and contend directly with the entrenched inequalities and injustices they see in existing service models and wider society.

Their models and approaches (and the values that underpin them) propose a radical break with the past and demonstrate a very different way of working to achieve impact.

Behind The Vermont Model is a 25-year history of system and culture change, underscored by the belief that the existing situation for people with a learning disability was not good enough and that people deserved, and could become, so much more. None of this came easily. Services in the old system were, over time, carefully de-commissioned. The Disability Service worked intensively with families to help them to understand and adapt to the change. A clear vision and set of values helped everyone understand and buy into the change.

Nickel Support uses the language of revolution in its mission statement. They aim to go beyond offering people with a learning disability something to do; theirs is a movement for empowerment and social justice (towards "people with a learning disability standing side by side with peers and valued as equals in society.")

"If you are not passionate and up for the fight – then leave the ring."

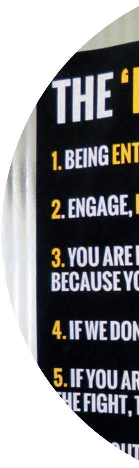
2. THEY SHOW US WHAT 'GUIDED BY VALUES' REALLY MEANS

Many organisations have values and principles that are intended to inspire, shape thinking and guide action. But so often these do not really influence different kinds of behaviours or ways of working.

In these initiatives, values matter and they powerfully shape what happens (and what is not allowed to happen).

Nickel Support has an explicit set of sharply-worded principles that show everyone how to work together creatively, purposefully and with maximum enjoyment. These are prominently displayed.

"If we don't love it, we don't do it. Ever."



There are clear values-driven beliefs and principles at the heart of The Vermont Model. These emphasise people's rights to full participation in society and to have a rewarding and productive life. They set high expectations for what people can do and achieve, and make a commitment to supporting individual aspirations to be realised. Leaders in the system say that 'principles of service' are an important tool for decision-making, for checking what should be commissioned or whether a service is performing.

"It's really important to start with principle and let the principle shape the service. We made a decision to not fund services if they do not uphold certain standards and principles so that we only pay for what we want to see happening."

3. THEY ENCOURAGE PEOPLE'S GROWTH AND POTENTIAL BY OFFERING GENUINELY PERSONALISED SUPPORT

The mantras of personalisation and 'choice and control' are familiar and pervasive.

Many organisations say they are ambitious for people offer a personalised service, but on closer inspection the levels of ambition, choice and control may be severely limited.

These initiatives show us what it looks like to be ambitious for people. They show us what it takes to work with people to identify strengths, create opportunities and tailor support that helps people to grow through their lives.

Halton Day Services aim to act as a bridge into employment by giving people with a learning disability the opportunity to learn pre-employment skills in work-based settings. Individuals work with social workers and others who know them well to determine which roles best suit their skills and interests. Strong collaboration with Further Education means people are thinking about their job interests and getting a taste of opportunities well ahead of starting in a role. By focusing exclusively on setting up and running enterprises, Halton also offers a much wider choice in work-based learning opportunities than is typically found in a local authority offer.

"Progression can take different routes for people. Lots of people when they start working with us come on council provided transport minibuses. We work with them to determine how they want to progress. Once they are settled we might provide travel training to enable them to come to work independently. We also introduce them to the idea of working weekends, and maybe some evenings. This is real life work. It isn't 10 to 3, like in a day centre."

The expectation that 'everyone can work' in some capacity is one of the most notable features of The Vermont Model. Everything about the approach aims to empower individuals to participate fully in the community and the world of work, on terms that suit them and with support that helps to make ambitions a reality. The concept of 'job carving' is crucial to the success of the Model. Staff work with individuals (and employers, and the wider community) to create jobs in existing organisations or new enterprises. These work with people's passions, but are also set up with hours and conditions that make it possible for people to perform at their best.

"This concept of customised employment is something that is beneficial to both employee and employer. We are not looking for charity jobs, we want people to be contributing."

4. THEY EMPOWER PEOPLE BY OFFERING 'JUST ENOUGH' SUPPORT

These initiatives attend carefully and closely to individual talents and needs. But the support also feels strategically 'just enough'.

This means that people can use their own creativity and initiative and make their own choices, but have encouragement and support where they need it from a wide variety of sources (including friends, family and employers).

They can push themselves, take risks and do new and different things, but are not left alone to fail.

Many people are surprised to learn that 40% of people with a learning disability are working in Vermont, and that many run their own micro-enterprises. 'Job carving' is one of the key features of The Vermont Model. But equally important is the coaching and mentoring that the Disability Service provides – not just as people search for and start in a position, but throughout their careers. A small measure of on-going sustained support helps people to live very independent, working lives.

"This is not a 'place, train and fade forever' system – this is a place, train, fade and follow along system. We have people who have been working for 20 years and they are still getting some level of service, based on what they want, what their employer wants. We always keep that supported employment door open. I don't think we would have been able to do what we have done in employment if we did not provide long-term follow along for everybody."

5. THEY AGITATE FOR FULL PARTICIPATION IN COMMUNITY AND PUBLIC LIFE

These initiatives strive to shift public perceptions of people with a learning disability and increase participation in public life.

They do this in a range of ways, but with the common aim of increasing opportunities for people and removing the many, many barriers people face to accessing things in the community.

The success of these initiatives relies on building new links and partnerships in localities, and growing a new system of support and engagement that goes well beyond a single service or 'centre'.

One of the enterprises that forms a part of Halton Day Services is Altered Image Hair and Beauty Salon. The salon is fully wheelchair accessible and trainees are trained by professional hairdressers and beauticians. The enterprise is both an employment opportunity, and a service that does something important for wider community perceptions.

"We know that families of people with learning or physical disabilities often shy away from visiting a salon as they feel a home appointment will be easier. We wanted Altered Image to change that by offering people the pampering they may miss out on."

Nickel Support has just started a group called Vocal Local. This encourages trainees to visit local places then blog/vlog about them for other people with a learning disability. The aim is to shine a light issues and problems that prevent people with disability from fully accessing the community. They recently went to Croydon Boxpark as a group on a trip, for example, and failed to find accessible toilets.

Increasing community participation is one of the key principles underpinning The Vermont Model. Each job created is one more person working and contributing visibly to community life. Over time, colleagues say that this has markedly influenced societal attitudes and behaviours – especially for employers, but also for the wider community – so that inclusivity and visibility are now the norm.

"I think it has been a cultural change over the years as we have moved away from Sheltered Workshops that employers are used to being asked to hire people with disabilities … we have been good at reaching out to employers and employers are good examples for others. I think it catches on after a while and becomes a public thing."

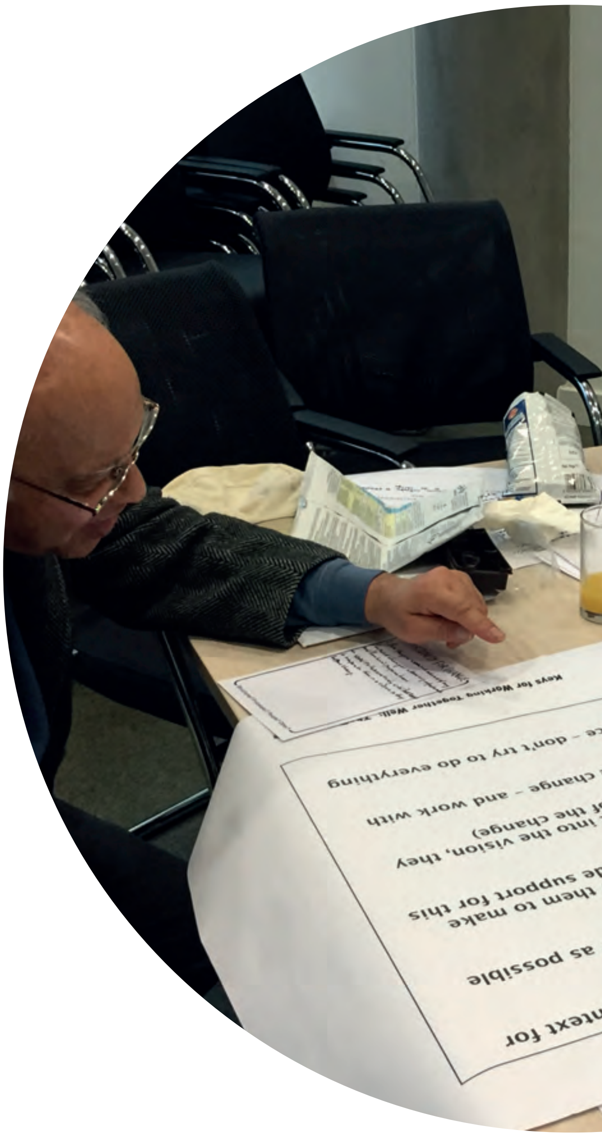
Catching the radical edge of these exemplars and learning from them requires a level of honesty about where existing provision currently falls short: it is all too easy to respond with a cursory ‘we are sort of doing that already’. There are wonderful and committed managers and practitioners in many places in Croydon, but these exemplars have a level of ambition designed into their fabric that demonstrates radically different attitudes and practices. In the case of Vermont, this has led to an astonishing shift in outcomes and in society in a generation.

Our hope is that the content of this report leaves people inspired and galvanised to lead a similar level of change for the people of Croydon. We think that:

- There is now much greater clarity about the fulness of what people want and need; some parts of which would be quite straightforward to achieve with small but determined tweaks to existing systems. How limited public sector resources can best be deployed in pursuit of those needs, with and alongside resources and assets from the wider community, is a question that needs to be addressed collaboratively.
- We have shone a light on some of the blockages and fissures in the current system, and this now need some careful design thinking in response. The underpinning conditions (including leadership, success, metrics, support and incentives for staff) will need to be explored and articulated as part of this design process.
- There are pockets of enthusiasm and energy where there is openness and appetite to explore very different solutions, if approached in the right way. There is a real opportunity to capitalise on what has begun and to continue to grow a relationship of trust and honesty, moving towards real collaboration and co-production.

Walking in the shoes of the people of Croydon is an immense privilege, and provides the foundation for new ways of thinking and working. If we can keep the ambition of the We must.. statements and the sharpness of the Design Principles at the heart of the work, the potential is exciting.

Start somewhere, follow it everywhere.



Making a difference where it matters

Thinking about each of these statements in turn:

- What would doing this well look like?
- What signs could we look for that would tell us we were making progress?
- What do we need to do more of? What do we need to do differently?

For people with learning disabilities:

We must ensure that the importance of relationships is considered through any changes to a person's current arrangements. Opportunities for people to develop and maintain friendships and a healthy social network must be a central and explicit aim of Croydon's system of support.

We must treat people as individuals, and ensure that the way they are cared for honours their individuality and uniqueness.

We must strive to make Croydon fully accessible and welcoming for people with a disability. This means addressing design of the built environment and changing the attitudes of the community.

We must involve people meaningfully in discussion and planning for the future, and support them as individuals through any change that directly affects their lives.

We must see all people as contributors to the world, and nurture individual capability and potential.

We must help people to do new and different things through their lives, encourage them and actively provide 'just enough' support, knowing how beneficial this will be.

We must respect people's right to be an active participant in decision-making. This must mean making meaningful efforts to enable those without a voice to speak up and be heard - both in decisions about their own lives, and in decisions that shape the future system - even when this slows things down or requires additional or different resources.

We must encourage and reward people's talents, contributions and achievements, and increase their visibility and participation in public and community life.

We must ensure that everyone can pursue their passions and apply their skills, in ways that are meaningful for them. Opportunities for this to happen can either be created or denied in every setting and on every day. This has to be a priority for design of services and training and support for staff.

And for families and carers:

We must listen to them, better understand their lives and work much more collaboratively to address problems and design solutions.

We must recognise the essential (and challenging) role that families carers play in helping their loved ones with a learning disability to lead good lives.

We must take seriously and respond to the specific ways in which they need support to do what they do. This includes helping to create in Croydon:

- Reliable, timely and dependable respite services and day opportunities, that are good quality
- Easy access to information about what's available
- Advocacy and support, and help to navigate the system
- Opportunities for emotional support, perhaps through peer support
- Support to help think about and plan for the future
- Open dialogue around the future of services to which carers and people with a learning disability can make a genuine contribution.

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