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AGENDA

Committee	COMMUNITY & ADULT SERVICES SCRUTINY COMMITTEE
Date and Time of Meeting	WEDNESDAY, 3 FEBRUARY 2021, 4.30 PM
Venue	REMOTE MEETING
Membership	Councillor Jenkins (Chair) Councillors Ahmed, Carter, Gibson, Philippa Hill-John, Lent, Lister, McGarry and Mackie

*Time
approx.*

1 **Appointment of Chairperson and Membership of Committee**

To note that Council on 26 November 2020, appointed Councillor Shaun Jenkins as Chairman to the Committee and the following as Members of the Committee:
Councillors Ahmed, Carter, Gibson, Hill-John, Lent, Lister, Mackie and McGarry.

2 **Terms of Reference** (*Pages 5 - 6*)

To note the Terms of Reference of the Committee.

3 **Apologies for Absence**

To receive apologies for absence.

4 **Declarations of Interest**

To be made at the start of the agenda item in question, in accordance with the Members' Code of Conduct.

5 **Minutes** (*Pages 7 - 12*)

To approve the minutes of the 2 December 2020 Community & Adult Services Scrutiny Committee.

To consider how the covid-19 pandemic has heightened social isolation and loneliness for Cardiff citizens aged 18+. Assessing Cardiff Council's role in addressing the issue and how the council is working with partners such as the Welsh Government, charities and religious communities in response to the challenges. During the meeting Committee Members will hear from a range of external participants on how demographics have been affected and the challenges faced. This scrutiny will be split into the following parts:

- **An Overview of how the Council has Responded to the Issue of Social Isolation and Loneliness Following the Pandemic Outbreak (4:40pm)**

The Cabinet Member for Social Care Health & Well-being and the Cabinet Member for Communities & Housing supported by officers from the People & Communities Directorate to brief the Committee on the how the council is addressing the issue and answer any questions raised by the Committee.

- **Evidence Session with the Welsh Government (5:00pm)**

For Members to receive an update on Welsh Government policy and to understand how the Welsh Government and Council work together on this issue.

- **Evidence Session with British Red Cross (5:15pm)**

For Members to receive information on how individuals have been impacted and the challenges the organisation faces and input into how local authorities can work in partnership with such organisations.

- **Evidence Session with Project Hope (5:30pm)**

For Members to receive information on how young adults (those aged 18 plus) have been impacted and the challenges they face.

- **Evidence Session with Age Connects Cardiff & Vale (5:45pm)**

For Members to receive information on how the older demographic have been impacted and the challenges they face and input into how local authorities can work in partnership with such organisations.

- **Evidence Session with Religious Communities Representatives (6:00pm)**

For Members to receive information on how certain religious communities (Church in Wales and Roman Catholic) have been impacted and the challenges they face.

- **Closing Remarks/Reflection (6:15pm)**

To provide the council's executive and committee members with an opportunity for reflection and any further remarks having heard evidence from the external participants

7 Committee Business (Pages 53 - 246) 6.30 pm

For Members to consider a draft Task & Finish report of the Committee entitled: *'Closer to Home' Project: Out of county Placements for Adults with a Learning Disability.*

8 Urgent Items (if any)

9 Way Forward 6.35 pm

10 Date of next meeting

Budget Scrutiny - 22 February 2021 – 1.30pm

Davina Fiore

Director Governance & Legal Services

Date: Thursday, 28 January 2021

Contact: Andrea Redmond, 02920 872434, a.redmond@cardiff.gov.uk

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Terms of Reference

To scrutinise, measure and actively promote improvement in the Council's performance in the provision of services and compliance with Council policies, aims and objectives in the area of community and adult services, including:

- Public and Private Housing
- Disabled Facilities Grants
- Community Safety
- Neighbourhood Renewal and Communities Next
- Advice & Benefit
- Consumer Protection
- Older Persons Strategy
- Adult Social Care
- Community Care Services
- Mental Health & Physical Disabilities
- Commissioning Strategy
- Health Partnership

To assess the impact of partnerships with and resources and services provided by external organisations including the Welsh Government, joint local government services, Welsh Government Sponsored Public Bodies and quasi-departmental non-governmental bodies and health services on the effectiveness of Council service delivery.

To report to an appropriate Cabinet or Council meeting on its findings and to make recommendations on measures which may enhance Council performance and service delivery in this area.

To be the Council's Crime and Disorder Committee as required by the Police and Justice Act 2006 and any re-enactment or modification thereof; and as full delegate of the Council to exercise all the powers and functions permitted under that Act.

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COMMUNITY & ADULT SERVICES SCRUTINY COMMITTEE

2 DECEMBER 2020

Present: Councillor Jenkins(Chairperson)
Councillors Ahmed, Carter, Gibson, Philippa Hill-John, Lent,
Lister and McGarry

105 : APOLOGIES FOR ABSENCE

The Chairperson welcomed Councillor Norma Mackie as a new member of the Committee.

Apologies had been received from David Jaques and Sarah McGill advised that she would be late attending.

106 : DECLARATIONS OF INTEREST

None received.

107 : MINUTES

The minutes of the 4th November 2020 were agreed as a correct record.

108 : HOMELESSNESS - AN UPDATE ON THE RESPONSE TO THE COVID-19
CRISIS AND DELIVERING THE FUTURE SERVICE MODEL

The Chairperson advised that this item provided Members with an update on homelessness and rough sleeping following the initial outbreak of covid-19 and in the current winter months.

Members were reminded that due to confidential information contained in Appendix 1, 2 & 4 this item will be considered in two parts and any questionings relating to the detail contained in these Appendices must be asked during the closed session.

The Chairperson welcomed Cllr Lynda Thorne, Cabinet Member for Housing & Communities and Jane Thomas, Assistant Director Housing & Communities.

The Chairperson invited Councillor Thorne to make a statement in which she said that the presentation will show the great work put in by Officers to respond to the pandemic to make sure that rough sleepers and those in emergency hostel accommodation were able to self-isolate. Councillor Thorne paid tribute to the Council's Senior Officers for their speedy response to the pandemic and the work of the homeless teams and the partner organisation team who have worked so hard to bring almost everyone in off the street.

Councillor Thorne noted that rough sleeping numbers had gone down to eight but had gone up this week stating that many of those were from outside of Cardiff.

Councillor Thorne paid tribute to Senior Officers who were putting measures in place to ensure there was no going back and to take the Council's vision forward of a no

first night out policy and that there would be no reason for anyone to remain sleeping rough.

Members were provided with a presentation after which the Chairperson invited questions and comments.

In reference to the YHA hostel, Members asked what date this provision had been extended to and were advised it had been extended to June with a break clause in March. Members further asked what the reason for the extension was and if Officers were confident in finances. Officers explained that they were confident up until March but they had Welsh Government assurances if they need to extend again. The reason for the extension is the level of need.

Members discussed the ASB/Crime issues reported in the press, asking if they had been resolved and also asking if Officer accept that sometimes third parties are adversely affected by the Council's decisions to temporarily house homeless people. Officers explained that the issues reported in the press related more to the OYO in Riverside where impacts had been felt more by the community and the Council took the decision to close it due to those impacts on third parties. In relation to the YHA, Officers explained it was in a more secluded location, not central to a community so there had been less complaints. Officers understand that these are difficult clients and understand community concerns; where there are complaints from residents, Officers take them very seriously and take prompt actions. The Cabinet Member added in relation to Tyndall Street that people have made it their home; there had been engagement with local Councillors and the Police; staff know to escalate issues; the hostel's number and email address with local residents so they can make direct contact with any issues. The Cabinet Member also noted that the issues experienced at Newport Road were caused by visitors rather than residents.

Members asked when Officers will know about funding and were advised they should know by the end of December when the Welsh Government gets its settlement from the UK Government. As contingency there is a phasing out of the smaller houses which will release funding over the next 3 years.

Members referred to homeless people from outside of Cardiff and asked which areas they are coming from; whether Cardiff is becoming a destination place for the homeless and if so what the other Local Authorities are doing about it. Officers explained that there have always been Out of County homeless people in Cardiff; they are not usually housed unless they are under the waiver system but at the moment Welsh Government are asking that everyone is housed. Cardiff offers a range of services but also begging opportunities. There are reconnection services run by the Salvation Army. Some people are have no recourse to public funds, again these would not normally be housed but are currently due to the public health crisis. With regard to the areas that they come from, it was a broad picture which could range from Cornwall, Merthyr and Bridgend; respective local authorities are supposed to house them.

Members asked why smaller houses are less successful and Officers advised that clients have changed; there are more substance misuse and mental health issues combined, to house these clients in a small house of 5/6 vulnerable people with no 24 hour support is not appropriate provision.

Members asked questions around capacity and noted there seemed to be a focus on short/medium term rather than long term. Officers explained that there are various move on schemes such as Housing First and SAIL; people need to be supported on different levels depending on need. There was also work to be done with the Private Rented Sector and single person units. There was a need for more move on accommodation and more supported accommodation as there are currently lot of people with high support needs.

Members discussed Giving Differently noting that the initiative could have been more successful if better locations and public messaging had been used. Officers explained that Giving Differently had been set up by For Cardiff and agreed it had not worked very well. During the pandemic, Officers started the Real Change Campaign whereby people report where they see rough sleepers, rather being asked for money. Currently there are 2/4 reported weekly and the outreach team go to the rough sleepers straight away to encourage them into services and provide support. Members welcomed this but noted that some people do want to give money to help when they see rough sleepers and that an immediate way to give to a charity could work. Officers stated they did not rule out trying Giving Differently in the future but it was important that people report rough sleepers so that immediate help can be offered. The Cabinet Member shared Members' frustrations around Giving Differently, stating that where people did give the money helped with into work and into training. The slow roll out had not helped the scheme. She added that it was important that people understand that there is no need for anyone to sleep on the streets as there is enough accommodation and support and she encouraged all Members to share the relevant contact details on their social media.

Members asked if there was work being done with Cardiff University or other organisations to try and root out homelessness at the very early stages. Officers advised that there is a project with Llamau to work with schools looking at very early prevention which was of the utmost importance.

Members referred to the five year lease system and wondered if it was an opportunity to get other families into the scheme. Officers advised that landlords were keen for five year schemes.

Members wished to commend the wonderful work of the outreach teams.

Members were concerned about timings with regard to the closure of provision in Adams Court and sought assurance that individuals affected by the works at Adams Court would not be negatively impact and receive continuation in service. It was confirmed to Members that all individuals affected by the work had been successfully moved out of Adams Court, with some individuals housed in the flats next door, who also wished to move, being successfully supported to do so. Members were further advised that half of Adams Court is being used as a winter night shelter in order to ensure adequate winter provision, and that as work is complete on the building it will be returned to the council on a phased basis in order to help facilitate capacity.

Members were concerned about the church night shelters not being used as extra winter provision due to the pandemic and asked if this leaves any gaps in provision.

Officers shared the concern over winter provision but reassured members there was enough provision.

Members asked about security in Adamsdown and Hayes Place, Officers explained that it was not just CCTV, although there was CCTV in place that reports directly to the ARC; there were also 'night guards' which allow staff to focus on supporting clients 24 hours a day.

Members referred to the Private Rented Sector and provision being reduced due to regulation and asked if Officers were concerned. Officers stated they were very concerned about the reduction; there was a need for a 5 year scheme meaning less risks for landlords; Officers were keen to expand this.

Members considered that the lease scheme sounded similar to the Calon scheme by Cadwyn; asking where in the City the schemes would be. Officers explained the scheme would be more favourable to landlords than the Calon scheme and it was longer term accommodation. With regards to area, they would be looking at areas closer to the City Centre where there was currently a lack of stock and where people/families want to live.

Members referred to issues at Thornhill previously with temporarily housed clients and asked if accommodation was let and there were subsequent issues such as ASB, whether the tenants would be moved on. Officers stated that they always respond to ASB issues and are working toward a new model for family accommodation, such as moving from, for example the Gasworks to permanent accommodation. This means less impact on schooling. There would still be hostel provision but there will be less people in temporary accommodation. Whilst it was impossible to guarantee there would be no ASB, there was a team to work with them.

Members asked how people are supported during the day time; noting that having their own bedrooms does help, there would be a need for training and support and asked how committed are the Council with this. Officers explained that there would be TV's in all rooms, activities in hostels, although that was difficult during the pandemic. Charities and Faith groups would be involved and it was also important to channel the goodwill of, for example, local Boxing Clubs, Knitting Clubs etc. The Cabinet Members assured Members of the Council's commitment and wanted to reiterate the importance on involving local clubs, citing an example of people from a Llanrumney hostel starting a local Boxing Club which led to engagement and subsequently have been rehoused.

AGREED: that the Chairperson, on behalf of the Committee, writes to the Cabinet Member conveying the observations of the Committee when discussing the way forward.

109 : COMMITTEE BUSINESS

Members were updated on Committee correspondence sent and received.

Members discussed the work programme and were advised that the January meeting would focus on social isolation and its impact on every part of society. There would be a wide range of external representatives in attendance.

110 : URGENT ITEMS (IF ANY)

None received.

111 : DATE OF NEXT MEETING - 13 JANUARY 2021

The meeting terminated at 6.07 pm

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**CYNGOR CAERDYDD
CARDIFF COUNCIL**

COMMUNITY & ADULT SERVICES SCRUTINY COMMITTEE

3 FEB 2021

Addressing Social Isolation & Loneliness faced by Cardiff Residents following the outbreak of Covid-19

Reason for the Report

1. To provide Committee Members with an overview of how the Council is addressing social isolation & loneliness for Cardiff's adult population following the outbreak of covid-19.
2. Members and meeting participants will note, that in line with the Committee's terms of reference, the remit of this work will be around the adult population of Cardiff, those aged 18 plus.

Background

3. When considering the Committee's work programme for 2020/21, Members agreed to undertake a piece of work around how the Council is addressing social isolation and loneliness following the outbreak of covid-19. With a particular focus on;
 - The Council's role in addressing and mitigating social isolation and loneliness following the outbreak of covid-19.
 - How the covid-19 pandemic has heightened social isolation for all demographics of Cardiff citizens aged 18 plus.

- To understand and assess how the Council is working with partners, such as the Welsh Government, charities and religious communities to understand and address this issue.
 - To discuss local issues and challenges and consider measures in place to both mitigate and address loneliness and social isolation brought forward by the pandemic.
4. Representatives from the following organisations have been invited to attend the Committee meeting to share their knowledge, views and perspectives of the impact of covid-19 on social isolation and how the Council can work towards addressing the issue:
- **Welsh Government**
To provide insight into the national context and their perspective on how challenges are being addressed at a local level. To also provide an update on national policy and facilitate understanding on how the Council and Welsh Government work together to address this issue.
 - **British Red Cross**
To provide an overview of how the full spectrum of society have been impacted by social isolation and loneliness and the demands and findings of the organisation. To also share their perspective on how social isolation can be best addressed by local authorities and to provide an overview of their published reports, [‘Life after Lockdown’](#) and [‘Lonely and Left Behind’](#)
 - **Project Hope**
To provide an overview of their organisation along with insight into how their demographic, young adults aged 18 plus, have been impacted. To also share their perspective on how local authorities can best engage with this age group.
 - **Age Connects Cardiff & Vale**
To provide an overview of how the older demographic have been impacted and the demands on their organisation in relation to social isolation and loneliness. To also share their perspective on how social isolation for the older demographic can be best addressed by local authorities

- **Religious Sector Representation; Church in Wales & Roman Catholic**¹
To provide their respective insight into how the religious sector have been impacted and to share their perspective on how local authorities can best address this issue and engage with religious communities.

Structure of Papers

5. Attached at **Appendix A** is a briefing note formed by the service area providing insight into how social isolation and loneliness is being addressed by the council following the outbreak of covid-19. The note includes sections on;
 - ❖ Keeping in touch;
 - ❖ Help for Local Volunteer Groups;
 - ❖ Digital Social Inclusion;
 - ❖ Removing Barriers to Digital Deprivation by Upskilling & Providing Equipment;
 - ❖ Activities & Learning
6. **Appendix B** is written evidence submitted by some of the external participants in order to aid Members consideration in advance of the meeting. Submissions have been received from
 - Welsh Government
 - British Red Cross
 - Age Connects Cardiff & Vale and;
 - Roman Catholic & Church in Wales attendees.
7. Attached at **Appendix C** is a short briefing note prepared by the scrutiny research team setting out the national context and outlining how policies and measures introduced in response to the pandemic have impacted various individuals and service user groups who benefit from the services provided by Cardiff Council.

¹ Being mindful of time constraints, and to ensure the meeting is of a feasible length it was determined that religious representatives for this meeting be based on the 2020 ASK Cardiff survey results, with the largest amount of respondents, 39.2%, being of Christian denominations.

8. When considering the attached Appendices and the information provided at the meeting, Members are reminded of the Committee's Terms of Reference. Members will note some areas contained within the Appendices fall outside of the Committee's remit, for instance funeral restrictions and education matters for those of primary or secondary school age. However, for contextual reasons, and to aid Members consideration, they are included as key elements which contribute to the issue of social isolation and loneliness.

Scope of Scrutiny

9. During the meeting, Members will have the opportunity to:

- Consider the impact of social isolation and loneliness and assess how the council is both addressing and mitigating social isolation and loneliness for Cardiff residents since the outbreak of the pandemic
- Understand how services have adapted, and discuss any known local challenges or issues
- Any new initiatives established by the council
- Determine if the Council is being proactive and preventative in its approach.
- Assess how the council works with partners on the issues of social isolation – such as charities, health boards and governing bodies.

Issues

10. The impact of social isolation and loneliness on the well-being of Cardiff residents' have been exacerbated during the pandemic. The introduction of lockdown and shielding measures means that the issue of loneliness and social isolation has increased amongst all demographics.

11. Research undertaken by the British Red Cross in June 2020² highlighted that those particularly at risk included people who lived alone and were shielding, younger people, people from Black, Asian and minority ethnic (BAME)

² ' Life after lockdown: Tackling loneliness among those left behind' Accessed 18 Jan, 2021 - <https://www.redcross.org.uk/about-us/what-we-do/we-speak-up-for-change/life-after-lockdown-tackling-loneliness>

backgrounds, people with long-term physical and mental health conditions and people who were financially insecure.

12. Conventional approaches toward tackling loneliness and social isolation are challenged by the social distance measures in place across the country. Digital technology can be used to tackle loneliness and isolation, however digital exclusion for certain demographics continues to be an acknowledged challenge. However, as detailed in **Appendix A**, in response to the pandemic council services such as Cardiff Hubs and Libraries, Independent Living Services, the Advice service and Adult Learning's digital support team have significantly increased the digital offer in a bid to combat social isolation.
13. The council's digital support team is working alongside both internal and external partners in order to stimulate digital inclusion across Cardiff's residents'. Partners who the team engage with include Social Services/Independent Living Services, BT, Digital Communities Wales, local volunteer groups and Public Health Wales. Referrals have been set up into the team to ensure that those who need help towards accessing online platforms can access it easily.
14. In a bid to further stimulate digital inclusion and address social isolation, Cardiff Council's advice service are also offering free tablets with internet access to individuals on a low income who do not have a device and internet connection at home and whose wellbeing is impacted by social isolation or wish to access online training.
15. In response to the crisis the council has introduced a range of measures and initiatives to support individuals who may be subject to loneliness and its challenges. A briefing note is attached at **Appendix A**. A brief overview of *some* of the work undertaken by the Council following the outbreak of the pandemic is summarised below.

Cardiff Hubs

October 2020 saw the launch of the new Cardiff Hub website³ providing information on Council services such as Advice Services, Adult Learning Cardiff, Into Work Advice and Library Services along with an overview of upcoming free online events, including but not limited to;

- a. Bilingual bookstart
- b. Keep On Moving
- c. Goldies Cymru
- d. Story Time
- e. Wellbeing Wednesday

Adviceline

Following the initial shielding advice by the Chief Medical Officer for Wales proactive work was undertaken by the Council's Adviceline to ensure contact was made with each individual to offer advice both during and post shielding. From 23 March to 24 August 2020, 18,772 outgoing calls were made and 15,720 calls were received by the Council's Adviceline, with 1,449 home visits also being completed. Over 7,000 additional wellbeing phone calls have also been made by volunteers. In addition, during the initial period of shielding individuals were supported with emergency food parcels and weekly food boxes from the Welsh Government⁴.

Social Services Review Team

The Review team has provided support to carers through regular phone contact. This has provided emotional support to carers and those at risk of isolation, the team also provided signposting and identified other needs such as support for collection of prescriptions where people have not been able to access normal support services.

³ www.cardiffhubs.co.uk Accessed: 4 Jan 2021

⁴ On average, there were 2,000 residents at any one time in Cardiff receiving a food box from the Welsh Government

Volunteer Cardiff Website

The Volunteer Cardiff website provided the platform for the 'Together for Cardiff' volunteering initiative' enabling volunteers to help ensure much needed food and medical supplies reached the most vulnerable. The website has also become a source of information and support bringing mutual aid groups and other local organisations such as Cardiff Third Sector Council together in one place. From the 1st April to October 2020 there have been over 100,469 hits on the website. To complement and further support the rapid increase of volunteering across the city, partners developed a network of trusted community groups, or Anchor Organisations, to enable key messages and resources such as e-learning to be disseminated to newly established volunteer groups. The network also provides an avenue for the food response coordinated by Food Cardiff.

Welsh Government Self Isolation Support Payment scheme

From November 16 2020, the Council's Benefits Assessment Team have administered the Self Isolation Support Payment scheme in Cardiff with Advice and Hub staff offering additional support to clients eligible to make a claim.

The Welsh Government-funded payments of £500 are available to people who meet all of the below criteria:

- on low incomes
- unable to work from home
- told to self-isolate by the NHS Wales Test, Trace, Protect service (TTP)
- will lose income as a result of having to self-isolate

Way Forward

16. At this meeting, the following witnesses will be in attendance:

- (i) Councillor Susan Elsmore (Cabinet Member for Social Care, Health & Well-being)
- (ii) Councillor Lynda Thorne (Cabinet Member for Housing & Communities);
- (iii) Sarah McGill (Corporate Director, People & Communities);
- (iv) Jane Thomas, (Director of Adults Social Services, Communities and Housing);
- (v) Louise Barry (Assistant Director, Adult Services)

(vi) Members will also receive evidence from the following:

- The Welsh Government
- British Red Cross
- Project Hope
- Age Connects Cardiff & Vale
- Church in Wales & Roman Catholic Representative

17. At the start of this meeting, Cabinet Members and officers will provide Members with an overview detailing how the council has responded to the issue of social isolation and loneliness since the pandemic.

18. Following the service area's overview, Members will hear evidence from the externals and enter into allocated Q&A sessions with each witness. Following discussions; the Cabinet Members and council officers will then be invited to comment and reflect on discussions at the end of the meeting.

19. Following the discussions, Members will be able to decide if they wish to feed any comments, observations or recommendations to the council's Cabinet for their consideration.

Legal Implications

20. The Scrutiny Committee is empowered to enquire, consider, review and recommend but not to make policy decisions. As the recommendations in this report are to consider and review matters there are no direct legal implications. However, legal implications may arise if and when the matters under review are implemented with or without any modifications. Any report with recommendations for decision that goes to the Cabinet/Council will set out any legal implications arising from those recommendations. All decision taken by or on behalf of the Council must (a) be within the legal powers of the Council; (b) comply with any procedural requirements imposed by law; (c) be within the powers of the body or person exercising powers on behalf of the Council; (d) be undertaken in accordance with the procedural requirements imposed by the Council e.g. Scrutiny Procedure Rules; (e) be taken having regard to the Council's fiduciary duty to its taxpayers; and (he) be reasonable and proper in all the circumstances.

Financial Implications

21. The Scrutiny Committee is empowered to enquire, consider, review and recommend but not to make policy decisions. As the recommendations in this report are to consider and review matters there are no direct financial implications at this stage in relation to any of the work programme. However, financial implications may arise if and when the matters under review are implemented with or without any modifications. Any report with recommendations for decision that goes to Cabinet/Council will set out any financial implications arising from those recommendations.

RECOMMENDATIONS

The Committee is recommended to:

- i. Consider the information set out in this report and its subsequent appendices;
- ii. Consider the information provided by witnesses to this meeting;
- iii. Decide whether it wishes to relay any comments or observations to the Cabinet; and
- iv. Decide the way forward with regard to any further scrutiny of this issue.

Davina Fiore

Director of Governance & Legal Services

28 January 2021

Helping to Reduce Social Isolation

Our teams across the council are carrying out vast amount to reduce social isolation in the city, working with internal and external partners to support anyone who needs it, but in particular the elderly and most vulnerable.

Keeping in Touch

Befriending Service

With funding from Age Cymru, the Into Work Volunteering team are providing a local befriending service to those aged over 50. Volunteers are trained to provide information on local services to help and signpost people to that support as well as being on hand for a chat.

Welfare Calls

Throughout the pandemic the Independent Living Community Engagement Officers have been providing daily welfare calls to vulnerable citizens. Most welfare calls are to existing service users who live alone or have little contact with anyone, however the need for welfare calls are identified by the Independent Living Service contact officers and through the Adviceline. On average, the team contact 15 citizens every day. Contact is regular, with the service user choosing how often they wish to be contacted. The call consists of a general chat but also ensuring medication is being taken, and that citizens are eating well and feeling safe.

The Community Living team are ensuring that the most vulnerable council tenants are supported at this time, carrying out extra welfare calls to residents and can arrange a wide range of services and support for the residents as needed.

The Telecare team also carry out proactive welfare calls and to date have carried out an additional 807 calls to vulnerable individuals.

Whilst delivering a meal, the friendly Meals on Wheels drivers provide a caring welfare check for all clients and refer to other services when needed. Customer numbers have increased for Meals on Wheels, with 475 customers and 2,500 meals a week being delivered.

Home Delivery of Click and Collect Books

For those that cannot access our Hubs and Libraries, the home delivery click and collect service has been set up so that books can be delivered to customers' front doors. People can call the Library line, pick the books they want to read

and they will be delivered. Nearly 1,000 deliveries have been made since April 2020.

Help For Local Volunteer Groups

There are numerous grassroots local organisations that have emerged and established themselves as a response to Covid-19. The Council hosts the Volunteer Cardiff website where, as well as the volunteering opportunities themselves, clients can search and access support in their local area.

In just 6 months (from the 1st April to October 2020) there have been over **100,469** hits on the website. For those without internet access, clients can call the Advice line and will be put in touch with local groups that can help.

The 'Anchor Organisations' who support smaller volunteer groups meet fortnightly with a manager from the Council's Advice Service. Information is disseminated, safeguarding is supported and training is also sourced and provided for volunteers. Any training required by volunteer groups can be organised through this forum.

Community Inclusion Officers in the hubs work with local organisations to help them establish groups or services, a grants officer is also available to assist groups to access funding from a range of sources.

Digital Social Inclusion

Online sessions

Across the Council, teams have rapidly stepped up their digital offer to ensure that the elderly and most vulnerable are been supported by using digital solutions as a way to reduce social isolation. These have included virtual catch-ups, clubs and meetings on platforms such as Zoom and Teams.

Independent Living Services have set up a number of virtual groups to help keep individuals and communities in contact and have worked with over 25 local groups to help them set up their own digital groups to keep members connected. These have included;

- *Monday Meet Up*
A weekly catch up with a cuppa & low impact exercise
- *Cardiff City Football Club (CCFC) Foundation Partnership*
Connecting Generations with CCFC Foundation Bringing 16-24 year-olds together with over 50's with fun, games and a quiz.

Appendix A: Service Area Briefing Note

- *Cardiff Sporting Memories Club*
Held weekly, giving the chance to share sporting memories

During December, Independent Living Services will be providing some Yuletide cheer by running three online Christmas events as part of its 50+ 'Healthy Body, Healthy Mind' festival. Each event will be packed with singing, quizzes, seated exercise and lots of information about council and partner services to help older people stay healthy and well in body and mind.

Online Events through Cardiff Hubs are currently providing a wide range of online events aimed at maintaining customer connection with the community, particularly those customers that may be isolated or vulnerable. The new Hub website is an easy place to browse many online sessions provided by not only Hub staff but by other services too. The website is easy to navigate and there are lots of free online events for customers to join in with. Events include:

- Keep on Moving,
- Goldies,
- Wellbeing Wednesday,
- The Social Hour
- Coffee and Book Talk.

Cardiff and Vale Wellbeing group – An online weekly lunchtime course is run by Adult Learning and the Pen and Paper Company. The sessions are structured around the five pillars of wellbeing and aims to explore personal wellbeing and mental health management through engaging activities (Creative Writing, Macro Photography, Arts and Crafts, cookery etc.).

Tea and Tech group – Run by Adult learning, this is an online weekly digital wellbeing group.

Removing Barriers to Digital Deprivation by Upskilling

There is a wide range of support available for those who are digitally excluded. The new Digital Cardiff team (part of Adult Learning) have been working incredibly hard since lockdown to offer training and learning sessions from basic digital support to more specific health and wellbeing related technologies, sessions include:

- **Daily digital surgeries** - free digital support and guidance that fits the needs of the individual. Clients can call the Advice line if they can't request help electronically and will be called back and given the help and support they need.
- **Digital health technologies online** – Weekly webinar sessions exploring how to manage personal health and wellbeing using a range of

technologies and software. Previous sessions include 'managing diabetes digitally' and 'mental health digital applications'.

- **Digital Support Live** – Weekly webinar sessions exploring general technologies and promoting online services. Previous sessions have included 'Using the NHS Track and Trace application' and 'using Google Classrooms'.
- **Basic Digital Skills (BT Skills for Tomorrow programme)** – Accredited one day workshops tailored to the client's needs. This basic digital skills workshop lets clients select their modules and tutors are on hand for any support they need. BT and EE volunteers from the Cardiff area support the ongoing delivery of the project.
- **Fit Bit Course** – Online digital health course that promotes the use of digital health technologies to take control of personal health. Working in partnership with Public Health Wales and Digital Communities Wales. The online classroom offers a space for individuals to share tips and experiences, access health resources such as tutorials and YouTube videos and learn how to use digital health technologies such as FitBits and MyFitnessPal applications.
- **Adult Learning digital courses**- Adult Learning moved from face to face delivery to online in May 2020, courses are currently offered digitally through Google Classrooms. Traditionally, the classroom setting has always been a space for individuals to socialise and learn new skills, which is why the team have used full course online engagement through Google Meet (video calling software). This allowed pre-existing groups and a host of new students the ability to communicate easily; learners have found this invaluable. Online courses include Gain Confidence Online, Digital Skills, Getting to know your Smartphone and Tablet and Computing for Beginners.

Removing the Barrier of Digital Deprivation - providing kit and internet access

As well as the digital learning sessions that have been run to improve digital skills, there are also various tablet gifting schemes, so those on low incomes and without access to the internet can apply for a tablet.

- **Devices Dot Now Tablet Gifting Scheme** – Free data enabled devices are gifted to the most vulnerable in the community using partner organisations to identify clients they work with who would benefit from a device including; Cardiff People First, Oasis, Women's Connect, Ty Canna Mental Health Services, Four Winds Mental Health Services, Independent Living Services, DICE disability program.

- **Cardiff Council Tablet Gifting Scheme** – The Cardiff Digital Team are offering free data enabled devices for the most vulnerable in the community. The tablet gifting scheme provides an encompassed digital support package to those who are socially and digitally isolated. Digital Inclusion Officers assist each individual in setting up their device and ensuring that they are able to access services. Officers check in regularly with clients. Eligibility criteria applies (no access to a device, no access to the internet and on a low income) 38% of individuals who have applied to the scheme so far have indicated that they are socially isolated.
- **Community Living Table Scheme** – tenants of our sheltered schemes will be able to access tablets to help them attend virtual activities, the team will be able to allocate tablets to those who cannot afford to buy their own.

In addition to this, there are many partner organisations who run their own schemes. Our Digital Cardiff team hold information about all of these schemes and who is eligible so clients can be referred into the scheme that best suits their needs.

What more is planned?

Face to Face Social Activities

As it is now permitted for 15 people to meet inside and 30 people to meet outside, for an organised activity, work is underway to commence offering conventional activities on a phased basis from the 7th December¹.

Organised outside activities will initially include:

- litter picks,
- walking for health,
- nature walks,
- tree planting,
- and gardening groups.

Organised indoor activities will initially include:

- knitting and crochet,
- book clubs,
- social mornings,
- friends and neighbour groups
- arts and crafts.

¹ Members are reminded that this was intended prior to Welsh Governments introduction of higher level restrictions during Dec 2020.

Appendix A: Service Area Briefing Note

In the New Year it is proposed to further develop the indoor programmes, these include jewellery making and working with acrylics, pottery, life drawing and indoor bowls.

There will also be a reintroduction of support group networks with regular Hub partners focused on health, wellbeing and overcoming isolation. These will include; Macmillan Cancer, the Dementia and Parkinson's café and Public Health awareness sessions. This proposal also lays out the plan to reintroduce the mobile library so resource can be accessed more easily within the community.

The Community Inclusion Officers in the Hubs can help organisations as they restart their services in the Hubs.

Classroom based Training and Learning

It is planned that from the 7th December, some face to face training and learning will be reintroduced. This will start with digital learning sessions in 4 Hubs with small groups of learners, to allow for social distancing. In the New Year it is proposed to increase the type of course and the number of Hubs that sessions are run from, to cover more local communities. Learning together is a great way of reducing social isolation.

Reintroduction of face to face digital sessions (by appointment) - It is proposed that the digital services provision is expanded and will be delivered in additional Hubs and libraries in the North of the city. One to one ICT support will be provided to individuals who are digitally excluded. This service will primarily target individuals that are socially isolated and looking to 'connect online' with friends and families.

Adult Services – Supporting the Most Vulnerable

Acknowledging the importance of maintaining social contacts with service users and carers across Adult Services, arrangements have been put in place to provide and maintain a weekly welfare telephone call checks to those individuals assessed as the most urgent, using the Red Amber Green RAG coded system.

In addition, for example, within older peoples' day services, at the lockdown in March all service users and their carers were offered at least weekly telephone contact by a member of staff from each of the three day centres – the majority took up the offer and these have continued. They have provided valuable continuity of links with day services and the staff, have

given carers ideas of activities to try at home and have been a consistent point of contact in these difficult times.

Adult Services has worked in close partnership with its commissioned service providers to support the delivery of alternative forms of service to support individual service users and their carers. This has provided funding continuity for organisations. Examples of these include:

- The Alzheimer's Society making weekly phone calls to their service users and delivering online the usual weekly Singing for the Brain sessions, and other social groups.
- Sight Life (previously called Cardiff Institute for the Blind) have regular telephone contact with members of the groups they usually hold, and have organised some online groups, supported to provide a specialist service for people with a visual impairment. This is in addition to the usual information and advice and assessment service they provide for the Council.
- Moorland Road Community Centre changing their luncheon club into a community meal delivery service. The staff and volunteers arranged for some mobile phones to be provided to some of the users so they could keep in contact with one another.

Information about e.g. carer organisations have been discussed with individuals and information provided.

Gradually and safely some sitting services are being resumed to support eg carers in most need. All situations are being carefully risk assessed, reviewed and monitored.

The Ty Canna team have changed their mental health services during the pandemic by facilitating 22 groups virtually including peer group counselling, cookery groups, language classes, drama and pampering sessions. Exercise groups have also been facilitated by a member of the team and strong links have been developed between Ty Canna and Sports Cardiff, with ideas afoot for future work together to support people in the future.

A network of businesses have supported the mental health outreach service by providing Tablet computers to support more people getting online. IT support has been provided by other service users, especially the youngsters who have been supporting some people who have never used the internet before. Funding was secured to set up counselling services to support people suffering with anxiety due to Covid. This included 3 sessions for individuals, and peer group support.

Ty Canna has also produced a newsletter that is reaching 230+ services user monthly. There has been some great feedback from service users regarding

Appendix A: Service Area Briefing Note

this including: *'Nice to see what was going on throughout Ty Canna. Thank you for all that you do for your service users - the service and its staff are priceless and the only reason I am still here '.*

Summary

Overall there is a very wide range of digital activity aimed at preventing social isolation, and there is also help for people to get on line. More face to face activity will be phased in during the winter both outside and in venues such as the Hubs. Help is available for volunteer organisations and any training needed can be provided to them. Community Inclusion Officers in the Hubs can help organisations who want to restart their groups to do so safely. External grant funding opportunities already exist and the Council's Grant Officer can help find the right grant for each organisation.

Loneliness and Social Isolation – Paper from the Welsh Government for Cardiff Council’s Community and Adult Services Scrutiny Committee, 3 February 2021

Background

There is a growing awareness of the problem of loneliness and unwanted social isolation across Wales and the UK as a whole.

Loneliness and isolation have tended to be associated solely with ageing. However we recognise now that anyone, at any age, can experience these feelings. From the young person moving away from home to start university, to someone with a long term health condition, or an older person caring for a loved one. In fact we have all probably experienced loneliness and/or social isolation at some point in our lives. It is when these feelings become long-term and entrenched that they become problematic.

Loneliness was measured for the first time in Wales in the National Survey in 2016-17. This found 17% of people reported being lonely. Mid-year population estimates for 2017 suggest there were approximately 2.6 million people aged 16 and above in Wales; 17% of this number would equate to somewhere in the region of 440,000 reporting being lonely in Wales.

The survey found there were certain characteristics which were related to a higher likelihood of loneliness; being younger (16-24 year olds); being of non-white ethnic group; not being married or in a civil partnership; experiencing material deprivation; using the internet; not having a sense of community; being dissatisfied with the local area as a place to live; not feeling safe after dark; not being a volunteer and having a limiting long-term illness.

The economic, health and social consequences of loneliness and isolation are significant, particularly in respect of their impacts on public services. The British Red Cross estimates each older person who requires services as a result of loneliness and isolation could cost £12,000 per person over the next 15 years. The Eden Project estimates the cost of isolation and disconnected communities to reach £2.6bn a year in Wales, including a £427m demand on health services, a £10m demand on policing and a £8m cost due to stress and low self-esteem.

Disconnected communities are linked to losses in productivity, costing the Welsh economy over £1bn each year. Conversely, greater integration within a community can benefit people’s health. The report estimates social cohesion saves £254m in health services and could be increased to £681m as a result of greater community participation.

Connected Communities – A strategy for tackling loneliness and social isolation and building stronger social connections

On 11 February, the Welsh Government published its first cross-government strategy to address loneliness and social isolation. ‘Connected Communities’ set out our vision for a connected Wales; one where everyone has the opportunity to develop meaningful social relationships and where people are supported at those trigger points in life when they are most vulnerable.

The strategy sets out four priorities: increasing opportunities to connect; a community infrastructure that supports connected communities; cohesive and supportive communities; and building awareness and promoting positive attitudes. Each of these priorities is supported by a number of commitments to help in their delivery.

The strategy makes clear that addressing loneliness and social isolation is not the role of Welsh Government alone. The strategy seeks to enable all parts of society to play a role and focuses on the role Government can play but also how it can support local authorities, public services, the third sector and also the private sector, as well as communities and individuals to play their part and support people's social connections.

It highlights how, through Regional Partnership Boards and Public Service Boards Welsh Government wants to work with local authorities, health boards and the third sector to facilitate sharing of what works and to enable organisations to learn from each other.

Impact of Covid-19

Good progress continues to be made in implementing the strategy across all areas. The Welsh Government has also taken the opportunity to review the strategy's 80-plus commitments to ensure they accurately reflect the changes which have taken place in society and to consider the impact of Covid-19 on loneliness and social isolation and what further action might be required as a result.

Whilst the most recent monthly National Survey data shows that feelings of loneliness and isolation appear to have been relatively constant over the course of the pandemic, we know that those who were lonely prior to the pandemic, have felt lonelier since social distancing and lockdown measures were introduced.

A number of actions have been taken since the start of the pandemic to try and support people to stay connected with family and friends and to access the support that they might need, including additional funding for the third sector and local government, and for mental health and emotional support services. We also made changes to our regulations to allow people to form an "extended household" if they live alone or single parent families.

An advisory group of key stakeholders from the statutory and third sectors and grass-roots organisations has also been established to help us better understand the impact of the pandemic on loneliness and isolation. Key issues raised by the group include: digital exclusion; overcoming barriers to re-engaging; types of ongoing support required; sustaining community based support and ensuring information is accessible to all.

The links that have been developed between statutory and third sector partners at the regional/local level and the widespread informal, community led support that has developed as a result of the pandemic were highlighted as particular strengths to build on by group members.

Briefing: Loneliness in Wales

Cardiff Council Community and Adult Services Scrutiny Committee Meeting, 3rd February 2021.

For further information, contact Georgia Marks, Policy and Public Affairs Officer, Wales at GeorgiaMarks@redcross.org.uk or on 07872839878.

About this briefing

This briefing covers research conducted by the British Red Cross in relation to loneliness. It draws on UK data from [Life After Lockdown](#), published in June 2020 and looks at Welsh specific data from the report [Lonely and Left Behind](#), published in November 2020. A case study on support provided by the Red Cross in Wales, before and during the national lockdown, is also detailed below. In responding to the Covid-19 pandemic, governments at every level have an opportunity to tackle the issue of loneliness. We welcome Cardiff Council's decision to investigate the issue and are grateful for the opportunity to present our findings.

Summary:

- > Before the pandemic, one in five people in the UK reported feeling often or always lonely.
- > Loneliness is often thought of as an older person's issue. However, loneliness affects people of all ages.
- > The pandemic is making loneliness worse.
- > Research we published in November 2020 shows rising loneliness across the UK, with enhanced restrictions coupled with the colder, darker winter period risking entrenching experiences of loneliness further.
- > Government at every level, as well as the voluntary and community sector, need to ensure that appropriate support is available for those at risk of loneliness, targeted at those most vulnerable.

Key Findings:

Life After Lockdown

- > The report highlights the **importance of meaningful conversations** when tackling loneliness. Polling commissioned by the Red Cross found that in the UK, 39 per cent of people who engaged in a meaningful conversation in the last week felt lonely, compared with 83 per cent of those whose last meaningful conversation was a month ago.
- > The report also highlights a **greater need for mental health and wellbeing support**. We have found pre-existing mental health issues have been exacerbated during the pandemic. Another issue raised was the discontinuation of many healthcare and wellbeing services and the impact of this on loneliness.
- > Research identified that certain communities in the UK are at **greater risk of loneliness**:
 - o **More than one in three** adults from BAME backgrounds feel no one would notice if something happened to them, **41 per cent** of BAME adults fear their loneliness will

get worse, and **over half** reported thinking their neighbours were like strangers (compared to 37 per cent of the UK population as a whole).

- **49 per cent** of adults with children below the age of five reported feeling as though they have no one to turn to.
- **58 per cent of 18-24-year olds** hadn't had a meaningful conversation with someone within the last week, and **57 per cent** thought their loneliness would get worse.

Other groups identified as being at a greater risk of loneliness included:

- People who live alone and those who are self-isolating or shielding.
 - People who have a long-standing physical or mental impairment, health condition, illness, or disability.
 - People who are digitally excluded.
- > **Digital exclusion is an issue for certain groups.** Many people have found technology to be a great tool in staying connected. However, certain groups, such as people who use our refugee services, have been unable to access Wi-Fi due to voluntary and community services being closed. Other groups, such as those who are dyslexic or have limited mobility, also face barriers in using digital platforms.

Lonely and Left Behind (General themes and Welsh Data based on 115 people 18+)

- > **The pandemic is making loneliness worse.** Isolation, financial insecurity and increased stress are making more people feel lonely. People living alone, living with a disability and younger people are particularly at risk.
- > **Loneliness is a problem for many.** In Wales, 27 per cent say they often feel alone, like they have no one to turn to.
- > **Too many people lack strong support networks.** In Wales, 29 per cent of people said they hadn't had a meaningful conversation in over a fortnight. In addition, a quarter of people (26 per cent) worry something will happen to them and no one will notice.
- > **People who are lonely are less able to cope.** There has been a sharp rise in the number of people who say they are too lonely to cope with the Covid-19 crisis since May. In Wales, over a third (37 per cent) said loneliness was having a negative impact on their mental health.
- > **Some people have never stopped shielding or isolating.** Despite restrictions easing over the summer of 2020, some people have not felt comfortable leaving their homes. Watching others resume their social lives has made these people feel 'left behind'.
- > **New lockdown restrictions and winter risk entrenching feelings of loneliness.** People told us that they feared more lockdowns would bring them back to 'square one' and were worried about their ability to cope. In Wales, 31 per cent of adults are concerned that their loneliness will get worse.

Our recommendations:

Local authorities should ensure that those most at risk of loneliness are able to access the mental health and emotional support they need to cope and recover from Covid-19.

- > Local authorities to ensure that they have the capacity, resources and skills to meet the increased demand for mental health services.

- > Local authorities should continue to invest in social prescribing schemes. Social prescribers should be rolled out and trained in psychological support to support people in local areas.
- > Local authorities should work closely with the Health and Social Care sector and Voluntary and Community organisations in their area to identify those most at risk.

Immediate planning is needed on loneliness.

- > Local authorities should include tools to combat loneliness in the support offered for those advised to shield or self-isolate.
- > Local authorities should consider integrating psychosocial support with other public service offers likely to encounter those most in need (such as those receiving Welsh Welfare support).

In the medium to longer term, tackling loneliness should be built into local COVID-19 recovery plans.

- > Local places, with support from Welsh Government, should create and deliver multi-disciplinary recovery plans. This should include a plan to:
 - Tackle loneliness among those most at risk in their areas.
 - Tackle the underlying causes of loneliness unpicked in our research.
 - Invest in reintegration and confidence building support.
 - Ensure shared spaces and transport foster connections while remaining COVID-19 safe

Our wider calls:

- > **Government should ensure those most at risk of loneliness are able to access the mental health and emotional support they need to cope and recover from COVID-19.**
 - Local systems should have the capacity, resources and skills to meet increased demand.
 - Social prescribers should be rolled out and trained in psychosocial support.
 - Psychosocial support should be attached to other public service offers likely to encounter those most in need (such as mainstream benefits and bereavement services).
- > **Government should launch a plan to tackle loneliness during the winter; engaging people with lived experience in developing this.**
 - Support for organisations tackling loneliness to adapt their services to be effective and in line with social distancing measures.
 - A financial package of support for tackling loneliness, building on the best practice identified during the initial lockdown period.
 - Support for local authorities and health systems to identify and address those most at risk of loneliness through a dedicated fund and guidance.
 - Strategic investment in tackling digital isolation so that people can stay connected under lockdown, data poverty, language barriers etc.
- > **Civil society organisations should continue to tackle loneliness, share learning and prioritise those most at risk**
 - Working directly with those most vulnerable
 - Sharing insights openly with each other

- Raising awareness of services – especially with the most vulnerable
- > **In the medium to longer term, tackling loneliness should be built into local and national COVID-19 recovery plans**
- Governments across the UK should support local places to create and deliver multi-disciplinary recovery plans to tackle loneliness. This should include a plan to:
 - Tackle loneliness among those most at risk in their areas.
 - Tackle the underlying causes of loneliness unpicked in our research, including financial hardship.
 - Invest in reintegration and confidence building support.
 - Ensure shared spaces and transport foster connections while remaining COVID-19 safe

Appendix: case study – Gareth, 58, Wales

A former sales manager with a busy life, Gareth, suffered a stroke which changed everything in December 2018. He spent seven months in hospital and has been living on his own in Llantrisant, Wales ever since he was discharged. Gareth, 58, talks about his experience of living alone and being supported by the British Red Cross before and during the coronavirus pandemic.

British Red Cross support

After being discharged, Gareth had to move to a new place in an unfamiliar area. He lives alone and was referred to the British Red Cross for support in October 2019. That's when he met Nina, Independent Living service coordinator at the Red Cross.

They discussed Gareth's top goals towards becoming independent. Initially, Gareth's goal was to be able to go out of the house in his wheelchair. But the dream that kept him going was walking barefoot on a beach. Nina said: "Gareth's first goal was to be able to go out, because at that point he had just come out of hospital. He had been in hospital for seven months and after he was discharged, he moved to a new house too. He was new to the area and was just getting acquainted with going out. He couldn't walk so he needed a wheelchair and his flat needed some adjustments to make it accessible. We were able to support with that by signposting Gareth to the local fire and social services.

"At the same time, we started going out in the wheelchair, initially to the nearest coffee shops, so that he could become more familiar with the area."

By February 2020, Gareth was able to go out by himself. Then lockdown came in March.

Life during lockdown

For Gareth the lockdown rules left him isolated at home.

He said: "Lockdown was horrific. I was very depressed. I'm a strong-willed person but there was just no contact with anybody. All the assistance stopped.

I know they had to do it, but it was very severe, very quick. It physically and mentally affected me, I'll be honest. It was not a nice feeling, I felt totally isolated."

In April, when the nation was in lockdown Gareth started receiving weekly calls from Nina.

He said: "It wasn't until Nina called me to check if I still wanted support that I knew I could get help during lockdown. At least I could ring her, or she would ring me. We spoke every week."

Gareth had a manual wheelchair but he got an electric one in May 2020. He spoke to Nina about his new goals and plans to learn how to use his new wheelchair.

Gareth said: "I had one goal when I was in hospital, it was the only thing that kept me going for seven months lying in the hospital bed. I wanted to walk on a beach with bare feet, to feel the sand beneath my toes again. That's what got me through hospital, that goal, because I was told I would never walk again."

One morning during the summer when Gareth was having a low day, Nina took him to Barry Island, half an hour away from where he lives. The beach has a special significance for Gareth because he used to go cycling there with his son before the stroke.

He said: "When we got to Barry Island, Nina pushed me in my wheelchair onto the sand. I removed my shoes and socks, stood on the sand and started to walk without a stick. Nina had to call me back because I kept going. I turned around, looked at her and literally burst into tears standing there because I'd reached my goal and I could not have done that without the help of the Red Cross."

...

Gareth has also set himself a fundraising challenge for next year. He is hoping to climb Pen-y-Fan, a strenuous mountain walk in the Brecon Beacons to raise money for the British Red Cross and two other charities close to his heart. On being supported by the Red Cross, Gareth said: "Nina has been absolutely godsent, because I have been very low. When I didn't see her during lockdown, she rang me every week.

"I hope to continue working together for my next goal."

"This is an amazing service offered by the Red Cross, the attention to detail was second to none, over and above the call of duty. This was a service with great support, the Red Cross helped me reach my main goal which was to walk bare foot on a sandy beach. I will always remember those moments, taking off my socks and shoes, leaving my wheelchair behind and walking without my stick. The emotion was sky high and I broke down in tears. Without the Red Cross this would not have happened, thank you all with all of my heart".

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Age Connects Cardiff and Vale – Written Submission for Meeting 3rd February

1 Background

In the first six weeks of the pandemic the Charity responded to 3,500 calls for direct support, for information and signposting. The main practical support requested was shopping, collection essential items such as medication and prescriptions. See Case study, Appendix 2.

The vast majority of clients were isolated elderly women, worried about how they were going to cope with the impact of the pandemic may have upon them. Many, initially, did not want to receive the shielding food parcels, preferring to remain as independent as they could, with some practical help.

The Charity went from delivering 30 essential shops as part of our normal business to 315 shops a week. In the initial three weeks our Volunteer Programme was overwhelmed with calls for assistance. This resulted in some of our part time staff working additional hours and we redeployed staff in our social nail cutting service and other LA/LHB funded contracts to help meet the increased demand whilst we maximised our social media appeal for volunteers.

Our appeal for assistance resulted in the recruitment 200 extra volunteers bringing our total volunteer workforce to over 500.

In our follow up work we contacted 950 clients to see how they were and if there was anything we could support them with including a regular telephone contact. As a result, 400 clients requested a regularly call each week. We believe this demonstrates the ongoing need to provide reassurance and respite from feelings of isolation and loneliness. It should be noted that these weekly calls were in addition to follow up responses made by staff in our public sector funded services.

2 Experiences

It is very clear to us that we could not have dealt with the initial volume of demand without key elements coming together at the right time, that included:

- The released staff from other duties to support the Volunteer Programme. LA and LHB agreements for this, meant we did not furlough these staff.
- The commitment of staff and volunteers to go far beyond their remit and duties to address the demand
- Significant new volunteer recruitment
- Being able to work remotely, with new investment and staff commitment
- Our Board of Directors prepared to underwrite escalating costs from our reserves
- The external funding from our charitable foundations, businesses and supporters
- Welsh Government grant programmes, communicated and supported through Councils for Voluntary Service (CVC)
- Some good examples of improved lines of communication with the public and third sector organisations

3 Conclusion - Perspective on how social isolation for the older population can be best addressed by local authorities and how local authorities could engage with partners.

Our engagement with older people between November 2019 and April 2020 included a focus on those who are ageing without children. We have continued this engagement work throughout this pandemic and have received some research funding from the Wales Lottery Board to expand this work given the impact of the pandemic.

It is estimated (UK wide) that 1 in 5 people over the age of 50 do not have children and it is further estimated that by 2030, there will be 2 million people in the UK over 65 years of age without children. Wales specific data is not available.

People ageing without children will include:

- People who have never had children
- People whose children have predeceased them
- People who are estranged from their children

We held an initial event with 55 staff and volunteers to gather their thoughts and views of priorities for the Charity.

This work has identified the need to focus on older people ageing with little or no family support. We explored this further by conducting 14 focus groups involving 104 older people and 12 focus groups involving 59 professionals and people working with older people. This was followed up by a survey of 85 clients. The challenges they identified fell into three main categories. Health and Social Care; Accommodation and Finance. See at appendix 1,

We are following up on these issues and believe that partners should focus their efforts on effective relationships that maximise the opportunities to address the wider factors highlighted in the table that contribute to isolation and loneliness.

4 Recommendations

- Telephone triage arrangements through call centres to improve responses and reduce costs in the third sector
- Better links to 'silver' and 'gold team' planning arrangements
- Communications plan across key partners to explain what actions/initiatives are underway e.g. shielding coordination – different approaches in the Vale of Glamorgan
- Strategic commitment to volunteering programmes to support fast track but safe recruitment processes

Appendix 1

<u>FINANCE</u>	<u>ACCOMMODATION</u>	<u>HEALTH AND CARE</u>
Lack of mental capacity	Remaining at home	Ill health
Lack of choice	Home maintenance	Planned and unplanned admission into hospital
Reliance on online services	Access to transport	Visitors in hospital, laundry
Banks closing – noon to speak to in person	Need for trusted tradespeople	Discharge to home or care home
Lack of support to navigate the system	Moving to suitable accommodation	Opportunity to make lifestyle choices
Banking facilities not accessible	Making home safe and comfortable	Loneliness, isolation and keeping connected
There is support but not knowing the right agencies to support and what capacity they have	Lack of support to navigate the system	Remaining active
Who will help pay bills?	Moving to a care home or one to settle you in. No closure with family home	Developing networks and support groups
Who will take me to the bank?	Downsizing Disabled Facilities Cleaning	Lack of support to navigate the system
Falling for scams	Proximity to shops and community facilities	Personal Assistants and Getting Reliable Care
Power of Attorney	Dealing with rubbish and waste	Carers need to be consistent in the approach. Some are good some not. Where there is a SW involve them. Some agencies provide poor quality services.
Learning computer skills	Climbing stairs and steps – access to home	No support for self-funders.
Advocating “talking” but not easy	Gardening	
If worried having someone to speak to	Shopping	

Appendix 2 Case Study. Ronnie and Jules

Sara, the niece of 80 year old Cardiff client, Ronnie has taken the time to email her thanks to Age Connects volunteer Jules.

Ronnie fell just before the coronavirus outbreak resulted in him being very immobile – effectively housebound, unable to use the stairs in his maisonette. With Sara living in the Midlands, Jules was allocated to support Ronnie to be able to continue living independently.

Sara wrote: ‘Thank you – to Age Connects and, more specifically, to Jules for being an absolute lifeline to Ronnie over the past few weeks. I honestly dread to think what the outcome would have been if you had not come to the rescue.

‘Jules has been a constant in his life the past few weeks. Her phone calls and shopping deliveries have been extremely supportive and her approach has been so kind and thoughtful. Jules has gone the extra mile and assisted with things such as taking out his rubbish as well as ensuring that he has all the basics to keep him going. She has been invaluable to both Ronnie and myself, an extra pair of eyes and ears.’ Sara added that: ‘this service has been superb and was up and running smoothly from the outset ... Ronnie and I are both extremely grateful, you have been a true godsend. Thank you – you are very much appreciated.’

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Catholic Archdiocese of Cardiff.

How the Coronavirus has affected the Catholic Archdiocese of Cardiff and my particular Parish.

In order to prepare this report, I have incorporated the experiences and input of His Grace Archbishop George Stack, for an Archdiocesan perspective, my parish representatives of St. Peter's Catholic Church, which chiefly, though not exclusively, serves the local Roath / Splott / Adamsdown / Tremorfa community areas, and one of the key support groups in St. Peter's Parish, the St Vincent De Paul Society (SVP). Although the charity has experienced a dramatic fall in income, parish priests and volunteers continue to respond to the pandemic in remarkable ways. In addition, the significance of the core activity of the Church, from care home sick calls to comforting grieving families, should not be underestimated. These and other initiatives have been supported from grants by Welsh Government, public institutions, private charities and companies as well as church donations. The invaluable contribution of volunteers in cooperation with social services must be recognised.

The Archdiocese of Cardiff's flagship response to COVID-19 (**Staying Together While Apart**) officially closed in December 2020 with the ending of 6-month's Welsh Government Funding of £168,890 (WCVA: Voluntary Service Community Fund). The elements of this have been simply acting as good neighbours – especially to those isolated and alone. The project had two objectives:

- *Maintaining mental health of older/ vulnerable adults:*
 - Parish volunteer teams contacted older/ vulnerable individuals by phone, email, messaging, social media, offering reassurance and comfort while providing moral support to sustain wellbeing.
 - The 'live streaming' of support messages online to connect self-isolating individuals with their traditional community reduced feelings of separation and loneliness and maintained a sense of belonging.
 - Regular audio and audio-visual broadcasts from trusted individuals, known to parishioners and their community, reduced feelings of anxiety and isolation.
- *Providing practical support for older/ vulnerable adults:*
 - Mindful of their physical wellbeing, parish volunteer teams provided food, care packages and prescription deliveries.

The key evaluation finding is the flexibility of parishes to respond, at speed, to changing patterns of need. Initially 'contact work' with those who were isolated took up the majority of priests and volunteer time. Increasingly, however, activity was directed towards providing direct food aid to all age groups as Autumn/Winter approached and personal finances became more challenging.

Centrally Funded Parish Projects

Responding to the growing need for direct support, three months funding was provided centrally across the Archdiocese of Cardiff to support local projects.

- 25 parish-led projects providing emergency food aid to alleviate the spread of poverty.
- 6 parish-led projects providing crisis support to aid people at risk of poverty.

Funding of £51,760 was raised from the Albert Gubay Charitable Foundation and £71,695 from the National Lottery Community Fund. This work is ongoing. Following initial parish reporting, it appears that 1,521 individuals and 1,086 families at risk of, or in poverty, as a result of Covid-19 have been supported by these 31 individual projects.

Archbishop's Supermarket Voucher Scheme

In December 2020 the Archdiocese made digital supermarket vouchers available to parishes and schools in the run up to Christmas and beyond. With many of the charity's foodbanks struggling to cope with local demand, the ability to send vouchers electronically proved advantageous. Vouchers can also be posted or given in persons to buy necessities for themselves and their families. By the 15th December, a total of £47,670 in digital vouchers for ASDA, TESCO and Morrison had been distributed. A more thorough evaluation of the first round will take place over the coming weeks

Appendix B - Written submission from Christian Denomination Representatives before the launch of a second round in late January / early February 2021. In total, the charity intends to distribute *circa* £150,000 in supermarket vouchers.

Summary

While the original goal was to support older people, demand grew to support wider families and children in collaboration with local schools. Alongside food poverty, digital poverty has become an increasingly recognised issue and the charity has responded by providing limited online digital skills training and support. It is clear that local need is not abating. Wales is entering what appears to be another sustained period of lockdown in the depths of winter. Financial support for food aid will persist and grow across all generations. Isolation continues to be a problem and the need for contact and outreach grows.

Understandably, during these times, many Council services have personnel working from home or covering unfamiliar roles. This can lead to, and has led to, confusion including the offering of contradictory advice or information. However, most staff are always courteous and helpful.

Major communication efforts have been made with Live Streaming of Services, Zoom Coffee mornings and individual consultations, telephone calls and email on an organised and structured basis. Many isolated individuals listen to the recorded messages of encouragement on more than one occasion during the day. They tell us they like to hear a comforting, human voice.

Delivery by volunteers of lunches, dinners, food parcels, Food Vouchers, Christmas Hampers, clothes, toys etc., has ensured that individuals and isolated families know they are not alone and may call on our charitable organisation known as the SVP. This is an International, Catholic charity that seeks to support all people of all faiths, or no faith, who may be in need of pastoral, financial and material support, the elderly, the vulnerable, asylum seekers, refugees, serving and ex-offenders, the homeless and those suffering from various addictions.

The SVP at St. Peter's, for example, formed partnerships with other faith groups in the delivering of food, most notably with the Hare Krishna community in Butetown. St. Peter's Parish, along with several other Church communities, were not able to run the annual Night Shelter project this year during the winter period. This project provides individuals with a bed, a safe, warm place to sleep, meals and washing facilities. Representatives of the Parish Night Shelter scheme have a very good working relationship with officers of the Council and there have been several meetings via phone or zoom relating to homelessness issues. The parish is hoping to move on and support the Council and other agencies (e.g. the YMCA) in providing diverse activities for those who, formerly homeless, now find themselves in temporary or even permanent accommodation. This has emerged as a particularly important priority since the Welsh government directed that all councils should provide accommodation for the homeless.

The on-going pandemic has certainly propagated financial and emotional poverty across the whole of the community. However, we have witnessed an unprecedented level of co-operation between all sections of society in an heroic fight-back, whether motivated by notions of civic responsibility, professional integrity, common humanity and /or a desire to live out the values sacred to all Faiths. The Parish SVP and Parishioners, in general, have been in constant communication with Council officials and this can be seen as a very positive sign moving forward.

Church in Wales

My experience of how the Coronavirus has affected my particular Parish within the Church in Wales.

The Parish of Glanely covers the Ely Electoral Division. It is a deprived area of Cardiff where families have been on low incomes with many relying on benefits.

The number one impact in our parish has been on mental health. Mental health has been hit very hard in Ely for a number of reasons:

In the many funerals conducted the restrictions of number of mourners was particularly hard for people to bear. In a parish where we typically have several hundred attending funerals, to only be allowed 10, and then 30 mourners was unbearably painful. In some large families not even all of the children of a deceased could attend and families were left to decide which family members could be present. The grieving process is always hard but under these restrictions in was particularly stressful.

Families were not even able to pay their final respects in funeral homes, and all arrangements had to be made over the phone so no meeting with either funeral director or clergy prior to a funeral. Then being ushered into the cemetery with security on the gates counting people in to make sure there were no more than 10, and locking the gates behind us, felt simply terrible.

When the deceased had died in hospital families had been unable to visit them there, which again had a massive impact on mental health of the families. And for patients too, some wondered if they would come out alive and ever see their families again. Ministers of religion were also not able to visit their parishioners but have kept in touch with the hospital chaplain who has been a vital contact with patients.

The suicide rate increased dramatically in Ely. 4 in the first week of lockdown alone! Total suicides now running at 17 since the start of lockdown! All of them were young men, many with pre-existing mental health issues, and others who lost their jobs and went into real despair about the future.

Many workers in Ely did not qualify for the furlough scheme, and those who are self-employed had to wait until June for their support payments to come through – what were they supposed to live on from end of March until June. Poverty became a real issue and still is.

Churches/places of worship being locked had a devastating effect on the mental health of many people.....the lack of understanding (by those in government making decisions) of the importance of Spiritual wellbeing, alongside mental and physical well-being, was clear to see.

The ban on singing has also had a devastating effect on the mental well-being of many people. There are many community choirs which have quite a number of members who joined them precisely because they suffer with depression etc, as well as choirs for those with dementia, and singing is proven scientifically to release endorphins which create a feeling of positive well-being. Also the ban on congregational singing once places of worship were allowed to open has had a huge impact on the way people feel in church. Many have asked the question why the ban on singing, especially in church, when we are all wearing masks anyway? Presumably masks stop transmission of droplets otherwise the government wouldn't be insisting we all wear them?!

Families in over-crowded homes being told to stay indoors has been a recipe for disaster for many with increased abuse behind the closed doors, borne partly out of the frustration of lockdown.

The stress of home-schooling for some families has been very hard to bear. Even more middle-class families, with parents having to work from home, have really struggled. Then there are the families whose parents simply don't care about their child's education, so made no effort whatsoever to engage with the online learning. As in other situations it is the poorest children that will suffer most in the long-term.

Family debt has increased as people have lost their jobs, particularly women who work on zero hours in the non-essential retail trade.

The real fear is that the mental health crisis which this pandemic is still writing will go on possibly for decades to come.....the unresolved grief of those who were not allowed to attend funerals of loved ones.....the loss of self-worth along with loss of work....loss of education for many.....the pain of isolation for those who had to shield for months on end (especially those without social media).

The added stress has been that families have not been able to visit their relatives in care homes. This has been particularly stressful for the family members not being able to see their loved ones but also for residents in the care homes, many suffering with dementia and not knowing why the relatives are not coming to see them. My church has kept in touch with the care homes and our online worship has been relayed on one particular home.

We have seen people who were incredibly resilient and confident completely lose their confidence, some have broken down in tears at how awful the situation is. My Vicar personally would sit in her car after every funeral conducted in the first few months of lockdown (between 5-7 funerals every week) and just cry at the awfulness of the situation, people being denied the possibility to grieve in the normal ways, and being treated almost like criminals by security on the gates of cemeteries if they tried to get in (of course the security staff were also acting out of a position of stress and fear).

The Churches are now allowed to open with procedures to keep people safe, but many there are places of worship where they are still not open. The vulnerable and elderly are still nervous to attend. On-line worship has attempted to keep the church community together and such media apps such as Zoom and WhatsApp has enabled people and groups to meet up virtually. However, there are those who do not have the equipment or knowledge to access these.

On a positive note, we in Ely have seen a great community spirit emerging (as it always does in Ely when times are tough!). People really looking out for their neighbours in many ways. The churches have worked closely with other agencies to set up telephone support etc, as well as weekly collections for the foodbank, shopping for those who were shielding etc.

Background

The national restrictions introduced following the outbreak of covid-19 has had a profound effect on the everyday lives of all Welsh citizens¹. Social distancing is at the core of the measures, and is likely to remain until it is considered safe for the population to interact. As the situation continues to evolve, it has become increasingly clear that both the disease and the policy response are having wide-ranging impacts on the health and well-being of the Welsh population, and that many of these impacts will extend beyond the short term.

This briefing paper is intended to set the context within a national setting, highlighting and outlining the key impact of 'lock down' policies and measures to various individuals and service user groups who benefit from the services provided by Cardiff Council.

The data sets presented in this briefing paper have been taken mainly from the most recent documents, publications and data sets that have been made available by key public service authorities and organisations. Much of the data has been taken from the work of Public Health Wales (PHW), Office for National Statistics (ONS) and Social Care Wales.

Mental Well-being

Social isolation brought forward by national restrictions has been found to have a significant negative impact on physical and mental well-being. One report (Brooks et al., 2020) found that the impact of being under restrictive measures presented as symptoms such as stress, confusion and anger. Research suggests those who were most at risk of the mental health and psychological impact of quarantine included, women, particularly those women with children, those with existing mental health conditions, those on low incomes and healthcare workers. A recent publication (Gurney, 2020) found a wide range of substantial and long-term negative psychological effects, including post-traumatic stress symptoms, emotional disturbance, depression, insomnia and feelings of confusion, anger, frustration, boredom, anxiety, isolation and loneliness, to which people with pre-existing mental health conditions were at greater risk.

For Wales, the evidence points to potential negative impacts across both society and individual mental health and well-being. Public Health Wales' Public Engagement Survey on Health and Well-being during Coronavirus Measures (Public Health Wales, 2020b) reported that toward the start of the outbreak 45% of Welsh people surveyed did not worry at all about their mental health, 35% worried a little, whilst 19% (a fifth of respondents) had been 'worrying a lot'. 20% were worried about losing their job and 65% were worried about their children's well-being². However, as restrictions continued, interviewees from subsequent PHW surveys identified that mental well-being and the long-term implications of the restrictions were of major concern. The surveys also highlighted that fear and anxiety levels were high particularly with the uncertainty around the timeframe of the restrictions and that the resilience of unpaid carers and shielded groups could also be an issue as the duration of the restrictions was further extended (INT 8)³

¹ Staying at Home and Social Distancing Policy guidance released on 23rd March 2020.

² <https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/how-are-you-doing/week-3-report-how-are-we-doing-in-wales/> [Accessed 19 Jan 2021]

³ [Public Health Wales public engagement survey - Public Health Wales \(nhs.wales\)](#) [Accessed: 19 Jan 2021]

Diet and Physical Activity

Data from the National Survey for Wales 2018-19 showed that only around half of adults undertake adequate physical activity (Welsh Government, 2019a). The lockdown policy initially introduced, included provisions for the population to take physical activity once a day outside of the home. From 8th May 2020, the restrictions were changed to allow people to undertake exercise outdoors more than once a day, although there was still a requirement to not travel a significant distance from home. This provided an opportunity for people to remain physically active; helping to promote mental well-being.

A rolling health and well-being survey carried out by Public Health Wales identified that 38% of respondents were snacking more (crisps / biscuits / cake) (Public Health Wales, 2020b). In terms of physical activity of 30 minutes or more, 30% of respondents stated that they were taking less physical exercise than before the restrictions were implemented, 42% stated it was the same and 23% responded that it was more than previously⁴.

In terms of evidence in relation to physical activity, diet and nutrition, there is an absence of peer-reviewed academic literature about the effects of quarantine and social distancing on such matters.

Alcohol and tobacco consumption, gambling

The World Health Organization (WHO) published a report, which highlighted that during the Covid-19 pandemic, movement restrictions could potentially increase alcohol consumption and therefore exacerbate health vulnerability, risk-taking behaviours, mental health issues and violence (World Health Organization, 2020a).

Public Health Wales Public Engagement Survey on Health and Well-being during Coronavirus Measures (Public Health Wales, 2020b) has also provided a snapshot of the populations' behaviour during the implementation of the restrictions in Wales. Of those surveyed, 27% stated that they were drinking more alcohol than the week before. Gambling was highlighted in a number of interviews as being of concern, with the potential for negative health and well-being impacts. It was identified that parents (and children) may do more online gambling or use games with in-game purchases (INT 1). However, there was no available academic literature evidence in relation to the impact of movement restrictions on gambling behaviours.

Delivery and access to Health, Well-being and Social Care services

While restrictions have been in place it is widely acknowledged that while many health services have remained open and operational, they have seen a fall in utilisation compared to before the pandemic. Both short and longer term negative impact of operations and appointments being cancelled or suspended is a recognised concern for both physical and mental health. In addition, the impact of the pandemic on Health and Social Care staff in terms of their mental well-being is also recognised.

⁴ <https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/how-are-you-doing/week-4-report-how-are-we-doing-in-wales/> [Accessed 19 Jan 2021]

Pre-existing Mental Health

It is to note that Wales has been the only UK nation to date to have commenced regulations in the Coronavirus Act relating to mental health (Clifton, 2020). Several published research reports have recognised the impact that quarantine and social isolation can have in exacerbating existing mental health and well-being conditions (Brooks et al., 2020; Lunn et al., 2020; Gurney, 2020). A recent publication (Kim and Su, 2020) noted that quarantine and isolation could have an accelerating detrimental impact on those with mental health problems.

Violence against Women, Domestic Abuse and Sexual Violence (VAWDASV)

Although national policy has allowed an individual to leave home to move to a place of safety, concerns have been raised about increased risks of VAWDASV during the restrictions. Since the introduction of the Staying at Home and Social Distancing Policy, there has been a marked increase in the number of domestic abuse reports, with an overall 25% increase in calls to the Domestic Abuse Helpline in the first two weeks (BBC Online, 2020i; Refuge, 2020).

Women

It is suggested that the Staying at Home Policy has, by limiting population movement, had a major negative impact on women in Wales. According to an Institute for Fiscal Studies report, women were about one third more likely than men to work in a sector that had shut down (17% of women compared with 13% of men) (Joyce and Xu, 2020). Workers in these sectors have also tended to have lower pay. As a group, women are also known to be disproportionately affected by domestic abuse and violence.

Welsh Women's Aid identified that self-isolation and social distancing could increase violence against women, domestic abuse and sexual violence and that community response and social solidarity were vital to tackle the issues (Welsh Women's Aid, 2020).

Men

It is believed that men are more likely than women to experience worse direct health effects and are more likely to pass away from Covid-19 (Office for National Statistics, 2020c).

The majority of drivers across the transport sector such as public transport drivers, delivery drivers and HGV drivers and tradesmen, for example, plumbers and electricians, tend to be male. Many of the latter are also self-employed, a category missed in the first economic measures for furloughing employees⁵. Such economic impact, through either a reduction or increased demand on their work, within a time of crisis, could also be considered a key contributor to feelings of isolation and loneliness.

The number of calls to Men's Advice Line for male domestic abuse survivors has also increased following the outbreak of covid-19 (Men's Advice Line (2020) cited in BBC Online, 2020i).

⁵ <https://careersmart.org.uk/occupations/equality/which-jobs-do-men-and-women-do-occupational-breakdown-gender> Accessed 21 Jan 2021

Black, Asian and Minority Ethnic (BAME) Groups

4.4% of the Welsh population identify as Black, Asian or other ethnic minority group (BAME) (Welsh Government, 2019g) and research suggests that Covid-19 has had a disproportionate impact on people from BAME Groups. Analysis of Covid-19 related deaths in England and Wales, undertaken by the ONS, shows that the risk of death among some ethnic groups is significantly higher than that of those of White ethnicity. The reasons for this are unclear, but may be partially explained by a higher prevalence of inequalities associated with socio-economic disadvantage (Welsh Government, BAME Covid-19 Advisory Group).

A further negative impact of the Staying at Home Policy and the guidance is that for some communities, where English is not their first language, there could be mistranslation of information, and an inability to access important information or support services (INTs 2, 6, 8,10), thereby intensifying any feelings of isolation or loneliness an individual may have.

Adults in Care and Carers

The Coronavirus Act 2020 regulations places time-limited modification to the Social Services and Well-being (Wales) Act 2014 to relax duties on local authorities. The changes mean that when deemed appropriate, local authorities no longer have to carry out needs assessments for adults and adult carers, and no longer have a duty to meet adults' eligible care and support needs, nor adult carers needs for support. However it has been stressed by the Welsh Government that the measures should only be activated in circumstances where staff numbers were severely depleted with the clear expectation that any changes to individuals' care and / or support will return to their pre-modification arrangements at the earliest possible opportunity⁶. Reasoning behind the modification was due to the understanding that within the peak of the pandemic, adult social care services may face surging demand and reduced capacity arising from higher rates of staff absence.

Individuals with Learning Disabilities

When the pandemic hit, learning disability care services were forced to cut back or close leaving many isolated. Over two thirds of respondents to a recent Mencap survey highlighted that their care package had been reduced since the start of the pandemic⁷. With support and activities being curtailed, a growing concern is the impact on individuals with learning disabilities losing their independence, physical and mental health and as a result requiring more intensive support; highlighting the potential for a concerning lasting impact. Findings from the ONS⁸ show people with disabilities are more than twice as likely as the general population to report a decline in their mental well-being and feelings of loneliness.

The reduction in respite and all-day services for individuals with a learning disability also brings into focus the potential for profound impact on unpaid carers and in particular, their well-being⁹.

⁶ [Adult social services during the COVID-19 pandemic: guidance \[HTML\] | GOV.WALES](#) [Accessed 19 Jan 2021]

⁷ ["COVID-19 must not become an excuse to dismantle people's care packages": Mencap responds to the Coronavirus Act renewal | Mencap](#) [Accessed 19 Jan 2021]

⁸ [Coronavirus and the social impacts on disabled people in Great Britain - Office for National Statistics \(ons.gov.uk\)](#) [Accessed 19 Jan 2021]

⁹ [COVID-19 and learning disabilities: reach out and connect | RCNi](#) [Accessed 19 Jan 2021]

Older People

Compared with the rest of the UK, Wales has the largest proportion of older people, and many of these individuals live in rural areas where there are high levels of deprivation (Clifton, 2019). Older people who live alone are more likely to rely on others for care and support. Movement restrictions and social distancing measures could make the provision of care and access to essential supplies more difficult (Lloyd-Sherlock et al., 2018). Movement restrictions have resulted in usual family connections being affected, for example with older people unable to see or receive care from children and grandchildren or being isolated from their social networks. Research also suggests that the restrictions may have led to increased feelings of isolation and a possible deterioration in both health and mobility; particularly for those in care home settings. (Wales Centre for Public Policy, 2020).

With only 49% of those aged 75 and over in the UK reporting that they accessed the internet for personal use in 2018-19, highlights the difficulties in older people feeling connected to wider society, particularly under current measures (Wales Centre for Public Policy, 2020; Welsh Government, 2019a).

Many older people regularly shop online. However, during movement restrictions, there was a marked increase in applications for delivery slots for supermarkets in Wales across all age ranges, leaving many older and vulnerable people unable to access or book delivery slots. This promoted stress and anxiety about obtaining access to good quality food and essential supplies; thereby exacerbating their well-being. Older people who are actively ageing well have also been potentially affected in a negative way by being confined to the house or by being 'shielded'. This could potentially have impacted their confidence, their mental well-being and mobility issues - especially if living in a home without a garden or access to space in which to take physical activity, or if digitally excluded.

Young Adults

Young people aged 18 to 24 years have been found to be most anxious about being separated from friends and family if they had to self-isolate (Mental Health Foundation, 2020b) along with rising concern for their future academic or employment prospects.

The major impact for children and young people has been in relation to education. Education settings provide an important role in children and young people's lives. This is not only in relation to education and learning, but also accessing facilities and services that protect and improve health and well-being, providing a routine, and socialising with peers and authority figures. For older children and young adults, the restrictions and policy has had a double impact. They have lost social connections and networks and at the same time any financial independence as young people are more likely to have been employed in sectors affected by the closures such as the leisure and retail sectors (Crawford et al., 2020).

Digital Inclusion

The restrictions introduced following the outbreak of covid-19 has seen a heavy reliance on digital technology. However, a recognised challenge is the potential for some individuals to be impacted by a reduced access to services due to no access to the required equipment (potentially due to age or economic limitations). A report published in British Gerontology

(British Society of Gerontology, 2020) highlighted that whilst for some older people digital connection made access to information easier, many relied on others to provide this information if they did not have digital access themselves. Therefore, whilst technology during the restrictions has facilitated access to healthcare and local services, this has not been the case for some populations, such as the elderly who may not have sufficient health, digital literacy or the skills to utilise and engage with different digital platforms.

Economic Impact

High levels of comparative deprivation exist within the cities and valleys of South Wales and coastal and border towns in North Wales (Welsh Government, 2019f). In Wales, at November 2019, there were 120,648 households claiming Universal Credit. In a recent survey, 74.4% of persons aged 16-64 in Wales report being in work (StatsWales, 2020d) compared with 23% recorded as economically inactive and 3.3% (of those aged 16 and over) as unemployed (Office for National Statistics).

Those on low incomes or who live in areas of deprivation experience worse health and mental well-being than more affluent individuals and communities (Public Health Wales, 2020b; StatsWales, 2020e; StatsWales, 2019a; Public Health Wales Observatory, 2018)

Evidence has emerged that the greatest impact from the Covid-19 pandemic and response is on the poorest and those already experiencing inequities. Recent research has identified that those on low incomes were more at risk of the mental health and psychological impact of quarantine, such as post-traumatic and depressive symptoms, anger and anxiety, which could be associated with the financial impact of the restriction and the loss of any financial support. The UK Government (2020b) also identified that policy measures including staying at home and school closures were likely to impact poorer families and single parents the most. This was a result of increased household costs such as utility bills; a reduction in income, for example not being able to work due to childcare needs; and difficulties in accessing usual support such as Free School Meals. Emerging evidence has shown that richer households were likely to make savings during social distancing, as they would be spending less on non-essential activities. However, as lower income households spend a higher proportion of spending on necessities such as rent, food and bills (55%, compared with 35% of higher income households), any reduction in income would be more difficult to manage (Crawford et al., 2020).

CYNGOR CAERDYDD

CARDIFF COUNCIL

COMMUNITY AND ADULT SERVICES SCRUTINY COMMITTEE

3 Feb 2021

CASSC TASK & FINISH INQUIRY COVER REPORT

Background

1. This report enables the Committee to consider approving the draft report of the Committee's Task & Finish Group; copy attached at **Appendix A**.

2. At a meeting of the Community & Adult Services Scrutiny Committee on the 7th November 2018, Members agreed to undertake an Inquiry on the decision-making process for supported living arrangements for adults with a learning disability. Focusing on the current pathways in place for transitioning identified individuals back into county.

3. The Committee agreed the following Terms of Reference for the task group:
 - To review current pathways (with a particular focus on the decision-making process) in relation to supported living arrangements for adults with a learning disability;
 - To review residential College placements and how decisions are made in terms of continuation;
 - To identify best practice in relation to transitioning individuals from an out-of-county placement back into Cardiff;
 - To engage with service users and their families in relation to the above whilst also understanding their level of involvement– placing them at the centre of any recommendations going forward;
 - To identify current funding arrangements, consider whether this is being used effectively and make recommendations accordingly;

4. Members of the Task & Finish group were:
 - Councillor Mary McGarry (*Chair*);
 - Councillor Ali Ahmed;
 - Councillor Susan Goddard¹;
 - Councillor Sue Lent;
 - Councillor Bablin Molik².

5. The Inquiry report was originally intended to be formally submitted to the Council's Cabinet during spring 2020, however, the subsequent onset of the Covid-19 pandemic and its unprecedented repercussions meant that formal submission of this report was delayed.

6. During the course of the inquiry the Task Group reviewed the evidence gathered from all stakeholders who engaged with the work, including but not limited to; the Cabinet Member for Social Care, Health & Well-being, Cardiff Council's former Director of Social Services, Operational Managers within both social services and education, frontline staff, both local and out of county providers, individuals with a learning disability and their carers. The Members also reviewed a number of publications, reports and guidance on upcoming legislation.

7. As part of the inquiry, the Task Group commissioned independent research into this area. Tasking Scrutiny's Research Officer to address, through consultation with parents and advocates, the current pathway in place for transitioning identified individuals in order to identify possible areas for improvement. A copy of the research findings are attached to the main body of the report at **Appendix 1**.

8. As a result of the analysis and assessment of all the evidence gathered throughout the Inquiry, a number of key findings were identified from which a number of recommendations were agreed; *as set out in the attached report at **Appendix A***.

¹ Cllr Goddard was a Committee Member until September 2019

² Cllr Molik was a Committee Member until June 2019

Way Forward

9. The draft report of the Task & Finish Group, is attached at **Appendix A**. Members' attention is particularly drawn to the recommendations section.
10. Members may wish to consider the report, make any amendments and agree whether to approve the report to be considered by the Cabinet.

Legal Implications

The Scrutiny Committee is empowered to enquire, consider, review and recommend but not to make policy decisions. As the recommendations in this report are to consider and review matters there are no direct legal implications. However, legal implications may arise if and when the matters under review are implemented with or without any modifications. Any report with recommendations for decision that goes to Cabinet/Council will set out any legal implications arising from those recommendations. All decisions taken by or on behalf of the Council must (a) be within the legal powers of the Council; (b) comply with any procedural requirement imposed by law; (c) be within the powers of the body or person exercising powers on behalf of the Council; (d) be undertaken in accordance with the procedural requirements imposed by the Council e.g. Scrutiny Procedure Rules; (e) be fully and properly informed; (f) be properly motivated; (g) be taken having regard to the Council's fiduciary duty to its taxpayers; and (h) be reasonable and proper in all the circumstances.

Financial Implications

The Scrutiny Committee is empowered to enquire, consider, review and recommend but not to make policy decisions. As the recommendations in this report are to consider and review matters there are no direct financial

implications at this stage in relation to any of the work programme. However, financial implications may arise if and when the matters under review are implemented with or without any modifications. Any report with recommendations for decision that goes to Cabinet/Council will set out any financial implications arising from those recommendations.

RECOMMENDATIONS

The Committee is recommended to:

- i. Consider the draft report of the Task and Finish Group, attached at **Appendix A.**
- ii. Endorse the report, subject to any comments the Committee may wish to make, for submission to the Cabinet.

DAVINA FIORE

Director of Governance and Legal Services

28 January 2021



An Inquiry Report of the:
Community & Adult Services Scrutiny Committee

**‘Closer to Home’ Project: Out of
County Placements for Adults
with a Learning Disability**

April 2020



Cardiff Council

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APPENDIX 1: PRIMARY RESEARCH.....[Parents Information & Support Needs](#)

DRAFT - NO STATUS

DRAFT - NO STATUS

CONTEXT

1. At a meeting of the Community & Adult Services Scrutiny Committee on the 7th November 2018, Members agreed to undertake an Inquiry on the decision-making process for supported living arrangements for adults with a learning disability. Focusing on the current pathways in place for transitioning identified individuals back into county. It was agreed that the Inquiry was to be chaired by Councillor Mary McGarry.
2. For many years, numerous Government and professional reports reporting on the care agenda have highlighted that people with learning disabilities and challenging behaviours are vulnerable to abuse, and are more likely to be placed in private residential and/or hospital settings which often generates concerns around quality and safeguarding.
3. The Ely hospital closure programme, (*subsequent to the All Wales Strategy 1983*), successfully resettled its residents (*adults with learning disabilities*) into community domiciliary settings in Cardiff. Whilst achieving the immediate objective of resettling people in the community, the programme has been seen as an end in itself as little planning had taken place in respect to how the growing accommodation needs of these individuals would be addressed or how the emerging increase in complexity of need could be met within a community setting.
4. Following the resettlement programme in Cardiff, the development of supported living reduced. This led to a growth in out of area placements due to increasing need, emergency placements and lack of local schemes to meet individual needs deemed too complex for local supported living.
5. The abuse of individuals with a learning disability in Winterbourne View private hospital in 2012 again raised the profile of this vulnerable client group, highlighting out of county placements amongst other issues of overall safeguarding. It brought to the forefront the need to have data on where people with a learning disability reside, how monitoring of out of county placements happens and whether non-professionals

such as family members should be part of the inspection frameworks. Concerns were further raised in 2019 following the BBC Panorama programme set in Whorlton Hall, a specialist hospital for adults with a learning disability.

6. Following the Winterbourne View scandal, the UK Government pledged to move all people with learning disabilities and/or autism, inappropriately placed in institutions, into community care; yet in order to achieve this vision, a large expansion in community provision would be required¹.
7. At the time of writing this report, there are 7081 people who have a learning disability living in Cardiff. 62% of whom live at home with their parents, 323 live in local supported living accommodation and 84 live in out of county provision (*this figure includes those residing in out of county specialist further education*).
8. Many of these individuals, residing both in and out of county, will have multiple conditions. For instance around 25-40% will experience mental health issues, 10-15% will have challenging behaviour and so on.

Population estimates for Cardiff show that the numbers of individuals with a learning disability in Cardiff will continue to grow. With people living longer and therefore requiring support for longer, this will place a significant pressure and demand on Cardiff's local services.

KF1

9. It should be noted that the figures in the following table, are indicative of a trend of increase in Cardiff's learning disability population, but do not show the numbers of adults who would be eligible for a service. Nevertheless, this population and trend data can be used to anticipate that the number of service users eligible for learning disability services is increasing and this trend is set to continue.
10. Research shows this is partly due to the learning disability population having an increased life expectancy, the increased number of young people moving through

¹ Winterbourne View – Time for Change, Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism, pg. 6 (2014)

Children’s Services to Adult Services and the overall population increase as over the next 20 years Cardiff is set to see a larger growth in population than the other 21 Local Authorities in Wales put together².

Data for: Cardiff					
People aged 18 and over predicted to have a learning disability, by age, projected to 2035					
	2017	2020	2025	2030	2035
Total population aged 18 and over predicted to have a learning disability	7,081	7,299	7,684	8,157	8,657

Table produced on 28/11/19 11:07 from www.daffodilcymru.org.uk

11. Further demand for services arises from the increased complexity of need of some individuals, and the propensity for adults with learning disabilities to develop dementia.

Data shows that Cardiff Council has a greater number of children and young adults with complex learning disabilities compared to any other Welsh local authority. This is primarily due to its city status and availability of local services such as the Children’s Hospital for Wales. Such factors will inevitably result in additional pressures on required accommodation provision; increasing the need for specialist provision for cases with complex health and social needs and/or behaviours, which require a high level of multi-agency support.

KF2

It is recognised by the service area that additional accommodation for individuals’ with the most complex needs is required locally.

KF3

12. During the inquiry the service area confirmed that in order for those currently placed in residential settings out of county who wish to return ‘closer to home’, and in order to offer individuals improved local options, a robust infrastructure is paramount.

² <https://www.cardiff.gov.uk/ENG/Your-Council/Strategies-plans-and-policies/Corporate-Plan/Documents/Corporate%20Plan%202019-22%20FINAL%20ENG.pdf> Accessed 26 March, 2020

The Wales Audit Office publication, *Strategic Commissioning of Accommodation Services for Adults with a Learning Disability*, published in 2018, states that local authorities require better quality financial, population and demographic projections to gauge future demand and ensure they make the most informed decisions. It is for this reason why the service area have confirmed the creation of a Business Analyst post.

KF4

Following the Children Act 1989, there was a move to create a specialist specific team for children with disabilities. However, in a bid to ensure cross cutting shared concepts, the service area is set to return to its original model and become an 'All Age Learning Disability Service' whereby staff across all areas of Learning Disabilities (*Children and Adults*) will merge. It is anticipated this should encourage better collaboration within the transitioning process, whilst stimulating the service area's culture for continuous improvement whilst remaining open and responsive.

KF5

DRAFT - NO STATUS

DEFINITIONS

What is a Learning Disability?

- D1. Within its fact sheet entitled “What is a Learning Disability?” the British Institute of Learning Disabilities states that an individual with a learning disability is said to have ‘*significant impairment of adaptive/social functioning*’. This means that the individual will have difficulties understanding, learning and remembering new things, and in generalising any learning to new situations. Because of these difficulties with learning, the person may have difficulties with a number of social tasks, for example communication, self-care and awareness of health and safety. A final dimension to the definition is that these impairments are present from childhood, not acquired as a result of an accident or following the onset of adult illness.³

What is Residential Care?

- D2. Residential care is a model of care provided within a shared residential setting, where support staff are present 24 hours a day, seven days a week (*to note this staff frequency is also equivalent in Supported Living models*). Residential care encompasses accommodation and care into one package meaning the individual in receipt of the package has a significantly reduced access to state benefits.

What is Supported Living?

- D3. Supported living is an alternative to residential care, and is a model of providing accommodation and support to people across the spectrum who may require substantial, regular or low-level support. It is argued that supported living provides more security, rights, choice and control to the individual than that provided in residential care. Unlike residential care, when an individual resides in supported living they receive their own tenancy. The individual will rent their accommodation from a housing provider (*generally a housing association*), and as a tenant receive legal rights.

³ British Institute of Learning Disabilities, ‘Factsheet – What is a learning disability?’ (file:///C:/Users/s757803/AppData/Local/Microsoft/Windows/INetCache/IE/2UVM0DNX/Learning_Disabilities_11.pdf) Accessed 15 Oct 2019.

- D4. The basic principles of supported living are:
- Individuals have their own home (*rented or owned*) with the care and support they need being provided separate from their tenancy;
 - Individuals receive personalised support, aiming to make them as independent as possible;
 - Unlike residential care, the separation of housing and care and support means that individuals are able to claim housing benefits in order to pay for housing costs.
- D5. Supported living is not a prescriptive model of care and can look very different for different people. For one person it may be a few hours' support a week to live alone in a rented flat, for another it may be round the clock support to live in a home they own, and for others it may be a shared house with onsite support.
- D6. Supported living can support someone at any point in their development. The level of need the individual requires will determine the model or level of support they receive - e.g. whether they require targeted or 24-hour support. Supported Living commissions, low, moderate, medium, high and enhanced levels of support - how it's delivered is tailored to the individual.
- D7. However, it must be recognised that this is on the proviso that the quality of care and support provided to the individual is efficiently meeting and developing their needs.

What is Specialist Further Education Provision?

- D9. The Welsh Government guidance document, '*Securing provision for young people with learning difficulties at specialist further education establishments*', sets out the policy and process by which the Welsh Government will make decisions about funding placements for young people aged 16–25 with learning difficulties who require access to specialist provision. It states that in regards to post-16 education, all young people who have a learning difficulty should be provided '*equitable access to further education (FE) at a mainstream FE establishment, through the delivery of inclusive options available locally to meet their needs*⁴'.

⁴ <https://gov.wales/sites/default/files/publications/2018-04/securing-provision-for-young-people-with-learning-difficulties-at-specialist-further-education-establishments.pdf> Accessed 10 Jan 2020

D10. The document notes that '*nearly all*' mainstream FE provision within Wales also provide discrete specialist provision which can help young people develop independent living skills, to prepare for work or to move on to mainstream learning opportunities, such as vocational programmes which help prepare an individual for work in their chosen field. However it is recognised within the document that sometimes a young person's holistic needs are too complex and may require more specialist FE provision. If opportunities for suitable provision are not available locally, under the current assessment process, (*undertaken by Careers Wales on behalf of the Welsh Government*) specialist further education provisions (*which are currently only located out of county*) will then be considered.

D11. Currently in Cardiff the local offer of further education for those with learning disabilities is provided through the mainstream further education sector, as a day learner, with additional support provided as necessary. What is not currently available locally within the further education option is the holistic provision of onsite accommodation which stimulates the independence factor of living away from home.

D12. Specialist further education provides education for young adults with a range of complex educational needs and, as evidenced during this inquiry, can come in a range of models. Along with providing educational courses and physical and emotional support for individuals with complex needs, on site residential provision is also provided under the framework.

What is transitioning?

D13. People undergo transition at many times in their life; it is for this reason why the term 'transitioning' can relate to a range of circumstances. For instance, for those known to services, an initial transition will be from Children to Adult services, then depending on assessment of need, an individual could then undergo a transition to an out of county provision and potentially back into their local county. For the purpose of this report, the term transitioning (*and its alternatives*) will be used when referring to an individual's movement from children services to adults, to an out of county provision and potentially back to local accommodation. The context in which it is referred to will be clearly laid out.

KEY FINDINGS

Throughout the course of this Inquiry it became apparent to the task group that there is no 'one size fits all' care model for adults with learning disabilities whose needs must be met in a variety of ways. As a result, the task group felt an individual approach to service provision is essential, with support and accommodation being specifically tailored to meet the needs of each individual. This vision was shared across the board, amongst all stakeholders who engaged in this work and it was clear that this ethos is at the forefront of the service area's daily operations. It also became apparent to task group Members that central to shaping this form of provision is the need for effective engagement between service users, relevant family members, advocacy groups, policy makers and professional care providers.

The Inquiry team wishes to commend the work of Adult Services management and staff who have developed and implemented many changes over the recent past which has in many ways started to address some of the issues presented in this report.

The below Key Findings have arrived after twelve meetings which included four full day visits to both local and out of country service providers with a variety of expert witnesses. The Inquiry was also informed by extensive desk based and primary research and an array of background documents. Following a review of the evidence, Members identified the following Key Findings:

Context

Population estimates for Cardiff show that the numbers of individuals with a learning disability in Cardiff will continue to grow. With people living longer and therefore requiring support for longer, this will place a significant pressure and demand on Cardiff's local services.

KF1

Data shows that Cardiff Council has a greater number of children and young adults with complex learning disabilities compared to any other Welsh local authority. This is primarily due to its city status and availability of local services such as the Children's Hospital for Wales. Such factors will inevitably result in additional pressures on required accommodation provision; increasing the need for specialist provision for cases with complex health and social needs and/or behaviours, which require a high level of multi-agency support.

KF2

It is recognised by the service area that additional accommodation for individuals' with the most complex needs is required locally.

KF3

The Wales Audit Office publication, *Strategic Commissioning of Accommodation Services for Adults with a Learning Disability*, published in 2018, states that local authorities require better quality financial, population and demographic projections to gauge future demand and ensure they make the most informed decisions. It is for this reason why the service area have confirmed the creation of a Business Analyst post.

KF4

Following the Children Act 1989, there was a move to create a specialist specific team for children with disabilities. However, in a bid to ensure cross cutting shared concepts, the service area is set to return to its original model and become an 'All Age Learning Disability Service' whereby staff across all areas of Learning Disabilities (*Children and Adults*) will merge. It is anticipated this should encourage better collaboration within the transitioning process, whilst stimulating the service area's culture for continuous improvement whilst remaining open and responsive.

KF5

The Joint Commissioning Strategy for Adults with a Learning Disability (2019-2024) sets out how Cardiff and Vale of Glamorgan Councils and Cardiff and Vale University Health Board will work together to respond to the needs and aspirations of the adult learning disability population within the context of national legislation and guidance, wider local plans and available resources. At a local level, the strategy will inform what services each of the three organisations will individually or jointly commission to meet personal outcomes, encourage participation and promote independence over the next five years.

KF6

Key priorities of the Cardiff and Vale Joint Commissioning Strategy relevant to this inquiry are:

- Information; accessible and easy to understand;
- Choice and control – listening to the person and carer's views;
- Right care at the right time – early crisis and respite support;
- Day opportunities – volunteering and work experience;
- Transitioning should be joined up and planned well.

KF7

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 (*hereafter referred to as 'The ALN Act'*) makes provision for a new statutory framework for supporting children and young people with additional learning needs. It replaces the existing legislation surrounding special educational needs (SEN) and the current assessment of children and young people with learning disabilities in post-16 education and training. The Act instead places the responsibility of learners with additional learning needs from the age of 0-25 with local authorities.

KF8

During the course of the inquiry, Members received a briefing from the Additional Learning Needs Transformation Lead for Central South Consortium and Cardiff Council's Senior Achievement Leader Inclusion and were advised that confusion can arise from the interpretation that the ALN Act provides a right for a child with additional learning needs to stay in education up until the age of 25. It was confirmed that the principles of the ALN Act stem around parity and are laid out to ensure that a child with Additional Learning Needs has equal rights in accessing further education courses as a child without Additional Needs, and can therefore access and receive a training course up until the age of 25.

KF9

Due to the consensus set by Welsh Government policy publications and guidance, the further education option for those with additional learning needs is seen by governing bodies to be one which offers the 'college experience' equating to two years of education, not the 'university experience' which would be three years of education.

KF10

A key element of the ALN Act is its endeavour to increase participation of the individual with learning disabilities, stating that it is imperative individuals see the planning process as something which is done with them as opposed to for them. As such, they and their families should actively be encouraged to participate in the planning process for their educational opportunities through the provision of clear, impartial advice, information and advocacy.

KF11

Primary research conducted for this inquiry has shown that the parents of people with a learning disability involved in this inquiry currently have limited or no knowledge of the ALN Act and the changes it will bring.

KF12

The ALN Act places greater emphasis on disagreement avoidance and dispute resolution. Due to schools maintaining Individual Development Plan's (IDP), the ALN Act will introduce different appeal procedures. Should a young person or parent (*or any other stakeholder*) wish to challenge an individual's IDP or the learning provision they have been provided with, there will be clear routes for them to do so and local authorities must provide access to independent advocacy services for this route.

KF13

Under the ALN Act, the assessment process for determining further education will focus on educational need; looking at the realistic prospect of an individual completing a course and achieving educational goals.

KF14

The challenge under the ALN Act will likely be around capacity and demand, and although responsibility for further education provision will begin at school, the ALN Act places emphasis on relevant bodies, such as adult services becoming involved to ensure every child and young person with a learning disability known to services is aware of all of the options available to them.

KF15

During the course of the inquiry, Members heard first-hand the concerns from some of the specialist further education providers on what the proposed arrangements under the ALN Act may bring. The concerns raised to Members included:

- There is a lack of recognition in the Draft ALN Code of specialist provision as part of the post-16 further education offer;
- A possible lack of provision for independent advice and guidance for parents and young people with both complex and low incidence additional learning needs;
- Possible risk of young people with complex needs being denied Additional Learning Provision by the nature of their ALN.

Further concerns raised were that local authorities:

- Could be compromised by their role as assessors, commissioners and funders;
- May only provide access to information about local post-16 options other than specialist further education provisions (*which are all currently out of county*);

- May end an IDP rather than consider a placement at a specialist further education provision.

KF16

The 'Multi-Agency Protocol for Children and Young People with Additional Learning Needs' (*currently in draft form*) is being developed in line with the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act (2018), the principles of the Social Services and Well-Being Act (2014) and the application of the Mental Capacity Act (2005) amongst other key legislation and guidance. The protocol has been coproduced with stakeholders from Education, Health Services, Social Services, schools, further education institutions and the third sector through attendance at meetings, workshops and engagement events throughout 2018-19. The protocol also links into to the Joint Commissioning Strategy for Adults with Learning Disabilities (2019-2024) as a work stream from the strategy will develop an action plan specific for those with learning disabilities within the transition period.

KF17

Funding (under current arrangements for specialist further education provision)

Currently, there are around 300 specialist post-16 placements funded across Wales by the Welsh Government at any one time. The average combined cost for these placements is currently around £21m per annum – with around 50% of cost coming from the Welsh Government, 42% social care (local authorities) and around 5% health funding.

KF18

The proposal under the ALN Act is for funding for all placements to come from local authorities; however the Welsh Government is yet to work out how this will be done in practice. At the time of writing this report, there is no known formula for how funding will be determined and for this reason there are significant concerns within this authority with regard to discrepancies between welsh local authorities. For instance there is concern that those authorities which display higher trends could be seen as having equal costs to local authorities with much lower trends and expenditure.**KF19**

It was agreed by the majority of stakeholders who engaged in this inquiry that in order to effect positive change, the decision on the duration of an individual's placement in further education should consider the individual's specific characteristics including their scope and abilities (rate of learning) for developing the skills that they hope to achieve. It is widely suggested by both providers and parents that governing bodies must sufficiently recognise that individuals with a learning disability will take time to settle into a course and that the first year of a course tends to act as an induction period, the second year is developing new skills and the third year provides opportunity for such skills to be consolidated.

KF20

The reduction in Welsh Government funding for further education provision from three years to two, has also had a knock-on effect for local authorities', as more 'move on' accommodation is now needing to be sourced.

KF21

During the inquiry Members heard from providers that frustration for both themselves and parents tends to arise where there is uncertainty or questions surrounding funding. Primary research commissioned by this inquiry found a strong desire amongst parents to better understand the funding process.

KF22

Finance

During this inquiry, an independent consultancy confirmed that Cardiff is a comparatively low spending authority in Wales on support for adults with learning disabilities whilst still maintaining good levels of satisfaction with support. This finding suggests scope to increase the quality of local provision for those with complex needs and to consider increasing access to out of county provisions when required.

KF23

Findings from an independent consultancy confirmed that currently there is a disconnect between local authority and health colleagues. It was reiterated that

better communication with health colleagues would ensure more efficient working and possibly greater levels of funding. Which in turn will provide more effective services.

KF24

Members were advised that due to the current climate of austerity and cuts there are requirements for officers to remain within certain budgets. Members were further advised that the level of justifying and producing sufficient evidence in support of a more expensive placement is due to the budgetary position along with Key Performance Indicator requirements.

KF25

The Transitioning Pathway

There are currently four Transition Social Workers who facilitate an individual's movement from Children to Adult Services within the authority.

KF26

Primary research conducted with parents during this inquiry found that most parents have limited knowledge and understanding of the assessment process for accessing specialist further education provision including eligibility requirements, duration of funding and the roles of various stakeholders involved in the process.

KF27

The current transition planning process following secondary education is set out in the Special Educational Needs Code of Practice for Wales (Welsh Government, 2004) and begins in Year 9 SEN annual review. During the inquiry Members heard that an individual with learning disabilities will typically transition from school to further education around the age of 19 and may transition again 2 – 3 years later. During the inquiry it was confirmed to Members that during this time an individual may remain with the same adult social worker or may be reallocated to another social worker depending on capacity.

KF28

During this inquiry, both parents and out of county providers highlighted the need for consistency in the representation of social workers during the review process of further education placements.

KF29

The primary research conducted by this inquiry highlights that under current arrangements, the majority of parents interviewed would request better understanding and guidance of the transition process involved in moving their child from specialist further education to the appropriate care and support arrangements in Cardiff. In particular, parents highlighted the need to improve engagement between themselves and the service area along with greater recognition that their input significantly assists the objective of meeting a child's 'best interest.'

KF30

Benefits of Out of County Placements

During the inquiry the following benefits of out of county placements (*both within further education colleges and residential settings*), proposed by out of county providers included:

- Better social mobility;
- Wider relationships;
- Increased self-understanding;
- Improved self-advocacy and self-reliance;
- Reduction of stress on families;
- Improved mental health outcomes;
- Families able to enter employment / increased employment opportunities;
- Improved health, well-being and quality of life and;
- Reduced elective and non-elective hospital admission.

KF31

Specialist further education institutions visited during the inquiry had the benefit of many on-site facilities and services, including but not limited to:

- Speech and language;
- Counselling;
- Occupational therapy assessment.

KF32

The benefits and outcomes were strongly acknowledged amongst the parents (*of those with children in out of county specialist further education provision*) who engaged with this inquiry who in the majority noted their content with the;

- Individualised support programmes;
- Availability of specialist staff;
- Remarkable development in their child's skills, knowledge and independence.

KF33

The importance of environmental factors and their significant benefit on an individual's (*with certain needs*) physical and emotional well-being was widely recognised by all stakeholders who engaged in this inquiry.

KF34

Although for some young people with disabilities, a specialist further education college may not suit, the perspective presented to Members by specialist further education providers during this inquiry is that the opportunity offered by a specialist setting, for an individual to learn and live amongst peers with similar needs and life experiences can be a very effective way to help them achieve long-term sustainable outcomes that enable them to become active participants in, and contributors to society along with aiding their progression into adulthood.

KF35

The majority of parents who engaged in this inquiry believe that within a specialist further education provision there is a much stronger opportunity for their child to grow in maturity, develop independence and gain additional skills away from the home environment and that recognition of such skills and opportunity by professionals is paramount.

KF36

Transitioning from an out of county provision

During this inquiry, Members were unable to obtain published information which confirmed and clearly laid out the transitioning pathway for adults with a learning disability who may undergo transitioning from an out of county provision. It became apparent that the service area lacked a published framework and guidelines on how identified individuals are brought back from out of county in a structured, personalised way. While a wealth of information was provided to the task group, there was no evidence that this had yet been consolidated into one robust 'pathway' used as a blueprint for returning identified adults into their local county.

KF37

If an individual transitions from an out of county residential provision there is a high multi-disciplinary team (MDT) involvement, including health colleagues, specialist behaviour team and so on. Further to this, a wealth of risk assessments along with a full assessment and analysis of care package is also undertaken. This is conducted in full consultation with the family and individual (as appropriate). It is to note that although full and thorough risk assessments and analysis of care package is provided for all individuals, MDT involvement does not commonly occur for those transitioning out of residential college.

KF38

The key drivers in determining an individual's provision were confirmed to Members as:

- The individual's wishes
- Families wishes
- Persons needs
- Budgetary position.

Each driver was confirmed as equal in weighting.

KF39

Based on the views of the parents who engaged in this inquiry, the guidance and scheduling involved in transitioning individuals out of specialist further education provision appeared to be considerably inconsistent.

KF40

Members heard from Council officers that for those placed in a specialist further education provision, the year before their course is due to end a reassessment phase will begin; this inquiry's research found that the transition period tended to be initiated (*with the parents*) around 6 months prior to course end. Parents perceived this as too late in the process with parent suggestions that discussion regarding transitioning for those currently placed in out of county further education provision should start at the end of first year (*for two year funding*) or at the end of second year (*for three year funding*).

KF41

During the inquiry it was confirmed to task group Members that a wealth of work goes into identifying properties for an individual – noting that compatibility with current residents, the environment, the needs of the individual and that staff members have the right skills is central to the decision making process. Members found that the significance of these factors was recognised amongst all stakeholders involved in this inquiry.

KF42

Although it was reiterated to Members that all provisions are equally acknowledged, valued and utilised, Members hold concerns that under current practice it appears that provisions perceived as 'intentional communities' and their benefit as a provision is not widely recognised. Members wish to reiterate the importance of seeing the value in every provision as stated in the Welsh Government's *Prosperity for All* document.

KF43

Through engagement with both parents and providers, this inquiry found that during the transition process following further education provision, incompatible options are suggested and it appears that a process is followed even when known and advised by stakeholders that the suggested placements won't work.

KF44

During their review of 20 cases' written records, the independent consultants found that information kept in an individual's case file lacked definition on how the decision-making process within a transition (either from a residential college or from the family home) was undertaken. To elaborate, it lacked detail on the contributing factors and how evidence was weighed. The review also showed that outcomes captured within the data appeared to be too generalised making it difficult to hold providers to account and effectively monitor an individual's progress when a transition has occurred.

KF45

An out of county provider who engaged in the inquiry, provided the group with an example of one resident who transitioned home after extended funding had not been agreed. The provider was then contacted by social services three weeks later inquiring if provision for this individual was still available as it had been determined that there were no suitable provisions available locally.

KF46

During a transition process, a Support Planner works with individuals to listen to their aspirations & needs with regards to meaningful occupations. The Support Planner has expertise in knowing what opportunities are available locally and becomes

involved with an individual following a referral from a social worker should an individual wish to do activities in the community, instead of college, or after college, or while also attending college. Support Planners are involved with over 80 providers and services in Cardiff with a wide range of volunteering, social, sport, arts, health and adult education (life-long learning) opportunities. Since introducing Support Planners, the service area confirmed they have been able to offer a much wider range of occupation options, increasing an individual's skills, confidence and social networks.

KF47

Primary research conducted with parents during this inquiry found variability in their understanding of the overall transitioning process. It became evident they require clarity on the roles of stakeholders involved in the process, including their own role, along with an indicative timeline and greater detail of the specific stages involved.

KF48

During the inquiry Members were informed by officers that when required, future placement options are continuously discussed with the individual and the family. Findings by the consultants further confirmed that, in the twenty cases they reviewed, good evidence was displayed demonstrating that young people and their parents/carers are actively involved in the process. However, primary research commissioned by this inquiry found that, out of six parents involved in the research whose children had gone through the transitioning process, two confirmed a positive experience. The other parents cited improvements could be made in engaging with them.

KF49

Lifelong Learning

The importance of a lifelong learning framework which allows for exceptional development of an individual, encouraging growth in confidence, developing an individual's independence and having an all-round positive impact on an individual's life was shared by all stakeholders who engaged in this inquiry.

KF50

Perception of Local Provisions

Although all local providers who engaged in this inquiry reiterated that the retention and development of an individual's skill set are at the forefront of their organisation, this inquiry's primary research found that out of the parents whose child had transitioned, most were unsure whether their child has sufficient opportunities in their current provision to undertake the activities and tasks that would help to maintain the knowledge and skills that they acquired during their college placement.

KF51

Croen et al (2015) identified that people with autism are at increased risk of physical health issues including diabetes, gastrointestinal disorders, high cholesterol, hypertension and obesity. Relationships with food can also be complex due to sensory needs, obsessive behaviour, anxiety or isolation. Such concerns were reiterated by some of the parents involved in this inquiry, who voiced their concerns that they were unsure if their child, who now resided in local provision, is encouraged to undertake sufficient physical activity and make healthy food choices.

KF52

The findings of the primary research, commissioned by this inquiry show that parents of those currently residing in local provisions are unsure whether activities for their child are carried out as planned.

KF53

The Capturing of Data

During the inquiry Members were informed that typically, incorrect assessments occur due to the variance of environments where an assessment is undertaken.

KF54

Conwy Council's 'Progression Project' is designed to assist the assessment process through the development of a more informed understanding of accommodation and support needs. The Project consists of a refurbished bungalow which provides individuals with a 'come and try it' service for independent living. With individuals residing for the day, overnight or staying for a few days in order to ensure their needs are best determined.

KF55

As a result of the Call for Evidence Members initiated with both local and out of county providers, it was confirmed that when an individual's placement is confirmed they, as the provider, will receive a Care Plan and/or a Unified Assessment which outlines the individual's abilities, capacity and needs, providing a brief overview of an individual's communication abilities, mobility, physical and emotional needs, special equipment, adaptations, educational need, medical information and so on. It was also confirmed that if the individual is a college leaver, they (*as a local provider*) would also receive a written assessment from the educational facility and/or a psychology report. However, one local provider noted that they tend to only receive such introductory information on an individual post entry.

KF56

In order to ensure the process of sharing information between providers is both efficient and effective, Cardiff Council's Learning Disability team are currently working with one out of county provider on developing an all-encompassing document to assist in this process.

KF57

When meeting frontline staff, Members queried what data is kept on those who have transitioned from an out of county provision and if the impact on an individual who has transitioned is specifically measured in order to ensure progress is sustained. Members were advised that following a transition, social workers will undertake an 8 week review which is then repeated at 6 and 12 months; to note, additional reviews will also be conducted if required. Such work is called 'person centred planning reviews' or 'pathway plans'.

KF58

Monitoring & Review

This inquiry's Call for Evidence confirmed that local providers (*in line with the Care Plan developed by social workers*) will develop a Personal Plan with the individual, which includes lifelong learning and skill development opportunities. This Personal Plan is reviewed at least 3 monthly by provider staff. However, a majority of the parents who engaged with this inquiry whose child resided in local provisions were unaware of such reviews.

KF59

Dr Edwin Jones' report on Western Bay's Closer to Home project places significant emphasis on the success of the Positive Behaviour Support model and the use of a core multi-disciplinary team within the transition process. In addition, the report also highlights the importance of data, which is captured both pre and post move, being utilised in order to best understand and monitor the impact on an individual who has moved in order to ensure full quality of life is achieved.

KF60

In line with the Wales Audit Office Report recommendation (*Strategic Commissioning of Accommodation Services for Adults with a Learning Disability, 2018, R6*), there appears to be a lack of formal, systematic monitoring and evaluation process on individuals who have transitioned which is managed by the authority .

KF61

Gaps in Local Provision

As stated in the National Commissioning Board's guidance document (*Commissioning Accommodation and Support for a Good Life for People with a Learning Disability, 2019*), provision of the right kind of housing can either help or hinder an individual's social integration. It can also be fundamental in achieving a number of the outcomes set out in the Social Services and Well-being (Wales) Act 2014. It is therefore essential that when a decision is made concerning accommodation provision, the full spectrum in meeting that individual's needs is considered.

KF62

Primary research conducted for this inquiry highlighted parents' expectations on the need to expand the availability of locally based care and support provision in the Welsh language.

KF63

The Mansell Report (*Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs, 2007*), described as 'definitive UK guidance on the development of services for people with challenging behaviour', recommends that local services, including educational, training and day services are developed and expanded for people with a learning disability. The report also recommends that specialist services be developed locally which can support good, mainstream practice and improve the quality of life for those served.

KF64

During the course of the inquiry it was confirmed to Members that the service area are currently planning to develop an accommodation strategy to assist with long term planning on local provisions and are also working toward developing clear transitional pathways to ensure individuals and their families acquire full understanding of the options available in line with their need.

KF65

DRAFT - NO STATUS

RECOMMENDATIONS

Members of the inquiry group were tasked to consider the current arrangements in place for those individuals who undergo transitioning from an out of county placement back into the locality, determining the effectiveness of the current approach and possible areas for improvement.

Following a review of the evidence received during this Inquiry, and the Key Findings detailed above, Members have agreed the following recommendations for Cabinet consideration:

Context

R1 Due to the Additional Learning Needs and Educational Tribunal (Wales) Act introducing clear direction for the Individual Development Plans of the most severe and complex cases becoming the direct responsibility of local authorities, Social Services should look to produce guidance which will provide all involved professionals with clear definition and distinction between complex and lower level needs and the necessary requirements to best support and develop such needs. This work could be developed by the newly formulated Business Analyst post who, within their role, should also look to take into account the projected demand of adults with a learning disability across the locality. Within their responsibilities it must be a priority of the Business Analyst to ensure and verify that all options offered to an individual with complex needs, in particular local options, are fully effective in providing said individual with an environment and opportunities that will encourage, develop and maintain their skills. The remit of the Business Analyst post should also include monitoring the service areas transition to an 'An All Age Learning Disability Service', providing the appropriate individual with their continued findings in order to ensure consistent monitoring. **(KF1, 2, 3, 4, 5, 23, 25, 31, 32, 33, 34, 35, 36, 39, 43, 50, 62, 63, 64)**

R2 The Business Analyst should also undertake a review of local lifelong learning provisions to ensure there is adequate local capacity to meet known demographical pressures. **(KF1, 2, 4, 50, 63)**

- R3** Look to establish a formal communication strategy surrounding the transitional process which confirms communication goals, target audience and communication plan and channels. Such a strategy will help identify the key stakeholders and key information to be communicated within a transition process, along with identifying how and when information should be communicated. This should ensure earlier communication and aid disagreement avoidance and dispute resolution. **(KF6, 7, 12, 13, 15, 22, 24, 27, 30, 37, 38, 40, 41, 48, 49, 52, 54, 59, 65)**
- R4** As part of the communication strategy, formally engage with service user representative groups on a set, regular basis to help shape, improve planning and inform decision making. Such engagement could also be encouraged and better stimulated more informally through the use of social media **(KF1, 2, 3, 4, 6, 7, 13, 17)**
- R5** Additional work is required in ensuring that a young person with learning disabilities and their carers feel more actively involved in the care planning process. Officers must ensure that care plans, including provider reviews are continuously written in accessible, appropriate language in order to improve understanding. Where deemed appropriate (*with strict adherence to data protection, the individual's capacity and regulations set out in the Social Services and Well-being (Wales) Act*) for an individual and/or involved family members to have sight of reviews and care plans, such information should be shared in a timely manner. **(KF6, 7, 11, 49, 58)**
- R6** Develop and/or support an informal parents' network specific to those parents who have a child currently placed out of county (*including further education provision*) and those who have transitioned back. This network would play a vital role in the dissemination of information. Provide parents with emotional support from peers and also provide a formal avenue for the service area to gain feedback on issues relating to services and accommodation. In order to stimulate relations and ensure effectiveness, the Cabinet Member, Director of Adults, Housing and Communities; and local providers should look to engage with the network directly **(KF3, 4, 6, 7, 8, 9, 12, 22, 27, 42, 47, 48, 49, 50, 52, 53, 65)**

R7 Through the parents' network, facilitate a conference once a year for parents of those who are due to transition or have transitioned from out of county provision. This conference would again aid in the dissemination of information and could also be utilised as an arena to provide parents with workshops such as crisis management, dealing with complex behaviour and so on. The Cabinet Member, Director of Adults, Housing and Communities and local providers should again look to engage in the conference, providing the parents with information on local provisions such as staff competencies, information and case studies on where alternative living provisions have improved and developed a young person's skills and outcomes. Such valuable assurance will significantly assist an individual and their support network both in preparation for and during a transitioning period. **(KF6, 7, 8, 12, 13, 17, 22, 27, 30, 47, 48, 49, 50, 51, 52, 53, 65)**

Strategies and Legislation

R8 Due to the proposal under the Additional Learning Needs and Educational Tribunal (Wales) Act for the responsibility of determining education provision (*including funding*) to come from local authorities, the Social Services directorate should look to review the working arrangements between themselves and the Education directorate to ensure robust collaboration workings are in place. **(KF8, 11, 15, 16, 20)**

R9 Ahead of the fundamental change in responsibility detailed in **R8**, and the current concerns surrounding how such funding will be subsidised by the Welsh Government, the local authority should continue to lobby the Welsh Government for an adequate funding formula citing the known demographical pressures. **(KF1, 2, 18, 19)**

R10 In line with the upcoming Additional Learning Needs and Educational Tribunal (Wales) Act and the Welsh Government's Prosperity for All Strategy, all involved professionals must ensure all provisions are discussed during the initial assessment process with both the young person and relevant guardian for their transition into adulthood. Although it is recognised that Welsh Government regulations state local options must be considered first in the assessment process, it is paramount that the

benefits of all provisions, including intentional communities must be recognised and therefore shared with individuals during the process in order to avoid ideological bias. This will also ensure that in line with the concerns of providers captured within this inquiry, the offer of specialist further education is not diminished and will ensure that the benefits of all provisions are recognised whilst mitigating the risk of the Council potentially being perceived as compromised in its role as assessor, commissioner and funder. **(K6, 7, 8, 11, 13, 16, 17, 31, 32, 33, 34, 35, 36, 43, 49, 50)**

R11 Under the upcoming arrangements of the Additional Learning Needs and Educational Tribunal (Wales) Act, officers, when relevant, should give due consideration to the possibility of an individual's educational college course being extended to three years if determined that the individual has not met their educational outcome and would benefit from an additional year. **(KF20, 23, 25, 35, 44)**

R12 There must be clear recognition that those who attend a specialist further education provision, in addition to receiving educational outcomes can also acquire additional skills such as social skills and increased autonomy; this must be more greatly portrayed by local authority staff. Such recognition could be reaffirmed within the possible handbook (R14). **(KF31, 32, 33, 34, 35, 36, 43, 50)**

Finance

R13 As part of the Joint Commissioning Strategy for Adults with a Learning Disability (2019-2024) look to ensure, and/or support, the establishment of a clear formal framework arrangement between the local authority and health board. Such a framework will provide clear roles and responsibilities for the bodies and potentially assist in the establishment of pooled budgets, avoidance of lengthy disputes and further strengthen collaborative working. **(KF6, 7, 24)**

R14 Look to develop a handbook which covers the full spectrum of a transition process which can then be utilised as a tool for disseminating information to those with learning disabilities and their family, setting clear guidelines and expectations and dispelling any confusion. It is essential that the handbook provides an individual with the full scope of the 'next steps' following secondary education and all available options. The handbook should also look to provide clarity on the assessment process for further education provision, including contributing factors, how decisions are made, the evidence which will be required during an assessment, a summary of the funding process, the timeline for which decisions are made and the appeal process which includes clear signposting to relevant regulators. The handbook should also provide a summary of relevant legislation and how it may directly impact on an individual along with information about benefits and entitlements the individual may be eligible for. The Handbook should also look to ensure clarity on average length of placement for an individual undertaking a further education course and also provide generic reasoning for potential discrepancies in course lengths. This handbook must be provided to each individual transitioning from children to adult services and must also be available in schools and any other relevant avenues deemed appropriate. Local providers should also consider contributing to the handbook to ensure their services are fully reflected. The Handbook should also be available electronically on Cardiff Council website and should also be available in alternative languages on request. **(KF5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 17, 22, 27, 28, 29, 30, 31, 32, 33, 34, 35, 37, 38, 40, 41, 42, 43, 47, 48, 49, 50, 51, 52, 53, 59, 60, 65)**

R15 There must be a specific, separate pathway and subsequent published guidance for further education leavers. The service area must ensure that the pathway addresses the full range of an individual's requirements, including but not limited to, accommodation provision, employment, life-long learning provision, long term health, friendships and relationships (*remaining mindful to both current and future needs*). **(KF6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 17, 27, 28, 30, 37, 38, 40, 41, 42, 43, 47, 48, 49, 50, 51, 52, 53)**

R16 A rigid schedule for the decision making process for transition between provisions should be formed which includes a set timetable of when all stakeholders must be informed of a decision outcome. Within all published guidance, and verbal discussions, all local authority officers must ensure clarity is provided to individuals and involved family members on the duration of placement length. If a placement is provided temporarily or it is known it will cease (*e.g. educational course*) clear guidelines on when a transitioning phase will begin must be provided to the individual and any relevant family members prior to a placement commencing. In order to ensure no undue stress for the individual with learning disabilities, subsequent provision must be confirmed prior to a placement ending. If provision is unable to be confirmed prior to a placement ending, where current providers are able to extend their provision for an agreed period of time, due consideration should be giving to facilitating such possibilities whilst permanent provision is sourced. This possibility should be considered early in the transition process. Greater structure around the decision making process will facilitate more enhanced communication between all involved stakeholders, avoiding potential disputes and ensuring more effective outcomes for all involved **(KF9, 10, 11, 13, 14, 23, 25, 37, 38, 40, 41, 44, 48, 49, 50)**

Transitioning from an of out of county provision

R17 Being mindful to known demographic pressures, undertake a review in order to consider if four transition social workers who cover the full transition spectrum from Children to Adult services is enough to adequately provide individuals, who may also undergo a transition in accommodation provision, with the required consistency to ensure their needs are best met, minimising any potential disruption and distress, and maximising a smooth transition. **(KF1, 2, 5, 26, 28, 29, 40, 41, 49)**

R18 Agreement amongst all stakeholders within a transition process must be a fundamental priority. This could be achieved by providing continued assurance that compatibility factors such as age group, sex, type of learning disability, complexity of support needs, personality etc. is considered throughout the transition process. Evidence gathered during this consideration should be

shared with both the individual and relevant family member (*where appropriate and in line with the adherence set out in R5*). **(KF38, 42, 45, 49)**

- R19** Look to develop an assessment centre which allows for onsite assessment which will subsequently ensure no individual is transitioned from any out of county placement, including further education provision, without appropriate accommodation being sourced and confirmed. Such a facility will help to avoid potential regression in skills and/or place unnecessary strain and disruption on both the young person and any involved family members and act as a tool for contingency planning. **(KF25, 44, 46, 54, 55)**
- R20** It is felt by Members that the move to support young people with learning disabilities to progress into adult life within their home area, further emphasises the importance of early planning and need for greater multi-disciplinary team working around the young person which is vital if the individual wishes to progress into more independent living. Therefore, where possible (and required) multi-disciplinary approach must be applied to those leaving further education provision. **(KF35, 39, 60)**
- R21** Look to gather feedback surrounding transition between provisions in a more strategic way by implementing a structured feedback process with all relevant stakeholders including the young person and family members who have undergone a transition from an out of county provision. The framework should look to determine service user satisfaction, performance monitoring and identify possible areas for improvement within the process. **(KF58, 60, 61)**
- R22** Work with local providers to ensure all documentary evidence such as risk assessments, house reports, and an individual's activity timetable and food intake is shared with parents (where appropriate) in a more structured manner. Such a process would help encourage and stimulate parents' confidence that their child and their needs are being met and developed and provide parents with assurance that each aspect of their son or daughter's life such as diet choice is being overseen. **(KF51, 52, 53, 59, 60)**

R23 Take an active role in encouraging providers to further develop their Positive Behavioural Support (PBS) approach through organisational strategies which focus on developing staff skills and enable PBS to become more widely embedded in routine practice. Encourage and facilitate providers to more greatly distribute this information to all relevant stakeholders. **(KF51, 52, 53, 60)**

R24 Encourage shared learning across providers. Such shared learning will not only provide an opportunity for individuals' with learning disabilities to meet other peers, but also provide a valuable assurance of the quality of care on offer within local providers. **(KF51, 52, 53)**

The Capturing of Data

R25 During the transition process, ensure the sharing of information between providers is facilitated as soon as new provision is confirmed and ensure this is continued as an ongoing process in preparation for the transition. Provide an active role in certifying that all relevant documents and information obtained on the individual during an out of county provision is transferred to the new provider prior to a placement commencing. Consider including this process of conveying information between providers within the Cardiff & Vale Multi-Agency Protocol for Children and Young People with Additional Learning Needs' (*currently in draft form*). The information which is transferred between providers, should be available (*where appropriate*) on request. **(KF17, 46, 56, 57, 60)**

Gaps in Local Provision

R26 If not already in practice, encourage local providers to consider enlisting parents onto their Board of Trustees. Such engagement and collaboration would stimulate and encourage better relations and understanding between parents and local providers. **(KF51, 52, 53)**

R27 As stated in the National Commissioning Board's guidance document, *Commissioning Accommodation and Support for a Good Life for People with a Learning Disability*, the service area requires clear focus when developing the provider market, ensuring that all provision developed adds social value and improves an individual's wellbeing.

In line with the growing demographic pressures, the service area should look to locally develop a specialist provision specifically catering for those with complex needs.

(KF1, 2, 3, 4, 23, 25, 33, 34, 36, 50, 62, 64, 65)

R28 When developing local options, formal evaluation should be drawn upon to ensure that the cost-benefit of different models are accurately assessed. The service area should consider commissioning an independent cost-benefit analysis and impact assessment on the immediate and longer term benefits of all out of county placements, which is to include health benefits and sustainability of the skills individuals may acquire when placed out of county, with a particular focus on those diagnosed with high, complex needs. Such work should also include benchmarking costs against other local authorities in order to determine the possibility of providing individuals with greater opportunities for alternative provision, including out of county placements where appropriate. Such formal evaluation will also greatly assist the development of local models. **(KF3, 23, 25, 31, 33, 34, 35, 36, 50, 62, 64, 65)**

R29 Within the work of the Accommodation Strategy which is currently being developed to identify, develop and improve local options, the service area should look to include buildings not currently in use, particularly those located in the suburbs of Cardiff with more grounds. **(KF3, 34, 62, 64, 65)**

Monitoring & Review

R30 A robust review process of an individual's health, well-being and skill set must exist for all individuals who have transitioned from an out of county provision. This process should include specific assessment measures, which are captured both pre and post move in order to determine any potential 'impact' of a transition. Such monitoring will more greatly ensure that an individual's quality of life and skill set are both maintained and developed within provisions. This plan for specific assessment measures should be developed in line with the providers and subsequently shared with all concerned parties including the individual and their family (*where appropriate*). **(KF45, 50, 57, 60, 61)**

Introduction

13. The task group reviewed a draft scope for the Inquiry at its first meeting and agreed for the terms of reference to be:

- To review current pathways (with a particular focus on the decision-making process) in relation to supported living arrangements for adults with a learning disability;
- To review residential College placements and how decisions are made in terms of continuation;
- To identify best practice in relation to transitioning individuals from an out-of-county placement back into Cardiff;
- To engage with service users and their families in relation to the above whilst also understanding their level of involvement – placing them at the centre of any recommendations going forward;
- To identify current funding arrangements, consider whether this is being used effectively and make recommendations accordingly;
- To identify and recommend a range of options and provision (based on best practice) that could be developed and implemented in Cardiff.

Members of the task group were:

- Councillor Mary McGarry (*Chair*);
- Councillor Ali Ahmed;
- Councillor Susan Goddard⁵;
- Councillor Sue Lent;
- Councillor Bablin Molik⁶.

⁵ Cllr Goddard was a Committee Member until September 2019

⁶ Cllr Molik was a Committee Member until June 2019

14. Members agreed to hold a number of meetings and to receive the following information:

- Overview and background – to set the context for the Inquiry and gain an understanding of the current projects, plans, proposals and assessment process around out of county placement for adults with a learning disability.
- Members also received evidence from the Cabinet Member for Social Care, Health and Well-being, senior officers within the Social Services directorate and external witnesses from both out of county and local providers during their visits including: Bridgend College, Coleg Elidyr, Glasallt Fawr, Values in Care, Vision 21, Dimensions Cymru, Innovate Trust and Mirus.
- In order to ensure the inquiry received far reaching evidence, a Call for Evidence was also requested to both local and out of county providers in order to further understand both the Council and provider's role within a transition process.
- During the course of this Inquiry, the task group also commissioned primary research with both parents and advocates in order to establish the information and support requirements of service users and their families within a transition process. The research relied on qualitative research methodologies such as one to one interviews and focus groups. In total 12 young adults with disabilities were represented within the work. Parents of a further two individuals who had transitioned from out of county residential settings were invited to participate however for different reasons the scheduled interviews could not be undertaken.
- Members also reviewed a number of background documents which had been identified as relevant to the work of this Inquiry.

POLICY CONTEXT FOR OUT OF COUNTY PLACEMENTS FOR ADULTS WITH A LEARNING DISABILITY

Legislative Framework

15. There are several pieces of legislation that have contributed to shape out of county provisions for adults with a learning disability in Wales. Chronologically they are as follows:

- **All Wales Strategy 1983** – this was designed to deliver a range of community services for individuals with a range of disabilities. Prior to the 1980's, there was no supported living accommodation for people with a learning disability in Wales – instead they resided in Hospitals or in their own homes. The vision of community based support for adults with a learning disability was the key driver of this policy and the subsequent hospital resettlement programme. Locally in Cardiff, Ely Hospital closed in 1999.
- **Welsh Mental Handicap Strategy 1994 (Guidance)** - recognised that individuals with learning disabilities should have the same freedom as anyone else to choose where they live and whom they live with.
- **Learning and Skills Act 2000** – holds the Welsh Government as responsible for securing the provision of a range of facilities for education and training for young people aged 16-25 (*with or without Learning Disabilities*). This includes the provision of further education institutions such as specialist post-16 education.
- **Social Services & Well-being (Wales) Act 2014** – focuses on improving outcomes for individuals by encouraging independence and keeping people out of long term or institutional care. The local authority has a duty to assess an adult if it appears that they have needs for care and support, and if they are ordinarily resident in the authority's area (s19). The duty to provide accommodation if required is laid out in s34-35 of the Act.
- **Well Being of Future Generations Act 2015** – requires the local authority to make “reasonable adjustments” in how services are provided in order to reduce preventable inequalities in health for people with a learning disability

- **Regulation and Inspection of Social Care (Wales) Act 2016** – provides the statutory framework for the regulation and inspection of social care in Wales. Regulations within the Act states that within seven days of an individual being placed, the service provider must assess how the individual's care and support needs can be best met, achieve their outcomes, ascertain the individual's views and assess any risks.
- **Additional Learning Needs and Educational Tribunal (Wales) Act 2018** – under the Act, local authorities will become responsible for learners with Additional Learning Needs from the age 0-25, ensuring they can access suitable education and/or training, including compulsory education and specialist post-16 education or training where necessary.

Although not legislation, the Joint Commissioning Strategy for Adults with a Learning Disability (2019-2024) sets out how Cardiff and Vale of Glamorgan Council's and Cardiff and Vale University Health Board will work together to respond to the needs and aspirations of the adult learning disability population within the context of national legislation and guidance, wider local plans and available resources. At a local level, the strategy will inform what services each of the three organisations will individually or jointly commission to meet personal outcomes, encourage participation and promote independence over the next five years.

KF6

Key priorities of the Cardiff and Vale Joint Commissioning Strategy relevant to this inquiry are:

- Information; accessible and easy to understand;
- Choice and control – listening to the person and carer's views;
- Right care at the right time – early crisis and respite support;
- Day opportunities – volunteering and work experience;
- Transitioning should be joined up and planned well.

KF7

Special Educational Needs (SEN)

16. Special Education Needs legislation is set out in Part IV of the Education Act 1996. Legislation relating to post-16 learners in further education with learning disabilities is included in the Learning and Skills Act 2000.
17. The Welsh Government currently have a general duty under sections 31 and 32 of the Learning and Skills Act to secure 'proper provision' for the education and training of learners aged between 16 and 19, and 'reasonable facilities' for those over the age of 19. This Act also requires Welsh Government to secure the provision of boarding accommodation for children and young people with learning disabilities if they cannot otherwise secure provision of facilities for education and training which are sufficient in quantity and adequate in quality for those aged 19 to 25.
18. Section 140 of the Learning and Skills Act 2000 places a duty on Welsh Ministers to make arrangements for the assessment of young people who have SEN, where they are likely to leave school at the end of the last year of compulsory schooling, to receive post-16 education, training or higher education. It also gives Welsh Ministers a power to do so in relation to those up to the age of 25 who do not have a statement of SEN but who appear to have a learning difficulty.
19. This legislative framework is based on a model introduced more than 30 years ago and is deemed as no longer fit for purpose.
20. A series of enquiries and reviews of SEN provision in Wales by Estyn, the Wales Audit Office and the National Assembly's former Education, Lifelong Learning and Skills Committee have highlighted that the current system is complex, bewildering and adversarial. The evidence points to an assessment process that is inefficient, bureaucratic and costly, as well as being insufficiently child-centred and user-friendly.

21. Key weaknesses which have been identified within the current SEN system are:

- The existing SEN Code of Practice is not always applied rigorously or is interpreted differently by different local authorities;
- Trust between parents and local authorities or schools, is often undermined and this leads to dispute;
- It is difficult to adopt a flexible approach to the delivery of special educational provision⁷.

The primary research conducted by this inquiry highlights that under current arrangements, the majority of parents interviewed would request better understanding and guidance of the transition process involved in moving their child from specialist further education to the appropriate care and support arrangements in Cardiff. In particular, parents highlighted the need to improve engagement between themselves and the service area along with greater recognition that their input significantly assists the objective of meeting a child's 'best interest.'

KF30

22. During the inquiry Members heard that within current systems, there is a vast variation in schools with regard to the practice of ALN, as currently there is no statutory expectation for schools to have a SENCo (*Special Education Needs Coordinator*), which at present, is just seen as good practice. The Additional Learning Needs and Education Tribunal (Wales) Act 2018 looks to unify practice by implementing a requirement that all mainstream schools have a designated Additional Learning Needs Coordinator.

23. During the course of the inquiry it was also confirmed to Members that prior to 2013, there was no disability register for children which also led to difficulties in assessment.

⁷ <http://www.assembly.wales/research%20documents/18-023/18-23-web-english.pdf>. Accessed 5 September 2019.

Additional Learning Needs and Educational Tribunal (Wales) Act 2018

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 (*hereafter referred to as 'The ALN Act'*) makes provision for a new statutory framework for supporting children and young people with additional learning needs. It replaces the existing legislation detailed above surrounding special educational needs (SEN) and the current assessment of children and young people with learning disabilities in post-16 education and training. The Act instead places the responsibility of learners with additional learning needs from the age of 0-25 with local authorities.

KF6

During the course of the inquiry, Members received a briefing from the Additional Learning Needs Transformation Lead for Central South Consortium and Cardiff Council's Senior Achievement Leader Inclusion and were advised that confusion can arise from the interpretation that this Act provides a right for a child with additional learning needs to stay in education up until the age of 25. It was confirmed that the principles of this Act stem around parity and are laid out to ensure that a child with Additional Learning Needs has equal rights in accessing further education courses as a child without Additional Needs, and can therefore access and receive training up until the age of 25.

KF9

Due to the consensus set by Welsh Government policy publications and guidance, the further education option for those with additional learning needs is seen by governing bodies to be one which offers the 'college experience' equating to two years of education, not the 'university experience' which would be three years of education.

KF10

23. It is proposed that the ALN Act will provide a complete overhaul and create:

- A unified legislative framework to support all children of compulsory school age or below with ALN, and young people with ALN in school or further education (FE);

- An integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions;
- Improved collaboration between local authorities and health boards; and
- A fair and transparent system for providing information and advice, and for resolving concerns and appeals.

Primary research conducted for this inquiry has shown that the parents of people with a learning disability involved in this inquiry currently have limited or no knowledge of the ALN Act and the changes it will bring.

KF12

A key element of the ALN Act is its endeavour to increase participation of the individual with learning disabilities, stating that it is imperative individuals see the planning process as something which is done with them as opposed to for them. As such, they and their families should actively be encouraged to participate in the planning process for their educational opportunities through the provision of clear, impartial advice, information and advocacy.

KF11

24. The Act continues the existence of the Special Educational Needs Tribunal for Wales, which provides individuals and their parents with the ability to appeal against decisions made by the local authority in relation to their or their child's ALN; it makes no changes to how the Tribunal will hear appeals but instead renames it the Education Tribunal for Wales.
25. During consultation and pre-legislative scrutiny of the Bill, Assembly Members criticised the Tribunal as having 'lack of teeth' in relation to directing health bodies. In response to these concerns, the Welsh Government inserted, through amendment, a power for the Tribunal to require health bodies to give evidence regarding a case of ALN and for the Tribunal to issue non-binding recommendations to an NHS body

(section 76). The NHS body must then report back to the Tribunal stating the action it has taken in response to the recommendation or why it will not be taking any action⁸.

Timeline of Additional Learning Needs and Educational Tribunal (Wales) Act 2018

26. The Additional Learning Needs and Education Tribunal (Wales) Bill was passed by the National Assembly for Wales on 12 December 2017, the legislation then received Royal Assent on 24 January 2018 and became the Additional Learning Needs and Education Tribunal (Wales) Act 2018.

27. Following consultation with stakeholders, the Welsh Government decided to adopt a phased approach to implementation. On 3 September 2020, the Welsh Government Minister for Education, Kirsty Williams, issued a Written Statement providing an update on the position in relation to Additional Learning Needs (ALN) reform in Wales. The statement acknowledged that 2020 has been an extremely difficult time due to the pressures and disruptions caused by the Covid-19 pandemic. However, the implementation of the ALN Act remains a government priority, and there will be no further extension to the timescales for implementation;

- Implementation will begin in September 2021, for completion by August 2024.
- The final ALN Code and operational guidelines will be laid before the Senedd in February 2021.
- The timeline for commencement of the three statutory posts is by January 2021. The three posts are
 - o ALN Coordinator, or ALNCO (a school post);
 - o Designated Education Clinical Lead Officers, or DECLO (a health post); and
 - o Early Years ALN Lead Officers, or EY ALNLO (a local authority post)
- To support the implementation of the Act from September 2021, information will be provided by Welsh Government around the implementation and transitional arrangements.

⁸ <http://www.assembly.wales/research%20documents/18-023/18-23-web-english.pdf> Accessed 5 September 2019.

Draft ALN Code

28. The Act requires the Welsh Government to produce an ALN Code⁹ which will provide most of the detail for the way assessments and decisions about provision will be carried out; with the Act setting the overall framework.

29. The ALN Code will impose mandatory requirements on local authorities in respect of:

- Information and advice services;
- Independent advocacy services;
- Preparation, content, form, review and revisions for Individual Development Plans (IDPs - *further detail later in the report*)

30. Initial consultation on the Code ended in March 2019 and received over 800 responses. It is believed that due to the high level of discussion and input within the consultation, along with the significant implications for local authorities and health boards, the Welsh Government agreed to change its timetable for implementation (*to that of point 27*).

31. Originally, the implementation period for the ALN Act was to begin in September 2020 and end August 2023. However, on 17 Sep 2019, the Cabinet Secretary for Education announced a revised implementation approach as follows:

- Three-year implementation period, to start in September 2021 as opposed to September 2020;
- mandatory phased approach - learners with existing Statements will transfer to the new system within two years, and all other learners with non-statutory plans within three years;
- old system entirely phased out by Summer 2024; and,
- mandatory new roles expected to be operational by January 2021.

32. It is to be noted that at the time of writing this report, the Welsh Government had not yet confirmed the date from which responsibility for specialist further education provision placements will transfer to local authorities.

⁹<http://www.senedd.assembly.wales/documents/s59527/Draft%20Additional%20Learning%20Needs%20Code%20February%202017.pdf>. Accessed 6 Sep 2019.

Early Years Additional Learning Needs Officers

33. The ALN Act will also bring the introduction of local authority Early Years Additional Learning Needs Officers (*one post for Cardiff*). The purpose of this role will be in contributing to improve early identification in relation to ALN along with ensuring better planning for future provision.
34. It will be the local authority's responsibility to designate an Early Years Additional Learning Needs Lead Officer to co-ordinate the strategic delivery of early year's functions. The Draft Code sets out guidance on the role, experience and expertise that is required. Early Years Additional Learning Needs Lead Officers are also expected to assist local authorities in the delivery of Additional Learning Need functions -such as provision.
35. Under the ALN Act, local authorities will also have a duty to take all reasonable steps toward securing provision in Welsh where required, and when reviewing Individual Development Plans (*detailed below*) consider the sufficiency of Welsh language within additional learning provision.

Primary research conducted for this inquiry highlighted parents' expectations on the need to expand the availability of locally based care and support provision in the Welsh language.

KF63

Individual Development Plan

36. As mentioned earlier in the report, the ALN Act provides a new, unified system for people with ALN; Section 11 of the Act sets out a duty on governing bodies of both schools and Further Education Institutions (*FEI*) to decide whether students have ALN 'where it is brought to their attention or otherwise appears to them' that they may have ALN¹⁰.
37. Where a governing body of a school or FEI decides that a student does have ALN, Section 12 of the Act requires them to prepare and maintain an Individual

¹⁰ <http://www.legislation.gov.uk/anaw/2018/2/section/11/enacted> Accessed 10 Sep 2019.

Development Plan (IDP) for them (bringing an end to the current distinction between school led interventions and local authority issued statements and integrating the current separate legislative arrangements that exist for pupils in schools and post-16 students in colleges). Meaning that all learners with ALN will have the same type of statutory plan irrespective of their age or whether they are in a school, a school sixth form or a FEI.

38. The Welsh Government state this will place learners in further education who currently have separate Learning and Skills Plans (LSPs) on a more equal footing with their school-based counterparts and improve transitioning between school and post-16 education¹¹.
39. In a further bid to improve transitioning, the Act also introduces the transfer of responsibility for access to specialist post-16 provision from the Welsh Government to local authorities. The Welsh Government believes this will encourage local authorities and post-16 providers to work together to plan and make provision, as well as incentivising local authorities to plan for the individual beyond the age of 16 in a way they do not necessarily have to at present¹².
40. The introduction of IDP's were originally scheduled to commence in 2020 within a three year roll out; however due to the pre-determined delays mentioned earlier in this report, implementation is expected to begin in September 2021.

Referrals

41. Under the Act, it will be the responsibility of the school to decide if their student has Additional Learning Needs (ALN). If a child is then deemed as having ALN, the school must provide additional learning provision for that child and formulate the IDP. Local authorities will only prepare and maintain an IDP where the young person's needs are more complex.

¹¹<http://www.senedd.assembly.wales/documents/s59527/Draft%20Additional%20Learning%20Needs%20Code%20February%202017.pdf>. Accessed 6 Sep 2019.

¹²<http://www.senedd.assembly.wales/documents/s59527/Draft%20Additional%20Learning%20Needs%20Code%20February%202017.pdf>. Accessed 6 Sep 2019.

42. As such, the ALN Act introduces a distinction with the most severe and complex cases IDP's becoming the direct responsibility of the local authorities, whilst the others remain the responsibility of schools or FEI's.
43. Along with an IDP being transferred to local authorities due to complex needs, schools can also refer cases to a local authority where the pupil has ALN:
- that may call for additional learning provision (ALP) which would not be reasonable for the school to secure,
 - the extent or nature of ALN which the school cannot adequately determine, or for which the school cannot adequately determine ALP
44. Before directing a school to maintain an IDP, the local authority needs to determine, with due regard to the guidance set out in Code, whether it is reasonable for a school to secure the ALP called for by the child or young person's needs.

Disputes to IDP's

The ALN Act places greater emphasis on disagreement avoidance and dispute resolution. Due to schools maintaining IDP's, the ALN Act will introduce different appeal procedures. Should a young person or parent (*or any other stakeholder*) wish to challenge an individual's IDP or the learning provision they have been provided with, there will be clear routes for them to do so and local authorities must provide access to independent advocacy services for this route.

KF13

45. Within a grievance process, schools can only take the dispute so far (for instance by holding a meeting with the parent to discuss and 'work through' their concerns). If no resolution is found, the school can then go to the local authority to ask for assistance in resolving the matter. It must be noted, that it is the local authorities' recourse to decide if they agree to get involved with disputes put forward to them by the school. As such, it is essential that local authorities provide schools with concrete arrangements for avoiding and resolving disagreements, ensuring any grievances are resolved at the earliest, local level.

46. It is also essential that the local authority puts in place clear guidance for schools on when they should incorporate local authorities in an appeal process.

47. If the local authority agrees with the school on the IDP, the parents would then be advised. However, if the parent is still in disagreement, they will have the right, and be provided with the option, in going to tribunal.

Post 16 Arrangements under the Act

48. As already mentioned, the ALN Act requires local authorities to become responsible for securing places for further education including within specialist further education institutions.

Under the ALN Act, the assessment process for determining further education will focus on educational need; looking at the realistic prospect of an individual completing a course and achieving educational goals.

KF14

49. To elaborate, regulation on post 16 specialist education placements will need to consider the following:

- Does the young person have reasonable need for education or training and if so, what are they?
- Is there a realistic prospect of the young person achieving a desired objective within a reasonable period of time by undertaking a course of education or training?
- Does the young person require additional time to complete post-16 education or training in comparison to the majority of others of the same age who do not have ALN?
- Has there been a previous period of post-16 education or training?
- What courses may be available which would be expected to equip the young person to meet the desired objective within a reasonable period?

50. During the inquiry it was confirmed to Members that under the new assessment process brought in by the Act, consideration will also be given to location and that the offerings of local provisions will be considered first in line with Welsh Government policy. However, as is with current arrangements, if needs cannot be met locally, out of county provisions will be considered.
51. In its document, *Securing Provision for Young People with Learning Difficulties at Specialist Further Education Establishments* (April, 2017) the Welsh Government states that, '*In regards to post-16 education, that all young people who have a learning difficulty should be provided equitable access to further education at a mainstream FE establishment, through the delivery of inclusive options available locally to meet their needs. It is therefore the Welsh Government's expectation that mainstream FE establishments will normally meet the education and training needs of the majority of young people who have a learning difficulty*¹³.'
52. Further education institutions (FEI) will normally be responsible for preparing and maintaining IDPs for their enrolled students, but as with schools, FEIs may also refer more severe and complex cases to local authorities to decide. Where a referral is made, a local authority will be required to prepare and maintain an IDP. However there is no power for the local authority to direct a FEI to maintain an IDP (*this is due to FEI's being independent bodies*).
53. Although, a local authority may request that a FEI takes over responsibility for an IDP, if the FEI does not agree, the local authority may refer the matter to Welsh Ministers for determination. The draft ALN Code describes some of the proposed regulatory detail around such referral including the timescales within which referrals to the Welsh Ministers can be made. However, due to the uncertainty in how this will be managed between the local authority and further education institutions specific regulation from the Welsh Government on determining decision making for post 16 is anticipated.

¹³ <https://dera.ioe.ac.uk/28271/1/170124-securing-provision-for-learners-with-learning-difficulties-en.pdf>
Accessed 27 Jan, 2020.

Impact on LA's

54. The local authority must ensure there are effective, efficient systems and process in place for the changes the ALN Act will bring.
55. The unification presented by the ALN Act stipulates great changes for schools as they will now be expected to become strategic leaders. As such, due to the current differing practice there is a need to influence and change the quality of learning for pupils with ALN – with the need to reinforce basic principles on what every school must do. During the inquiry it was confirmed to task group Members that preparation within this respect has begun and that both school and social services staff are beginning to receive training on this Act and its implications.

The challenge under the ALN Act will likely be around capacity and demand, and although responsibility for further education provision will begin at school, the ALN Act places emphasis on relevant bodies, such as adult services becoming involved to ensure every child and young person with a learning disability known to services is aware of all of the options available to them.

KF15

56. During evidence gathering sessions for this inquiry, Members received the concern from one out of county provider that within the upcoming ALN Act there is a lack of recognition towards specialist provision as part of the post-16 education offer which could result in local authorities acquiring and distributing information about post-16 options which do not include specialist provision.

Funding (under current arrangements)

57. Under current arrangements, funding of post-16 specialist placements is currently provided by Welsh Government. All year 11 plus pupils with 'statements', who are expected to leave school at the end of the current school year and wish to continue their educational provision will receive assessment by Careers Wales under section 140 of the Learning and Skills Act.

58. Where the outcome of an assessment proposes placement for a learner at a specialist further education institution, an application for funding on the learner's behalf is made to the Welsh Government.

59. The Welsh Government considers applications in the light of its published guidance, 'Securing provision for Young People with Learning Difficulties at Specialist Further Education Establishments' (April 2017). When appropriate, Welsh Government will look to health or social services to enter into an arrangement to joint fund specialist placements.

60. Within the current system there is no direct responsibility of the local authority in determining further education provision however as detailed within this report, this will change under the ALN Act.

The proposal under the ALN Act is for funding for all placements to come from local authorities; however the Welsh Government is yet to work out how this will be done in practice. At the time of writing this report, there is no known formula for how funding will be determined and for this reason there are significant concerns within this authority with regard to discrepancies between Welsh local authorities. For instance there is concern that those authorities which display higher trends could be seen as having equal costs to local authorities with much lower trends and expenditure.

KF19

61. Due to the high numbers of those with ALN residing in Cardiff (*and the high numbers likely to move in due to city facilities*) there is major concern with the parity of the formula. It was confirmed to inquiry Members that although the exact funding formula is not yet known what is known is that an average cost will be determined when the Welsh Government are considering the formula which could mean no additional funding and /or increments. It was confirmed to Members that Cardiff is in consultation with the Welsh Government regarding the formula and officers are ensuring that concerns are being widely communicated.

62. In terms of timing, Members were advised that the formula will likely be in place by April 2021.

Children and Families Act 2014

63. It is to be noted that similar reform to that of the ALN Act has already been implemented in England. The Children and Families Act 2014, obtained royal assent and became law (in England) on 13 March 2014. It is seen as a wide-ranging Act designed to fully reform services for vulnerable children by providing them with greater protection, paying special attention to those with additional needs.

64. Part 3 of the Act deals with laws and provisions relating to children who have special educational needs or disabilities. In line with the reasoning's for the requirement of the ALN Act in Wales; it was also determined that the existing system in England did not perform well enough for these particularly vulnerable groups of people, and that a new approach was required.

65. Provisions put in place by the Children and Families Act included the following:

- A new Education, Health and Care (EHC) Plan (*English equivalent to IDP*) based on a single assessment process to replace special education statements. EHC plans are documents that support children, young people and their families from birth to 25.
- The commissioning and planning of services for children, young people and families is now run jointly by health services and local authorities as a result of the Act.
- Local services available to children and families must be made available in a clear, easy to read manner.
- Local authorities must involve families and children in discussions and decisions relating to their care and education; and provide impartial advice, support and mediation services.

Lessons Learnt from the Children and Families Act 2014

66. Due to the requirement of both social care and medical professionals being involved in the assessment of children with special educational needs, it became apparent that there were not enough medical professionals and social workers to meet requirements.

67. The Children and Families Act also placed requirements on local authorities to carry out a complete Education, Health and Care (EHC) needs assessment when transitioning from a Statement of SEN. It was expected and known, that the cost of transitioning all

Statements to EHCs would come at considerable cost to local authorities. An estimate of the national cost is around £1.2 billion – however little planning by the Department of Education appeared to have taken place in preparation for such costings, nor was additional funding provided.

68. Discrepancies in local authorities' in issuing an EHC assessment has also become apparent – with some authorities seen to be only transferring an individual's statement of SEN into a new document with a different layout¹⁴ - as such failing to adhere to any of the assessment process requirements.
69. During an evidence gathering session of this inquiry, Members were also advised that under this Act, only one year of funding towards further education provision is provided by English government to local authorities.

Proposed Arrangements under ALN Act (2018)

During the course of the inquiry, Members heard first-hand the concerns from some of the specialist further education providers on what the proposed arrangements under the ALN Act may bring. The concerns raised to Members included:

- There is a lack of recognition in the Draft ALN Code of specialist provision as part of the Post-16 further education offer;
- Possible lack of provision for independent advice and guidance for parents and young people with both complex and low incidence additional learning needs;
- Possible risk of young people with complex needs being denied Additional Learning Provision by the nature of their ALN.

Further concerns raised were that local authorities:

- Could be compromised by their role as assessors, commissioners and funders;
- May only provide access to information about local post-16 options other than specialist further education provisions (*which are all currently out of county*);
- May end an IDP rather than consider a placement at a specialist further education provision.

KF16

¹⁴ <https://www.senexpertsolicitors.co.uk/site/news/the-children-and-families-act-2014-one-year-on> Accessed Nov 2019.

Increased Collaboration between Local Authorities and Health Boards for Educational Provision

70. The Additional Learning Needs and Educational Tribunal (Wales) Act seeks to improve collaboration between local authorities and health boards, by ensuring that local authorities and health bodies work together in the best interests of the learner.
71. Section 61 of the Act imposes a duty on health boards to appoint a 'Designated Education Clinical Lead Officer' who will serve as a primary point of contact for local authorities. It is anticipated that this officer will not only prompt and facilitate effective collaborative working between the health boards and local authorities, but also ensure appropriate health board input into an individual's IDP.
72. To note, the Wales Audit Office publication, *Strategic Commissioning of Accommodation Services for Adults with a Learning Disability* states that '*despite progress in many areas, local authorities and their partners must do more to integrate services and resolve a number of complex challenges if they are to achieve the ambition of sustainable accommodation-based services.*'
73. Findings from an independent consultancy review which occurred during the course of this inquiry stated that due to current difficulties, Cardiff should look to improve its multi-disciplinary team working. During the inquiry this challenge was also confirmed by staff members who noted that possible solutions, such as possible co-location of working environments between local authority and health board colleagues are being looked into.

Multi-Agency Protocol for Children and Young People with Additional Learning Needs: Cardiff and the Vale of Glamorgan

74. During the course of this inquiry, Members were informed of the development of a regional multi-agency Transition Protocol which is being developed as a result of the Additional Learning Needs and Education Tribunal (Wales) Act (2018) which will look to provide and reinforce joint working, and align process across various partners.

The 'Multi-Agency Protocol for Children and Young People with Additional Learning Needs' (*currently in draft form*) is being developed in line with the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act (2018), the principles of the Social Services and Well-Being Act (2014) and the application of the Mental Capacity Act (2005) amongst other key legislation and guidance. The protocol has been coproduced with stakeholders from Education, Health Services, Social Services, schools, further education institutions and the third sector through attendance at meetings, workshops and engagement events throughout 2018-19. The protocol also links into to the Joint Commissioning Strategy for Adults with Learning Disabilities (2019-2024) as a work stream from the strategy will develop an action plan specific for those with learning disabilities within the transition period.

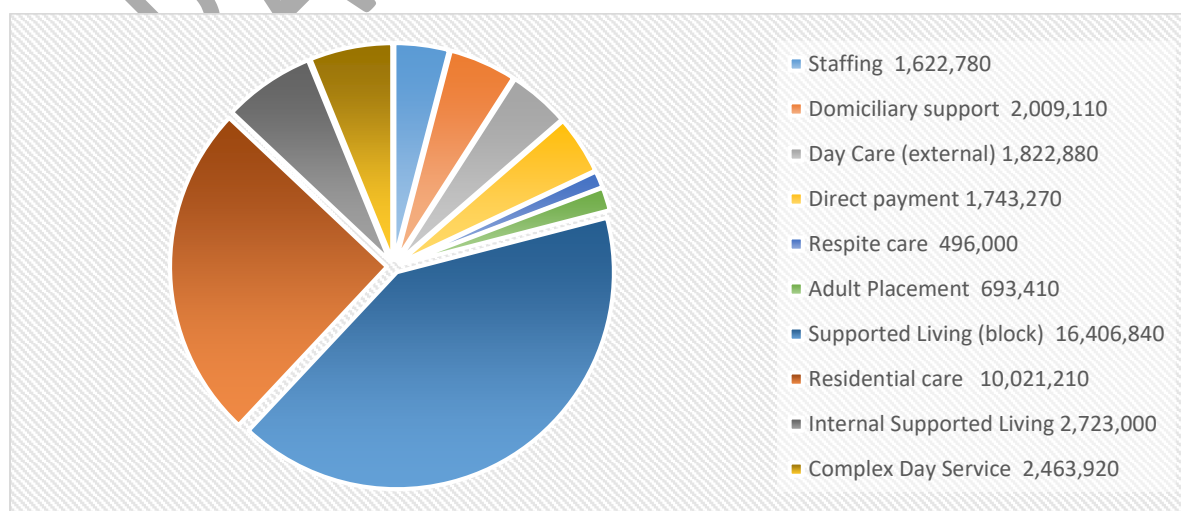
KF1

75. This multi-agency development of the draft protocol looks to strengthen transition services into adult life or further education, and should help ensure consistency and standardised practice across not just the region but inter-departments of Cardiff council. At present, there is a Transition Steering Group of operational managers to oversee the final phase of protocol development and set out expectations across the service area. The expected launch date for this protocol is to be confirmed.

THE CURRENT POSITION IN CARDIFF COUNCIL

Finance

76. As illustrated in the National Commissioning Board's guidance document, *Commissioning Accommodation and Support for a Good Life for People with a Learning Disability* (March, 2019) the financial context for health boards and local authorities over the past ten years have proved very challenging; with sustained pressures on budgets along with increasing demand for services. Such settings have consequently impacted upon people with a learning disability and poses a significant risk to the sustainability of services.
77. During the course of this inquiry it became apparent that there is a shared, collective vision on the significance of funding and need to achieve required savings across the service area.
78. At the time of writing this report, Cardiff Council's budget for adults with a learning disability is £38,970,590pa. Due to the cost pressures mentioned above, a key priority for the service area is to ensure they are using resources wisely to certify maximum quality and effectiveness in meeting people's outcomes. The chart below outlines the service area's key expenditures.



During this inquiry, an independent consultancy confirmed that Cardiff is a comparatively low spending authority in Wales on support for adults with learning disabilities whilst still maintaining good levels of satisfaction with support. This finding suggests scope to increase the quality of local provision for those with complex needs and to consider increasing access to out of county provisions when required.

KF23

Cost of Supported Living

79. As detailed in the above chart, contracts for supported living services for adults with learning disabilities represent a significant proportion of expenditure within Social Services. The overall cost of this service, prior to the recent retendering process, came to £18.2m (domiciliary care element £16.3m, housing related support element £1.9m). Within this figure, support packages range from £9,256.00 per year (less than 20 hours targeted support per week) to £79,746.16 per year (over 112 hours support per week) however, it is to note that costs do differ between support providers.

Cost of Residential Care

80. The average the council fund for residential care for people with learning disabilities is £76,048.96 per year. This figure reflects the fact that many of the Council's residential placements tend to be joint funded with the Health Board as the average price of a residential placement for people with challenging behaviour is £133,217.24 per year. However, it is to note that residential costs have increased significantly as during the last year, residential placements for people with challenging behaviour have been costing on average over £156,000.00 per year.

81. Within residential placements, the council funds the individual's care and accommodation costs (including food, household costs and some activities). The benefits the individuals are entitled to, are reduced as care is provided. On average, an individual within residential care has benefits of approximately £29.50 a week to fund necessities. Additionally, they also retain eligibility for any mobility benefits. In Supported Living, individuals are given tenancies and have control over their own benefits and are entitled to claim for housing benefit to cover rent.

Cost of residential colleges

82. Under current arrangements, the council generally only funds the social care element of residential college courses as typically, along with funding educational costs, the Welsh Government will also fund boarding costs (*unless the person was previously identified as requiring accommodation*).
83. Previously the Welsh Government tended to initially agree course funding for a period of three years, however as of 2019 this has reduced to a period of 2 years with exception sometimes being passed for three years funding if the Welsh Government assess that the individual's identified educational outcomes have not been met during the second year.
84. During this inquiry it became apparent that such discrepancies in placement duration, and the lack of reasoning for such discrepancies stimulates confusion, uncertainty and angst amongst the parents who engaged with this inquiry, with the consistent concern being that such discrepancy could potentially jeopardise their child's learning and development.

It was agreed by the majority of stakeholders who engaged in this inquiry that in order to effect positive change, the decision on the duration of an individual's placement in further education should consider the individual's specific characteristics including their scope and abilities (rate of learning) for developing the skills that they hope to achieve. It is widely suggested by both providers and parents that governing bodies must sufficiently recognise that individuals with a learning disability will take time to settle into a course and that the first year of a course tends to act as an induction period, the second year is developing new skills and the third year provides opportunity for such skills to be consolidated.

KF20

The reduction in Welsh Government funding for further education provision from three years to two, has also had a knock-on effect for local authorities', as more 'move on' accommodation is now needing to be sourced.

KF21

85. Under current arrangements, the local authority does not hold a statutory duty to fund education costs. For instance if an individual requests another year at college to continue receiving educational provision, the council is not able to fund the education element. The council is however able to fund residential placements within a college site if the individual's needs cannot be met locally.

86. Between 2018-2019 residential college funding from social services ranged from £46,000 to £178,000 for a 38-week education year, depending on the college and the student's level of need.

Currently, there are around 300 specialist post-16 placements funded across Wales by the Welsh Government at any one time. The average combined cost for these placements is currently around £21m per annum – with around 50% of cost coming from the Welsh Government, 42% social care (local authorities) and around 5% health funding.

KF18

87. These figures, along with the upcoming shift in responsibility for determining an individual's further education provision (from the Welsh Government to the local authority), and the uncertainty surrounding the funding formula to facilitate this change, presents a significantly concerning reality.

Requests to fund an extension to an agreed programme of study

88. Policy laid out in Welsh Government's, '*Securing provision for young people with learning difficulties at specialist further education establishments*' states that request to extend a young person's educational placement beyond the programme's original agreed end date will only be agreed in exceptional circumstances. The policy specifics that the Welsh Government will need to be satisfied that the circumstances giving rise to the need for the extension were unavoidable and that the extension is objectively necessary to ensure that the young person's identified educational and training needs are met.

Funding will not usually be provided for more than one extension to the same agreed programme of study¹⁵.

89. Further to this, the policy states that the Welsh Government will not consider any extension requests seeking to offer additional time at a specialist FE establishment for the reason of transition planning. The document also outlines responsibility for further education provisions to submit requests for extension to the Welsh Government. In the best interests of the young person, extension requests must be submitted in the individual's final academic year as soon as the need for an extension is known, but no later than 30 April. Where the request is submitted after this date, the Welsh Government cannot guarantee to make a decision before the end of that academic year¹⁶.

Health Funding

90. During their meeting with frontline staff, Members were informed that when determining eligibility for health funding a Decision Support Tool will be utilised by the social worker to determine if any health needs are present in order to assess if an individual may qualify for health funding within their package. There is also a continuing Health Care Court of Protection which ensures the right funding is in place.

Findings from an independent consultancy confirmed that currently there is a disconnect between local authority and health colleagues. It was reiterated that better communication with health colleagues would ensure more efficient working and possibly greater levels of funding. Which in turn will provide more effective services.

KF24

Communication on Funding

During the inquiry Members heard from providers that frustration for both themselves and parents tends to arise where there is uncertainty or questions surrounding funding. Primary research commissioned by this inquiry found a strong desire amongst parents to better understand the funding process.**KF22**

¹⁵ <https://gov.wales/sites/default/files/publications/2018-04/securing-provision-for-young-people-with-learning-difficulties-at-specialist-further-education-establishments.pdf> [Accessed 30 Jan 2020, pg20]

¹⁶ <https://gov.wales/sites/default/files/publications/2018-04/securing-provision-for-young-people-with-learning-difficulties-at-specialist-further-education-establishments.pdf> [Accessed 30 Jan 2020, pg20]

The Transitioning Pathway

91. Currently in Cardiff, individuals are placed in out of county accommodation when local provision is not available to meet their needs. This also occurs for individuals who require specialist further education provision. Occasionally the service area may also have a request to place someone out of county due to the family moving away.

92. It is important to note that many people accessing out of county residential provisions have complex needs. Below is a table detailing the number of individuals (*aged 18-30*) placed within out of county accommodation during the years 2013-2019.

	Supported living	Colleges (Res)	Residential	Adult Placement Scheme
2013	4	13	25	4
2014	7	20	24	10
2015	7	24	27	11
2016	0	20	27	12
2017	0	21	29	11
2018	1	17	25	11
2019	1	14	25	12

93. During the course of the inquiry, the task group had the opportunity to meet with frontline social workers to discuss the current parameters for decision making and the processes currently in place which help determine appropriate pathways for individuals who require transition between provisions.

94. The task group found Cardiff Council social services work-force to be highly professional and were assured by their recognition that every individual is different, and that such uniqueness will undoubtedly always result in different needs. During a meeting with frontline staff it was reiterated to Members that although cost is a factor within the decision-making process, the most important factor is meeting and developing an individual's outcomes.

95. Currently, Cardiff's Learning Disability team is divided into two areas; Cardiff East and Cardiff West, with each area holding team managers, social workers (two of which are transition social workers addressing an individual's transition from children to adults' services), social worker assistants and support planners.

Children to Adult Services Pathway

96. During the meeting Members were advised that if an individual is known to Children Services, around the age of the individual turning 15/16 the Children's Transition Social Worker (TSW) will complete a transition report and forward it to the Adults Services TSW. The transition report is conducted at home with the young person and parent/guardian. This meeting is used to inform the individual of the transition process, the expected next steps (which is when the full assessment of needs will be undertaken), and to obtain the individual's plans/goals/outcomes. The Adult TSW then meets with the family, child, school, Children's TSW to complete a Wellbeing Assessment and Care & Support Plan.

97. Provided the individual meets the eligibility criteria as per the Care and Support (Eligibility, Wales) Regulations 2015, the young person will transfer over to Adult Services at the age of 18.

98. During the course of this inquiry an external consultancy undertook a review of twenty cases and found that generally cases were transferred from Children Services to Adult Services in a timely manner. However seven of the twenty cases reviewed found that assessments were not completed until late in the process.

Determining Accommodation Provision

99. If an individual is identified as requiring accommodation, (under the Social Services Well-being (Wales) Act 2014), this will lead to an accommodation referral which will specify what kind of accommodation they may need.

100. During this time the Supported Accommodation team will offer to meet with families to discuss supported accommodation options in more detail and answer any questions – leaflets and DVDs are also available to help individuals understand the accommodation options available to them. The team also offer to take families and individuals to see

some of the supported living schemes, working with the individual and their family to identify the right option.

101. At the age of 18, a Financial Assessment is undertaken as, depending on circumstances, there is a possibility that an individual can contribute to their care. To note, it is the Council's finance department who undertake these assessments on the individual's financial position via Financial Visiting Officers – the finance team are also informed if an individual receives health funding.

102. If it is not possible to meet the individual's needs locally, it is likely the individual will have multi-disciplinary input with involved social and health care professionals¹⁷ working with the person and their family to identify what provision they require. A complex needs accommodation referral will then be completed which has more in-depth information; this is used to identify what kind of placement is required.

The Current Pathway into Further Education

The current transition planning process following secondary education is set out in the Special Educational Needs Code of Practice for Wales (Welsh Government, 2004) and begins in Year 9 SEN annual review. During the inquiry Members heard that an individual with learning disabilities will typically transition from school to further education around the age of 19 and may transition again 2 – 3 years later. During the inquiry it was confirmed to Members that during this time an individual may remain with the same adult social worker or may be reallocated to another social worker depending on capacity.

KF28

103. As detailed earlier in the report, under the Learning and Skills Act 2000, the Welsh Government are currently responsible for securing the provision of further education and will carry out an assessment (through Careers Wales) of educational needs with the person, their family, the school and Cardiff and the Vale College (under s40 of the Act). Policy specifies that a placement at a local college must be considered and only if this is not suitable, alternative placements will be identified.

¹⁷ This could include social work, community nursing, psychology, psychiatry, occupational therapy, speech and language therapy, physiotherapy and other services who know the person such as education, day service and domiciliary agencies.

104. In order to secure a placement at a specialist further education provision (*which are currently all placed out of the authority*) – the local colleges must first express that they cannot meet an individual's 'reasonable' education and training needs. It is then for Careers Wales to start an application process (S140) whereby the Welsh Government administers applications and monitors progress.

105. During the assessment process a 'school review' is held between the child's current school, Careers Wales, family, social worker and the individual (*if able*) and is usually conducted when the individual is around the age of 14 (*year 9*). Due to the social care element within the S140 application, social services will also provide their assessment to Careers Wales and in turn Carers Wales will provide a copy of their assessment to social services.

106. When the Welsh Government agrees the college placement, they advise the local authority and request funding for the social care elements of the placement such as support for personal care, daily living needs etc. For those pupils, where there are healthcare costs (*such as equipment / therapy*) Cardiff and the Vale Health Board are responsible.

107. Although most out of county residential students with significant disabilities have an element of local authority funding, there are some students with no social care needs who only receive education funding (through the Welsh Government). Thus, under current arrangements, the vast majority of funding comes from the Welsh Government.

Primary research conducted with parents during this inquiry found that most parents have limited knowledge and understanding of the assessment process for accessing specialist further education provision including eligibility requirements, duration of funding and the roles of various stakeholders involved in the process.

KF27

During this inquiry, both parents and out of county providers highlighted the need for consistency in the representation of social workers during the review process of further education placement.

KF29

108. The specialist further education providers who engaged in this inquiry confirmed to Members that course enrolment is matched to both the individual and the students already engaged on the course. This is to ensure the dynamics are right and that no one's learning experience is jeopardised. 'Taster days' are also offered to each potential new student in a bid to ease transition and reduce anxiety. The individual's parent/carer and support worker/social worker are also involved with the 'taster day'.

Benefits of Out of County Placements

109. In the out of county provisions visited by the task group, many of the learners (and/or) residents came from local authorities across England and Wales. The range of disabilities encountered was very broad and often complex. Most have moderate to severe learning difficulties accompanied by another disability and may also exhibit emotional and behavioural difficulties or challenging behaviour.

During the inquiry the following benefits of out of county placements (*both within further education colleges and residential settings*), proposed by out of county providers included:

- Better social mobility;
- Wider relationships;
- Increased self-understanding;
- Improved self-advocacy and self-reliance;
- Reduction of stress on families;
- Improved mental health outcomes;
- Families able to enter employment / increased employment opportunities;
- Improved health, well-being and quality of life and;
- Reduced elective and non-elective hospital admission.

KF31

Specialist further education institutions visited during the inquiry had the benefit of many on-site facilities and services, including but not limited to:

- Speech and language;
- Counselling;
- Occupational therapy assessment.

KF32

The benefits and outcomes were strongly acknowledged amongst the parents (*of those with children in out of county specialist further education provision*) who engaged with this inquiry who in the majority noted their content with the;

- Individualised support programmes;
- Availability of specialist staff;
- Remarkable development in their child's skills, knowledge and independence.

KF33

110. During the course of the inquiry it became evident to Members that there appears to be a clash in ideologies, between the professional perspective of governing bodies and that of the parents on the benefits of alternative provisions and it is strongly felt amongst Members that this discrepancy must be resolved.

The importance of environmental factors and their significant benefit on individual's (with certain needs) physical and emotional well-being was widely recognised by all stakeholders who engaged in this inquiry.

KF34

111. To further elaborate on the environmental benefits of the out of county providers visited by the task group, Members were informed that residents within certain sites were also provided with the opportunity of working on an on-site working farm, and/or tending to animals along with access to on-site allotments.

112. It was felt by Members that due to the environmental settings of out of county provisions, along with onsite access to facilities, the majority of out of county

provisions offer an environment where an individual's skill set is continually developed.

113. In terms of the location of out of county provision, many sites visited were set within rural, spacious settings. During the inquiry it was also reiterated to Members by the out of county providers that although more rural in nature, sites do have easy access to their local community and that the providers strive to help residents build and maintain strong relationships by establishing strong links with the local community. To note, during the course of the inquiry Members were also informed of the benefit of more urban settings which can help an individual develop further strategies for managing daily life within more busy, urbanised settings.

114. During evidence gathering sessions for this inquiry Members witnessed residents in out of county provisions having access to onsite, arts and crafts, weaving and cookery classes (amongst others). Members were further informed that Residents are also encouraged to undertake work experience in the local community.

Although for some young people with disabilities, a specialist further education college may not suit, the perspective presented to Members by specialist further education providers during this inquiry is that the opportunity offered by a specialist setting, for an individual to learn and live amongst peers with similar needs and life experiences can be a very effective way to help them achieve long-term sustainable outcomes that enable them to become active participants in, and contributors to society along with aiding their progression into adulthood.

KF35

115. Both out of county and local provisions visited during this inquiry placed emphasis on the importance of self-advocacy skills (such as social, communication and listening skills) which promote health and well-being through the encouragement of hobbies, healthy eating, and household skills such as cooking and laundry.

116. During the inquiry Members were informed of the HACT Social Value Bank¹⁸, which is a tool used to provide a social impact measurement. During the course of the inquiry Members were provided with information from two out of county providers which states that within specialist provisions every £1 spent sees a social return of £1.38. It is to note, that further information is required on whether this measurement is verified and for what institutions.

117. All provisions visited during the course of this inquiry recognised and placed emphasis on the importance of effective staff who receive continuous, high quality training (*as set out in the Regulation and Inspection of Social Care (Wales) Act 2016*) along with the importance of a low staff turnover.

118. Although recognised in all provisions, Members noted that the specialist further education provisions visited during the inquiry hold the benefit of offering an on-site multi-disciplinary team, including a speech and language therapist and a clinical psychologist (amongst others).

The majority of parents who engaged in this inquiry believe that within a specialist further education provision there is a much stronger opportunity for their child to grow in maturity, develop independence and gain additional skills away from the home environment and that recognition of such skills and opportunity by professionals is paramount.

KF36

119. During their engagement with local authority officers, Members felt that such positive recognition of the benefits of provisions such as specialist further education was not as commonly replicated.

¹⁸ <https://www.hact.org.uk/social-value-bank> accessed: 20 Jan 2020

The Current Pathway for an Individual Returning from an Out of County Placement

During this inquiry, Members were unable to obtain published information which confirmed and clearly laid out the transitioning pathway for adults with a learning disability who may undergo transitioning from an out of county provision. It became apparent that the service area lacked a published framework and guidelines on how identified individuals are brought back from out of county in a structured, personalised way. While a wealth of information was provided to the task group, there was no evidence that this had yet been consolidated into one robust 'pathway' used as a blueprint for returning identified adults into their local county.

KF37

120. While officers were able to provide information when requested and articulate how the transition is accomplished, this had not yet been set out and evidenced into a formal framework. Members were concerned that a structured strategy for those adults with a learning disability, identified as wishing to, or those benefiting from a return to their local county along with college leavers in out of county placements had not yet been completed.
121. At the time of writing this report, there are currently around 150 individuals on the Council's 'move on' list which include those placed out of county identified as wanting to return to the authority, residential college leavers, those currently living at home and so on. Although those labelled as 'high priority' within this number are very small, it is recognised by the service area that this figure does indicate the need to ensure the right properties are being developed locally.
122. In line with the recommendation found in Welsh Government's *Improving Lives Programme* (2018), and *Joint Commissioning Strategy for Adults with a Learning Disability 2019-2024* which endorses an increase in local accommodation options for adults with a learning disability through collaborative working between local authorities, housing, health board and the third sector, Cardiff and the Vale of Glamorgan Council have developed a 'Closer to Home' project which is an informal collaboration between Health, local authority social services and the third sector to

explore ways in which the professional bodies could better collaborate to deliver better accommodation and support services to those with learning disabilities.

123. The project places emphasis on co-production, integrated working, collaboration with the third sector, prevention, evidence-based practice, person-centeredness, quality of life and wellbeing.

124. It is recognised by the service area that placing even a relatively small number of people out of area places major financial strain on statutory bodies which in turn can prevent investment in local service infrastructure and expertise. It is also contended that higher cost and better care are not always correlated and that out of county placements can also place local commissioners in the position where they recognise the need to develop appropriate local services but are unable to do because of lack of available resources to invest. As such, there is a growing consensus, across the UK that the solution lies in the proactive commissioning of local infrastructure of services.

125. It is important to note that individuals who are identified for this project are those who have expressed a wish to return to the authority, where there are concerns surrounding the placement, or where local supported living provision has been identified as meeting their need. During the meeting with frontline staff Members were informed that if an individual has capacity and does not wish to be moved from their out of county residential placement they will not be moved; movement only occurs for those identified as wanting to move or not classed as residential.

126. Currently, the majority of people who have returned from out of county residential care have been individuals stepping down from a history of hospital care.

127. During the course of this inquiry, an independent consultant was commissioned by the service area to undertake a review on the quality and cost effectiveness of current practice. The review included the following key considerations:

- Current service;
- The incorporation of choice and control within the current decision making process;
- Closer to Home Regional Services;
- An opportunity assessment on learning disability provision;
- Quality assurance on the initial transition into Adult Services and;
- To include, and make reference to national academic research on service models for provision.

128. Toward the end of the inquiry Members were presented with the findings from the external consultancy which found that there is a coherent vision across the service area to ensure individuals have equal access to support, which in turn ensures independence and control, and that an individual's outcome and quality of life is at the centre of the authority's decision making. It was also confirmed that there is a strong culture for improvement and self-drive across the service area in order to continue on its 'journey for improvement' and in order to ensure it operates within an open and responsive culture.

If an individual transitions from an out of county residential provision there is a high multi-disciplinary team (MDT) involvement, including health colleagues, specialist behaviour team and so on. Further to this, a wealth of risk assessments along with a full assessment and analysis of care package is also undertaken. This is conducted in full consultation with the family and individual (as appropriate). It is to note that although full and thorough risk assessments and analysis of care package is provided for all individuals, MDT involvement does not commonly occur for those transitioning out of residential college.

KF38

129. Members were also pleased that the sensitivity of such movement is also recognised by staff as it was confirmed to Members that an individual's wants and rights are always at the forefront when decisions are made. However, Members were concerned to hear from frontline staff that due to the lengthy nature of the transition process, on occasion it can be perceived as taking too much time and being too resource intensive.

130. If a local opportunity is deemed the most appropriate option, or can be developed for an individual currently residing in out of county residential accommodation, staff will approach the person and family to consider whether a move back to Cardiff would be beneficial.

The key drivers in determining an individual's provision were confirmed to Members as:

- The individual's wishes
- Families wishes
- Persons needs
- Budgetary position.

Each driver was confirmed as equal in weighting.

KF39

131. Local authority staff who engaged in this inquiry confirmed they always support 'choice' so long as it is in line with the service user's best interest. Members heard that essentially the final decision for the package of care is down to managers. However key stakeholders such as family members, providers, educational facilities are key toward the information gathering which lays the foundation for such decisions.

Members were advised that due to the current climate of austerity and cuts there are requirements for officers to remain within certain budgets. Members were further advised that the level of justifying and producing sufficient evidence in support of a more expensive placement is due to the budgetary position along with Key Performance Indicator requirements.

KF25

132. During the meeting with frontline staff, Members were informed that if an individual is placed out of county, it does place difficulties on the social worker to effectively monitor an individual in their placement due to distance and time required for travel—presenting the argument that it could be deemed that those out of county could be perceived as more vulnerable.

During their review of 20 cases' written records, the independent consultants found that information kept in an individual's case file lacked definition on how the decision-making process within a transition (either from a residential college or from the family home) was undertaken. To elaborate, it lacked detail on the contributing factors and how evidence was weighed. The review also showed that outcomes captured within the data appeared to be too generalised making it difficult to hold providers to account and effectively monitor an individual's progress when a transition has occurred.

KF45

133. However, the independent consultants found there to be strong, coherent positive visions within the service area with regards to transition, with a significant amount of good practice displayed.

Schedule of Transitioning Process

134. The importance of early planning when an individual transitions was both recognised and emphasised by all stakeholders involved in the process. There appeared to be a shared view amongst all stakeholders within this inquiry that early, detailed planning for those due to transition will ensure an individual's needs are best met, minimising disruption and distress and maximising smooth transition.

Based on the views of the parents who engaged in this inquiry, the guidance and scheduling involved in transitioning individuals out of specialist further education provision appeared to be considerably inconsistent.

KF40

Members heard from Council officers that for those placed in a specialist further education provision, the year before their course is due to end a reassessment phase will begin; this inquiry's research found that the transition period tended to be initiated (*with the parents*) around 6 months prior to course end. Parents perceived this as too late in the process with parent suggestions that discussion regarding transitioning for those currently placed in out of county further education provision should start at the end of first year (*for two year funding*) or at the end of second year (*for three year funding*).

KF41

Disputes

135. During the inquiry both local authority staff, providers and the consultants drew Members' attention to difficulties which can arise when there are discrepancies between an individual and a parent's 'wants'.
136. It was further mentioned how in some cases, parents 'wants' could dominate and therefore override the wants of the young person; in turn reducing an individual's opportunity. An out of county providers engaged in this inquiry informed Members that challenges can also arise if parents have unrealistic expectations in terms of their relative's requirements.
137. It was confirmed by local authority staff that disputes are always aimed to be avoided, however if they do occur, they are always looked to be addressed early.

Transitioning from a Residential College

138. If a further year at a residential college is requested, and Welsh Government funding has been denied, the service area will assess an individual's outcomes through a wellbeing assessment and consider the options of a residential placement along with local options with a mindful approach to current resources.
139. During the meeting with frontline staff, it was confirmed to Members that decisions made always have to be evidence based and taken on a need not want basis. As such, when making decision over a possible continuation of placement (*at a residential college*) a level of evidence would be required in order to determine if

continuation at the placement is required and why it would be deemed as being in the best interest of the individual.

Support Planners

140. During the year before a transition is due, Support Planners come in to the process specifically addressing what the service user wants – drawing up possible activities and timetables to suit the individual.

During a transition process, a Support Planner works with individuals to listen to their aspirations & needs with regards to meaningful occupations. The Support Planner has expertise in knowing what opportunities are available locally and becomes involved with an individual following a referral from a social worker should an individual wish to do activities in the community, instead of college, or after college, or while also attending college. Support Planners are involved with over 80 providers and services in Cardiff with a wide range of volunteering, social, sport, arts, health and adult education (life-long learning) opportunities. Since introducing Support Planners, the service area confirmed they have been able to offer a much wider range of occupation options, increasing an individual's skills, confidence and social networks.

KF47

Determining Provisions

During the inquiry it was confirmed to task group Members that a wealth of work goes into identifying properties for an individual – noting that compatibility with current residents, the environment, the needs of the individual and that staff members have the right skills is central to the decision making process. Members found that the significant of these factors was recognised amongst all stakeholders involved in this inquiry.

KF42

141. As supported living is seen as the main model of care which can accommodate the broadest range of needs, supported living routes are the ones explored first in an assessment. It is significant to note that each individual will receive individual care when formulating their care package, for instance some individuals may request a

more holistic approach whilst others may not consider themselves as having a disability and will not want (*or necessarily need*) high level provision.

Although it was reiterated to Members that all provisions are equally acknowledged, valued and utilised, Members hold concerns that under current practice it appears that provisions perceived as 'intentional communities' and their benefit as a provision is not widely recognised. Members wish to reiterate the importance of seeing the value in every provision as stated in the Welsh Government's *Prosperity for All* document.

KF43

142. Once accommodation has been identified, an individual will have the opportunity to visit the property, meet other residents and those that will be supporting them. Once provision is agreed, together, with the individual and involved family members the service area will implement a detailed plan for the move including 'tea visits' and overnight stays before the final moving date. In order to ensure there is compatibility, the service area look to have this 'transition' period complete within three months however in some instances, this can take longer. The average duration of a transition period significantly highlights the sensitive approach taken by the service area and reaffirms that compatibility is at the forefront of an individual's transition.

Through engagement with both parents and providers, this inquiry found that during the transition process following further education provision, incompatible options are suggested and it appears that a process is followed even when known and advised by stakeholders that the suggested placements won't work.

KF44

An out of county provider who engaged in the inquiry, provided the group with an example of one resident who transitioned home after extended funding had not been agreed and the provider was then contacted by social services three weeks later inquiring if provision for this individual was still available as it had been determined that there were no suitable provisions available locally.

KF46

Primary research conducted with parents during this inquiry found variability in their understanding of the overall transitioning process. It became evident they require clarity on the roles of stakeholders involved in the process, including their own role, along with an indicative timeline and greater detail of the specific stages involved.

KF48

Engagement with parents during the transitioning process

143. Improved access to information is a key priority in the Cardiff & Vale Joint Commissioning Strategy and a stakeholder project group is being set up under the Learning Disability Stakeholder Group to develop an implementation plan regarding this.

During the inquiry Members were informed by officers that when required, future placement options are continuously discussed with the individual and the family. Findings by the consultants further confirmed that, in the twenty cases they reviewed, good evidence was displayed demonstrating that young people and their parents/carers are actively involved in the process. However, primary research commissioned by this inquiry found that, out of six parents involved in the research whose children had gone through the transitioning process, two confirmed a positive experience. The other parents cited improvements could be made in engaging with them.

KF49

144. Such information suggests that although engagement is happening, there are questions surrounding its effectiveness.

Incorrect Assessments

145. During the Call for Evidence undertaken by the inquiry, both local and out of county providers alerted Members to the potential ramifications of incorrect assessments which fail to capture relevant or accurate data, which could possibly result in negative consequences for the individuals and family members during a transition process. Members' raised this issue with frontline staff who confirmed the importance of the final transition meeting (*which includes all professional bodies and family members*

along with the individual) along with the significant need to ensure that there is a correct balance between all of the pertinent factors when determining placements. During the inquiry Members were informed that typically, incorrect assessments occur due to the variance of environments where an assessment is undertaken.

KF54

146. The ramifications of incorrect assessments were recognised by the service area who confirmed to Members that in order to address these issues they are currently working with providers to initiate earlier provider assessments. It is hoped that such assessment would be carried out several months before the individual was due to finish college in order to help understand the individual's needs better and match them with upcoming vacancies earlier in the process. Members were advised this approach has been discussed with all providers with a view to formalising this arrangement in the near future.

147. During their attendance at a Learning Disability Wales conference, Members became aware of Conwy Council's work in partnership with a third sector organisation to deliver a 'Planning for the Future Service' which is designed to support individuals with learning disabilities and their parents/carers to plan for and help during their transition period into more independent living.

Conwy Council's 'Progression Project' is designed to assist the assessment process through the development of a more informed understanding of accommodation and support needs. The Project consists of a refurbished bungalow which provides individuals with a 'come and try it' service for independent living. With individuals residing for the day, overnight or staying for a few days in order to ensure their needs are best determined.

KF55

148. During an individual's stay at the bungalow, assessment is undertaken of their daily living skills and support needs led by an Occupational Therapist. It is felt that spending time at the bungalow not only provides an individual with the opportunity to see if they are ready to move on from their current living arrangements but also helps to:

- Understand what the person needs to do to become ready to move on;
- Develop a thorough understanding of the person's outcomes and;
- Consider how the person's outcomes can be best supported before a longer term service is commissioned.

149. When visiting a specialist further education institution who engaged in the inquiry, Members learnt about their onsite 'independent training flat' which the provider draws on in preparation for an individual transitioning.

150. It was highlighted by the provider, that such facilities are a firm avenue for potentially avoiding 'incorrect assessments'. It was felt by Members that such resources would help better gauge correctly how an individual's needs can be both met and developed. It was also discussed that such facilities could be accessed if any delays should occur in sourcing longer term provision. Ensuring an individual's skills are maintained during a potential interim period, resulting in better transition planning and ensuring smooth transitions.

As a result of the Call for Evidence Members initiated with both local and out of county providers, it was confirmed that when an individual's placement is confirmed they, as the provider, will receive a Care Plan and/or a Unified Assessment which outlines the individual's abilities, capacity and needs, providing a brief overview of an individual's communication abilities, mobility, physical and emotional needs, special equipment, adaptations, educational need, medical information and so on. It was also confirmed that if the individual is a college leaver, they (*as a local provider*) would also receive a written assessment from the educational facility and/or a psychology report. However, one local provider noted that they tend to only receive such introductory information on an individual post entry.

KF56

In order to ensure the process of sharing information between providers is both efficient and effective, Cardiff Council's Learning Disability team are currently working with one out of county provider on developing an all-encompassing document to assist in this process. **KF57**

Supported Living Placement Following Out of County Provision

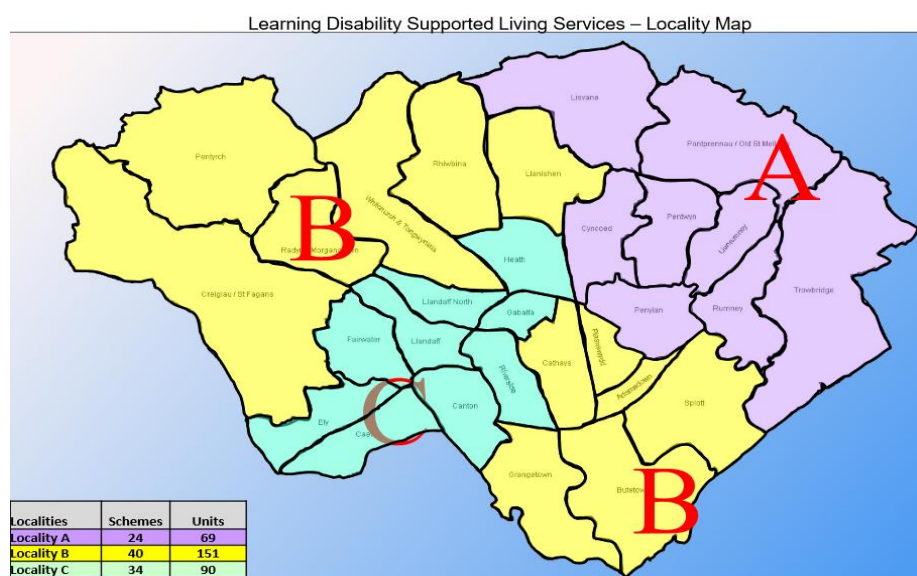
151. Supported living models currently available in Cardiff include:

- Living in a rented or owned property and getting an individual support package;
- Shared Housing - sharing with other adults with a learning disability in a rented property (*usually a Registered Social Landlord*) with each person receiving an individual support package;
- Extra Care or Sheltered Housing;
- Adult Placement / Shared Lives - lodging in someone else's home and receiving an individual support package;
- Living in an extension to a family home and receiving an individual support package;
- Core and Cluster accommodation and support - living in a network of houses or flats with others whilst in receipt of an individual support package.

152. Within Cardiff support is delivered by commissioning with external organisations in the main, with internal support offering a service to 27 individuals. During the course of the inquiry Members were informed that the Council has recently completed a supplier and gap analysis which has identified the need to develop more supported living services locally.

153. During 2019, Cardiff Council undertook a competitive retendering of its supported living providers, with Supported Living Service being divided into geographical localities across the city and independent providers bidding to provide and manage the schemes within each locality.

The geographical locality used within the retendering process was as follows:



154. It is to note, that the evaluation process for the retendering was 60:40 (*with 60 being on quality of care 40 on cost*). This approach was implemented in order to ensure all providers selected presented robust, high quality support. After thorough assessment, 8 year contracts were awarded to the following providers:

- Innovate Trust
- Dimensions Cymru
- Mirus Wales

Local Provision for Lifelong Learning

155. It was confirmed to Members that the provision for lifelong learning is initially assessed within an individual's Care Plan and then developed in the individual's Personal Plan. Within the assessment, it may be identified that an individual would benefit from, or may request, formalised learning where they attend providers such as Vision 21, Community Adult Education and Innovate Training Work Opportunity, whereby formal accreditation is offered.

156. During this inquiry Members had the opportunity to visit some of the lifelong learning opportunities available within Cardiff. One of the providers visited, provides realistic, work-based training opportunities for people with learning disabilities across 17 training enterprises located across South Wales. An example of some of the training delivered by this provider included:

- Horticulture experiences,
- Retail,
- Catering,
- Woodwork,
- Ceramics,
- ICT
- Small Animal Care,
- Pottery

157. Local vocational provision available in Cardiff is available to individuals with a range of abilities from high need to low need. Support levels vary according to the individual's needs and the type of project. Members were informed that a lot of trainees tend to be on a staffing ratio of around 1:5, although there are trainees with 1:1 ratio support, it was confirmed to Members those with the higher level of need tend to bring in their own support staff.

158. In line with the Cardiff & Vale's Joint Commissioning Strategy priority (*Work, Volunteering & Day Opportunities*), local provisions also offer individuals work experience.

The importance of a lifelong learning framework which allows for exceptional development of an individual, encouraging growth in confidence, developing an individual's independence and having an all-round positive impact on an individual's life was shared by all stakeholders who engaged in this inquiry.

KF50

Although all local providers who engaged in this inquiry reiterated that the retention and development of an individual's skill set are at the forefront of their organisation, this inquiry's primary research found that out of the parents whose child had transitioned, most were unsure whether their child has sufficient opportunities in their current provision to undertake the activities and tasks that would help to maintain the knowledge and skills that they acquired during their college placement.

KF51

Croen et al (2015) identified that people with autism are at increased risk of physical health issues including diabetes, gastrointestinal disorders, high cholesterol, hypertension and obesity. Relationships with food can also be complex due to sensory needs, obsessive behaviour, anxiety or isolation. Such concerns were reiterated by some of the parents involved in this inquiry, who voiced their concerns that they were unsure if their child, who now resided in local provision, is encouraged to undertake sufficient physical activity and make healthy food choices.

KF52

The findings of the primary research, commissioned by this inquiry show that parents of those currently residing in local provisions are unsure whether activities for their child are carried out as planned.

KF53

159. The concerns captured by parents within this inquiry's primary research are recognised by the service area who informed Members that greater communication and more publications for those who have transitioned is required in order to strengthen the parents knowledge and dispel any possible concerns.

160. During the course of the inquiry Members were informed of a mobile 'app' developed by one local provider which provides family with a safe environment to communication with each other – share pictures, stories etc. See written reports on their child and be provided with 'live' class information, for instance if a class their child was due to attend was postponed / cancelled – providing involved family members with accessible monitoring information. Members were informed that families have responded well to the app and due to the successful feedback the

provider are hoping to be Cardiff wide and are therefore looking at possibly expanding the app out to all support users. However to ensure regulations are met, particularly with regarding to personal data which could be stored on the app the provider noted that Care Inspector Wales will need to be involved.

161. It is felt that such proposed development could also be utilised to address the issues captured within the primary research surrounding parents perception on staff competencies and the effective delivery of care and support plan by local providers.

Positive Behaviour Support

162. During the course of the inquiry, Members received a wealth of information surrounding the nationally recognised Positive Behaviour Support (PBS) model (*which was both recognised and in practice in the majority of out of county and local provisions visited during this inquiry*).

163. Members were informed that PBS is an evidence-based, values-led, person-centred, proactive model which focuses on improving an individual's quality of life and preventing challenging behaviour.

164. PBS looks to promote an individual's physical and emotional well-being, addresses physical and mental health issues, emphasises personal and skill development, promotes human rights, dignity and respect and aims to enhance an individual's living accommodation whilst striving to reduce challenging behaviour for individuals with a learning disability.

165. PBS is widely recommended across the UK (and internationally) as best practice in supporting individuals with challenging behaviour. Within the model of PBS, emphasis is placed on understanding the factors which influence behaviour whilst developing strategies which seek to improve quality of life and minimize (or eliminate) challenging behaviour.

166. During the course of the inquiry, Members were also informed by a local provider of the (national) STOMP project which looks to stop the over medication of psychotropic medicines for individual's with a learning disability. Members were informed by the

local provider that, where appropriate, they will undertake this project looking at an individual's needs, understanding why the medication may have been prescribed (and when), verifying how the medication is reviewed and undertake relevant analysis to see if there are other methods (*such as PBS, active support or certain communication strategies*) which could be drawn on to determine if a reduction plan could possibly be put in place to support an individual more effectively.

167. Members were further informed of one service user supported by the local provider who went through the STOMP project who 'had an exceptional turnaround with an unrecognisable amount of new energy'.

Monitoring & Evaluation Arrangements

Supported Living & Residential Placements (CIW regulated)

168. Whether an individual resides in a supported living model of care, or residential, their placement is closely monitored by their social worker and any involved family. The individual will also receive a wellbeing review at least annually, or more often if required. The service provider will also hold an annual placement review with the individual which the social worker and family are invited to – although again this may occur more often if required. For example, some providers will have 6 weekly multi-disciplinary meetings if required for those with more complex needs. Social Workers tend to visit those people who are experiencing difficulty or crisis regularly to monitor and review their wellbeing and support. Family's may also visit regularly and are encouraged to feedback any concerns or observations.

Residential colleges (Estyn regulated)

169. Colleges tend to hold bi annual or annual reviews of the person's education and social progress with the individual, their family, college staff, Careers Wales and the social worker. It is during such reviews that Careers Wales will assess the educational progress in order for the Welsh Government to decide if the person has met their educational outcomes or whether to extend funding. Social Work wellbeing assessment reviews are also held as required (*at least annually*). In some instances, the individual may have a different care and support package during college holidays

so the social worker will therefore monitor their progress both at college and in the local services.

Dr Edwin Jones' report on Western Bay's Closer to Home project places significant emphasis on the success of the Positive Behaviour Support model and the use of a core multi-disciplinary team within the transition process. In addition, the report also highlights the importance of data, which is captured both pre and post move, being utilised in order to best understand and monitor the impact on an individual who has moved in order to ensure full quality of life is achieved.

KF60

When meeting frontline staff, Members queried what data is kept on those who have transitioned from an out of county provision and if the impact on an individual who has transitioned is specifically measured in order to ensure progress is sustained.

Members were advised that following a transition, social workers will undertake an 8 week review which is then repeated at 6 and 12 months; to note, additional reviews will also be conducted if required. Such work is called 'person centred planning reviews' or 'pathway plans'.

KF58

170. Members believe that a clear, defined focus on an individual's outcomes following a transition in provision is paramount toward providing, developing and maintaining effective services. Although it was confirmed to Members during this inquiry that the outcomes of a person who has transitioned is a crucial part of the current process and actively tracked in line with the requirements set out by the Social Services Wellbeing Wales Act, it was unclear what specific measures were used to effectively capture the data.

171. During the meeting with frontline staff Members were advised that there is an element of quantitative scoring mechanism within the assessment process, however the effectiveness of the data it provides could easily be questioned which is why a narrative /qualitative approach is drawn upon more.

In line with the Wales Audit Office Report recommendation (*Strategic Commissioning of Accommodation Services for Adults with a Learning Disability, 2018, R6*), there appears to be a lack of formal, systematic monitoring and evaluation process on individuals who have transitioned which is managed by the authority .

KF61

Providers Assessments

172. In line with Regulation and Inspection of Social Care (Wales) Act 2016, Supported Living providers develop an outcome-based service delivery plan with the person which includes preferred daily routines, occupation, skill building and social opportunities. This is monitored by involved families, professionals and the supported living team.

173. The Call for Evidence undertaken by the inquiry confirmed that a structured needs assessment is in place by both local and out of county providers. However, it was unclear how information captured by local providers is shared with parents. It was also unclear what Cardiff Council's role was in facilitating the movement of such data.

This inquiry's Call for Evidence confirmed that local providers (*in line with the Care Plan developed by social workers*) will develop a Personal Plan with the individual, which includes lifelong learning and skill development opportunities. This Personal Plan is reviewed at least 3 monthly by provider staff. However, a majority of the parents who engaged with this inquiry whose child resided in local provisions, were unaware of such reviews. **KF59**

Cardiff Council's Role in Monitoring Provider Services

174. It was confirmed to Members that Cardiff Council has a good relationship with providers and undertakes monitoring of providers in a variety of ways. Some of the examples provided to Members of such monitoring included through feedback from social workers and other health professionals and writing to families for their feedback.

175. Of the 20 cases reviewed by the external consultants, 10 cases confirmed that the provider was reviewed and monitored, 2 cases partially confirmed monitoring, 1 case was unclear and 7 were not applicable (*for instance the individual's placement had only just begun*).

176. Primary research conducted for this inquiry highlighted how parents would like to have a better understanding on how Cardiff Council monitors the effectiveness and quality of services provided by commissioned care providers. With some parents holding the perception that the Council is not fully aware of the issues parents have on the effectiveness and quality of services provided. Parents would like to understand how they can support Cardiff Council in monitoring the delivery of care and contribute to validating the effectiveness of the commissioned care and support services.

Current Provisions Available in Cardiff

177. The Council has developed 97 schemes across the city that offer supported accommodation for up to 342 people. The schemes vary greatly as the service is aimed at meeting a wide range of need. To date, the current schemes available in Cardiff can be broken down as follows;

1 person schemes	9
2 person schemes	27
3 person schemes	34
4 person schemes	17
5 persons schemes	4
6 person schemes	1
Core & Cluster schemes	5

Total : 97

178. Community Residential Care provision is utilised when an individual is identified as requiring nursing needs. During the inquiry it was confirmed to Members that Cardiff is limited in this area and further provision is required.

Core & Cluster

179. Core & Cluster schemes provide a group of houses or flats with individual tenancy. Within the schemes, individuals are able to access specifically determined direct support within the comfort of their own property. However staff are based at the scheme twenty four hours a day, providing tenants with the safety and confidence along with ensuring early intervention should any unforeseen issues arise.

180. During this inquiry, Members heard from a local provider that Core & Cluster schemes allow for individuals to reach their maximum independence, providing them with space to grow and develop in ways they might not in other provisions. Members were further provided with an example of one individual who previously resided in a shared house supported living scheme who has thrived since moving to a Core & Cluster.

181. Members concurred that the Core & Cluster flats visited during this inquiry were of a very high standard, and were informed that all were developed with full Occupational Therapist specification. In terms of costings, it was confirmed to Members that support packages within Core & Cluster properties are around the same price as a shared house supported living support package.

182. However during the visit, it was recognised that, as with all provisions, this scheme would not work for all, and alternative schemes such as shared housing with more social interaction may work better for some individuals.

Developing Local Accommodation

183. The vision for ensuring local authorities develop appropriate local accommodation for people with learning disabilities is laid out within recent Welsh Government guidance; *Learning Disability Improving Lives Programme* (June, 2018) and the *Commissioning Accommodation and Support for a Good Life for People with a Learning Disability* (March, 2019).

184. Local accommodation is also a commissioning principle for Cardiff and the Vale Regional Partnership Board and ensuring good local provision and supporting people to live close to their families and friends (if appropriate), is also one of the 8 priorities in the Cardiff and Vale Joint Commissioning Strategy.

Gaps in local provision

185. The Wales Audit Office, Strategic Commissioning of Accommodation Service for Adults with a Learning Disabilities recently found that although local authorities are generally meeting accommodation needs of adults with a learning disability, the existing commissioning arrangements are unlikely to be fit for the future.

186. At the time of writing this report, there are currently 38 individuals placed in out of county specialist further education. During the inquiry Members were informed that officers are currently in the initial scoping phase, mapping out needs in order to understand what is required to meet more of these needs locally and that both strategic and operational discussions are currently ongoing along with a pilot project.

187. Members were further advised that Cardiff Council's Supported Living team are continuously looking at what local provisions need to be developed to better suit peoples need. Their most recent work found that Cardiff requires a 'complex needs' core cluster and additional adapted bungalows.

The Future

188. The number of people with a learning disability is increasing. People with a learning disability are living longer and there is a known expectation surrounding an increase in the number of adults with profound and multiple needs transitioning from children's into adult services over forthcoming years.

189. In general, individuals placed out of county due to a lack of suitable local provision, tend to have more complex needs including challenging behaviour. The common consensus shared amongst all stakeholders who engaged in this inquiry is that careful consideration is required for all future accommodation and support models to ensure the specific needs of these individuals are met.

As stated in the National Commissioning Board's guidance document (*Commissioning Accommodation and Support for a Good Life for People with a Learning Disability, 2019*), provision of the right kind of housing can either help or hinder an individual's social integration. It can also be fundamental in achieving a number of the outcomes set out in the Social Services and Well-being (Wales) Act 2014. It is therefore essential that when a decision is made concerning accommodation provision, the full spectrum in meeting that individual's needs is considered.

KF62

190. It is essential that local authority housing strategy teams identify the accommodation needs that are emerging over the next three to five years to inform decisions which commission the right provision. Members were pleased to be reassured by officers throughout the inquiry that work has begun in this respect and the service area are looking to develop an 'Accommodation Strategy' to assist in identifying, developing and improving local options to ensure individuals are offered with a wider range of choice.

The Mansell Report (*Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs, 2007*), described as 'definitive UK guidance on the development of services for people with challenging behaviour', recommends that local services, including educational, training and day services are developed and expanded for people with a learning disability. The report also recommends that specialist services be developed locally which can support good, mainstream practice and improve the quality of life for those served.

KF64

During the course of the inquiry it was confirmed to Members that the service area are currently planning to develop an accommodation strategy to assist with long term planning on local provisions and are also working toward developing clear transitional pathways to ensure individuals and their families acquire full understanding of the options available in line with their need.

KF65

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INQUIRY METHODOLOGY

The Community and Adult Services Scrutiny Committee task group was tasked by the full committee with delivering a report for its consideration. This report uses the evidence gathered by the task group to make key findings and recommendations to the Cabinet of the Council in respect of the current arrangements in place for transitioning identified individuals with learning disabilities who reside out of county. To achieve this, the Principal Scrutiny Support Officer has worked closely with the Council's Social Services teams to identify appropriate witnesses and taken a steer from all members of the task group.

The task group received evidence from the following witnesses:

Date of Meeting	Witnesses
Meeting 1 – 7 Feb 2019	<p>Cllr Susan Elsmore (Cabinet Member for Social Care, Health & Well-being)</p> <p>Claire Marchant (Cardiff Council's Former Director of Social Services)</p> <p>Louise Barry (Assistant Director, Adult Services)</p> <p>Emma Mulinder (Operational Manager - Learning Disabilities)</p> <p>Denise Moriarty (Strategic Lead Planning Officer, Social Services)</p>
Meeting 2 – 5 March 2019	<p>Members of the task group were invited to attend the launch of, <i>Improving Lives Improving Practice Guidance: Commissioning Accommodation and Support for a Good Life for People with a Learning Disability.</i></p>

<p>Meeting 3 – 16 July 2019</p> <p>Briefing Report and site visit to Values in Care</p>	<p>Emma Mulinder (Operational Manager - Learning Disabilities)</p> <p>Emma Jo McDonald (Supported Living)</p> <p>Senior Management Team of Values in Care.</p>
<p>Meeting 4 – 17 July 2019</p> <p>Site visit to Glasallt Fawr & Coleg Elidyr</p>	<p>Emma Mulinder (Operational Manager - Learning Disabilities)</p> <p>Denise Moriarty (Strategic Lead Planning Officer, Social Services)</p> <p>Senior Management Team of Glasallt Fawr</p> <p>Senior Management Team of Coleg Elidyr</p>
<p>Meeting 5 – 19 Sep 2019</p> <p>Site Visit to Vision 21 and Bridgend College</p>	<p>Denise Moriarty (Strategic Lead Planning Officer, Social Services)</p> <p>Emma Jo McDonald (Supported Living)</p> <p>Senior Management Team of Vision 21</p> <p>Senior Management Team of Bridgend College</p>
<p>Meeting 6 – 30 Sep 2019</p> <p>Meeting with frontline staff</p>	<p>Meeting with frontline staff, including three social workers (two of which were transition social workers) and a social worker assistant.</p>
<p>Meeting 7 – 1 Oct 2019</p> <p>Briefing with Education officers on the upcoming Additional Learning Needs and Education Tribunal (Wales) Act 2018.</p>	<p>Jennie Hughes (Senior Achievement Leader Inclusion)</p> <p>Elizabeth Jones (Additional Learning Needs Transformation Lead Central South Consortium)</p>
<p>Meeting 8 – 3 Oct 2019</p> <p>Site Visit to Local Providers</p>	<p>Emma Mulinder (Operational Manager - Learning Disabilities)</p> <p>Emma Jo McDonald (Supported Living)</p>

	<p>Denise Moriarty (Strategic Lead Planning Officer, Social Services)</p> <p>Senior Management Team of Dimensions Cymru,</p> <p>Senior Management Team of Innovate Trust</p> <p>Senior Management Team of Mirus.</p>
<p>Meeting 9 – 18 Dec 2019</p> <p>To receive the findings of the Primary Research</p>	<p>Therese Gladys Hingco (Principal Research Officer)</p>
<p>Meeting 10 – 6 January 2020</p> <p>To receive the findings from independent consultants - Alder Advice</p>	<p>Cllr Susan Elsmore (Cabinet Member for Social Care, Health & Well-being)</p> <p>Claire Marchant (Director of Social Services)</p> <p>Louise Barry (Assistant Director, Adult Services)</p> <p>Emma Mulinder (Operational Manager - Learning Disabilities)</p> <p>Denise Moriarty (Strategic Lead Planning Officer, Social Services)</p> <p>Rob Griffiths (Alder Advice)</p> <p>Paula Close (ICF Outcome Delivery Officer)</p>

Written evidence was also received from both local and out of county providers during the inquiry's Call for Evidence. The Call for Evidence sought to obtain information on the whole transition process including initial assessment, review of placement, the providers' involvement in any transition and the monitoring arrangements in place from any individuals who may have transitioned.

Inquiry Members also commissioned independent research into this area, tasking Scrutiny's Research Officer to address, through consultation with parents and

advocates, the current pathway in place for transitioning identified individuals in order to identify possible areas for improvement.

Although the scope of the research was to engage with parents of those who had transitioned from both out of county residential placements and out of county specialists further education placements, the parents of those who had resided in out of county residential placements were unfortunately unable to engage with the inquiry. As such, the primary research conducted, liaised with parents who had children placed in out of county educational provision; pre or post transition.

The key findings and recommendations are the unanimous view of the task group. Details of all evidence considered by the task group and used in the preparation of this report are contained within a record of evidence that is available for inspection upon request

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LEGAL IMPLICATIONS

The Scrutiny Committee is empowered to enquire, consider, review and recommend but not to make policy decisions. Any report with recommendations for decision that goes to Executive/Council will set out any legal implications arising from those recommendations. All decisions taken by or on behalf the Council must (a) be within the legal powers of the Council; (b) comply with any procedural requirement imposed by law; (c) be within the powers of the body or person exercising powers of behalf of the Council; (d) be undertaken in accordance with the procedural requirements imposed by the Council e.g. Scrutiny Procedure Rules; (e) be fully and properly informed; (f) be properly motivated; (g) be taken having regard to the Council's fiduciary duty to its taxpayers; and (h) be reasonable and proper in all the circumstances.

FINANCIAL IMPLICATIONS

There are no direct financial implications arising from this report. However, financial implications may arise if and when the matters under review are implemented with or without any modifications

COMMUNITY & ADULT SERVICES SCRUTINY
COMMITTEE MEMBERSHIP



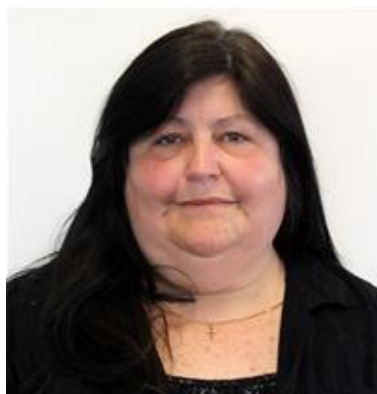
Councillor Ali Ahmed



Councillor Shaun Jenkins
(Chairman)



Councillor Joe Carter



Councillor Andrea Gibson



Councillor Norma Mackie



Councillor Ashley Lister



Councillor Philippa Hill-John



Councillor Sue Lent



Councillor Mary McGarry

TERMS OF REFERENCE OF THE COMMUNITY & ADULT SERVICES SCRUTINY COMMITTEE

To scrutinise, measure and actively promote improvement in the Council's performance in the provision of services and compliance with Council policies, aims and objectives in the area of community and adult services, including:

- Public and Private Housing
- Disabled Facilities Grants
- Community Safety
- Neighbourhood Renewal and Communities First
- Advice & Benefit
- Consumer Protection
- Older Persons Strategy
- Adult Social Care
- Community Care Services
- Mental Health & Physical Impairment
- Commissioning Strategy
- Health Partnership

To assess the impact of partnerships with and resources and services provided by external organisations including the Welsh Government, joint local government services, Welsh Government-sponsored public bodies and quasi-departmental non-governmental bodies on the effectiveness of Council service delivery.

To report to an appropriate Cabinet or Council meeting on its findings and to make recommendations on measures which may enhance Council performance and service delivery in this area.

To be the Council's Crime and Disorder Committee as required by the Police and Justice Act 2006 and any re-enactment or modification thereof; and as full delegate of the Council to exercise all the powers and functions permitted under that Act.

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Scrutiny Research Report

**Parents Information and Support Needs on the
“Closer to Home” Project for Young Adults with Learning Disabilities**

**Research report for the
Community and Adult Services Scrutiny Committee**

April 2020



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1. Introduction

The Community and Adult Services Scrutiny Committee commissioned this research to look into the impact of Adult Services' "Closer to Home" project to young people with learning disabilities and their families who will be affected by the move from out of county residential college placement to supported living accommodation in Cardiff. This research will establish the information and support requirements of service users, their carers and their families as a result of the implementation of the "Closer to Home" project.

More specifically the research will:

- Identify information and support needs that young people have in accessing college placement, while at college and during the transitioning phase from college to the appropriate supported living accommodation.
- Identify information and support needs that service users and their families have when at supported living accommodation in Cardiff.
- Establish service users' families views on how Cardiff Council and its key partners can improve their current services and support for those who will be accessing out of county college and residential placement and for those who have completed their out college residential placement.

The findings of this research will inform the Task & Finish recommendations on how the Council and its key partners can better support young people with learning disabilities by identifying improvement areas in the commissioning and delivery of its learning disability services.

The structure used in presenting the research findings in this report follows the care pathway that the individual goes through in accessing out of county college residential placements until completion and the process that is involved in bringing them back to the appropriate supported living accommodation in Cardiff.

2. Methodology

The conduct of this research was informed by relevant documentation as well as the information shared by Cardiff Council's Adult Services Learning Disability Team.

The support of key managers in this team was crucial in enabling the success of this research project. The managers provided the relevant contextual background information on the delivery of services to young adults with learning disabilities. They also supported the research by initially contacting the parents of this target group to determine their interest in being involved in the research. With consent from the parents, Learning Disability Managers provided scrutiny research with the names and contact details of those who wanted to be involved in the research process.

In addition to the list provided by the Learning Disability Team, a number of parents directly contacted scrutiny research and expressed their interest in being involved in the research. These respondents were made aware of the research and the Scrutiny Task and Finish Inquiry through "word of mouth" from other respondents who were involved in the research. Those who have contacted scrutiny research after the scheduled data collection phase were not able to contribute their views to the research data available to scrutiny. The Scrutiny Team was not able to extend the data collection phase due to limitations in research capacity.

Types of Research Respondents

The primary research respondents who were invited to participate in this research included those who are regarded as the primary representative, or parent of the "service user" with learning disability. These respondents included:

- Parents of those who are currently in out of county residential college accommodation
- Parents of those who are transitioning from out of county college residential placements.
- Parents of those who have moved from out of county residential college placement into supported living accommodation in Cardiff.
- Parents of those who have moved back from out of county residential placements to their current accommodation in Cardiff.

In selecting these respondents, the following service user characteristics were also considered in the sampling scheme:

- Type of learning disability
- Variation in complexity of need or dependency
- Age
- Gender
- Any other relevant characteristic as advised by colleagues from Cardiff Council's Adult Services Learning Disability Team.

This research relied heavily on the use of qualitative research methodologies during the data collection involving mostly the parents of young people with learning disabilities. These included semi-structured interviews and focus group interviews.

One to one semi-structured face to face interviews were undertaken with a randomly selected representatives from each respondent category. The researcher sought the consent of each respondent prior to the conduct of the interviews. Respondents were made aware that they could withdraw consent at anytime during the interview. Assurances were made to respondents on the confidentiality and anonymity of the information that they have shared with scrutiny research.

The information collected from the semi-structured interviews informed the various issues that were explored and discussed during the subsequent focus groups.

The number of one to one semi-structured interviews undertaken were:

- 1 set of parents whose child is in out of county college residential accommodation.
- 1 set of parents whose child is transitioning to supported living accommodation in Cardiff
- 1 set of parents whose child has moved into supported living in Cardiff.
- 2 respondents from an Advocacy groups for adults with LD

Each interview lasted for at least one hour, with some of them lasting up to 1 ½ hours. In total 18 hours and 55 minutes of semi-structured interviews were undertaken.

The parents of two respondents from out of county residential placements who have come back to Cardiff as part of the Closer to Home strategy, were also invited to be involved in the interviews. Although confirmations were received from both respondents, the scheduled interviews could not be undertaken. One of the respondents failed to attend the scheduled interview in County Hall. The interview with another respondent had to be terminated due to security issues.

Focus groups were also undertaken involving the three broad categories of respondents. These focus groups explored the views of respondents on the types of information and support that they would benefit in moving their child to supported living in Cardiff. The focus groups explored respondents' views on their involvement on the decision making processes in accessing out of county residential college placements and in selecting the appropriate accommodation following college placement. The focus group also looked into the parents' experiences and views on the information and support that they need before, during and after the out of county college placement. The focus groups also explored their views and suggestions on improvements that Cardiff Council and its service providers can make in its services to young adults with learning disabilities.

Due to limited capacity and resources, only one focus group was undertaken for each respondent category. Each focus group had between 6 - 8 participants. Consent was sought from respondents prior to the conduct of focus groups and they were also informed that they could withdraw consent at anytime. Respondents were assured of the confidentiality and anonymity of the information they shared.

The following focus groups were conducted for this research:

Focus Group 1 - Parents of those in out of county college residential placement

Focus Group 2– Parents of those in out of county placements who are transitioning or in the process of moving to supported living in Cardiff.

Focus Group 3 – Parents of those who have completed out of county college residential placements and currently in supported living accommodation in Cardiff.

In total 12 young adults with learning disabilities were represented by their parents during the conduct of this research.

The proceedings of all the interviews and the focus groups were recorded using a digital recorder with prior consent of the participants. The recordings were transcribed by an external service provider to facilitate the processing and analysis of data. All audio recordings and transcripts of the interviews and focus groups undertaken are to be stored securely to comply with GDPR requirements.

The conduct of the research also considered the risks involved in the data collection process. Lone working risk assessment was undertaken in relation to the conduct of one to one interviews. The conduct of data collection was also sensitive to any indicators of safeguarding issues.

3. Executive Summary

This research report was commissioned by Cardiff Council's Community and Adult Services Scrutiny Committee (CASSC) to look into the impact of moving identified adults with learning disabilities from their out of county residential college and residential placements to the appropriate care and support arrangements in Cardiff. More specifically, this research will identify the information and support needs that these young adults and their families have during the following stages: when accessing college placement; during their stay at residential college; during the transitioning stage of moving back to Cardiff and during their stay in the appropriate care and support provision in Cardiff. This research will also establish parents' views on the areas that Cardiff Council and its key partners can improve on in delivering services and support to young adults with learning disabilities.

This research relied heavily on qualitative research methodologies such as one to one interviews and focus groups in data collection. Managers in Cardiff Council's Adult Services provided significant support in selecting and contacting service users' parents to encourage them to participate in this research. In total, 12 young adults with learning disabilities were represented in the one to one interviews and focus groups. Another two from out of county residential placements were invited to participate but were not able to attend the scheduled interviews.

Accessing further learning and development opportunities

Most parents of young adults with learning disabilities have limited knowledge and understanding of their child's entitlements and options for further learning and development following the completion of their secondary education. Some of them became aware of these opportunities via "word of mouth", by undertaking their own research and a limited number have been informed by school or health and social care professionals that they have been in contact with.

Variability in access to Information

Most of the parents are concerned that information on how to access these opportunities are not widely available. They believe that secondary schools, Careers Wales and Cardiff Council should have a more proactive role in making individuals and their families aware of further learning and development opportunities that are available through the local college

provision or from specialist college provision. Due to the unfavourable experiences that others have had, some of them suggested that an independent body or facility should have the responsibility for disseminating information, providing guidance and supporting individuals and their families in accessing these opportunities.

Respondents believe that all parents would benefit from having clarity, guidance, and support from the local authority on how they can access these opportunities. They believe that this information should be made available early on during their child's secondary schooling. This will enable families to have sufficient time to consider their options and work with the school and other professionals towards accessing further education opportunities. More specifically, they would like to have a better understanding of the Section 140 assessment, the process and the timelines involved, the types of evidence and input required from various professionals in education, health and social care services and from the parents. Additionally, they would also benefit from having some clarity on the eligibility criteria for applying for funding and placements in specialist colleges. In cases where parents disagree with the findings and recommendations of the Section 140 assessment, they believe that they would also benefit from guidance and support on how they can effectively challenge this.

Parents are also concerned over the variability in the duration of funding and placements at specialist out of county colleges and have raised questions on the rationale behind this. They expect Cardiff Council to provide them with some guidance and clarity on how decisions are made regarding the duration of funding and placements in specialist colleges and the scope for extending this as necessary.

Access to locally based specialist college provision

The majority of parents believe that the Welsh Government and Cardiff Council should consider and plan to set up a specialist residential learning and development provision for young people with learning disabilities in or near to Cardiff. They cited the various benefits that had been delivered by this type provision for young adults with complex care and support needs. They believe that this has effectively helped their children to achieve significant improvements in their skills sets, health and well-being outcomes. This had helped to further improve their child's skills sets and capabilities towards more independent living, including their communication and social skills. Their access to various professional support in residential setting has been vital in improving the skills and abilities that they achieved during placement e.g. in terms of mobility and communication and personal confidence. Some of the parents also believe that the outcomes achieved during placement will not

only lead to a better quality of life, but will also provide significant long-term savings in care and support costs for the local authority. Some of the parents also highlighted the need to provide further learning and development opportunities to meet the language preference of Welsh speaking individuals with learning disabilities. They believe that provision in the Cardiff and Vale College does not currently offer this. It was strongly recommended that further learning and development provision delivered in the Welsh language should be developed by Cardiff Council in collaboration with other local authorities in South Wales so that this can benefit Welsh speaking young people with learning disabilities across these areas.

At residential college placement

All of the parents confirmed that they were happy with the level of engagement that they have with the specialist out of county colleges and the support provided to their child. They were particularly complimentary of the information and reports that they received on the progress achieved during placement.

Most of them were unsure of the level of engagement and support that they should expect from the social worker during the period that their child is in college placement. Some of them were concerned that they have limited contact with the social worker. They believe that it would be useful if they had a named social worker who could provide some degree of continuity and stability in supporting their child throughout the duration of placement. At the minimum, they expect their social worker to attend the annual reviews arranged by the colleges, so that they gain a good appreciation of the progress that their child has achieved, the challenges they have and the areas where further support may be required. Furthermore, parents also expect to receive guidance and support from their social worker in how they can effectively prepare and support their child in moving on from college placement to the appropriate care and support arrangements in Cardiff.

Extending college placements

Those who have applied for the extension of placement funding in specialist provision, felt that Careers Wales and Cardiff Council could have been more supportive to them. This was particularly important to those parents who believe that the extension of placement would lead to significant further improvements in their child's knowledge, skill sets and long-term outcomes. Most the parents are currently unsure of the scope for and the eligibility criteria for extending placements at specialist out of county residential colleges. They believe that it would be useful for all to have some clarity on the criteria for extension, the procedures and time lines involved in applying

for additional funding beyond the two year period. Parents suggested that the decisions to extend funding of specialist college placements should be more timely, and should be released long before the start of the new school term. This would avoid the stress and anxiety felt by families due to uncertainty in the continuation of placement.

Some of the parents also cited disagreeing with Careers Wales and Cardiff Council on the duration of their child's placements in specialist college provision. During these situations, they believe that better arrangements for resolving disagreements should be in place. It was suggested that Cardiff Council should adopt a better approach in engaging with and having dialogues with parents to resolve issues and to avoid having to go through a legal challenge.

Transitioning from college placements

Parents have differing knowledge and understanding of the transitioning process involved in moving on their child from college placements to the appropriate care and support arrangements in Cardiff. Most of them agreed that they would benefit from having a better understanding of the key stages and the timescales that are involved. They also believe it would be useful for them to be made aware of the various roles and responsibilities of the professionals and individuals who have a part in the process. Although they have varying knowledge on when this should start, they all believe transitioning should start early so that they can effectively support the process of identifying the suitable accommodation and care and support provision that meets the needs and specific requirements of their child.

There was a suggestion that Cardiff Council should also consider the best practice approach in transition planning in England where different pathways and aspects of an individual's life is taken into account during the planning for the support that will be provided. This would involve not only planning for housing and care support but also planning for other aspects of life such as employment options, healthy living and developing friends and relationships.

Issues with care and support arrangements offered.

Some of the parents expressed their concern on the care and support options that are available to their child following their college placement. They believe that the option to continue residential placement should also be available alongside the offer of moving on to supported living arrangements. Their children were only offered the supported living option and have limited choice between providers due to limited availability of housing stock.

Some of them were very concerned over the suitability of moving their child from a residential care setting into supported living in Cardiff. They believe that the change in the environment and care arrangements could have detrimental impacts on their child's skills, their well-being and their overall quality of life. They are worried over the changes in the level staffing support and their competence, access professional expertise and the level of social interaction and social activities their child can be involved in and benefit from. They also believe that supported living arrangements does not provide their child with same level of security and independence in exploring the environment around them. They anticipate that this change would have negative impact on their child's well-being and mental health and could cause anxieties to develop. They are unconfident that supported living arrangements will provide their child the same opportunities that will help them to maintain the knowledge and skills sets and confidence that they achieved at residential placement.

Parents stated that they would benefit from having assurance and provided some exemplars by Cardiff Council and care providers that the change in care arrangements will not bring about the negative impacts that they fear. They believe that Cardiff Council should ensure that care providers have sufficient arrangements to support the maintenance of the knowledge and skills acquired during college placement and the level of support to achieve their child's health and well-being outcomes.

Some parents also expressed their concerns on the delays that they and others have experienced during the process of moving their child into supported living in Cardiff. They believe that Cardiff Council and care providers should ensure that the allocated accommodation are available on time for those who are leaving their college placement. It was suggested that the timings should avoid temporarily bringing them back home as this would risk the regression the knowledge and skills that their child has developed.

As part of the process of selecting the suitable supported living placement, parents also worried about their child's compatibility with their future "housemates" in accommodation that will be allocated to them. Parents believe that their child should only be offered placement in a housing cluster with other young adults who share similar characteristics and interests. They suggested that the social services team should consider variables such as age, gender, personality and complexity of support needs in matching their child with potential housemates. Parents are concerned that inappropriate matching would have a detrimental impact on their child's well-being.

Experience at supported living placements

Parents whose children are placed in supported living arrangements in Cardiff, highlighted a number of issues that are concerned with and would like Cardiff Council to address.

Most of them have limited knowledge and understanding of their children's care plan in supported living and how this is developed and delivered. Some of them would like to have a better understanding of the types of input and evidence that inform the formulation of the care and support plan. Parents are unsure on what input is expected from them, and whether annual review reports that their children had during college placement and the professional staff there are able to inform the supported living care plan.

Most of the parents are unsure whether their child has sufficient opportunities in supported living to undertake the activities and tasks that would help to maintain the knowledge and skills they acquired during their college placement. Some of them stated that they do not know enough of their child's schedule of activities and on how their child is progressing with making use of these knowledge and skills. They also stated that they are not fully aware how support staff are enabling their child to utilise their knowledge and skills sets.

Most of the parents were particularly concerned with the level of social and cultural activities that care providers and support workers are enabling their children to be involved in. They have the perception that child do not seem to be involved in various social i.e. planned or spontaneous activities that involve their peers and/or other young people with learning disabilities. They believe that it is important for them access various organised opportunities e.g. Hijinx and Vision 21 as well being involved in other social activities e.g. trip pubs or seaside, quiz or bingo nights, with others in their peer group so that they could practice and enhance their communication and social skills. Some of them are particularly worried about what is referred to as "chilling out" weekends and the perceived lack of planned social or physical activities during this time.

Some of the parents believe that their child should be offered more activities and opportunities that would help in maintaining and improving their health outcomes. They are particularly concerned over the amount of weight that their children have gained since moving into supported living. They raised questions on how the care provider and support workers encourage their child make healthy food choices and facilitate opportunities to enable them to undertake sufficient physical activity to keep healthy. Parents believe that Cardiff Council should work with care providers to ensure that there are sufficient opportunities and staffing to support and enable their children to

undertake activities that will help to maintain their skills and improve their physical and mental health and overall well-being. They are also unsure whether there is a structured process in reviewing how their children's skills and knowledge have improved or declined while at supported living. Parents would like to feel confident that support workers are providing their child with sufficient opportunities and challenges to help maintain or further develop their skills and knowledge and improve their well-being.

Effective delivery of care plan

Parents generally worry whether supported living arrangements would be able to effectively look after and provide the level of support their child requires. Some of them are unsure whether the level of care required and activities or tasks identified in the care plans are carried out as planned.

Some of them would like to have a better understanding of how the care provider monitors and reviews the quality of support provided by support staff and whether the planned tasks, activities and targets are achieved. In cases where they may have concerns, they would also like to have a better understanding of the arrangements for sharing or reporting these and how this will be dealt with by care provider or by Cardiff Council. For example, some of them have expressed concerns on the tardiness of support workers and the changes in the scheduled timings for available support. Parents believe that having knowledge and understanding of the monitoring and quality control arrangements would assure them of the quality of care and support that their child receives.

Measuring progress with well-being targets

Based on the concerns cited previously, most parents would like to know how the care providers ensures that that their child are able to maintain their skills, remains in good physical and mental health and remain safe and happy. They are unsure how providers set health and well-being targets that their child can achieve and how parents can inform and effectively support this. Parents also believe that it is important for providers to have measures in place so that they can evidence any progress or deterioration that occurs.

Although they have not had involvement in periodical and annual reviews, they expect to receive periodical updates from the care provider on how their child is managing in supported living. They believe that they would benefit from having structured dialogues on how their child is getting on the different aspects of their lives including their diet, overall health, self-care, social interaction, access to leisure or cultural activities and any other changes, or improvements in their health and well-being. They also believe that this could

be used by the care provider as opportunity to seek structured feedback from parents on the care and support they provide.

Confidence with staffing levels and competencies

Parents have the perception that some of the supported living providers struggle with managing high staff turnover and maintaining their staffing levels. Some of them have heard via word of mouth that this is an issue particularly in supported living arrangements for those with less complex support needs. They are concerned that these staffing issues will have significant impacts on the quality of support and care provided in supported living. Parents would like to be assured how these issues are managed effectively so that the safety of residents are not compromised.

Although parents are generally happy with the quality of care provided, most of them stated that they are not very confident with the competencies of staff. They stated that they do not know much about staff qualifications, the training they receive, and whether they have the level of competencies to deal with differences in learning disabilities and the associated challenging behaviours. They believe that improving their knowledge and understanding of staff competencies will help to improve their confidence on the quality care and support that their child receives.

Parents' awareness of regulatory inspection schedule for learning disability services

A few of the parents felt that it was important to have the opportunity to provide feedback to the social services inspectorate on their experiences of services for young people with learning disabilities. They would like to be made aware of the schedule of regulatory inspection of the learning disability services and how they can inform what the areas that the inspectorate can focus on and how they can provide input in the inspection process.

Other support for parents

Parents highlighted the various types of support that they have benefited from other parents. They cited how helpful others have been providing information and advice on accessing services that their children would benefit from. Additionally, they value the emotional support that they received during challenging times. Some of them believe that Cardiff Council should encourage and support this informal network. Through this network they believe that Cardiff Council can better engage and disseminate information to parents and young people with learning disabilities.

Mental health support and support during crisis

Most of the parents were in agreement that they would benefit from having immediate access to advice and support in dealing with crisis situations. This is particularly important when parents feel that they are unable to deal with and cope with their children's challenging behaviours. They suggested that it would be useful for them to have access to a telephone helpline that can provide independent advice and support during times of crisis or when they feel overcome with the stress arising from their caring responsibility.

Learning disability carer card

Some of the parents suggested that it would be useful for them to carry a card that identifies them as responsible for the care of someone with learning disability. They feel that this would be particularly useful should something unfortunate happen to them or during an emergency situation.

Parents' involvement in planning the long-term care and support

Some of the parents are particularly concerned over the long-term care options for their child. They would like to have some involvement in the long-term planning for the care and support for their child. This would provide them with the assurance on the future safety, health and the quality of life that their child will have when they are no longer around.

Benefits and entitlements

Parents believe that currently, information on various types of support for young people with learning disabilities and their families is not readily available. Most of them rely on other parents to share information the services and entitlements that their children can access and benefit from. Others stated that they have to undertake their own research on the current legislation and on local policies on educational, health and social services provision for families and children with learning disabilities

Parents believe that it would be useful for them to be made aware of the range of support and services available to individuals with learning disabilities and their families. This should include support in helping them to gain a better understand the statutory benefits and entitlements that they can access while their child is in education and when in supported living.

Information resources for parents and carers

Parents believe that they need to have better access to information and support that they cited in various sections of this report. Parents believe that they would benefit from having this information made available in a “handbook” or an interactive on-line reference facility that provides information on various services and support that are available to them as their child progresses through their key life stages. It would be useful for them to have this information be presented in a format that follows the key life stages and the care pathway that the individual with learning disability goes through in their life. The information that is made available should identify and signpost parents or individuals to the appropriate services and support that are relevant to the each different type of learning disability and the variation in complexity of care and support needs. They believe that these information should be made available at schools and from key services such as the GP and other NHS services and professionals that individuals with learning disabilities come into contact with regularly. It is was suggested that the on-line information resources should be available in an interactive format so that users of this facility can be easily directed to the relevant information and services that they require.

Resolution of disagreements

Some of the parents have disagreements with Cardiff Council Social Services on the suitability of care and support arrangements that are offered to their children following their specialist college placements. They were particularly unhappy with the communication approach that Cardiff Council had taken in response to the challenge they made. These parents also suggested that social services should explore a different approach in working with them to resolve their disagreements or issues with the care provision offered to their child. They feel that it would be better to resolve these through constructive face to face dialogues where parents can feel that Cardiff Council is truly listening to their views and are willing to work with them to resolve issues.

4. Accessing specialist out of county residential college placements

4.1. Limited information available on options and entitlements

Some of the parents of young people with learning disabilities believe that they need to have a better understanding of the various entitlements and statutory benefits that can be accessed by their child following the completion of their secondary education. They stated that they would benefit from being made aware of the educational options that are available as well as the processes involved for accessing these.

Some of the parents stated that they had not been formally informed of the various options that are available following their children's completion of secondary education. Other parents believe that there should be a structured process for letting parents know about various options various learning and development opportunities that are available following secondary education.

“We were not aware that they would have done that, but it would have been useful..., I would have said, with at least a year's notice, they should have said, “You need to start thinking about this. Here is a range of places that you might want to find out about...”

“There's an awful lot of managing expectations out there, where I think a lot of parents who, perhaps, aren't well informed... You don't really get, I don't think, a comprehensive picture of what's out there....”

4.2. Reliant on word of mouth and the parents' network

Most parents stated that their links with other parents have been vital in making them aware of the further learning and development options for those learning disabilities after they completed secondary education. Most of them obtain these information via word of mouth from other parents they meet at school or from members of the Cardiff & Vale Parents Federation. Through these networks, they were able to share and exchange information on how to access specialist further education for their child and the processes and challenges involved. Some of the parents stated that the help and advice offered by key figures in the network was invaluable in navigating the processes involved in accessing these further learning and development opportunities. Other parents relied on the advice of those who would gone through similar processes and challenges of accessing out of county college residential provision.

“...as parents we do talk to each other so we do know what’s going on, and a lot of the advice we do take from other parents and we do follow their lead”

4.3. Parents undertaking own research

Some of the parents stated that they conducted their own research in exploring and determining the suitability of local provision in comparison to specialist out of county college provision. Some of them cited that they started their research as early as 2 years before their child was due to finish secondary schooling in Cardiff.

“I think everybody has to do that, but I’m not sure if we hadn’t, I don’t know what would have happened if we hadn’t had the idea of what we wanted”

Some parents cited that they were able to get hold of a catalogue of specialist provision and had explored suitability of these different specialist colleges for their child. Their initial research enabled them to have sufficient time to review and evaluate what they believe as the most suitable further education placement for their child. Two of the parents stated that they started thinking about specialist further education option when their child was between 14-15 years old.

Most parents have been encouraged by others who have gone through the system to undertake their research early on, so that they have sufficient time to look into, visit and evaluate the suitability the various specialist out of county colleges that are available. Some of them believe parents would need at least a year to be able to effectively look into consider and evaluate further education options for their child. They believe that the early work they had undertaken had enabled them to be well informed during their dialogue with Careers Wales on further education options. Their initial research allowed them to present their preferred option on what they believe is most suitable for their child.

4.4. Limited availability of information on specialist provision

Some of the parents were concerned that information on how to access specialist further education provision is not more widely available. They declared that they would not have known about these options had they not

conducted their own research or heard via word of mouth from other parents. Most of them believe that Careers Wales and Cardiff Council should have a more proactive role in making information more widely available on the local college provision and specialist provision and the processes involved in accessing these.

“Here is a range of options that are available to you, the associated funding that could be accessed and process involved for accessing the provision and the criteria for eligibility to these funding streams..”

“That is what I mean by entitlements, it is the clarity of what is out there, whom you need to contact, who you need to speak to”

Parents believe that it is important to have easy access to information and guidance in accessing suitable further education options including specialist college provision for their child. Making this information readily available will be particularly helpful to working parents and to those who feel that they do not have the time and the ability to undertake their own research. It will also be helpful to those who have less ability to contact other parents or to those who have yet to be connected with various informal parents, networks.

“I feel that the parents who don't have the ability to follow some of these routes themselves, the young person loses out. Because, very often, you've got to have a reasonable degree of intelligence to be able to work your way through this minefield”

4.5. Limited information from schools and other professional contacts

A number of parents reported that one of the specialist secondary schools have been particularly helpful in making them aware of out of county specialist college provision. They felt that the teachers and the Head of the School have been supportive in providing them with necessary information as well as in encouraging their child to access specialist college provision. They made information on specialist college provision available at dedicated school fairs where external specialist providers were available to talk with parents and make presentations about the services that they provide. The school staff had also been helpful in making suggestions to parents on specialist college provision that would be suitable to the needs to their child.

Some of the parents believe that all secondary schools should have a key role in in making parents aware of the future learning and development options for the child and in advising them on the suitability of options that are available.

They felt that staff secondary schools are best placed to advise them on this matter as they have in depth knowledge of their child's skills, abilities and capabilities. They believe that the teaching staff in these schools are in a strong position to advise them of the scope for further learning and development for their child.

“... It can't be the Council. It won't be the social worker, because we don't have them at that point. It won't be Careers Wales, they don't know the child. The only person who knows the child at that point is the school. I had a number of those conversations with the school. As long as the school maintains that, and says, “These are the options...”

Other parents reported that they have benefited from their contact with medical professionals who signposted them specialist college provision that would be most suitable for their child's development and care needs.

4.6. Variability of information support from Cardiff Council

Parents have differing experiences on the support that Cardiff Council's Social Services have provided in accessing further learning and development options for their child.

Some of the parents stated that Cardiff Council had not given them information on options that their child have following their secondary education. A parent who has a child with complex needs stated that they did not have social worker throughout the time that their child was in secondary education, was not offered the support of a social worker and had not received any information from them.

In contrast, other parents felt that their child's social worker had been helpful in signposting them to information resources on specialist residential college provision that they could look into and consider. One of parents felt that they were fully supported by the social worker in preparing the necessary documentation and evidence to enable their child to access out of county specialist college placement. Another parent was also access a social worker's support in completing their child's placement to an out of county specialist college provision.

Parents believe that there should be a consistent approach from Cardiff Council in making parents aware of further learning and development options that are available for young adults with learning disabilities.

5. Parents' concerns with the Section 140 assessment process

Most of the parents expressed concerns over the assessment process involved in determining their child's access to learning and development opportunities following their secondary schooling.

5.1. Better information on the Section 140 assessment process.

Most parents felt that they needed to have a better understanding of the process that is involved in applying for further education provision for their child. More specifically, they felt that they needed to understand the stages and the timelines that are involved in the current Section 140 assessment process.

They also believe that more clarity would be useful to parents on the role and involvement of the Cardiff and Vale College during the assessment process. Additionally, they also believe that it would be useful early on to be made aware of the criteria for eligibility to local or specialist residential college as well as the necessary supporting evidence required to support their child's application for placement. It is also important for parents to understand how the learning and development aspirations of their child are considered during the assessment and how this is used to inform Career's Wales decisions on the suitability of the college placements.

During the interviews, one of the parents indicated that to date, they remain unclear on the scope and process involved in the Section 140 assessment, how the young person's learning and development needs are assessed and the factors are considered in determining eligibility to the out of county specialist college provision.

Parents also stated that they need clarity on how much of their input during the assessment process are considered in determining the suitable college placement for their child. And how child's aspirations are considered in determining their placement.

5.2. Role of Careers Wales and other LD professionals

Not all of the parents involved in the research are fully aware of and understand the role that Careers Wales have in the assessment of their child's eligibility to further education provision. One of the parents initially thought that the role of Careers Wales was to find a suitable job placement for

their child following completion of secondary school education. Her lack of understanding of Careers Wales' role had caused her some distress prior to meeting with them.

Parents felt that they need to have a better understanding of the role and support that they can expect from Careers Wales in supporting further learning and development options for their child. Some of them have the expectation that Careers Wales should inform parents of various options that are available including the suitability of various specialist out of county residential colleges. A number of parents felt that Careers Wales had not been pro-active enough in making them aware of the range of specialist college provision that their child can access. On the contrary, they felt that Careers Wales have endorsed and pushed heavily towards accessing the local Cardiff and Vale college provision for young people with learning disabilities. These parents also expected Careers Wales to inform them of the existing eligibility criteria for accessing specialist out of county college provision that would benefit their child.

5.3. Role and input of other health and public sector professionals

Some of the parents expressed frustration over conduct of the assessment process undertaken by Careers Wales. They felt that there was a lack of coordination and effective sharing of information and available evidence sets that are relevant to the assessment of their child's eligibility to specialist out of county college placement. One of the parents was particularly frustrated with the perceived inability of Careers Wales to consider the input and views of secondary school professionals on the suitability of the local Cardiff and Vale College to meet their child's learning and development needs.

"I find that the authorities do not listen to other people who are professionals,I just think why they are not taking the word of a professional who is employed in a school. You shouldn't have to have all that fight when you've got a professional there saying this is the only thing that's suitable for xxx, there's no way she can go here or here, it's not adequate, but they don't seem to listen to one another."

Some of the parents believe that the collection of evidence to inform the current assessment process should be better coordinated. Most of them were in agreement over the statement made by one of the parents saying:

"There is a lot of money being wasted on collecting the same data over and over again".

They believe that the required evidence should be prepared and collected ahead of time and coordinated between various agencies that provide services for their child. The assessment process would be more efficient if there was more joined up working between the various public sector bodies involved. They were in agreement that Careers Wales, Cardiff Council's Social Services, the secondary schools, health care professionals should more coordinated in sharing information that are required by the Section 140 assessment process.

In cases where children with learning disabilities have low level support needs and do not have a social worker, parents felt that it would be useful if guidance was available on how and when they support from social workers.

One of the parents was very concerned that she was advised by a call handler in Cardiff Council, that she was unlikely to access social work support because she lived in the more affluent area in Cardiff.

“I spoke to her on the phone and said that I was registering for a social worker, and she said, “Can I have your postcode,” and because we live in xxx she said, “I don't think you're going to get a social worker up there living in that area”

5.4. Cardiff and Vale College's assessment input

In cases where their child has well evidenced complex needs, the parents expressed frustration over the need for input from the Cardiff and Vale College in the Section 140 assessment process to confirm that their learning, development and care needs cannot be met locally.

Most of them are questioning the requirement those with high and complex support needs to be physically present in the Cardiff and Vale College campus so that they can determine whether they can meet the learning and care needs. Parents believe that the assessment process could be more straightforward in making use of current evidence such as recent or previous medical or health assessments, including those undertaken by speech therapist, occupation health, etc. to evidence the complexity of the young person's learning and support needs.

At least four parents who believed that their child's needs would be best met at a specialist out of county college, had to go through the process of taking their child to the local Cardiff and Vale College to get the confirmation required by the Section 140 assessment process.

..“The issue is, we knew we would have to be rejected by the local college in order to access external provision, which seems crazy, crazy”

“First of all, although the school had recommended that our daughter went to specialist college, we then had to.... physically take xxx to Cardiff and Vale, for them to decline xxx going to college,”

“...in order to basically qualify for it you had to be rejected by Cardiff and Vale College, because xxxx needs were too high and complex for them. We had to take xxxx to one of Cardiff and The Vale College’s sites, and xxx had to be assessed.”

“It’s very obvious, it’s just box-ticking, isn’t it? The visit to Cardiff and Vale College was a waste of time because Cardiff and Vale College was never going to meet the needs”

Some of the them believe that Cardiff and Vale College agree views that should be required from the local education provider to avoid unnecessary processes.

"I'm really sorry that you've had to come, but it's just a tick box you have to do. We know this college isn't going to meet your xxx (child's) needs We don't have any of therapies on site. We do not have one-to-one support. We can't meet xxx needs, but you have to come here and go through this. I'll show you around this college where your child can't go."

"I knew that I was going to have to do that because I was told that I would have to go and visit a local college. It is a completely pointless step because, as you say, it's, "This is what you could have had. "It's a lovely college, Cardiff and Vale College. "This is what you could have had, but you can't have it."

The Cardiff and Vale College’s input in the assessment process involving young people with complex need is regarded by these parents as an unhelpful, waste of time and mainly a tick box exercise for Careers Wales. They believe that this is an unnecessary step particularly in cases where there is sufficient evidence available that supports the need for a specialist college placement. Having to go to the Cardiff and Vale College to present their child, is regarded as “immensely stressful and a waste of everybody's time”.

5.5. Further education “choices” for young people with learning disabilities

Some of the parents believe that the Section 140 assessment process involved in determining the eligibility for specialist out of county college provision is an unnecessary step. They believe that their children should be afforded the same facility in choosing the education provider that they believe would best meet their learning and development needs. They felt that it is discriminatory to limit the options available to young people with learning disabilities and their access to specialist college provision

“And I recognise that the financial implications of xxxx are different, but that shouldn’t be the reason for discriminating against them”

5.6. Engagement with the parents during the assessment process

Parents have variable experiences in how they were engaged with during the Section 140 assessment process. Only two of them, gave positive feedback on the support they received from Careers Wales throughout the process of securing a placement for their child in a specialist out of county college. They praised the Careers Wales engagement with them in preparing the necessary documentation and seeking their input in the process.

Unhelpful attitude from Careers Wales

Most of the parents expected to have positive engagement with Careers Wales at each stage of the assessment process and their views. They also believe that their views should have been given sufficient weight as the main advocate of their child’s learning and support needs. However, some of their experiences have been contrary to their expectations.

One of the parents declared that they have not been fully engaged by Careers Wales:

“I do get a little bit uneasy when Careers Wales see our children without us. Partly, we're losing a chance to get some information, but also to advocate for the child a little bit, really.”

Some parents refer to staff they dealt with from Careers Wales as unhelpful, “totally negative, they were just obstructive”. A parent cited that:

“What happened was Careers Wales, the guy who worked for them, who was overseeing xxxx application to the Welsh Government for xxx funding. He was very, very negative about it all. He basically was saying, “You have to go to Cardiff and Vale College to have a look.” He was just being very negative and telling me, “You probably won’t get into xxx college”

Another parent felt that their input was unwelcomed.

“...your input into that process is currently unclear-And unwelcome. Our input is made, we are made very much, ...well, it’s unwelcome.

Other parents also confirmed that Careers Wales Officers had not been supportive to them and had made conclusions over the outcome of assessment even before the completion of the process.

“Yes. The role of Careers Wales, in our experience, was totally negative, they were just obstructive. They said, “You’re not going to get into xxx College-”

Most parents also believe that Careers Wales and Cardiff Council were keen to manage down their expectations in accessing specialist out of county college placement. Some of them felt that they are not provided sufficient information on options that are available to them and were being discouraged from exploring options beyond the local provision.

“I do feel there's a lot of managing expectations, especially from Careers Wales and social workers too. Now, I know it's right and proper not to raise parents' expectations where there's little chance of them being realised and you need an honest conversation, but I do feel there is an awful lot of, "Oh well, don't ask for that because you won't get it," "We don't like 'out of county',"

They felt that Careers Wales staff’s negative attitude towards parents will discourage those who want to access specialist out of county college provision, particularly those parents who are less confident in challenging the views and assessments of Careers Wales staff.

5.7. Duration of funding for approved college placements

Parents’ understanding varied on the duration and availability of funding for specialist out of county placements. Some reported that they have been made to understand that their child can only access two years placement and

funding. Others stated that their child had been granted two years and can apply for an additional one year funding subject to review. Another parent who cited that their child was awarded a confirmed three year funding for a placement at a specialist college. One of the parents reported that their child's placement and funding is for one year and its continuation subject to an annual review.

These information has led parents to raise questions on the rationale for the variability in the duration of funding and placement in a specialist college on outside Cardiff. They believe that Cardiff Council and Careers Wales should provide parents with guidance and some clarity on this issue.

Those who have been able to access two year specialist FE funding felt that they needed more clarity on their child's eligibility to a third year funding. Most of them agreed that the two years was not sufficient. They felt that a third year placement was necessary to enable their child to demonstrate and practice the knowledge and skills acquired as well as gain confidence in using these.

The parents whose children have accessed a third year funding confirmed that during this period their child's knowledge and skills "really came on". Most of them believe that there should be better flexibility in allowing a third year placement particularly in cases where the individual can further achieve significant progress in improving their skills and achieving intended outcomes. They believe that a third year placement would enable their child to consolidate the knowledge and skills that they have achieved as part of their preparation for future independent living.

Parents suggested that Cardiff Council and Careers Wales provide more clarity and guidance to parents on existing policies and guidance on the prescribed duration of specialist placements and the scope for extending these placements when necessary.

5.8. Local Education Authority's role on Section 140 assessment

Not all of the parents were aware that the responsibility for the Section 140 assessment will move to Cardiff Council as the Local Education Authority. One of the parents who was aware of this future change expressed concern over the independence of conduct the section 140 assessment. There was a view that the local authority's budget financial pressures could affect decisions on access to and funding for specialist out of county college placements.

Most of the parents stated that it would be useful for others to be made aware of these changes so that they can engage and work with Cardiff Council early in accessing further learning and development options for their child.

6. Parents information support needs in accessing further learning and development opportunities.

During the focus groups, parents identified various types of information which they believe would be useful to those whose children would like to pursue further learning and development following their secondary education.

6.1. Independent information advice to parents

Due to their negative experience of dealing with Careers Wales, some of the parents suggested that an independent body or group should be created to provide the parents with independent information and advice on future options for learning and development that their child can access following their secondary education. This should not only include the local college provision and but the option for accessing specialist out of county college provision. They believe that these information need to be more widely available so that there is greater awareness of opportunities and choice that are available to young people with learning disabilities. Parents should not have to rely on their own initiative i.e. undertaking their own research or rely on word of mouth on the availability of services that would benefit the knowledge, skills and well-being of a young person with learning disabilities.

6.2. Early dissemination of available options

It was suggested that information on further learning and development options including specialist provision should be made available to parents even before their child's final year at secondary school. One of the parents cited that it should be made available from when child is 14 years old. This would allow parents sufficient time to consider or get used to the idea of, accessing further learning and skills opportunities locally or at a specialist college provision. This would also give them time to work with different professionals to help determine their child's scope for further development and their eligibility to available provision. They also felt that it is also important to make these options known to their child as early as possible so that they would have time

to consider being away from their parents and home if they choose to go to a specialist out of county college.

6.3. Information on the assessment process and the roles of professionals

As mentioned previously in section 5.1, parents believe that they would benefit from gaining a better understanding of the Section 140 assessment and the evidence that this process requires.

They believe that that it would be useful for other parents coming into the system to be made aware early, of the evidence that would be required during the assessment process. This will enable them to make an early start of securing and collating the various health and medical documentation required for the Section 140 assessment. They believe that it is important to be aware of the required documentation as there are often long waiting lists involved in securing these from the relevant medical or health professionals. This will help to ensure that the necessary medical and assessments are available in time to inform the Section 140 assessment on the level of care and support that will be required.

One of the parents believe that Careers Wales (or in the future, the Local Education Authority) should work with parents early on to establish their preference or expectations on the type of college provision that they would like their child to access. This will enable both parties to work collaboratively to collect and collate the necessary evidence required in assessing the young person's eligibility to the appropriate college provision.

This information would also be particularly useful to Careers Wales (or the Local Education Authority) and Social Services in forecasting the demand for further education placements locally and in specialist placements outside of county for those with complex needs. The early consideration of these options will enable parents and their children to work with secondary schools in preparing them to access the suitable local or specialist college placement.

This early consideration of options will also help the parents to familiarise with and acquire the relevant information on either the local or specialist provision so that they can review and gain confidence on the services that their child will benefit from.

6.4. Availability of information specialist provision.

Parents also believe that information on the local Cardiff and Vale College provision and on specialist out of county college provision should be made available to all. This information made available in an easily accessible format. Most parents have limited time due to their caring responsibilities and the need to balance this work other household demands for their time. They believe that this should be considered in designing the format on how this information should be made available.

6.5. Parents access to the Section140 assessment report

Most of the parents believe that they should more input in the Section 140 assessment process. In finalising the assessment document, they believe that parents should be given the opportunity to review the assessment for accuracy and ensure that the case for accessing the preferred provision is presented well. It was also suggested that all parents should be encouraged to proactively engage in the assessment process. Support should also be offered to those who are less confident or less articulate presenting their case for accessing what they believe as the appropriate provision for their child.

6.6. Disagreement with the findings of the section 140 assessment process.

Some of the parents suggested that there should be structured process for challenging the findings of the section 140 assessment in cases, particularly in cases where the parents' views are contrary to its findings and recommendations.

6.7. Availability of specialist college provision in Cardiff.

Majority of the parents involved in this research believe that the Welsh Government and Cardiff Council should consider and plan to develop a locally based specialist residential college for young people with learning disabilities. They suggested that this local provision should model itself on the services and support provided by Coleg Elider and Star College and other notable out of county specialist colleges. One of the parents stated that

“if Bridgend can do it, Cardiff as bigger local authority should be able to offer this”

Another parent suggested that locally there should be:

“A proper centre for learning disabilities with residential accommodation that will provide opportunities for young people to be better integrated in social and economic activities in their communities in Cardiff”

Perceived advantages of local residential college provision

Some of the parents believe that having a specialist residential college in Cardiff would allow more young people with learning disabilities would benefit from the outcomes offered by this type of provision. Additionally, parents would not have to worry on having to undertake long journeys to visit their child.

“A lot of children from xxx school went to Cardiff and Vale because the parents didn’t want them to go anywhere else. If the residential element had been available, they might well have chosen it because it was on their doorstep. They weren’t prepared, like I was, to send xxx away. There might be a much higher take-up”

Most of them believe that there would be less take up of specialist out of county colleges if similar provision is available in Cardiff. They stated that they would choose a local residential college instead of sending their children out of county which would be a two or three hour drive away from Cardiff.

Due to the lack of residential college provision in Cardiff, most of the parents involved in the research stated that they have chosen to send their child to a specialist out of county residential college because of the types of personalised support that these colleges offer and outcomes that it can support their child to achieve.

Reasons for preference in residential college provision

Most of the parents involved in the research believe that more young people with learning disabilities should be offered the opportunity to access specialist college residential provision. They believe that this facility enabled their child to develop independent living skills that they thought was not possible or otherwise would not have been achieved he or she had stayed at home.

Another advantage that these specialist residential provision offers is the level of security and safety that their child has as well as availability specialist professional staff that are with staff that are supportive of the development of independent living skills sets.

Parents whose children have complex needs, believe that provision in the Cardiff Vale College would not be able to help and support their child to achieve the learning and skills outcomes they will have acquired during their out of county residential college placement. They also believe that being away from the home reinforces the development of their child's independent living skills and social skills.

“..... xxx wasn't able to learn in the sense that when xxx home, it's, 'Mummy do it.. Daddy do it'. That was one of the main reasons for not going to a local FE college. We knew xxx wouldn't move on while xx was in the house setting...”

“Yes, because it's a very hard decision to send somebody so vulnerable away from home. But we also knew from experience that at school even, during the day, they would be able to get xxx to do things at school that we would not have been able to get xxx to do here.”

“our hope was that xxx would be able to be a little bit more independent, that xxx would be taught some skills that he wasn't able to learn at home”

Furthermore, they also believe that the residential placement helps to pave the way for their child towards living independently and moving into supported living arrangements. In residential setting, their children can get themselves up and ready in the morning. They learn how to undertake tasks independently such as taking public transport, going shopping, cooking, doing the laundry etc. which wouldn't have been achieved at the Cardiff and Vale College.

“It has to be eased in. I felt that was the key, if I could get to go to a college where xx would have experience of living out and doing things that xxx would be doing later on”

“(learning these skills) was actually fundamental because I knew it would be difficult for xxx to go from home directly to supported living”

“In terms of the academic side of things, they're secondary considerations, but we still wanted him to learn – we hoped – with

numeracy and dealing with money, and that would happen..... It was about leaving home, socialisation, improving behaviour, speech and language.”

Being away in residential college provision also provides their child with various opportunities to develop their social skills. At residential college parents believe that there are more opportunities for social interaction with their peer group and not just with family members. They also believe that these opportunities enables their child to gain confidence in dealing with other people. One of the parents felt that it was very important their child develops their social skills further, and are able to develop abilities such as patience and cooperation and to have their confidence reinforced.

The development of these independent living and social skills provide parents with assurance on their child’s ability to cope with living independently in the future when they can no longer be around to support them.

Access to specialist support and services

Another advantage that out of county residential colleges offer is access to specialist professional support such as speech and language therapy, physiotherapy etc. One of the parents cited that their child had greatly benefited from specialist professional support at his placement.

“We wanted, basically, xxx to grow in confidence and to come out of xxx shell. The other key thing for us, really, was the speech and language therapy, which didn't really happen in school. We knew xxx would get some specialist speech and language therapy”

Other long-term preventative benefits of residential college placement

Most of the parents recommend that the Welsh Government and Cardiff Council should recognise the long-term benefits and outcomes achieved during their child’s placement at a specialist residential college. The skills sets they developed in these settings led to better the health and care outcomes.

One of the parents reported that before the out of county residential college placement, their child needed 2 support workers 24 hours a day.

“By the time xxx came out of college, xxx needed one support worker, and sometimes that support worker is shared.”

This parent also believes that outcomes achieved during this placement has led to significant long term savings for the local authority. They recommend that Cardiff Council should consider the longer term outcomes that are achieved in terms of improvements in their child’s quality of life and savings in care costs that are generated in comparison to costs that are involved in supporting these specialist out of county college placements.

Another parent cited that the out of county college residential placement had enabled their child to access a range of professional medical and health support such as speech therapy, aqua therapy that has led to significant improvements on their mobility and health.

“But we’re saving society money in the long-run because, you know, they’re not getting ill, they’re not needing all sorts of extra support. There’s an opportunity in some cases that they might actually be able to do some supported work, you know.”

Most parents involved in the research also believe that the provision at Cardiff and Vale College cannot replicate the outcomes that are achieved by those who have accessed specialist out of county residential college provision.

“Our kids don’t go to further education college to get, I don’t know, HND or things like that. The biggest thing that they go to college for there is to learn to live without us. You can’t replicate that in Cardiff and Vale, because you come home.”

“I mean, with our xxx, xxx was totally against going away to college but we knew that was right for xxx because, if we died, xxx would be completely at sea. Now, three years later, xxx incredibly independent. xxx takes the train to places, xx come on in leaps and bounds, xxx really transformed xx life as, I think.

As a result of their placement at one of the specialist out of county colleges, these parents believe that their children achieved remarkable levels of independence and confidence that they previously thought was not possible.

Positive impact on parents’ well-being

Their children’s out of county residential placement have a positive impact to the parents’ well-being. During this period, some of them felt that they were

able to “get a little bit of their life back”, “go back to work” and “do other things and not have a life that is solely dedicated to caring responsibilities”. Being in out of county placement gave parents assurance and confidence that their child is in a safe and supported environment where they will gain skills and knowledge that could further enhance their abilities for coping with living independently in later life.

6.8. Support Welsh language preference

Two of the parents highlighted the need for Careers Wales and Cardiff Council to ensure that the further learning and development opportunities are able to meet the language preference of Welsh speaking individuals with learning disabilities. They believe that current learning and support the provision in the Cardiff and Vale College is not able to offer this. These parents strongly recommend that local providers should offer learning and support services in the Welsh language for those young adults who would require this facility. It is further recommended that learning and development provision delivered in the Welsh language should be developed by Cardiff Council in collaboration with other local authorities in South Wales so that this can benefit Welsh speaking young people with learning disabilities across these areas.

6.9. Schedule decision on funding applications

Parents were unified in their concern over the timings of the release of decision on funding for specialist out of county residential college placements. Some of them reported that were not informed of the decision until August, which is just a month before their child is expected to start the college placement which has resulted in a lot of stress for themselves and their child.

Parents suggested that the Welsh Government should provide the decision for funding as early as possible and should review the current time line in releasing their decision on funding to the parents. One of the parents reported the FOI request they made have shown that approximately 40% of the funding applications were informed of the decision, late in year i.e September, a month after the expected start of the school term.

Impact of late decision making

The late announcement/notification of decision on funding of out of county placements have caused a lot of stress for those families awaiting this. Parent reported that the uncertainty over the funding is not only stressful to them as

parents but also their child. They believe it is important for the funding decision to be released earlier so that their child has sufficient time to get used to the idea of being away from home. This will also enable them to effectively support their child and prepare them for residential placement.

“Any change for young children like that is a big thing, or when they don’t know if the change is going to happen or not. It’s really very stressful.”

The early release of decision will also enable longer transition process from being at home and moving on to residential college placement. One of the parents stated that that the late decision on funding and the hasty transition has affected the way that their child settled in their out of county placement.

7. Experience at residential college placement

7.1. Satisfaction on engagement with out of county college staff

All of the parents were very happy and satisfied with how the specialist out of county residential colleges have supported the development and care of their child.

They were happy with the structured and regular engagement that they have with the college. In particular, they were really pleased with how the residential staff had helped their child to settle in this placement. Additionally, they were also content and satisfied with the reports and narratives that they receive from staff on the progress achieved by their child. They felt very assured with the progress reports have received and satisfied with their involvement the college annual reviews.

Parent cited that these progress reports provided them with updates on learning and skills achieved as part of the curriculum as well as the skills that their child has developed around on self-care, eating, housekeeping skills, socialisation etc.

Parents also felt that the engagement that they initiated with out of county staff are very much welcomed. They reported that staff were always happy to answer questions, provide assurance and were happy to receive suggestions and feedback on the services and support that they provide. This level of personal engagement that they have with the staff allowed them to further monitor their child’s well-being and the progress made in addition to the more periodical and structured progress reports that they received and meetings

they attended at the college. Parents were all in agreement that they felt very informed and assured with the development and progress made by their child.

Parents believe that significant outcomes have been achieved by their children as a result of their out of county college placement. Despite the costs involved in funding these placements, the parents believe the long-term benefits these placements provide represent value for money.

One of the parents summarised the remarkable progress and outcomes that their child had achieved in saying:

“once we realised the sort of progress xxx was making, it gave us hope that xxx would actually become a more useful member of society than we would ever have dreamed xxx could be... a degree of independence and a degree of happiness in xxx own life, xxx was going out to do a job that xxx was able to do, which gave xxx satisfaction...”

7.2. Improving contact with social workers at college placement

Some of the parents expressed their concern over the limited contact that they have with social work staff during child’s placement at out of county college. Most of the parents cited that their contact with social workers mostly during crisis situations or when there is an issue associated with the care for their child.

Parents believe that they would benefit from having more regular contact and support and advice from social work staff not only during the time that their child is in college placement. Most felt that social work contact and including information and advice should be available throughout their child’s schooling period i.e. from primary school to secondary education and during specialist college education where applicable. They also have the expectation that social workers should provide information and advice in preparing them for the key transition periods as their child goes through the education system.

“My son is going to be leaving school in three years’ time. What’s going to happen?” because it feels like you go from cliff edge to cliff edge, you know, the transition from primary to secondary school, well, that’s scary so you have to have some real contact then. They get to the end of secondary school, you honestly don’t know what’s going to happen..”

This issue was further confirmed by one of the parents who reported that they had to ask on several occasions for a social worker to be assigned to them to support them in the process of getting their child to a specialist college.

One of the parents reported that they only had contact with their social worker during their child's first year annual review at his college placement and had not had any contact in the following year. They did not pursue contact with them as they felt that their child did not require any specific help or support from their social worker. Although one of the parents reported that they had a named social worker for 2 years, the latter never attended any of the college annual reviews. Other parents confirmed that it is very rare for them to see a social worker in attendance during the college annual reviews. Some of the parents stated that they had very limited or no contact with the social worker up until their child's transition period during their final year of their college placement.

Parents stated that they were unsure of the schedule and frequency and the type of engagement that they should expect from social workers during the time that their child is at an out of county college placement.

Most parents however have the expectation that their child will have a named social worker throughout their college placement. They believe that a social worker should be present during the college annual reviews so that they have some understanding of the progress that had been achieved while in college placement. This will provide the social worker with useful evidence in assessing whether the college placement achieved the intended outcomes and provided value for money.

In cases where parents have been successful in accessing social worker support, they stated that most of their experiences has been positive and felt that they had been supported well. They were also pleased that their assigned social workers had taken the time to get to know their child well.

Most parents believe that they need to have better engagement with their social worker during the time that their child is at college. This engagement should go beyond form filling, ticking boxes and a regurgitation of what is already been outlined in the college's annual review report.

They also believe that it is important to have a named social worker who can provide some continuity and stability in supporting their child at college and particularly during the transitioning phase. Additionally, parents believe that this will enable them to develop a positive relationship with a social worker who understands their child's progress and capabilities and the challenges during placement

Knowledge of meeting agenda

In having contact meetings with social workers parents suggested that it would be useful for them to be made fully aware the meeting agenda so that they make the necessary preparations for it. One of the parents cited their experience where in:

“I didn't have a complete understanding of what the purpose of the meeting was. My understanding was that it was something to do with funding... but it turned out that it was all to do with the potential of moving him to independent living... which was a bit of a shock at the meeting”

Parents praised the good practice adopted by out of county colleges in setting up meetings with them. Prior to the meetings, the colleges' provide them with a written agenda and other relevant documentation for review. The advance receipt of these documentations enables them to effectively prepare for the meeting.

Positive experience with Social worker

Only two of the parents involved in research cited that they have had excellent support from their social worker during the time that their child was in college. They felt that the social worker has taken the time to get to know their child and the progress that they had achieved. They also both appreciated the visits that their social workers had made at the college outside the scheduled review visits.

Only one of the parents confirmed that their social worker attended the annual review meetings conducted by the out of county college.

7.3. Duration and extension of out of county placements

It is known to most of the parents that there are individuals who have been able to extend their out of county placements beyond two years. However, most the parents remain unsure of the scope for and the eligibility criteria for extending placements at specialist out of county residential colleges.

Role of Careers Wales

Most of the parents stated that they need to have a better understanding of the role of Careers Wales in determining and supporting their child eligibility for extending their of county college placement when appropriate. They felt that Careers Wales should support extended college placements of those who need more time to fully develop and consolidate the skills sets that they hope to achieve.

Some of the parents cited that Careers Wales staff have not been supportive in helping them with their application for an extension of placement so that their child can have opportunity to further develop the skills sets she needs to live independently and have some gainful employment. They felt that that Careers Wales were very negative attitude towards developing a new learning and skills plan that can be achieve through an extension of the college placement. They reported that Careers Wales did not fully engage with them and did not share with the parents the additional assessment forms. One of the parents felt that Careers Wales did not fully consider their child's need and aspirations. She told Careers Wales that:

“You're not working on xxx behalf. You're not listening to what xxx wants, what xxxx needs.

Some of the parents believe that Careers Wales and Cardiff Council are more concerned over the budgetary implications of extending out of county placements rather than ensuring that the young person is able to achieve better skills and outcomes for future independent living.

Parents expectations of Cardiff Council

Some of the parents expect that Cardiff Council's Adult Services should be more supportive of applications for extension of out of county placements particularly in cases where significant further improvements in knowledge and skills can be achieved. Some of them felt that that Cardiff Council generally has a negative attitude towards these applications. They believe that in recent years it has been more difficult for parents to access funding extensions for and specialist college placements. They believe that Cardiff Council would be more supportive if social workers were more involvement in college annual reviews and have a good appreciation of progress that the young person has achieved and can further achieve. They also raise questions to Cardiff Council on how other young people have managed to extend their college placements and funding beyond the two year period.

Parents' perception on duration of out of county placements

Some of the parents believe that the 2 year placement in specialist colleges is not long enough to enable their child to fully develop and be confident of the knowledge and skills acquired. Most of them agree that that a third year placement is necessary as the two years more suited for a more academic, individual with no learning difficulties or anxiety issues.

For those with learning disabilities, they believe that the 1st year of college placement is the "settling in period", the 2nd year is the period "thriving" and developing new skills and knowledge. And the final, third year, is perceived as critical for consolidating the new skills and knowledge achieve and vital in in preparing them to moving on to alternative accommodation and more independent living.

During a three year placement, parents suggest that a managed transition should start towards the end of Year 2. These timescales would allow them sufficient time to work with the college and Cardiff Council to effectively support their child in moving them on to the suitable living arrangements in Cardiff "rather than scramble around at the last minute".

Eligibility criteria and the timeline of decisions

Parents stated that they would benefit from having a better understanding of the eligibility criteria and the procedures involved in applying for extensions for out of county placements. It would useful for them to understand the timelines involved, the evidence that would be required to support the applications and the role or input of the educational provider in supporting these.

Those who had summited applications for extension of out of county placements would like to have a better understanding of the timelines involved in decision making and the scope for submitting an appeal in cases when an unfavourable decision has been made.

Those who applied for an extension of their child's placement suggested that the Welsh Government and Cardiff Council should review the time line for releasing the decision on these applications. These parents reported that they were informed of the decision late in the summer, just before the start of the new term in the third year. The long wait for the decision created a lot of stress for the parents and the child due to uncertainty in the continuity of placement. Parents believe that the decision should be made earlier, so that "you're not hanging around, you're not getting stressed, and you're not

worried” and they can support their child’s expectations. One of them summarised their experience in saying:

“And it really does affect these individuals, their anxiety levels and everything, when they don’t know what’s happening the next year. Because any change is very difficult for a young adult with additional learning needs. And I just don’t feel that there’s any consideration given to their wellbeing.”

Some of the parents who shared their experience of waiting for the decision felt that:

“what happened was cruel. It was cruel to xx because xx didn’t know... I couldn’t actually say to xx, “Yes, you’re definitely going back to college” in case xx couldn’t go, in case they said no, they wouldn’t fund it. I had to keep saying, “We’re hoping that you will. We’re just waiting for the very last confirmation.”

“It’s so unfair, so worrying for xx not knowing where xx going. This is a child that has additional needs that needs to plan ahead, needs to know where xx going, needs to feel secure”

Process for resolving issues on extension of placements

Some of the parents have been very upset over their disagreements with Cardiff Council on the suitability of learning and care provision for their child. They believe that there should be a better process for resolving disagreements over the extension out of county placements and the suitability of care and accommodation package on offer. They felt that the resolution of these issues should not have to go through the legal process and could be achieved through better engagement and dialogue between Cardiff Council and the parents.

These parents suggested that Cardiff Council should engage better with parents through face to face dialogues in deciding the future care and development options for their child. They believe that social work staff should listen to their views ‘as parents’ and as the ‘best advocates’ of their child’s future development and care needs. They also suggested that Cardiff Council should work with them in finding the best approach to resolve their disagreements. This would avoid extended email exchanges and unhelpful

meetings where no agreements or compromises are achieved. Their experience of the process in seeking a resolution of their dispute with Cardiff Council had caused so much distress and had taken up so much time that could have been better used in improving services.

7.4. Evaluating progress made at college

Benefits of periodical evaluation

Parents stated that they would benefit from having a structured process of getting information on the progress their child has achieved against his learning and development objectives. This should be in addition to the verbal feedback that they receive during their periodical visits at the college and during the annual reviews. They would find it useful to receive a detailed report of what their child has achieved against the classroom based objectives or academic targets. Additionally, it would also be useful for them to be informed of various social and non- academic tasks and activities that their child had been involved in. This will enable them to have an appreciation on how their child copes and deals with these activities.

They believe that they should be provided a copy the year-end report on progress that their child has made against their learning and development objectives and any other skills that have developed or achieved during the year. Such information would enable them to gain a full appreciation of the knowledge and skills that their child had developed and track the progress they have achieved during placements. Parents are also unsure whether the out of county college submits a formal report to Careers Wales and Cardiff Council on knowledge, skill and outcomes that their child has achieved.

Most of the parents declared that they had not received any formal written report that provide details of their child's progress and achievements while at college placement. The format and scope of the progress reports that they receive from the colleges vary. They all confirmed receiving verbal progress reports during the annual reviews conducted by the out of county colleges. One of the parents stated that they had to request for a specialist Occupational Therapist report from the college to gain a more in-depth understanding of the physical improvements their child had attained. Another parent cited that the college prepared for them a "home to college" book that provides information on various activities that their child has been involved in. Only one confirmed that they received a copy of an in-depth report comparative information on their child skills at the beginning of the college placement and what has been achieved at end. This was particularly useful in

providing them with a detailed understanding on where significant improvements were achieved in developing their child's knowledge and skills and where support would be required.

Most of parents believe that information from the formal assessments made by the college on the progress that has achieved should inform the authority's decisions on applications for extending placement and funding in out of county colleges. These data sets should be key in determining whether there is the scope for further improvement in the knowledge and skills that their child has achieved during placement.

They also expect that the information from these progress reports will be used as baseline data to inform the social services assessments and their providers care plans when their child moves on from college placement to the appropriate accommodation and support in Cardiff. Furthermore, these data sets will also be important in determining whether the knowledge and skills they have achieved are maintained in following the move from college placement.

8. Transitioning from college placement

8.1. Understanding of the transitioning process

The views shared by parents illustrate the variability in their knowledge and understanding of the transitioning process from out of county college placements.

Some parents were unsure when the transitioning period should start. One of them believes that this starts in January during the final year of college placement. Others cited that this stage happens during their child's last 6 months at college. One of the parents declared that they instigated transitioning process early because of their concerns on the availability of future accommodation for their child. Another claimed that their child had not gone through a proper transition process. One of them said that they are not sure of what this stage involves and when it should happen.

Most parents agreed that they would benefit from having a better understanding of the key stages and the timescales that are involved in transitioning their child from out of county college placement to the appropriate accommodation and support in Cardiff. They also stated that it would be useful for them to be made aware of the various roles and

responsibilities of the professionals and individuals who will be involved in the process. More specifically, they declared that they need to have better understanding of the social worker's role, the support planners, the staff in out of county college and the future care and accommodation providers, the parents and their child's input or advocates input this process.

Parents suggested that it is useful for them to have a summary diagram that illustrates the key stages as well as the key individuals and stakeholders that have involvement and input in the transition process. They also expect to be made aware of the process and arrangements for resolving disagreements or issues that may arise during the transition period.

8.2. Earlier start of transitioning from college

Some parents were informed that this process should start 6 months before the end of the final year. Another parent believes that transitioning should start even before the last 6 months of their child's final year in college placement. Everyone however agreed that transition planning should start earlier than the timescales prescribed by Cardiff Council.

For those whose children are in college for three years, they believe transition planning during the last 6 months of the final 3rd year could be too late. They believe transitioning should start at the end of the second year. This would give Cardiff Council sufficient time to plan and appropriate accommodation and care arrangements to be in place. They believe that the suitable accommodation and care package should confirmed even before the end of the final term in college. Parents believe that that it is important to get this ready in time so that their child can move straight into the appropriate provision by the end of their final year.

The timing of letting parents know on when should start thinking about their child's transition from college placement should be consistent with all parents involved. One of the parents thought that it was inappropriate for the social worker to ask them to start thinking about transitioning soon after their child has started at college.

Starting the transition planning early, will enable parents to effectively support the process of finding the suitable accommodation and support provision that meets the needs and specific requirements of their child. If transition planning is started late, parents believe that suitable accommodation may not be arranged on time and can cause undue stress to parents and their child.

Most parents recognise the importance of transition planning in preparing their child to get used to the idea of moving on from college placement. As part of successful transition planning, their child should be emotionally ready to move on to the appropriate accommodation and care provision. Some of them questioned whether the 6 months transition period is sufficient time to prepare their child to move on from their college placement. They questioned whether this timeframe would provide Cardiff Council's transitioning team with sufficient time to find and arrange the suitable accommodation and care arrangements.

8.3. Planning to meet the demand

Parents suggested that Cardiff Council should gather and collate the necessary information that will help them to make accurate projections on the demand for accommodation and support from young people who would be completing their college placement. They believe that it is important for Cardiff Council to have sufficient capacity to:

“help them to prepare and count up the numbers and the numbers that they need to be preparing for in terms of providing the support and in terms of providing the accommodation..”

“...why you need the reliable figures early on. You do all the plans with the Health Board. You do all these population needs assessments. You know how many there are with... You really should know”

In doing so, parents believe that Cardiff Council and the accommodation and care providers can plan ahead of time to meet the current and future demand from this group.

“That's the weakness, and that's why these people aren't getting picked up until the last month or two in college. Six months to go: "Oh, we want him housed or her housed." They need to know these people coming. It's an impossible job, otherwise”

Parents recognise that that planning ahead of time is as vital due to the limited availability of housing stock and care support that would meet the needs of each individual. These preparations would help to avoid the unnecessary delays or waiting time in securing the suitable accommodation.

Parent also expect that Cardiff Council should make use of the out of county college data and reports in transition planning for each individual. Information on each individual's characteristics, skills and abilities will be considered by

the Cardiff Council Team in determining the suitability of accommodation and care arrangements.

“I think reports from the college would be really useful for that because obviously they’re doing that with xxx now, so that we can have a better idea of how xxx got on in the xxx on xxx own.”

To improve success of the transitioning process, parents suggest that Cardiff Council should consider the unique or specific needs of each individual. The planning team should also consider the differences timescale that each one would need to get used to the idea of moving on to another accommodation and to adapt to a new environment and care arrangements so that any distress can be avoided.

“had the input of the central special needs team at xxxxx asked for advice about transition. And what xxx had said was, “If you’re thinking of moving xxx next July, that place needs to be there now and, really, xxxneeds a year or two to adapt.”

Some parents were in agreement with the following perception of the transition planning team:

“they don’t know enough about the young people who are coming through to plan for their accommodation”.

Most of the parents appreciate that there is a shortage of suitable accommodation and care provision for young people with learning disabilities. In helping to choose their child’s accommodation, parents believe that they have sufficient time to consider this. They should not feel compelled to take up what is on offer because this is available for their child to occupy.

8.4. Engagement with parents during transitioning

Parent suggested that Cardiff Council should adopt better ways engaging with them during the transitioning phase from college placement.

“ they don’t come to you and say, “Oh, xxx is going to be moving on in two years’ time. Here’s what we should be doing. What can I help you with?” and, “Here’s some information.” That’s where this flowchart would be a Godsend.

At the minimum parents expected that social workers should inform them the schedule agenda of meetings on transitioning of their child from college placement. Two of the parents stated that they attended meetings where they had not been informed that transitioning was the main agenda. They felt that they should have been informed in advance so that they could prepare ahead of time.

More importantly they felt that Cardiff Council should seek their views on the suitability of future the accommodation and care arrangements that will be provided to their children following their college placement. They also believe that sufficient weight should be given to their views in deciding the appropriate accommodation as well and the care and support arrangements that will be put in place.

Parents also expect the Cardiff Council team to provide them with updates on progress made with finding and arranging the suitable accommodation and care placement in Cardiff. Parents stated that they should not have to chase up the accommodation team to gain assurance that the necessary preparations to enable their child to move on to the appropriate provision can be delivered on time.

“Yes, literally, on the Friday, I had to say to the support planner, “What’s happening on Monday? Does the care agency know? Does the taxi firm know?” I was scrambling around with xxx sorting all this out on Friday for things that were supposed to start on Monday.

Parents also suggested that Cardiff Council should provide opportunities for parents of those sharing the same accommodation to meet. This will enable them to get to know each other and share information and support in the future.

8.5. Improving the scope of transition planning

A number of parents have also made some suggestions on how Cardiff Council could further improve the scope of its transition planning. One of the parents believe that the approach adopted by Cardiff Council in transition planning is quite narrow and very much focused mainly in moving the individual to the appropriate accommodation and care arrangements. They believe that the transition process should also cover various other aspects of the young person life.

This parent highlighted the best practice on transition planning as exemplified by the work based in England as undertaken by the Valuing People Initiative. This approach in transition planning considers the different pathways and aspects of the young person's life that the educational provider and social services can support and plan for. This includes not only planning for housing and care support but also planning for other aspects of life such as employment options, healthy living and developing friends and relationships.

This approach requires social services, the school and parents to work together to towards a smooth transition from out of county college. This will involve early planning for activities and support arrangements that the young person can access following college placement. The parents involvement in this process would provide them with assurance and confidence that they have effectively contributed in providing a "good and happy" life and ensuring the "best possible outcomes" for their child. This best practice adheres to the person centred and holistic approach in transitioning the young person from college placement to the appropriate support and accommodation provision.

Another parent stated that it was important that support planners would worked with them in determining various activities that their child can be involved in moving on from college placement. Support Planners can tap into their knowledge and understanding of their child's personality and preferences and provide useful advice on activities that their child will enjoy and benefit from.

A number of parents were very complimentary of their experience with support planners in engaging with them to identify various support activities that their child can undertake. They felt that work of the support planners arranging various activities that their child can be involved in continue to support their personal development and wellbeing.

Some of the parents expressed that they were quite unsure of the difference in the roles and support that provided by the social worker and the support planner. They believe that they will benefit from having some clarity on the various roles that Cardiff Council staff have in supporting their child's transition from college placement to the appropriate accommodation and care arrangements in Cardiff.

Some of the parents also believe that transition planning should help prepare their children to consider employment when appropriate. Additionally, they believe that plans should be made to ensure the young adult has opportunities to undertake tasks and activities that would help to maintain the knowledge and skills they have developed during college placement.

8.6. Issues with the supported living arrangements on offer

8.6.1. Limited choice and options

Parents feel that their child have very limited choice on the accommodation and care arrangements that are available in Cardiff. Most of them reported that their child had been offered a placement with one of the specialist supported living providers Cardiff.

“I don’t know about anybody else but we weren’t offered- We were offered one accommodation, which was fine... But I don’t know what else is out there. But nobody has said, “Oh, would you like this, this or this?”

That’s not a problem, it’s just if the council think we’re getting a choice, we’re not.

In cases when the accommodation offered to the child is deemed unsuitable, they feel that they have no other recourse but wait a long time for another accommodation to be available and for their child to go back home.

8.6.2. Timely access to accommodation and care arrangements

Parents expressed their concern over the delays that others have experienced in moving their child back to in Cardiff. This could mean bringing them back home, and risk the regression the skills that their child developed during college placement

“It’s back to home routines. It’s back to Mum and Dad to live, where we do things for them which they were doing for themselves in college. You’ve lost a lot of what they’ve learnt through college life...”

“You need to have that in the system for planning...Everything that you’ve worked on or tried to achieve by sending them to college is going to be taken away by them then coming home..”

This perception was also confirmed by those who had temporarily housed their child at home while due to delays in availability of accommodation. They cited that their child’s skills regressed as their behaviours revert back to dependence on their parents in doing specific tasks. The limited types of activities that they can do at home further compounds this issue. Other

parents agree that they can see them losing some of their skills when their child comes back home during term breaks.

Parents expect Cardiff Council to ensure that the appropriate accommodation and care arrangements should be ready by the time that their child leaves college placement. However most of them worry about this and are unconfident that the suitable accommodation would be in place. One of the parents cited their experience when:

“We’ve got ten weeks before xxx finishes college and we know absolutely nothing about what’s happening with transition, with xxx coming into supported living.”

One of the parents was particularly unhappy with the delays involved in moving her child into her designated accommodation in Cardiff. They feared their child would revert back to full dependence on them lose the independent living skills acquired at college placement:

“xxx had already been home for six weeks. The longer xxx was at home, the harder it was going to be to move xxx out. I hadn’t sent xxx miles away to learn independent living, for it to be undone. That was the whole point about xxx going away, to help xxx to live as independently as xxx possibly could.”

“I didn’t send xxx away for xxx years to college, to come home and have it all undone within the following year”

8.6.3. Availability of care and support provision in Welsh

Some of the parents have expressed their concern on the availability of care staff who can provide support in the Welsh language. They expect Cardiff Council to plan for and make provision for these young people to have access to care and support in the Welsh language particularly for those come from Welsh speaking families and have accessed education in the welsh medium. . Parents cited that their child have not been able to consistently get support staff that are able to speak in Welsh.

8.6.4. Knowledge and familiarity of arrangements on offer.

In helping to choose the supported living accommodation for their child, one of the parents were concerned that the social worker showing them around

was not familiar with the accommodation and have not visited it before. This experience did not give them confidence with the supported arrangements that was on offer. Parents expect social work staff to be sufficiently knowledgeable and familiar with the living arrangements and the facilities in supported living accommodation. They believe that this will help assure them of the suitability of the arrangements that their child will be moving into.

One of the parents stated that they were shown supported living accommodation that their social worker regarded as unsuitable for the needs and support required by their child.

8.7. Concerns with the suitability of supported living

Some of the parents confirmed that they have disagreements with Cardiff Council on the suitability of supported living arrangements in meeting their child's needs and well-being outcomes. These parents felt that Cardiff Council's social services have not fully listened to their views and concerns on the impact that the change in care arrangements will have on their child's health and well-being.

8.7.1. Impact of change in care arrangement on skills and well being

Some of the parents were very concerned about their child's welfare in moving them on from an out of county residential setting to supported living arrangements in Cardiff. They believe that the change in the environment and care arrangements would have detrimental impacts on their child's skills, their well-being and their overall quality of life. Moving on their child to supported living arrangements would mean significant changes in the level of support, staffing competence and expertise and social activities and interaction that their child can access and benefit from. They believe that this change in living and support arrangements will not provide their child with same level of security and independence in exploring the environment around them. Some of the parents anticipate that this change would have negative impact on their child's mental health and would cause anxieties to develop.

These parents believe that they benefit from having some assurance that their child will continue to thrive and have a good quality of life in moving on to supported living arrangements.

“He's happy, he's thriving, he's improving, we would never have believed how successful it would be, and you're offering us a, sort of, leap into the unknown”.

“it is providing a very comprehensively good service for all of us and our children. We have trust and faith in the place that it’s being run really well, so why undo that and risk these... I’m scared of the anxieties that will hit all of these young people.”

They believe that Cardiff Council could provide them with evidence on how supported living can ensure the sustainability of knowledge and skills developed at residential setting. Additionally they would like to be assured on how these arrangements can continue to support their child’s development, maintain their skills and help to support their well-being outcomes.

“you’re offering us a, sort of, leap into the unknown when you say that you can deliver all of these things but you’ve not proved any of it, there’s no insurance, there’s no evidence, and you really don’t know what you’re doing and you can’t prove that you’re able to do it.

Some of the parents were not confident that the change in the model of care could deliver the same outcomes with those achieved at college placement. They were particularly worried that moving to supported living would lead to a regression of the knowledge and independent living skills sets that their child had developed while in college residential accommodation.

“We know that when he is at home he regresses. We have had really stark demonstrations of that.... that’s right, because there isn’t the stimulation. We can work as hard as we like to try and stimulate him”.

They believe that Cardiff Council and the supported living providers should provide parents with assurance on how the care and support that they be providing will continue to support the maintenance of knowledge and skills and how these living arrangements will enable the achievement of their child’s well-being objectives and desired outcomes. They feel that resulting evidence from these arrangements would provide them with assurance that the move to supported living enable their child to continue to thrive.

Parents also suggested that positive outcomes achieved by others in supported living could provide them with assurance on issues that they are concerned with. It is important for them to learn about the experiences of other young people who have moved into supported living arrangements and how this has impacted on their skills and their well-being.

8.7.2. Knowledge of supported living arrangements and its benefits

Most of the parents confirmed that they have limited knowledge and understanding of the supported living model. The majority of the information that they have on this type of care arrangements are based on the knowledge and feedback shared by other parents that they have networked with. They are not fully aware of the benefits of supported living, its effectiveness and its ability in meeting different support and care needs. Parents believe that they would benefit from gaining a better understanding of the impact that moving to supported living arrangements can have on the maintenance and development of skills and the well-being.

“Because, usually, we’re just frightened about any type of care, aren’t we?”

The anticipated change in their child’s care and support arrangements and the limited knowledge that they have about these have caused some distress. They are worried on the impact that this will have on their child’s safety, skills sets and their well-being. They believe that need have assurance that this change will not have a detrimental impact on their child and have confidence that these new care and support arrangements can meet their child’s needs and aspirations.

“They need to take away the fear of what you’re going through”

“Yes, that’s right. The fear of the unknown all the time...”

“An assurance that there’s a plan that is in place. Yes, that there’s a plan and that the support will continue, yes.”

8.7.3. Impact on sustainability of skills

Parents cited various other reasons why they are in disagreement with Cardiff Council on the suitability of supported living arrangements for their child.

Some parents are unconvinced that the supported living arrangements on offer will provide their child the same opportunities that will help them to maintain the knowledge and skills sets that they developed during at residential college placement. They cited that that Cardiff Council has not provided them with sufficient information or plans that would provide them with assurance on how these issues and concerns will be addressed. They believe that they do not know enough on how the change in the model of care

and the types of support will impact on the skills their child has achieved and how the different arrangements will maintain and improve their health and well-being.

“We do our best, all of us, but, you know, I think it’s reasonable for us to expect there to be no deterioration in these young people, whether it’s their behaviour or their health, their weight, or what have you, when they move on”

“Yes, there shouldn’t be any question of things getting worse. I mean, and it shouldn’t even be that we have to settle for things just being as good as. The whole point is that if they’re developing and improving, let’s keep that trajectory”

8.7.4. Staffing levels and their competencies

Some of the parents expressed concern over the ability of supported living staff to provide the level of care and support that they believe their child needs. They have the perception that in supported living residents will have limited access to professional expertise that could provide them with the necessary behavioural and physical support.

Parents have become aware through word of mouth that staffing levels is generally an issue in supported living and providers make use of agency staff. Some are concerned that the high turn-over or changes in staffing would be distressing for their child. Associated with the staffing issue, are the parents’ concerns on the competencies and training of staff. They have the perception that supported living staff generally have limited training in providing the care and support to their child. These parents are not confident that that these support workers will have a good understanding of the nature and characteristics of learning disabilities. They are also unsure whether support staff have the level of competencies and confidence to deal with and support a range behaviours associated with particular learning disabilities.

Parents believe that they would benefit from having from assurance from Cardiff Council and the care providers that staff at supported living have the required competencies to meet the care and support needs of their child. Parents would like to be assured that support workers have a good understanding of their child’s learning disabilities and personality. They also expect them to have the ability to effectively communicate and engage with them and have the knowledge and abilities to deal with various challenging

behaviours. Furthermore, they also want to be assured that staff will treat their child with the same level of care and respect that they receive at home.

“What matters is the continuity of care, the loving environment, the interest in him as an individual as opposed to him as a problem”

These parents are also not confident that the staff at supported living are able to provide the level of support and challenge help their child to maintain or further develop his skills e.g. personal hygiene, cooking, housekeeping, personal safety when out and about etc. that was has acquired while at residential college. They are worried that their child’s skills and abilities would regress in supported living arrangements. The parent would ideally like supported living to provide the support that will enable their child to continue on developing his skills and knowledge in a supportive and challenging environment.

“That’s where we are going to be looking for assurance. But you know, we’ve just been told, “Yes, it’s all marvellous.” That’s that. That’s all we’ve heard so far. But you see, what we hear from other parents whose sons and daughters have gone into supported living is there are huge teething problems and all sorts of things.”

8.7.5. Social interaction with peers

Parents are unsure whether their child will continue to have similar opportunities to interact with their peers and access a range organised social activities with other young people. Parents fear that the level of social interaction that they will have will be limited as a result of the change in living arrangements. One of the parents stated that would like think that in supported living their child can continue to have interaction with:

“the right group of contemporaries or peer group, if you like, with varying needs, and support workers and social workers, or carers, and the people who are helping him to develop his skills in terms of day-to-day.”

8.7.6. Living with their peers - compatibility

Parents stated that they have limited understanding of the factors that social services consider in determining their child’s compatibility with their future housemates in supported living. Parents are concerned that inappropriate

matching could have detrimental impacts on their child's well-being. They believe that the social services team should consider variables such as age, gender, personality and complexity of support needs in matching their child with potential house mates. In determining the suitable match, some of the parents cited these key expectations:

“...because we want our youngsters to be with their peers. I don't want xxx to be in a home with 50-year-olds and 60-year-olds”

“...need to be “a right mix” of young people with learning disabilities in the right areas to avoid the housing offer from “falling through..”

Some of the parents were concerned in hearing that a young adult with learning disability was placed in supported living with other residents who were 3x and 4x older. In assigning accommodation, parents expect Cardiff Council to match their child with others in their peer group and those that they have something in common with.

However, one of the parents cited that the accommodation that they were asked to consider was “out right unsuitable” in relation the nature of their child's learning disability.

“It was a small, tiny room. Xxx would just have stayed in xxx room all the time. Then we went to one house, and again, this was where there was a 63-year-old xxx and an 85 year xxx, and xxx at this point was xxx (citing child's age) or something. It was just ludicrously wrong. It seemed as if we were going through a process.”

8.7.7. Familiarisation with accommodation and staff

In cases when the suitable accommodation had been agreed, parents would like to receive further advice from Cardiff Council and/or care providers on when their child can familiarise themselves with their accommodation, meet their designated support worker and other residents that they will be living with.

Parent also believe that useful for them to meet other parents of other residents so that they can share information and support each other.

9. Parents concerns at supported living placement

9.1. Informing the supported living care plan

Some parents stated that they were quite unsure on how much they can inform their child's care plan in supported living. One of them was particularly concerned that the care provider did not "seem to know enough" about their child's background and support that they would need. They felt that the provider was dependent on them to provide input on the levels and types of support that their child needs. They were worried that they were unable to advise the care provider on the specific skills and abilities that their child has achieved during their college placement. They also felt that they were also unconfident in advising the provider on the level of support and assistance that their child would need in undertaking various day to day activities such as cooking, washing, cleaning, etc.

"...I think they depended on us to say, "How much-?" You know, we went to a meeting there and they said, "How much help do you think xxx needs?" But it was up not to us, really, to say how much help she needed and maybe it would have been better if somebody from xxx residential college had been involved in that process"

Parents would like to have some clarity on what input they are expected to provide in the formulation of the providers support plan for their child. They believe that the professional staff at the out of county college attended by their child would be best placed to inform the provider's care plan. They suggested that that the progress and annual reports produced by the residential college should be used as reference documents as this will contain specific details on the abilities and skills that their child has achieved.

"... They are the people who'd been with xxx without us, and they're the people who were best placed to say exactly..."

Parents raised questions on how much of these information are available to the local authority and the commissioned care provider. They believe that these reports should provide care providers with baseline information and sufficient details on the existing skills and abilities that their child has and the level of support that they will need.

9.2. Sustaining knowledge and skills

Most of the parents are unsure whether their child have sufficient opportunities in supported living to undertake the activities and tasks that

would to help to maintain the knowledge and skills that they acquired during their college placement. One of the parents also expressed their concern that their child did not have a schedule of structured activities that he can undertake or be involved in during the week.

“No activity timetable arranged for the week despite being told it would be done by staff. I would have done this much sooner myself had I realised”

Others said that stated that they do not know enough on how their child is progressing with making use of these knowledge and skills.

“I don’t know, xxx seems happy enough. Is she achieving all xxx can? I can’t tell you. I know that sometimes they help with the preparation of the meals. Sometimes they... I don’t know if they do the washing, I don’t know about that. They do make them do chores in the house, that’s good, help clean, help whatever it is.”

Parents stated that they are not fully aware how support staff are enabling these to happen. And are also unsure whether there is a structured process in reviewing how their skills and knowledge have improved or declined while at supported living.

“. I don’t know, within the house, whether the skillsets have... I suspect they’ve regressed”

... I don’t think xxx writes shopping lists. They plan... I don’t think, but I’m not sure, that they sit down and plan, “What are we going to eat next week? Therefore, what do we need to shop for?” I don’t think xxx doing the washing, I think the carers do that. Not that xxx be bothered, but it’s something xxx was learning to do.

They believe it is important that providers have arrangements to monitor these so that their child do not end up becoming fully dependent on their support worker. They would feel assured in receiving periodical updates how their children are making use of their skills and abilities in dealing with day to day activities and how they are progressing with it.

“I have no idea if they are aiming to teach xxx anything in the house, to say, “Actually, xxx ready.” I don’t think it’s being done, because I keep saying to them they need to do a risk assessment”

Parents would like to feel confident that support workers are providing their children with sufficient opportunities and challenges to help maintain or further develop their skills and knowledge as part of in supporting their well-being.

9.3. “Chilling out” at weekends

Parents were worried that their children could be spending too much time sitting in their rooms or watching TV. They feared that their children would gradually lose their skills and become more dependent on their support worker in undertaking tasks that they were capable of.

Parents were also quite concerned over what is referred to by support staff as “chilling out weekends”. This appears to be a shared practice across the supported living, where residents are expected to do very little and “just chill out”. They believe that during this period their children:

“stay in for long periods of time and watch TV”.

“They’re all sitting around”

“Sitting around watching the television, yes”

Parents expect their children’s support workers to organise spontaneous activities or days out during weekends so they (child and their housemates or friends) can enjoy being out and about and have fun. They believe that support staff could take them to the seaside i.e. Penarth to enjoy being outdoors and have some “fun and ice cream”. However, parents believe that support staff do not initiate such activities.

“What happens at the moment is, for most weekends, xxx comes home because there’s nothing going on in the house..... The other two mums, and I, are in contact. We’ve all been saying the same sort of thing.”

“The mothers have said, on a number of occasions, ‘For goodness sake, on a Saturday, they’ve all got bus passes, why don’t you put them on a bus and go to Penarth and have an ice cream on the pier and come home?’....None of the children are difficult, they’re not.... That never seems to happen.”

One of the parents believe that their child is unable to do some of the activities that she enjoys during weekends due to staffing issues at supported living.

“One of the things that I wanted xxx to be was near shops, so that they could actually get to shops and walk around, but they don’t take them out. That’s because, I think, they haven’t got enough (staff) with the kids that are there.”

Parents believe that Cardiff Council should work with care providers to ensure that there are planned social activities and sufficient staffing to support their children in undertaking activities that will help to improve their quality of life and well-being as well. They believe that this will help to ensure that their children maintain the independent living skills and knowledge they acquired during college placement.

9.4. Social interaction with peers

Some of the parents have the view that their children do not seem to be participate in many social activities that involve other young people with learning disabilities. They believe that it is important for their children to be engaged in various social activities with others in their peer group so that they could practice and enhance their communication and social skills. Although they live in a shared house, it seems that do not undertake social activities with other residents in the same house. Parents have the perception that support staff in the same housing cluster do not coordinate activities with other residents and would rather undertake activities separately.

Parents suggested that support workers and activity planners from different providers such as Mirus and Dimensions should work together to coordinate and plan events and activities that would allow their residents to meet one another and interact socially.

“that somebody needs to be picking up and running with this, in terms of providing group activities”

“much more joined up thinking between the activity planners,so everybody was much more involved and not doing their own little thing,...and thinking everything else is marvellous because they all want it to be”

As there are very few youth clubs that cater for young people with learning disabilities, parents feel more investment should be made to support this type of provision so that young people with similar characteristics and needs can meet socially and develop friendships. Currently they believe that there are limited organised opportunities available from Vision 21 and Hijinx that will enable their child to interact and socialise with other young people.

Furthermore, parents also suggested that providers should also organise activities where residents in the local area meet with residents in supported living, get to know them better and help to integrate them into the local community.

Parents also suggested that support staff should be more pro-active in looking into scheduled local events, activities and social venues that they can go to during the week, instead of just sitting around supported and watching television. They also expect support workers to initiate spontaneous activities or trips to various venues such as libraries, pubs and clubs during the day and early evenings so that their children have opportunities to meet people in the communities that they live in.

“There’s a pub evening, there’s karaoke down at the xxx, which is about two minutes’ walk from xxx house, and not that far from where xxx is, a ten minute walk. And they could meet there in the evening. We’ve been asking and asking for that.”

Parents believe that these social activities do not happen due to staffing issues during the evening shifts.

“Well, that’s- We know why it doesn’t happen, because it will mean effort and extra staff.”

9.5. Confidence in staffing levels and competence

Parents have the perception that some of the supported living providers are struggling with managing high staff turnover and maintaining their staffing levels. Some of them have heard via word of mouth that this is an issue particularly in supported living arrangements for those with less complex support needs.

“I tell you why, they’re so short staffed, they don’t know who is going to come in and cover half the time. I think they’re struggling just to get the basic provision in, never mind, “Are we going to progress”

One of the parents stated that they were particularly concerned over the availability of staffing support during the evenings. They have the view that this lack of adequate staffing during the evenings could compromise the safety, security and well-being of their child.

“No-one in the office during the evenings to monitor front door access in and out of the building. There was no member of staff at all in the whole building on one evening that I was told about and this may well have been the case on other occasions. It was unusual to see a member of staff until we left around 10pm after visiting each evening (due to my child having no support after 4pm)”

Most parents believe that these staffing issues will have a significant impact on the quality of support and care provided in supported living. Parents would like to be assured how these issues are managed effectively so that the safety of residents are not compromised.

Parents believe that support staff have to be better paid and trained well so that they do not move on quickly to other jobs. They suggested that supported living care providers should target the more mature and experienced workforce. They believe that this category of staff are less likely to move on to other jobs and thus provide stability and continuity of care for their child.

“You’d like to get the people in, young and train them up and think there’s a career in it, but for the vast majority, it’s not going to happen, is it”

Although parents are generally happy with the quality of care provided, most of them stated that they are not very confident on the competencies of staff. Parents confirmed that Cardiff Council have assured them that support staff are vetted and have received the appropriate training. However, the parents cited that they do not know much about staff qualifications and the training they have received. Improving parent’s knowledge and understanding of staff competencies will help to improve their confidence on the care and support that their child receives.

Some of them believe that the staff skills in supporting young people with learning disabilities are limited and needs to improve.

“Everything is aimed at a level It’s going to fit lots of people, and I’m sure the supportive living that they have got will work for lots of people.....”

“It’s a one-size-fits-all kind of thing”

Parents would also like to be further assured that support staff are well trained and experienced in supporting the varying complexities of learning disabilities and in managing a range of challenging behaviours.

9.6. Effective delivery of care and support plan

Parents worry whether staff in supported living are able to effectively look after and provide the level of support their child needs. Some of them are unsure whether the activities or tasks identified in the care plan are carried out as planned. This is a particular concern for parents whose children have limited verbal communication skills as they believe that there is no way of validating whether these are carried out.

“I’m not convinced that xxx actually does the activities that they’re telling us that xxx does, because xxx doesn’t communicate very well, it’s very difficult to confirm that. But I’ve seen xxx- We’ve had a timetable from them recently, and I am convinced that xxx is not doing the things that are on that timetable, which is something I’m taking up with them separately”

They believe that verbal feedback from those with low level support needs can be sought easily but is more challenging from those with more complex needs and those with limited verbal communication skills

Parents stated that they would like to have a better understanding of the monitoring and review arrangements that are in place to ensure effective the delivery of their child’s care plan. Parents feel that they need to have some clarity of the roles and responsibilities of the care provider and Cardiff Council in these processes. More specifically, they would like to understand how the care provider monitors and reviews the quality of support provided by staff and whether the planned tasks, activities and targets are achieved. When parents have concerns, they would also like to know the arrangements for reporting this to the care provider and how these will be dealt with.

Parents believe that having an experienced manager onsite to monitor the support the staff would assure them of the quality of care provided.

“And we think having a manager on-site would make a world of difference to the quality of care that xxx gets”.

One of the parents recommends that to be assured of the safety, security and well-being of their child:

More frequent checks, at different hours of the day, could be made on the support that is being delivered.

Some of the parents stated that they are currently quite pro-active in checking that their child's planned activities gets delivered. However, they worry that as they get older they may not be available to continue doing so.

"Worryingly, there, of course, if you're not around, that potentially could go right downhill."

"If we're not on top of it, saying, "What's happening with this, what's happening with that?" and we're not going to be at some point, then I dread to think, I honestly do."

They would like to be assured that care providers have effective monitoring and management arrangements in place to ensure that their child receives the care and support to ensure that they are safe, healthy and in their current living arrangements.

Parents would also like to have a better understanding on how Cardiff Council monitors the effectiveness and quality of services provided by commissioned care providers. Some parents have the perception that Cardiff Council is not fully aware of the issues that parents have on the effectiveness and quality of services provided.

"Cardiff buys the services from these providers... where's the quality assurance, where are the checks, you know?"

"But I don't think Cardiff has the slightest handle on what is actually being delivered against what is planned"

They would also like to understand how they can support Cardiff Council in monitoring the delivery of care and contribute and to validating the effectiveness of the commissioned care and support services.

Their knowledge and understanding of the monitoring arrangements will provide them with assurance on the quality control involved in delivering of care and support for their child.

9.7. Feedback during settling in period

During the early stages of moving into supported living, parents believe it would be useful for them to receive regular updates on how their child is settling in and coping with day to day activities. To ensure that their child gets the level of support needed, they believe that care providers should pro-actively seek feedback from the parents and their child on how satisfied they are with the care and support is provided whether the level of support delivered has been adequate.

One of them received feedback their child was not getting the level of support needed for tasks such as cooking and washing. Although this was rectified immediately, the parents were concerned that the need for support in these areas were not identified immediately.

9.8. Scheduling and availability of support workers

One of the parents cited that their child benefits from a daytime package of support that should start at 9:00 am. However, they believe that the support staff often arrives at 9:45 or much later. This parent are concerned whether this is known to the management of the care provider and whether Cardiff Council aware of this issue.

“Our xxx has quite a reasonable daytime package of support. It starts at 9:00 am, at 9:45 am xxx is often arriving or afterwards. Cardiff is paying for that. Does Cardiff know? No, they don't. I think there is quite a lot that is down there... as being delivered. And we can't trust xx saying what xxx's done, to us. We just can't attach any faith to that, we have to have some independent assessment of that”

“the staff turn up and they do as they do.. And I'm positive Cardiff City Council doesn't know what is being delivered against what they're paying for being delivered”

Another parent also expressed concern over changes in the timings of availability of support. They cited that their child was supposed to have 24 hour 1-1 support. As a compromise, they have agreed with the provider that this can be reduced to a shared night-time support. They are unhappy with the various changes on the schedule of support that is made available. The shared support was supposed to start at 10:00 pm but this had changed many times and now start earlier at 6 pm. They believe that the reduced level of support has taken away the opportunities for their child to attend the social

and cultural events he used to enjoy during the evenings. Parents are unsure whether Cardiff Council has been made aware of these changes.

“But they needed to put on an extra staff member because it was beyond the 6:00pm deadline. Now, I don’t know whether Cardiff Council are paying for somebody to be working until 10:00pm on a one-to-one or whether Cardiff Council have agreed that they can change it at 6:00pm, I have no idea how that works.”

Another one of the parents who had an unsuccessful supported living placement felt that their child had inadequate level of support during most of the day

“support hours used for another resident, leaving my child to his own devices: in bed all day, up till early hours of the morning watching youtube videos..... No support during the evening”

9.9. Feedback and complaints arrangements

One of the parents was particularly concerned over their ability to make contact and get feedback from the care providers on how their child is managing during his supported living placement. They found that it was:

“Very difficult to contact the staff at the building as phone was often not answered. We were not always contacted by management regarding problems. We had little feedback as to how my child was doing on a day-to-day basis and no check on how his money was being spent”

Some of them picked up minor issues on how support is provided, however these parents stated that they are generally quite reluctant to formally raise these or their complaints to the care provider’s management staff. They fear that raising issues and or complaints could affect the quality of care and support and care that their child receives. They believe that they need to be quite careful on how they communicate their concerns to get the support of the provider in addressing this and avoid any adverse repercussions on the quality of care and support that their child receives.

Parents would also find it useful to be advised on how Cardiff Council and the care provider can support them when they have some minor issues and concerns about the delivery of care and support for their child.

9.10. Supporting health outcomes

Some of the parents were particularly concerned over the amount of weight that their children have gained since moving into supported living. They raised questions on how the care provider can provide effective support in helping their children to make healthy food choices. They have the perception that their children are not necessarily encouraged to undertake sufficient physical activity to keep healthy. They worry that in allowing them to have an unhealthy diets and limited physical activity would increase their children's risk of diabetes and circulatory or heart diseases in the future.

“xxx has four sugars in xxx tea and xxx was having tea every hour. And we knew that xxx was putting on weight and weight and weight ...and we kept saying, “xxx putting on weight.”

“Oh gosh, the amount of times we've said, “Can we have a menu, can we have a healthy-” I'm just about to send an email, because xxx has a personal trainer twice a week and xxx weighs xx and xxx raised it now, the weight is going up again”

It is unclear to parents whether Cardiff Council and the care providers have guidelines in supporting their children to adopt healthy lifestyles in terms of their physical activity and diet. They believe that supporting this will have a preventative impact in to their children's longer term physical health outcomes.

Some of them have highlighted these concerns with the managers in supported living. However they are unsure how support workers are ensuring the balance between supporting individual choices vis a vis the achievement of better health outcomes through improved physical activity and having a good diet.

“We have problems with weight. I need somebody to... If it's portion control, I don't know. The problem is, we just get on top of it and then we have a change of staff and... I don't know whether there is now, or not, a sort of... What xxx should be eating, and whether the portion is controlled. Xxx needs- Two of them in the house need to lose weight. One of them had put on weight and has now lost it, but the other two haven't.”

“Things that worry me are, xxx is not doing enough exercise, for example. Not eating healthily enough now that xxx can buy sweets and

crisps when xxx wants to. That sort of thing. These are some of the things we were going to raise in the meeting”

“So, we’d like xx to do more exercise. Xxx good at swimming, good at dancing, those sorts of things, to try and keep the good habits going.”

Parents were all in agreement that providers and their support workers have vital roles in enabling their children to have healthy diets, to make healthy food choices and to undertake more exercise during the week.

One of them has provided the following example where they believe the support worker could have helped in managing their child’s diet and level of food intake during the day.

“while xxx is at xxx, xxx is bringing sandwiches and also eating the dinner that they provide there.....which could be the reason for the xxx putting on weight. Is it the house, though, or is it when xxx is out at xxx...

“I’ve asked them to check that xxx not taking sandwiches and eating dinner, because that was happening. Xx was having dinner wherever xxx was going and.... But that’s up to them, to say to xxx, “Don’t feed xxx, xxx got sandwiches.”

Parents are unsure on how much of these expectations can be supported by the care providers and how the health goals and outcomes can be prioritised and achieved.

9.11. Challenges with achieving health and well-being outcomes

Parents highlighted a number of factors that they believe pose a challenge for providers in effectively supporting the health and well-being outcomes of their child.

They were concerned that due to frequent changes in staffing, the information on the specific activities and interest of their child are not effectively handed over between staff.

“Because when xxx first went into the house, we were very pleased, we had a good set-up there. Having been in there 12 months, we’ve probably had three, if not four, different teams of staff in there, and we’ve had three different managersbut I don’t think the message,

the information, is transferred. As the team changes, that is where I think the problem....

They believe that the high turn-over of staff has a disruptive effect on the continuity and consistency of support for their child. They expect care home managers to have the responsibility in ensuring that such information is effectively handed over to new staff so that consistent support is delivered.

“Is it our role to be telling them,... or is it their manager’s role? Because we’re only there periodically, whereas I believe it should be the manager that is giving that information..”.

They expect managers to monitor and ensure there is consistency in how care and support is provided to their child particularly in cases where there are changes in staffing. Parents believe that they should not have to check whether newly appointed support workers are fully aware of their child’s daily routine, diet and their preferences and the tasks where they child needs extra help on.

9.11.1. Measuring for progress of health and well-being targets.

Most of the parents stated that are unaware of the arrangements that care providers have in place to monitor the health and well-being of residents in supported living. Parents would like to know how providers ensure that that their child remains in good physical and mental health and remain safe and happy. They would also like to gain an understanding of how providers set health and well-being targets that their child can achieve and how parents can inform and effectively support this. Parents also believe that in monitoring the health and well-being of their child, providers need to have measures in place so that they can evidence any progress or deterioration that occurs.

“If they’re enjoying the eating, I dread to think what the portions are like” But anyway, what I’m saying is, ... , there should be measured outcomes, but the measured outcomes have to include the health and wellbeing. I mean xxx, like most of our kids here, could be living to 80, but she’s going to die of a heart attack at 40, at the moment, because of-

“And diabetes, I do worry about”

One of the parents suggested that the monitoring of these measures should be an integral part of the periodical and annual review of their child’s care and support plan.

9.11.2. Providers periodical review arrangements

Some of the parents stated that they are unaware of what is involved in the care provider's periodical and annual review arrangement. They would like to know what is involved, when this happens, and who are involved and what input parents have into the process.

Parents expect that they should receive periodical updates from the care provider on how their child is managing in supported living. They believe that they would benefit from having structured dialogues on how their child is getting on the different aspects of their lives including their diet, overall health, self-care, social interaction, access to leisure or cultural activities and any other changes, or improvements in their health and well-being. They also believe that this could be used by the care provider as opportunity to seek structured feedback from parents on the care and support they provide.

9.11.3. Knowledge of the care plan and well-being outcomes.

Some of the parents stated that have no knowledge of the supported living's care and support plan for their child. Only a few parents are aware of the purpose or significance of this plan and how it relates to the care and support that their child receives and his overall health and well-being at supported living.

"We haven't got a plan. Have you got a plan?"

"Well, if I've got one, I don't remember using it. I mean, if the outcome is... we'll try and encourage her to do X, Y and Z, then..."

"We've got one but, to be honest, especially given my background, I should pay attention to it a lot more. It gets filed away and I haven't looked at it for a year."

Most of the parents also do not have a good understanding of what their child's "personal outcomes" are and how this relates to the care and support that provided to them.

"I've got no idea what you're talking about."

"Are there specific outcomes,... has she achieved this, is she working towards that?" I have no idea, I have no idea."

Only a few of them have some understanding of the significance of what health and well-being outcomes are for.

“... I know all about personal outcomes and they’ve got to link to the national outcomes, wellbeing outcomes, I think it says. But... It’s never been explained to me by a social worker. I don’t know, do you know the significance?”

...“It’s absolutely fundamental, if you don’t get your personal outcomes written right, you’re not- It’s crucial, it’s the key. But if people don’t know that, how can they ensure that the kids’ care plans are correct?”

Although most parents do not have a good understanding of the significance of identifying and recording their child’s personal outcome, would like to be assured that care providers and their support staff to make arrangements to ensure that their children have good physical and mental health. It is also very important to parents that their child retains the knowledge and skills they have acquired from college placement so that they can be confident that their child has a good quality of life while living independently.

9.11.4. Parents involvement in periodical and annual reviews

Some of the parents who have children in supported living have not had any involvement in their child’s periodical or annual reviews.

“That would be helpful, wouldn’t it?”

“No, ours don’t review it with us,

Another parent declared that their child’ review did not happen as scheduled due to staff sickness.

Although they have not had involvement in periodical and annual reviews, they believe that it would be beneficial for them to be involved in the process so that they can received progress updates on their children’s health and well-being and provide feedback on the care and support that their children receive.

9.11.5. Parents' awareness of regulatory inspection schedule for learning disability services

A few of the parents felt that it was important that they have the opportunity to provide feedback to the social services inspectorate on their experiences of services for young people with learning disabilities. They would like to be made aware of the schedule regulatory inspection of the learning disability services and how they inform what the areas that the inspectorate can focus on and how they can provide input in the inspection process.

9.12. Parents awareness or knowledge of benefits and entitlements

Parents believe that information on various types of support for young people with learning disabilities and their families is not readily available. Most of them rely on other parents to share information the services and entitlements that their child can access and benefit from. Others stated that they have to undertake their own research on the current legislation and local policies on educational, health and social services provision for families and their children with learning disabilities.

“The thing is we end up having to become experts in all of these different situations, the law, the regulations, education, health, because otherwise you don't know what you're entitled to, you can just be ignored”

A family stated they had no knowledge of the statutory entitlements for those with learning disabilities up until their child's last few years in secondary school.

“But I think we did miss out in some ways because I wasn't aware of some of xxx rights as far as allowances – So, xxx didn't get one benefit until xxx was 15.”

Some who have children in supported living stated that they need further support the gaining a fuller understanding of their child's financial and service entitlements and how this should be managed.

Parents believe that it would be useful for them to be made aware of the range of support and services are available to individuals with learning disabilities and their families. This should include support in helping them to

gain a better understand the statutory benefits and entitlements that they can access while their child is in education and when in supported living.

9.13. Managing food expenses and shopping at supported living

One of the parents expressed concern on how budget for their child's food is managed at supported living. She believes that each person in the house contributes £50.00 and have a combined total of £200.00 towards food expense each week. She has been made aware that food shopping undertaken in bigger supermarkets and premium brands are chosen instead and is concerned that the food budget is not spent wisely.

“They choose Tesco's finest while I shop in Aldi”

Some of the parents would like to understand how the meal plans are made how weekly food shopping is managed so that the food budget is spent well in supporting a healthy diet. Some of parents believe that support staff should have a key role in supporting their child during shopping activities so that they are able to make reasonable economic choices.

They believe that support staff partake of the food that is intended for residents in supported living, and question the appropriateness of this practice.

9.14. Support for Parents

9.14.1. Support for the parents network

Parents declared that they have benefited from invaluable support from the informal network of parents who have children with learning disabilities. Some of these parents have been particularly helpful in sharing information on the services that Cardiff Council and other bodies provide. Others have helped make them aware of the various entitlements of and statutory benefits that their children can have and the learning and development activities and opportunities that they can access. They are also a source of emotional support during challenging times and support in seeking solutions to shared issues relating to the services for their children.

“but it is quite therapeutic to have somebody to listen to us because it's a very isolating experience having a child with special needs, as you've all said.

“But that’s why as parents we seek one another out too because you need to”

They believe it is important that they are able to connect with other parents they believe can experiences and challenges that they have in caring for an individual with learning disabilities.

The informal parents network is also regarded as very useful as a source of feedback on services or activities that other young people with disabilities are making use of or benefiting from.

“The best thing I think is, to talk to parents that have already been through it, so to ask parents who might be a couple of years down the process.”

Parent stated that through this informal network they were to hear about are the experiences of other young people in supported living arrangements in Cardiff.

“We’d love to meet people in a room like this where they say my son or daughter is in supported living and it’s been marvellous because of this, this and this.”

This informal parents network is seen as an effective vehicle for disseminating or spreading information on the success stories in supported living as well as the challenges that others have experience in moving into these settings. Parents also believe that their connections are an effective channel for sharing information on various social activities that their child can be involved in.

Some of the parent believe that Cardiff Council Adults Services should provide support to this informal network and where appropriate support activities the social activities and interaction that they have. They believe that through this network Cardiff Council can better engage and disseminate information to parents and young people with learning disabilities.

“the Council and the social services department should welcome that informal network and encourage it and even find ways for it to be facilitated, instead of an underground fifth column activity as it were trying to undermine their great solutions for everything.

9.14.2. A parent helpline – mental health support

Most of the parents felt that they would benefit from having immediate access to advise and support in dealing with crisis situations. This is particularly important when parents feel that they are unable to deal with and cope with their children's challenging behaviours.

More specifically it was suggested that it would be useful for them to have access to a telephone helpline that can provide independent advice and support during times of crisis or when they feel overcome with the stress arising from their caring responsibility. Some of them stated that they are currently unsure whether they can use the 24 hour social services emergency telephone line to seek help and advice during these times.

One of the parents has cited that at one point they had to call 999 because they were physically and mentally struggling in dealing with their child's challenging behaviours.

“But I'd been driven to that however extreme because I said if somebody doesn't do this I'm going to put xxx in a car and I'm going to drive us both off a cliff, so get around here.”

They believe that at the least this helpline should be made available during the daytime. Where resources are available they believe that it would be more beneficial if this service can accessed 18 or 24 hours in a day. Parents also expect that they could seek help and advice anonymously from this service.

“maybe a helpline 24 hours or 18 hours or something like that-

“Or even daytime, just a time-“

“it provides independent advice-“

“But it needs to be people on the phone giving advice..”

“Like the Samaritans.”

Parents suggested that this telephone helpline should also be available to provide information and support in dealing with stress and mental health issues.

“.... going to the doctor and getting antidepressants, maybe not even taking them but just so somebody would listen to them, just say look, I had to do this”

Parents acknowledged that their mental health can have suffered due to the demands of their caring responsibility. They believe it is important that they are able to access mental health support. This will prevent cases where parents end their lives or attempt to do so due to their inability to cope with their caring responsibility.

“one of the mums actually took her son to a hotel just outside xxxx, she actually killed him, attempted to kill herself but they found her, he'd passed”

Parents also believe that it would be useful for them to have some form of guidance and support on how they can effectively manage challenging behaviours, without having to call emergency services.

9.14.3. Learning disability carer's emergency card

It was also suggested that it would be useful for the parents to carry a card that identifies them as responsible for the care of someone with learning disability. They feel that this would be particularly useful should something unfortunate happen to them or during an emergency situation.

9.14.4. Information and support resources for parents

The need to better access to information and support as has been cited in various sections of this report. Parents believe that they would benefit from having this information made available in a “handbook” or an interactive on-line reference facility that provides information on various services and support that are available to them as their child progresses through their key life stages.

It was suggested that the information and guidance for those with learning disabilities could be structured following the care pathway and the key life stages that a child with learning disability goes through. In particular, this should identify and highlight the key life stages and the key transition phases that have an affect the services and support that are available to them.

“.. and maybe some kind of handbook or flow chart to be given to those parents, because at least then it's covering everything, what will happen during the transition..”

“...idea of a flowchart or the lady who suggested a flowchart is a great idea”

Some of the parents suggested it would be useful to have the information summarised and illustrated visually e.g. a flow chart, so that parents can have better appreciation of the different life stages that will have an impact on their child's life and the support that they will need. This should include the transition period, home life and schooling, between primary to secondary school, secondary school to specialist further education or secondary education to the appropriate care and support arrangements.

Parents agreed that at that at each key stage, information should be presented on the different services and support that are available, the statutory entitlements that are relevant to each type of learning disability. This should also include the different voluntary and non-statutory services that they could support from.

“You know, one, two, three, like this. “People who might able to help you,” and then a list of the sorts of people. People with titles, you know.”

“Do you know what would be useful? Something really simple saying something like, “Does your child have the following problems?” For example,... very anxious or something like that. Ask your doctor about a clinical psychologist. You know, that sort of thing. Yes, something really simple. “Do they have these problems? People who might able to help you, and then a list of the sorts of people. People with titles, you know....”

Parents believe that it is important for them to have access to such information as it will provide them with the knowledge and understanding of the future care and support services that are available to their child as he moves into adulthood. This will help to mitigate their fear of the uncertainty of what lies ahead regarding the care and support that is available. This would give them assurance of the services and various types of support that their child can access and benefit later on.

“It's almost like taking away the fear, isn't it?”

“But the question is then what comes next, isn't it? You know, it's the whole point. It is scary..”

“..you know that there are things that can be done to help, if only people were aware of them..... they need to look at the bigger picture, and it might be savings in the future.”

Parents believe that currently, a compendium of information or a reference resource on services and support that are available for those with learning disabilities are not readily accessible from Cardiff Council's Social Service and the Welsh Government.

“...idea of a flowchart or the lady who suggested a flowchart is a great idea but we're so far away from that it feels like it's in outer space compared to where we are at the moment”

The information that is made available should be able to signpost parents or individual to the appropriate services and support that are relevant to the type of learning disability and complexity of support needs.

“The one thing I wanted to say to go back to the flowchart is this is why the flowchart is important part. Where individuals are on the spectrum....It's the perfect example of how one size does not fit all, so that flowchart would point xxx first in the direction of a further education college, and that's what xxx did.”

Some of them believe that the local authority does not present detailed information on the services and support that they provide, so that they can manage demand for these, in line with budget constraints.

“Because they're not going to want to put things on a flowchart because they don't want you to know the options because they know best what it's like, you know”

“But they're saving money, they don't want to give you these options”

Schedule and format of information

Parents suggested that they feel that information on various services and support should be made available in a timely way. In particular, information on various educational or learning and development options should be made available ahead of time so that that the parents and their child have time to

consider this and prepare the necessary documentation and evidence required to access these provisions.

“And you need to get that in plenty time because the various colleges that are special needs colleges are spread out all through, there's nothing local. You need to look at”

A suggestion was made that information on services and provision that would be relevant to the individual's immediate future care and support needs should be made available during the annual reviews of the child's care plan.

“Or even if it was presented at one of the annual leave reviews. It could be marked as a document that had been passed over even if it was some kind of handbook of what happens next.”

Information availability

Parents also believe that these believe that these information should be made available at schools and from key services such as the GP and other NHS services that individuals with learning disability get into contact with regularly.

“I don't think it can be offered too much. I think they should get it in school. I think they should be in the surgery. You now, “Ask your doctor if... this, this and this.” It should be everywhere, so that people don't miss it. “There might be help available.” You know, that sort of thing Yes, it's just something really simple. “There is help out there,” sort of thing”

Information on Cardiff Council website

Some of the parents stated that they are currently unaware of what information is available on the Cardiff Council website for the parents and individuals with learning disabilities. However, most of them agreed that information on services and support that that are available and how these can be accessed at each key stage should be made available or signposted from Cardiff Council Social Services website.

“I think it should be on the website of Cardiff. Perhaps I haven't looked enough on Cardiff website to see what's available to parents but they should really provide all of this with clarity. There is a way of presenting these things to us all online now”

As previously mentioned, some of the parents suggested that Cardiff Council could present the online information in a flow chart format following key life stages or care pathway. This should be made available in an interactive format so that users of this facility can be easily directed to the relevant information and services that they would like to look into.

9.15. Parents involvement in planning the long term care and support

Some of the parents expressed that “they’re worried as they’re getting older” and are concerned on “what would happen” in the future. They raised questions on how Cardiff Council will plan and ensure that the long-term care needs of their child are met. They stated that would like to have some involvement in the long term planning for the care and support of their child. They feel that this will provide them with the assurance on the future safety, health and the quality of life that their child will have when they are no longer around.

9.16. Resolution of disagreements on the suitability of accommodation

Some of the parents stated that they have been quite distressed over their disagreements with Cardiff Council Social Services on type of care and support offered following their child’s out of county college placement. They were particularly unhappy with the communication approach that Cardiff Council had taken in response to the challenge they made on the suitability of the care and support provision on offer.

These parents believe that Cardiff Council should adopt a better and less time consuming approach in resolving disagreements on suitability of the proposed care provision. They feel that it would be better to resolve these disagreements through constructive face to face dialogues where parents feel that Cardiff Council is truly listening to their views and are willing to work with them to resolve issues.

“The first thing, I think, is that they need to show that they are listening to us, as opposed to telling us what they think.”

In deciding the future care and support placement after residential college, some of them felt that their views were not seriously considered by the Social Services team. Parents felt that they “need to shout” and have to resort to various strategies to get their views listened to.

Parents believe that Social Services should try to understand the parents' perspective in challenging the suitability of accommodation and try to acknowledge the validity of their concerns as the "primary advocate" of their child's best interest.

One of the parents are particularly unhappy with Cardiff Council's proposal that an "independent advocate" could make representations on behalf of their child.

"what has made us unhappy, me unhappy, is there is a sort of ideology now where they actually believe that they know best, and that we don't have his best interests because we don't agree with them, that they tried to insist that they should bring in an advocacy service to determine what xxx really wants as opposed to what we think xxx wants."

"We have cared for him and stretched him and done everything we could. The idea that now we are getting it wrong, and we are being told we've got it wrong by a group of people who either don't know him at all, or scarcely know him, that's what has made us unhappy and don't know why they suddenly think we are not doing things for xxx best interest...."

These parents also suggested that social services should explore a different approach in working with them to resolve their disagreements or issues with the care provision offered to their child. They believe that it would be beneficial to both parties if Cardiff Council makes use of a more collaborative approach in engaging with the parents.

"what we actually want is, "These are your options. What would you like to happen? How do we work together to achieve the best result?" so it's really two-way dialogue, isn't it? It's not just being told what's going to happen to you."

Where disputes continue to remain unresolved, these parents also suggested that Cardiff Council can take a "kinder approach" in informing and supporting parents on "what should be done, what could happen next". However they felt that they are not supported or well advised on how they can effectively appeal unfavourable decisions and to find a way forward that they perceive as would be best interest of their child.