



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 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 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 happens 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 have 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 for 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 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 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 out 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 achieved 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 to 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. Parent 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’s 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 receive 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 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.

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 be 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 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 effect on 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.