The Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities

Getting it Right in the Black Country

Family Survey

NHS
Black Country Healthcare
NHS Foundation Trust

COMMUNITY FUND

Black Country family carer survey findings

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Methodology

This survey was created using SurveyMonkey[1] and was open for 4 weeks (2nd November 2021 until 29th November 2021). The survey was shared amongst family carers, schools, and local services across all of the Black Country, which consists of Dudley, Wolverhampton, Walsall, and Sandwell. There was also the option to complete the survey over the phone or via video call with a member of staff from the Challenging Behaviour Foundation to increase accessibility, however this option was not requested by any participants.

A majority of the questions were multiple choice with options recommended by members of the Black Country Steering Group. However, some questions also gave the option to add additional comments and other questions allowed participants to openly write a response. The full survey is listed in Appendix 1.

The survey questions were devised from desired outcomes shown in a logic model (see Appendix 2), created following discussions with the Black Country Steering Group. This group stated outcomes that they thought would be valuable to gain more information on during the 'Getting it Right' project within the Black Country. These outcomes included:

- **Confident**: Families have the knowledge and confidence to use PBS techniques to understand and respond appropriately to challenging behaviour.
- **Connected**: Families feel well informed about useful services and support in the Black Country and know how to access them. Families feel less isolated and better connected to local support networks
- **Able to contribute**: Families are routinely involved as valued co-producers in developing and improving services and support. Professionals learn from families (through this project and beyond) and use learning to strengthen support and services they are offering
- **Trauma**: Local professionals/leaders understand prevalence of secondary trauma amongst family carers. Local professionals/ leaders have a good knowledge base around provision of existing services and support for families with secondary trauma

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[1] Survey Monkey. Available here: https://www.surveymonkey.co.uk/

- **Transition**: Local professionals understand gaps and barriers in current provision in support and services around transition.

Due to the sensitive nature of some of the questions within this survey, participants were given the option to 'opt out' of the trauma section, and links to support pages were provided at the start and end. These support links included the NHS Black Country Healthcare 'Help in a crisis' page, the Challenging Behaviour Foundation's Family Support contact details, and the Challenging Behaviour Foundation's 'When things go wrong' page.

Throughout this report, respondents' results are reported as a whole for some questions, but for others they are split into groups based on respondent's relative's diagnosis. Those who selected my relative has 'a severe learning disability (little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe, have difficulties with social skills, need life-long support)' and 'been diagnosed with profound and multiple learning disabilities (profound intellectual and multiple disabilities, very severe communication problems, often extreme physical and/or sensory disabilities, and complex health needs)' were put into one group, henceforth referred to as the "Severe Learning Disabilities, or Profound and Multiple Learning Disabilities group" (SLD/PMLD). Those who did not select either of these options when asked what their relative's diagnosis was, are in a group henceforth known as the "non-Severe, Profound and Multiple Learning Disabilities group" (non-SLD/PMLD).

Demographic

A total of 62 participants took part in the survey, and 37 completed the survey. The mean age of all respondents was 42 years old, and 74% (45) described themselves as English/Welsh/Scottish/Northern Irish/British, with the next most common ethnic group being Pakistani (9.8%) (6). Most respondents were parents (91.8%) (56) and also had other caring responsibilities (86.4%) (51) which predominantly consisted of caring for another child over 5 years old (40.7%) (24). The most common location participants reported living in was Wolverhampton (40.3%) (25) (Figure 1).

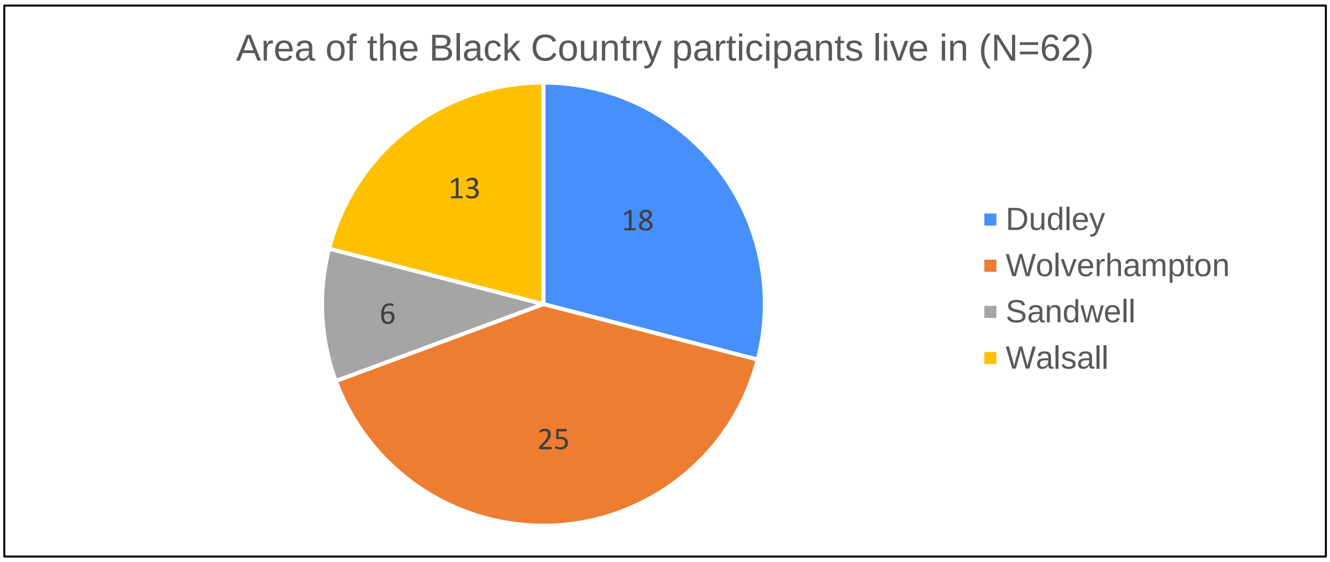

Figure 1 – Graph to show the area of the Black Country that respondents live in

Most of the participant's relatives were males (77.8%) (42) who lived at home (96.4%) (53), however one individual lived in a residential school. The average age of the participant's relative was 12 years old. Participants were asked to indicate any disability diagnoses or suspected disabilities that their relative had (Figure 2). 24 participants reported their relative having a severe learning disability or profound and multiple learning disabilities.

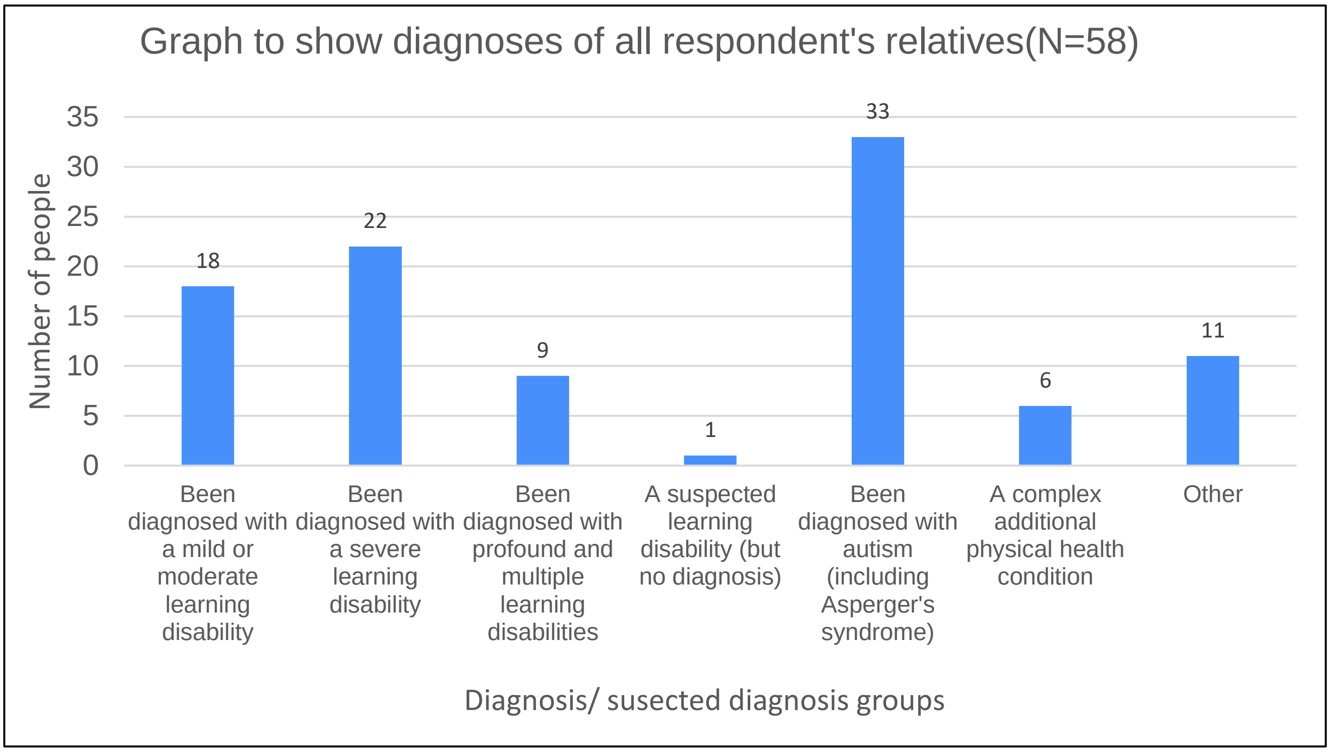

Figure 2 – Graph to show all respondent's relative's diagnoses

See Appendix 3 table 1 for full demographic response information.

Key points

- The mean age of survey respondents was 42 years old, and the average age of their relative was 12
- Most respondents were English/Welsh/Scottish/Northern Irish/British, and most lived in Wolverhampton
- Most respondents were parents of their relative with SEND that they care for, and most also had other caring responsibilities
- Most of the respondent's relatives were males who lived at home, and the most common diagnoses were autism, and a severe learning disability

Behaviour

Most respondents reported that their relative behaved in ways that challenged them, or others around them in both groups, with 73.9% (17) reporting these behaviours happening daily for SLD/PMLD, and 50% (16) for non-SLD/PMLD. For the SLD/PMLD group, 54% (12) reported receiving behaviour support, either by asking for it, or by being referred by professionals, however 31.8% (7) reported not receiving behaviour support despite asking for it. 50% (12) of the non- SLD/PMLD group reported not receiving support despite asking for it, whilst 33.3% (8) received support. For participants who did receive behaviour support, the most common provider for both groups was Specialist CAMHS-LD/Challenging behaviour team (72.7% (8) SLD/PMLD, 62.5% (5) non-SLD/PMLD).

Overall, the wait time for receiving behaviour support varied across both groups, with some waiting under a month, and others waiting years (Figure 3). The responses regarding quality of support varied, with 54.5% (6) SLD/PMLD respondents being happy or very happy with the support they received, and 28.6% (2) non-SLD/PMLD respondents being happy or very happy with their support (Figure 4).

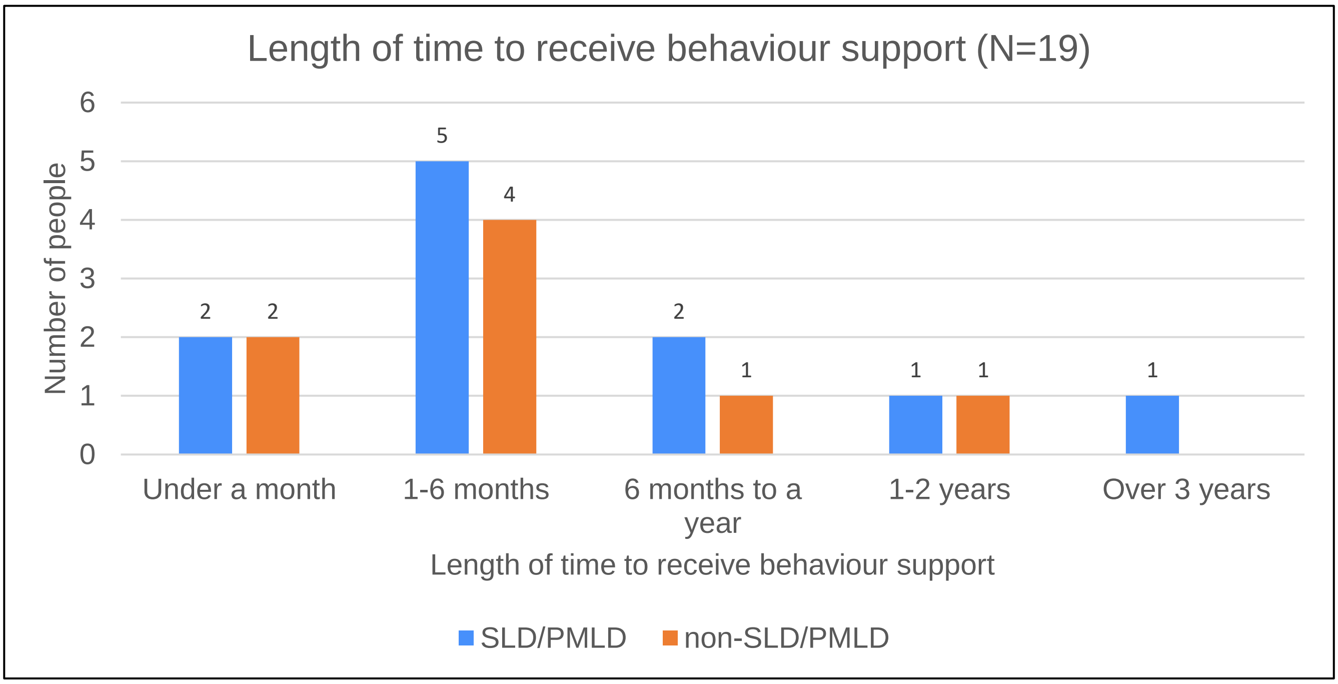

Figure 3 – Graph to show length of time to receive behaviour support

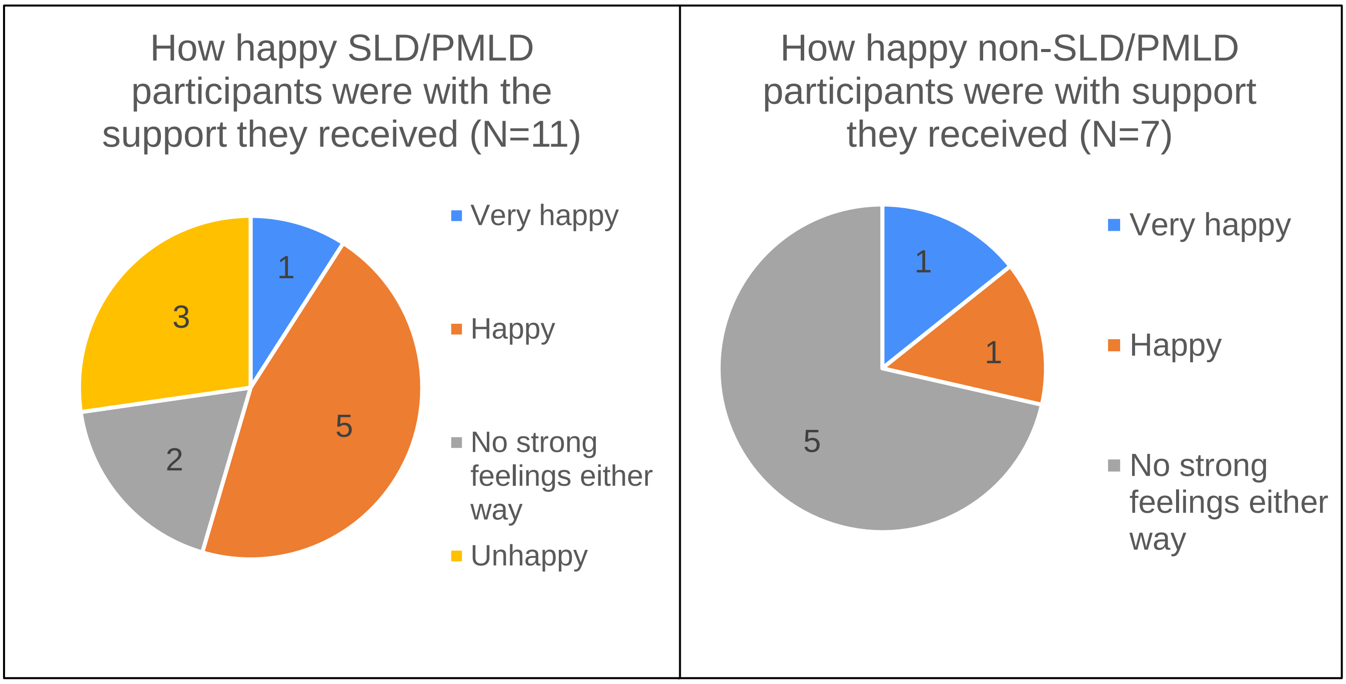

Figure 4 – Graphs to show how happy respondents were with the behaviour support they received

The SLD/PMLD group claimed that information on various support areas was hard to find, unable to access at all, or they could only access some information for each support area (Figure 5). Similarly, for the non-SLD/PMLD group, respondents indicated that information was difficult to find across most areas of support for them and their relative (Figure 6), and the information that was accessed was generally rated as being poor or reasonable in quality for both groups in each area of information (Figures 7 and 8). Ways in which respondents prefer to access information varied greatly across both groups; the SLD/PMLD group favoured websites the most (84.2% (16)), closely followed by email (52.6% (10)). The non-SLD/PMLD group also favoured websites the most (87.5% (21)).

Behaviour and education

Of respondents who reported their relative attends nursery, school, or college outside of Covid-19 restrictions, 43.4% (9) SLD/PMLD and 41.7% (10) non-SLD/PMLD group reported that their relative's behaviour negatively impacts their education attendance. The most common barrier to education attendance for both groups was 'Fear or anxiety around attending nursery/school/college' (85.7% (6) SLD/PMLD, 90% (9) non-SLD/PMLD). For both groups, 'Reduced timetable offered by the nursery/school/college' was another very common barrier to education for their relatives (42.9% (3) SLD/PMLD, 40% (4) non-SLD/PMLD). Although one non-SLD/PMLD respondent said "*reduced timetable has actually helped us access education more effectively*". 'Lack of reasonable adjustments for their relative's needs' (3) and 'Lack of suitable transport' (3) were also popular among SLD/PMLD respondents.

Respondents in both groups generally believed that their relative's place of education supported them well (38.9% (7) reporting 'Very well' and 33.3% (6) reporting 'Quite well' for SLD/PMLD, and 33.33% (8) 'Very well', 29.17% (7) reporting 'Quite well' for non-SLD/PMLD respondents). Similarly, most respondents reported feeling as though their relative's nursery/school/college listened to them and worked with them well across SLD/PMLD and non-SLD/PMLD groups (44.44% (8) reporting 'Very well' and 22.2% (4) reporting 'Quite well' for SLD/PMLD, and 29.16% (7) 'Very well', 37.5% (9) reporting 'Quite well' for non-SLD/PMLD respondents).

Those who responded 'Less well than hoped' or 'Not well at all', suggested ways that their relative's education could be improved. Across both respondent groups, responses included improving staff understanding and protocols: "*Not all staff understand my sons disability*", "*…Previously in mainstream school they did not put in place adjustments that met his needs unless pushed to…", "He's not getting right help according to his needs*", "*Adhere to EHCP*" and improving communication: "*I don't get told about how my kids have coped in school only get told the negative of they have been naughty", "…too many mixed messages/boundaries", "They could listen*".

Ability to contribute to services

In order to understand ways in which participants felt able to contribute to their relative's care, they were asked if they have contributed to the development and improvement of their relative's education, health care and social care services, and if so, how. 72.2% (13) SLD/PMLD respondents and 50% (12) non-SLD/PMLD respondents have contributed suggestions for developing and improving their relative's education services. However fewer people reported contributing towards their relative's health care, (50% (9) SLD/PMLD, 32% (8) non-SLD/PMLD), and social care services (38.9% (7) SLD/PMLD, 33.3% (8) non-SLD/PMLD).

Of those who had contributed, the most common method across all three service areas was 'Engaging in discussions with professionals' (10, 9, 7 respectively for SLD/PMLD and 11, 8, 6 respectively for non-SLD/PMLD).

See Appendix 3 table 2 for full behaviour response information.

Key points

- Most respondents' relatives in both groups displayed challenging behaviours, but 31.82% (7) SLD/PMLD respondents and 50% (12) non-SLD/PMLD respondents did not receive behaviour support despite asking for it
- The most common provider of behaviour support for both groups was CAMHS-LD/Challenging behaviour team
- Overall, a large majority of respondents in both groups found it difficult to access information surrounding behaviour support, but respondents said that websites and email were the most preferred methods of receiving information.
- Respondents' relative's behaviours impacted their education attendance, and the most common barrier to education was fear or anxiety, reduced timetable and lack of suitable transport
- Respondents felt as though their relative's place of education was supportive, listened to them and worked with them regarding their relative's behaviour, however methods for improvement include improving staff understanding and protocols, and improving communication
- At least half of respondents in both groups contributed suggestions for developing and improving their relative's education, but less had contributed to their relative's health care of social care services

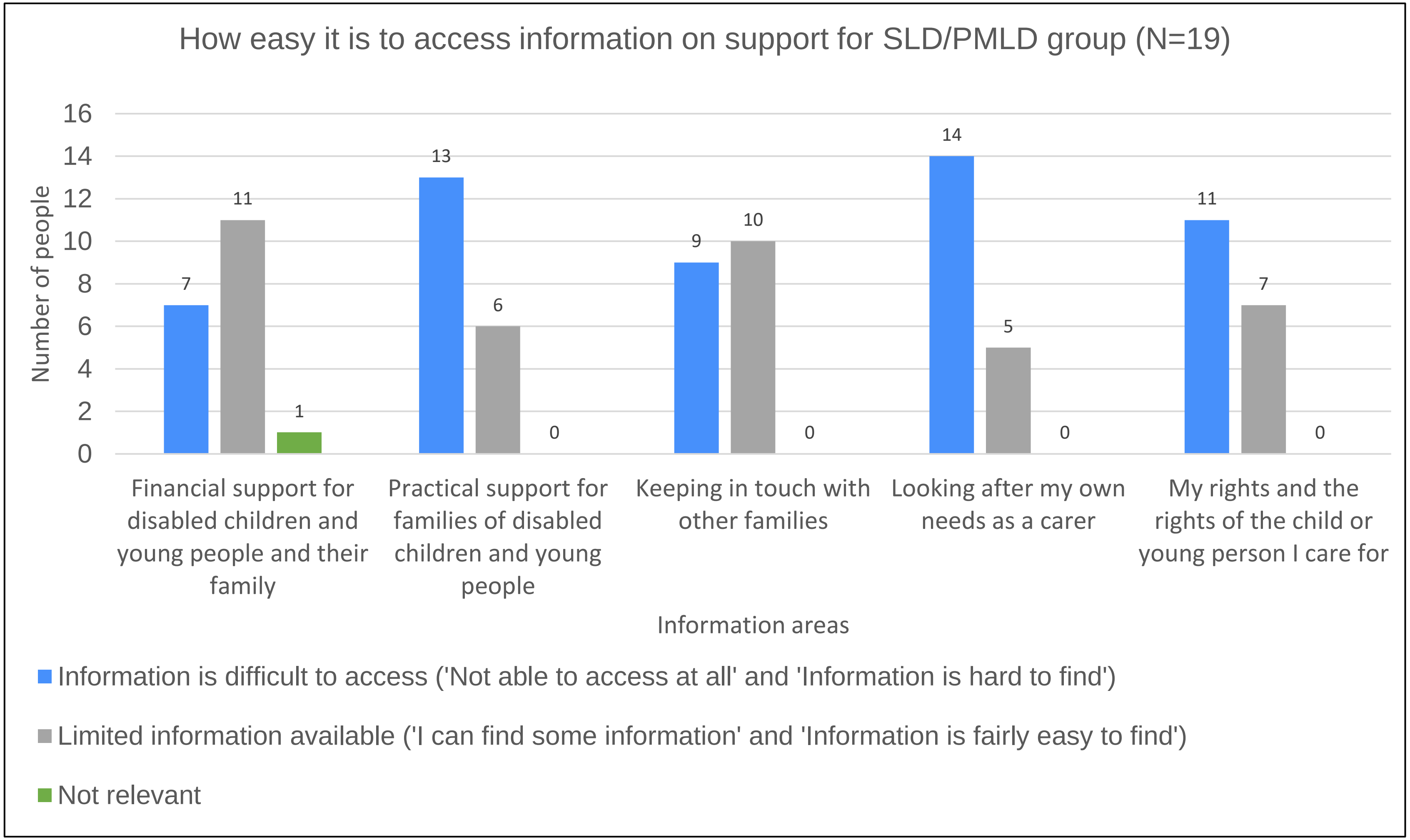

Figure 5 – A graph to show how easy SLD/PMLD respondents found it to access information in various areas

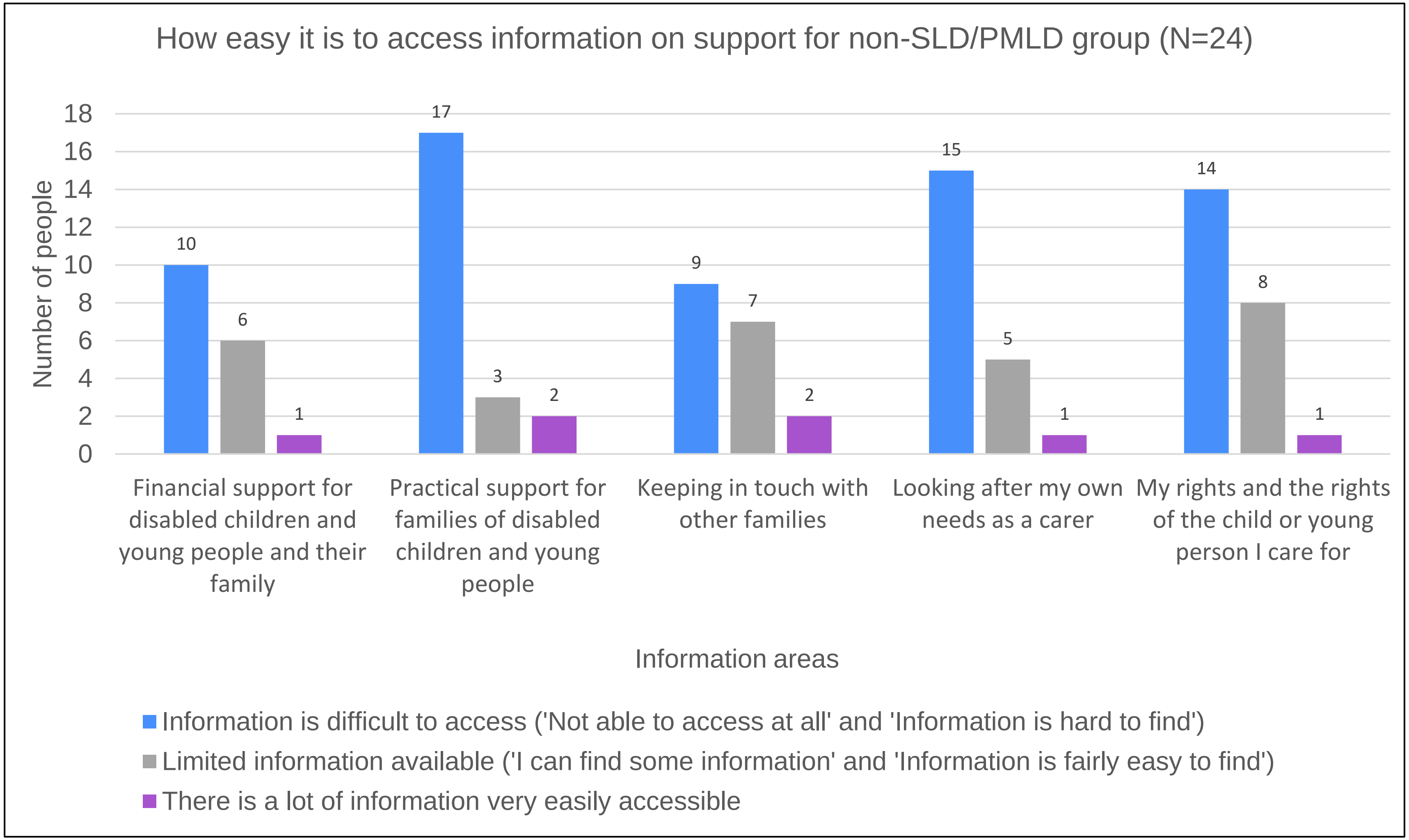

Figure 6 – A graph to show how easy non- SLD/PMLD respondents found it to access information in various areas

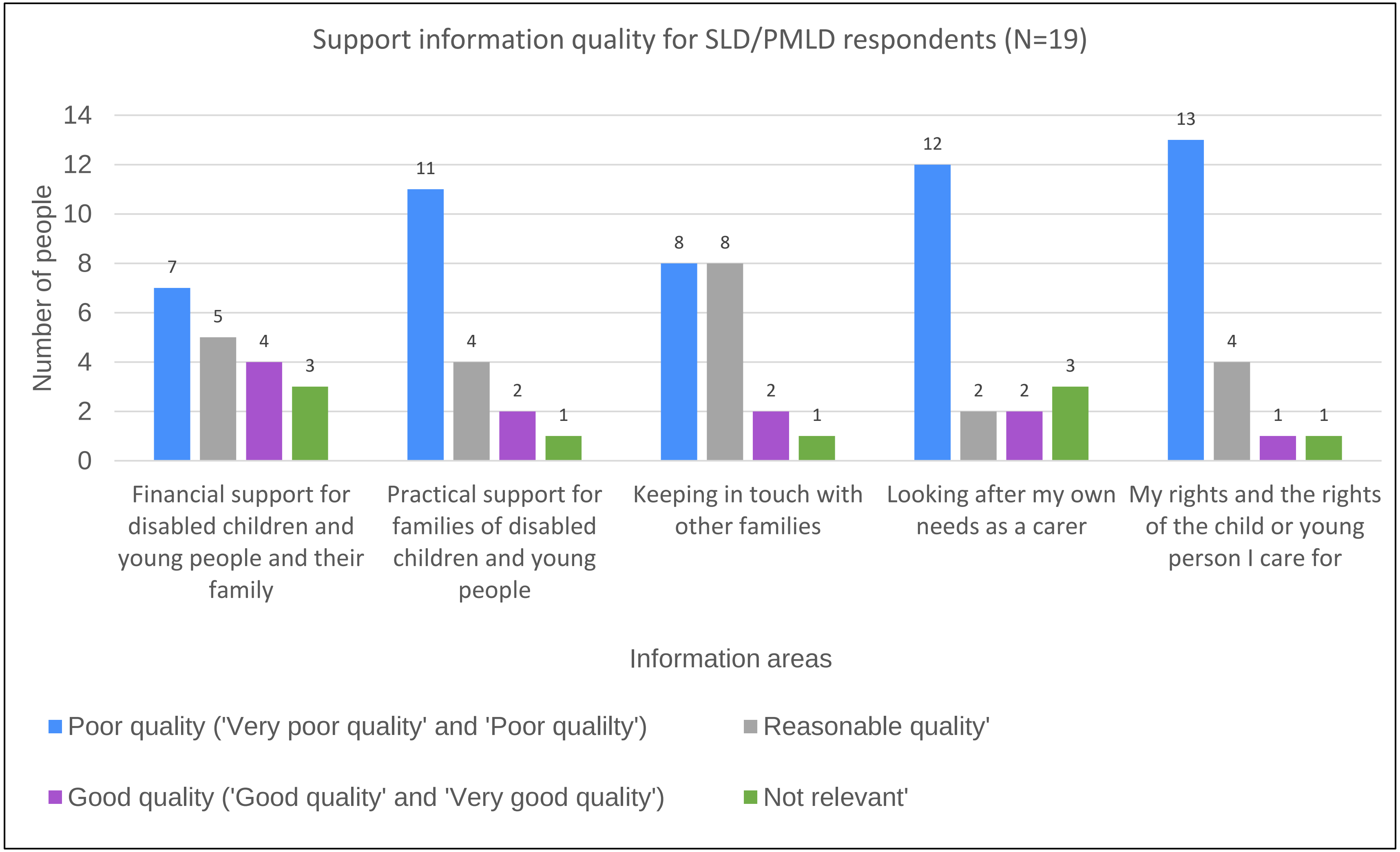

Figure 7 – A graph to show the quality of support information for the SLD/PMLD group

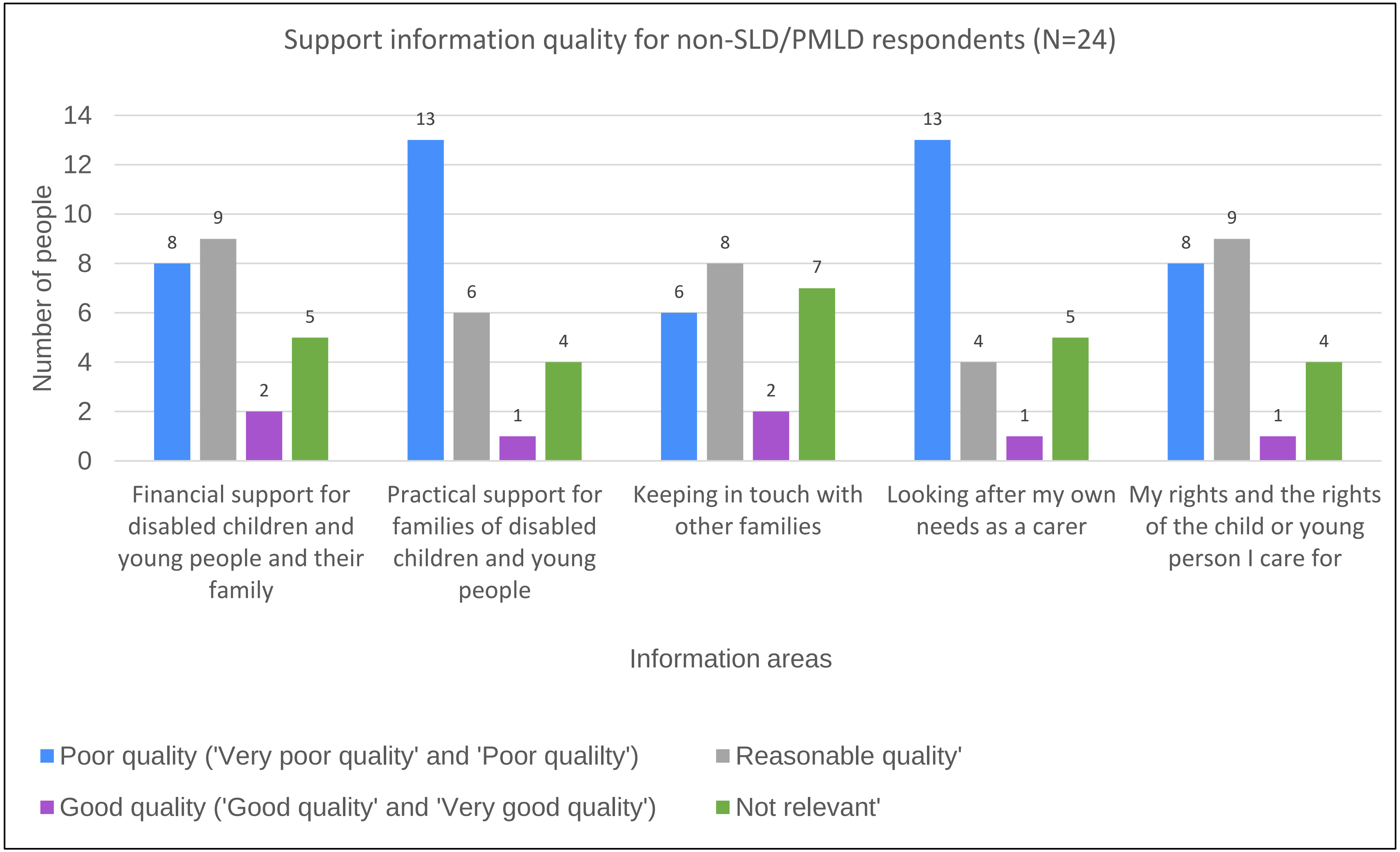

Figure 8 - A graph to show the quality of support information for the non- SLD/PMLD group

Services in the Black Country

To understand how services in the Black Country could be improved, and how families could feel more confident, connected, and able to contribute, the survey asked people if they had heard of and used different services, and those who had used these services were asked how useful they were. Participants were also asked how these services could be improved in the future. For Child and Adolescent Mental Health Services (CAMHS/CAMHS-LD) and the Disabled Children's Team, this information is broken down into regions within the Black Country as requested by members of the Steering Group.

Only respondents who reported that they had heard of a service in the Black Country were asked if they had used their services, and only respondents who reported that they had used a service were asked how useful they found it.

SEND Local Offer

Slightly more SLD/PMLD respondents had heard of SEND Local Offer (61.11% (11)) and used their services (72.7% (8)) than non-SLD/PMLD, of which 50% (12) had heard of SEND Local Offer, and 46.2% (6) had used their services. Across both groups, SEND Local Offer was rated at 'Somewhat useful' by the majority, with others saying the services are in some way not useful (Figure 9). One non-SLD/PMLD respondent commented "*Difficult to find information on it. Info isn't in there.*".

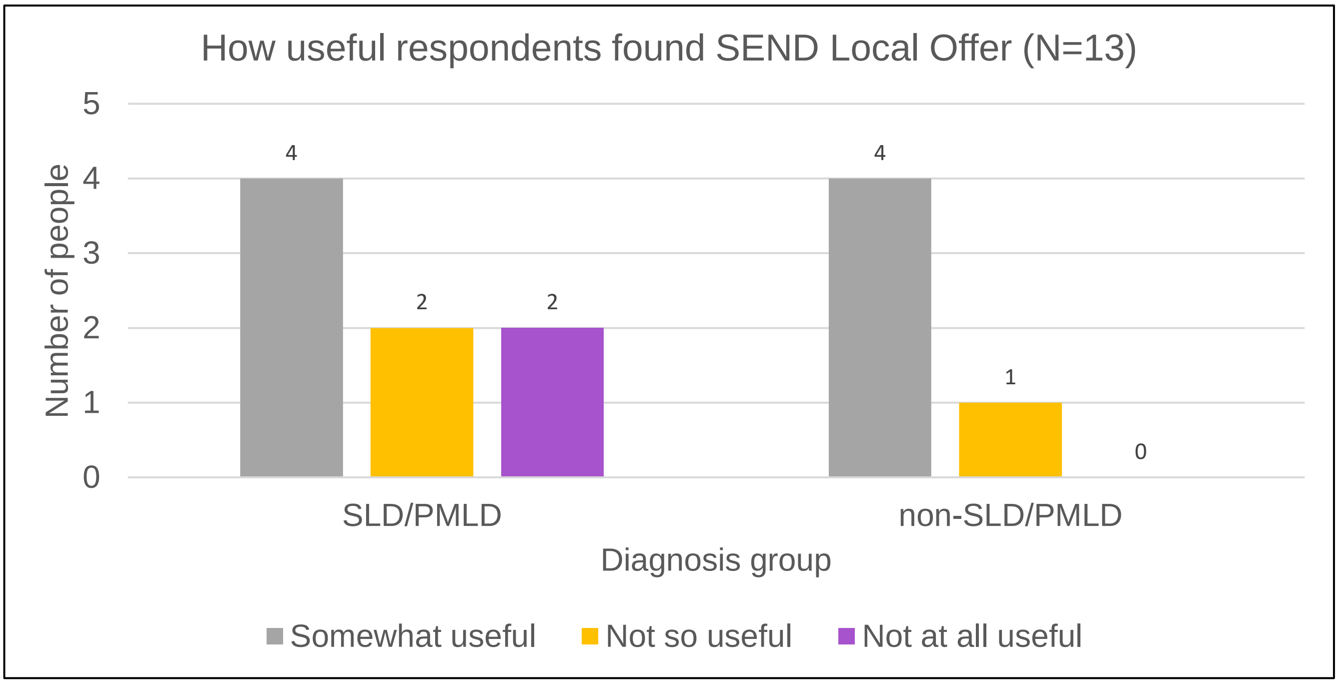

Figure 9 – A graph to show how useful SLD/PMLD and non-SLD/PMLD respondents found SEND Local Offer in the Black Country

Inclusive Learning Service

Only two of the respondents had heard of the Inclusive Learning Service, both of whom were non-SLD/PMLD respondents, with only one person reporting using their services, which they stated was extremely useful.

Child and Adolescent Mental Health Service (CAMHS) or Child and Adolescent Mental Health Service for children and young people with learning disabilities (CAMHS-LD)

Dudley

5 SLD/PMLD respondents had heard of CAMHS/CAMHS-LD, 80% (4) had used their services. Support was rated as at least somewhat useful by all respondents. Among non-SLD/PMLD respondents, four had heard of CAMHS/CAMHS-LD, of which 75% (3) had used their services. This support was equally rated as 'Not so useful', 'Not at all useful', and 'Somewhat useful' (Figure 10).

Wolverhampton

9 SLD/PMLD participants had heard of CAMHS/CAMHS-LD, 77.8% (7) had used their services. Support was rated as at least somewhat useful by most, and 'Not so useful' by others. Eight non-SLD/PMLD respondents had heard of CAMHS/CAMHS-LD, of which 62.5% (5) had used their services. Support ratings varied with votes for 'Very useful', 'Somewhat useful', 'Not so useful', and 'Not at all useful' (Figure 10).

Sandwell

1 SLD/PMLD respondent had heard of CAMHS/CAMHS-LD and had used their services. They rated this support as ‘Not so useful’. Among non-SLD/PMLD respondents, four people had heard of CAMHS/CAMHS-LD, and 75% (3) of these had used their services. This service was rated as not useful by all respondents (Figure 10).

Walsall

1 SLD/PMLD respondent had heard of CAMHS/CAMHS-LD, and they had used their services, which they rated as ‘Somewhat useful’. Five non-SLD/PMLD respondents had heard of CAMHS/CAMHS-LD, of which all used their services. This support was rated as at least somewhat useful by all respondents (Figure 10).

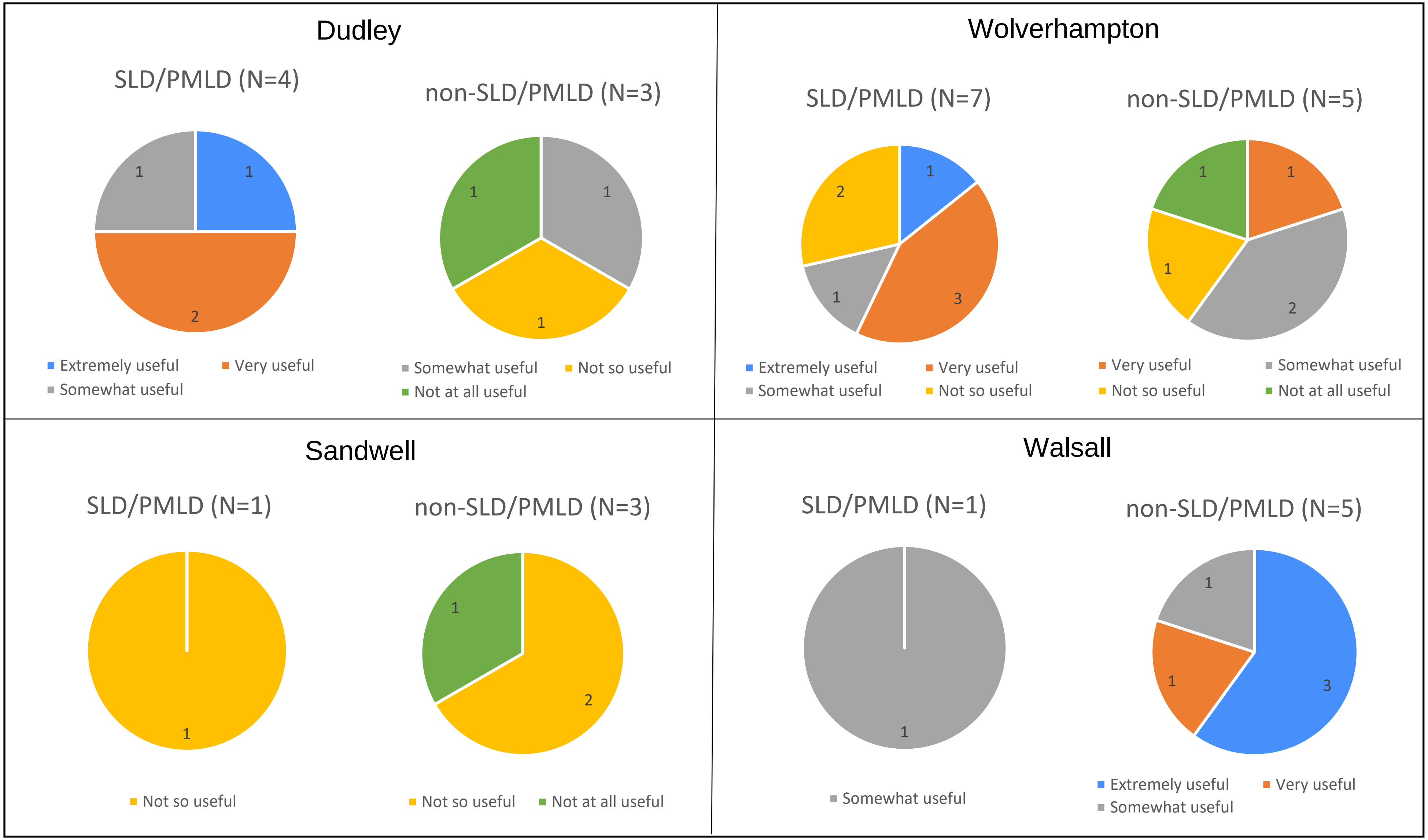

Figure 10 - Pie charts to show how respondents rated the usefulness of CAMHS/ CAMHS-LD

Disabled Children's Team

Dudley

4 SLD/PMLD respondents had heard of Disabled Children's Team, 75% (3) had used their services. Support was rated as at least somewhat useful by all respondents. For the non-SLD/PMLD respondents, four had heard of the Disabled Children's Team, of which 50% (2) had used their services. Support was rated as 'Somewhat useful' and 'Not at all useful' (Figure 11).

Wolverhampton

7 SLD/PMLD respondents had heard of the Disabled Children's Team, 71.4% (5) had used their services. Support ratings varied from 'Extremely useful', 'Somewhat useful', 'Not so useful', and 'Not at all useful'. Additional comments regarding Disabled Children's Team include: "*they are not supportive, they just put up blocks to support*", and "*Not much support constantly changing the person who is supposed to help. Mixing up information of my children.*". Among non-SLD/PMLD respondents, four people had heard of Disabled Children's Team, of which one person (25%) used their services, which they rated as 'Not at all useful' (Figure 11).

Sandwell

1 SLD/PMLD respondent had heard of Disabled Children's Team, and had used their services, which they rated as 'Not at all useful'. Similarly, one non-SLD/PMLD respondent had heard of Disabled Children's Team but had not used their services (Figure 11).

Walsall

1 SLD/PMLD respondent had heard of Disabled Children's Team, and had used their services. They rated this support as 'Not at all useful', and additionally wrote "*They just talk and never do as they say.*". Three non-SLD/PMLD respondents had heard of Disabled Children's Team, of which one person (33.3%) had used their services, they rated this support as 'Somewhat useful' (Figure 11).

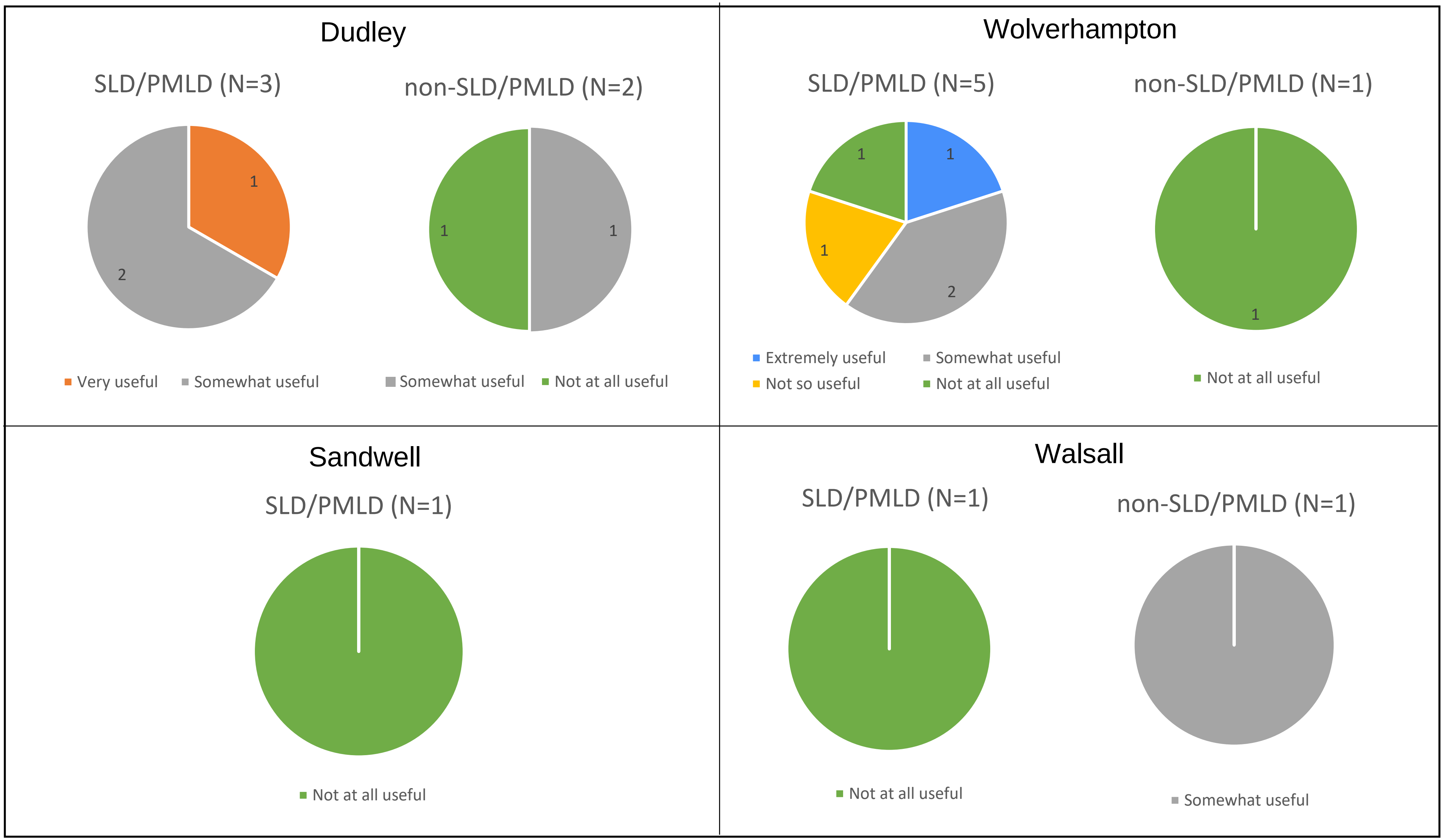

Figure 11 - Pie charts to show how respondents rated the usefulness of Disabled Children's Team

When asked what could be done to improve these local services, several key themes were identified across all participants, these were information and advice, co-ordination of services/continuity, accessibility and inclusivity, communication, gaps in services, waiting times. Response analysis is in appendix 4, table 1.

Information and advice

Being able to access more information surrounding support was highlighted as important by multiple respondents "*More relevant information*", "*More information about services and how to access them*", "*Information about groups via email*".

Additionally, advice was mentioned as being important for participants "*Help with behaviour and manage access to social care*", "*More information and handling about challenging behaviour children*", "*More interaction, more information*".

Co-ordination of services/continuity

Continuity across services was mentioned as something that would improve services "*That services are linked up*". More specifically, multiple respondents mentioned having one professional working across all services in order to improve co-ordination "*One person allocated to help support carer to tie all the services together. too much chasing up of professionals.*", "*A key worker across all services. To be listened to. Not to keep repeating our journey*".

Accessibility and inclusivity

Services being more accessible would be beneficial for respondents in the Black Country, with responses including "*To be more accessible*", "*Leisure ASC accessible services and leisure*".

Communication

Respondents reported feeling as though services do not listen to them "*They need to listen to parents", "listening to the parents first because they know their children best.*", "*Listening to parents the first time rather than years later.", "Better communication*". However, respondents also mentioned that they feel services do not empathise with family carers enough "*Listen to parents/carers the first time , tell it once, be supported from the beginning,* *prevention of family breakdowns, stop parent blaming*", "*To be more understanding and have more empathy for parents.*".

Gaps in services

Within the theme of gaps in services, several participants mentioned that they were unable to access support services "*my son is self-harming and harming others due to anxiety and difficulties and they are still ignoring him.", "Actually have a appointment", "Access to them!!*". Whilst others mentioning that once a diagnosis is given, little further support is offered "*Offer services that support us as a family. Diagnosis given and then left with very little help or flexibility in what was offered. provide services for children with autism as there are none unless they have co morbid mental health issues. Gap in service where these children are failed with sensory issues eating issues as some examples.", "Cahms said they couldn't find the right service to help my son so did nothing", "More help around autism", "Stop affirming girls with ASD as boys help them to feel comfortable in their own bodies*". Another mentioned not receiving support as they do not have a diagnosis "*Applied for support and not been offered anything as we don't have a diagnosis*".

Waiting times

Reducing waiting times was mentioned by a large amount of participants as something that could improve services across the Black Country "*Reduce waiting times for services*", "*The waiting for assessments be shorter time", "Better resources to respond in a timely fashion. Long wait times for support", "Shorter waiting lists for families. More sessions*". This included wait times for a diagnosis "*Finding a way to reduce waiting times for diagnosis of neurological disorders such as ASD, ADHD, ADD etc*", as well as ensuring that families are not waiting until crisis to receive support "*Nothing happens until u hit crisis and it takes months even after that*", "*Things need to move faster when people ask for help. parents only come for help when they have reached crisis. Then everything takes too long", "acting when families reach out for support and not after they have a breakdown, stop breaking the law …*"

Local Parent Support Groups

More SLD/PMLD respondents reported having heard of local Parent Support Groups (such as Sandwell Parent's Voices United, or Triple P Positive Parenting) (61.11%) (11) than Non-SLD/PMLD respondents (37.5%) (9). Of these respondents, most participants have joined a Parent Support Group, or used their services or support (100% (11) SLD/PMLD, 77.78% (7) non-SLD/PMLD), and found them useful in some way (92.31% (12) SLD/PMLD, 85.71% (6) non-SLD/PMLD). Whilst a number of respondents claimed to feel connected to Parent Support groups in the Black Country in some way, a majority of participants felt in some way isolated from Parent Support Groups (Figure 12).

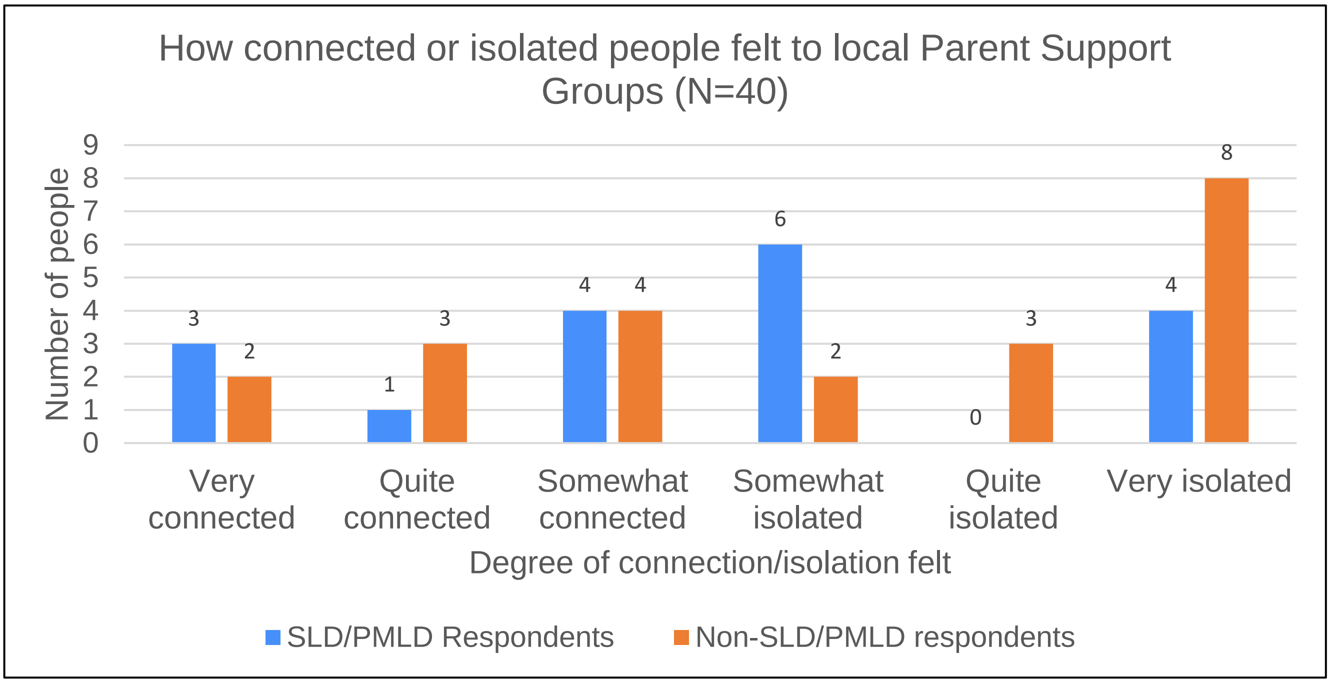

Figure 12 - A graph to show how connected or isolate respondents felt to local Parent Support Groups in the Black Country

Across all participants, when asked what changes could be made to help participants feel more connected to other family carers in their community, several key themes were identified, these were information, advice and activities, peer-to-peer support and involvement, accessibility and inclusion and awareness of support available. Response analysis table is in appendix 4, table 2.

Information, advice and activities

Respondents highlighted that receiving more information and awareness of how to receive support could be improved "*We requested training in autism* *and never received", "More information*", "*More awareness of where to go who to see*". Additionally, it was mentioned that it would be beneficial if more activities within the Black Country were available "*A broader range of activities offered*".

Peer-to-peer support & involvement

The importance of peer support and involvement was echoed by participants, some mentioning that they would appreciate the ability to discuss their relative's needs with others "*Meet ups face to face listening ear/befriending service*", "*Career meetings where we can discuss about our special needs kids needs*", whilst one respondent raising the importance of allowing family carers to feel involved in support groups and to make an impact "*Not just seating and listening to what they have to say, give parents chance to speak up, change their ideas in different area where they struggle ask questions, how to improve the quality of care of their love one without feeling a lone.*".

Accessibility & inclusion

Improving inclusion was important for respondents, with ways of improving this including "*more cultural diversity*", "*Support by other language too (Punjabi) to understand things more clearly*" and "*Group in my area as disabled my self don't go out cause there group are not local to me*".

To improve accessibility, respondents suggested that there could be multiple different ways to get involved in support groups "*Maybe a virtual groups, Facebook groups etc", "More localised meet ups*". Additionally, it would be beneficial for respondents if support groups could take place outside of specific hours "*at times that do not clash with work time." "Instead of specific times have an open timetable".*

Awareness of support available

Improved awareness of support available is important to respondents in the Black Country, this included improving advertising of support groups *"Better advertising."* and providing family carers with support resources when their relative is diagnosed "*When child is diagnosed to be given information about groups local to home*".

See Appendix 3 Table 3 for full services in the Black Country response information.

Key points

- Most respondents had heard of the SEND Local Offer, and those who used the services said it was either somewhat useful, or not useful
- A very small minority of respondents had heard of the Inclusive Learning Service
- Most respondents had heard of CAMHS/CAMHS-LD, and overall, it was rated as useful to some extent by over half of respondents. CAMHS was rated as useful by 100% respondents in Walsall.
- Over half of respondents had heard of the Disabled Children's Team, and it was rated as useful by just over half of those who had used its services. The area that rated it the most useful was Dudley
- Ways that local services could be improved encompassed themes of information and advice, co-ordination of services/continuity, accessibility and inclusivity, communication, gaps in services, and waiting times
- Most parents who had heard of local parent support groups had joined one at some time, and most found them useful to some extent. However, most respondents also reported feeling isolated from local parent support groups
- Ways that parent support groups could be improved encompassed themes of information, advice and activities, peer-to-peer support and involvement, accessibility and inclusion and awareness of support available

Transition

For questions relating to transition from child to adult services in the Black Country, participants were first asked to indicate which age bracket their relative fell under, to ensure that they were asked the most appropriate questions. Of the participants who answered the question, 30 indicated that their child was under 13, therefore they were deemed too young to have experience of transitioning from child to adult services and as a result skipped this section. 12 stated that their relative was 13-17 years old and none had relatives aged between 18-25 years old. All following responses in this section are from participants with relatives aged 13-17 years old.

'Transition from child to adult social care' was voted as the hardest transition service to access information and support on for the SLD/PMLD group, with two participants (50%) unable to access information on this at all, and 2 (50%) saying information is hard to find. For the non-SLD/PMLD group, it was hardest to find information on 'Transition from child to adult social care', 'Transition within education and training beyond school' and 'Transition from child to specialist health services (learning disability or mental health)', each receiving 5 votes across 'Not able to access information at all' and 'Information is hard to find'. When asked about the quality of support offered by a professional, a majority of participants selected 'Not relevant' for most transition areas in both groups, except 'Transition from child to specialist health services' and 'Transition within education and beyond school' for the SLD/PMLD group (see Figure 13 below).

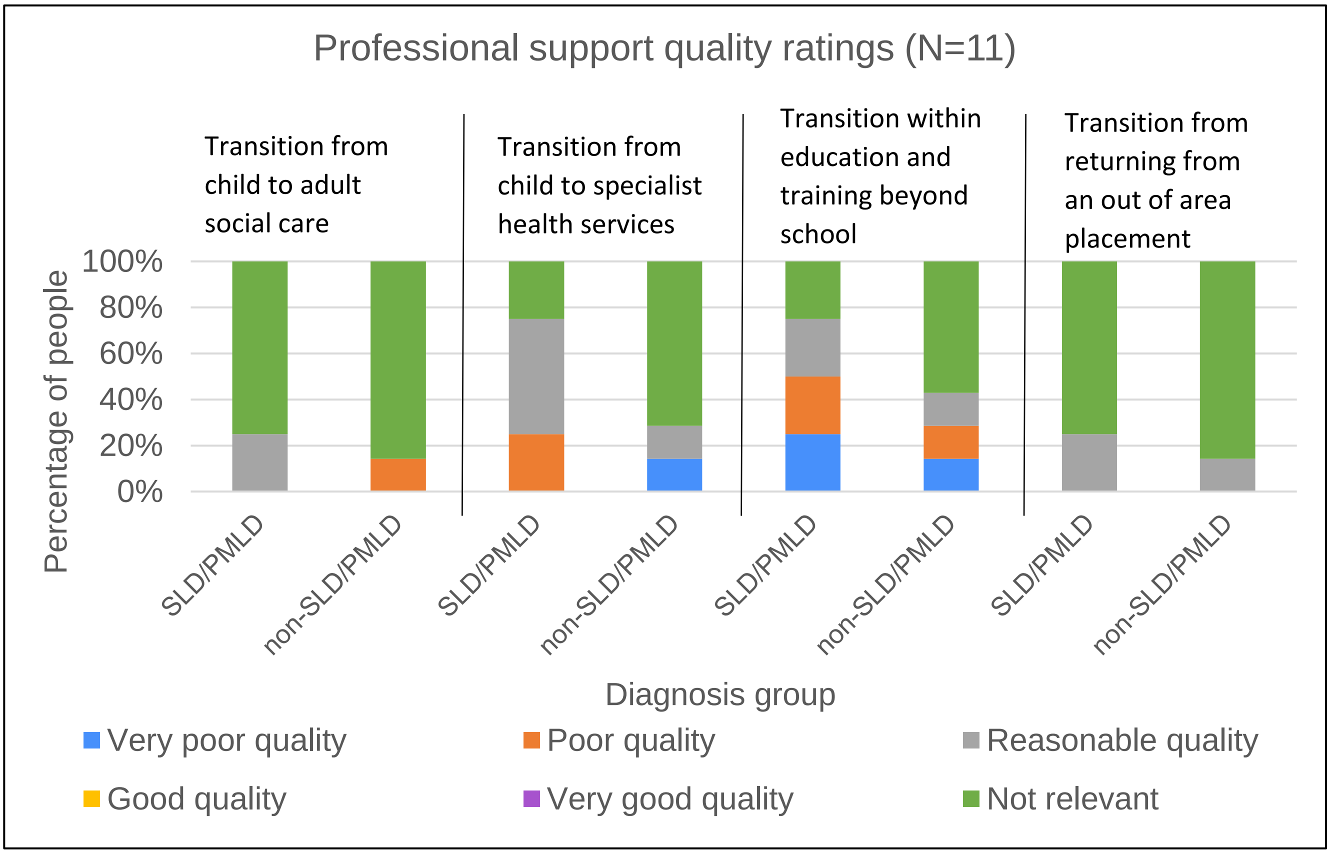

Figure 13 – A graph to show the quality of professional support across the Black Country

Preparedness and anxieties surrounding transition

A majority of participants in both groups felt unprepared for their child's transition from child to adult social care (50% (2) SLD/PMLD, 57.14% (4) non-SLD/PMLD), transition from child to specialist health services (75% (3) SLD/PMLD, 42.86% (3) non-SLD/PMLD), and transition within education and training beyond school (75% (3) SLD/PMLD, 42.7% (3) non-SLD/PMLD). Participants who indicated feeling unprepared were asked to share their concerns regarding their relative's transition. SLD/PMLD group participants mentioned "*Lack of services and placements beyond 19+, uncertain of what the future holds*", "*We have not been given explanation how it's work, the impact of those changes in his life, outside world. We don't know what to expect.".* Non-SLD/PMLD group participants wrote "*no communication. no discussion", "How the services differ will they support him how they previously have done".* The most commonly identified way in which this anxiety could be reduced was 'access to better information' with 'Planning well in advance of my relative's transition' and 'Better communication with relevant services' also chosen often in both groups (Figure 14).

See Appendix 3 Table 4 for full transition response information.

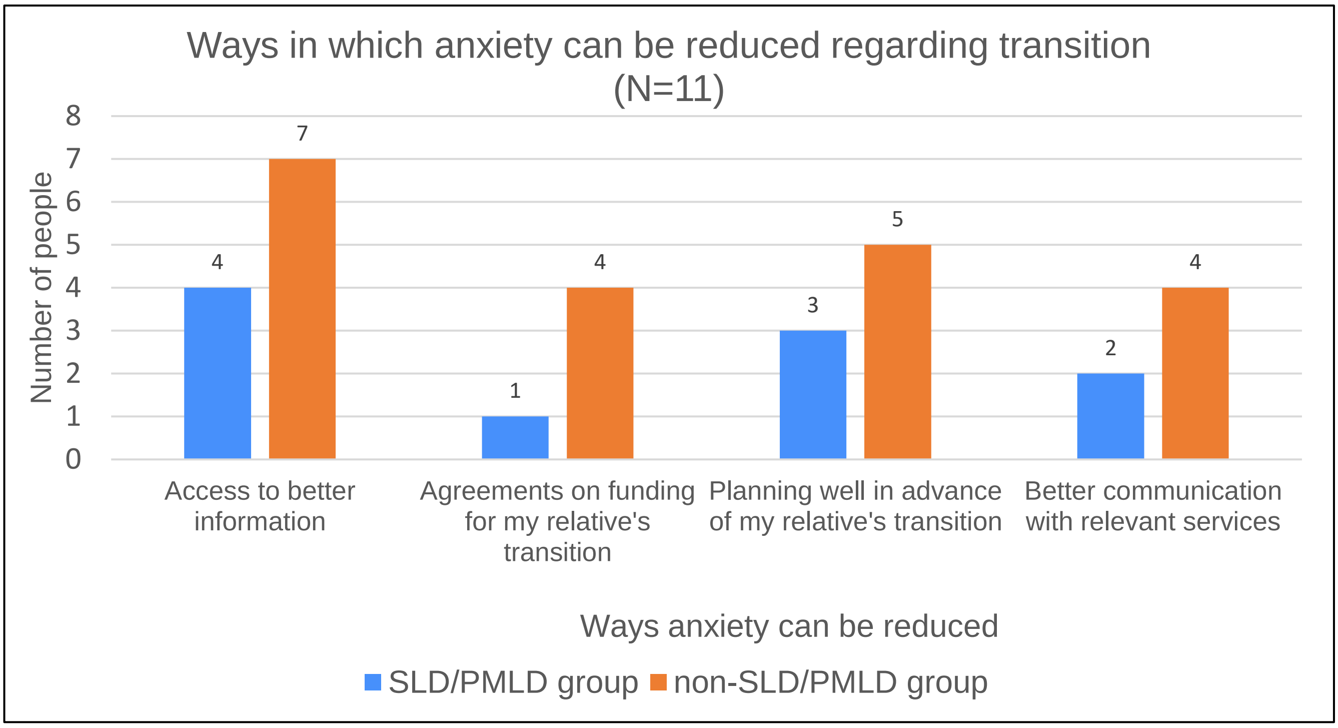

Figure 14 – A graph to show the ways that respondents believe their anxieties or worries surrounding their relative's transition could be reduced

Key points

- Transition from child to adult social care was the hardest to find information on for both groups, with the non-SLD/PMLD group also finding transition within education and training beyond school, and transition from child to specialist health services difficult to access information on
- Most rated the quality of professional transition support not relevant, or reasonable.
- Most respondents felt unprepared for their relative's transition from child to adult social care, child to specialist health services, and transition within education and training beyond school
- Concerns related to transition included an uncertainty of the transition and future, lack of communication, lack of services. Ways that anxiety could be reduced included access to better information, planning well in advance of the transition, and better communication with relevant services

Secondary Trauma

Due to the sensitive nature of the discussion of trauma, participants were given the option to skip this section entirely, without seeing any of the questions. Across both groups, 21 participants chose to skip the section on secondary trauma, 20 chose to view the section. Less than half non-SLD/PMLD respondents reported that their relative had not experienced a traumatic event e.g., restraint, seclusion, abuse, separation from family etc. (9.1% (1)) and 55.6% (5) SLD/PMLD respondents said their relative had not experienced a traumatic event. In both groups there were respondents who were unsure whether their relative had experienced a traumatic event (22.22% (2) SLD/PMLD, 45.5% (5) non-SLD/PMLD). Participants who stated that their relative had not experienced any events that they felt were traumatic did not view any further questions in this section.

For the SLD/PMLD (100% (2)) and non-SLD/PMLD (83.3% (5)) group, the most frequently identified traumatic experience was 'Loss of familiar routines, environment, people'. Other frequently mentioned known traumatic experiences were 'Subject to 'rules' which may not be understood (e.g., not allowed access to preferred items/activities)' (100% (2)) for the SLD/PMLD group (Figure 15) and 'Not getting support care needs met in a timely manner' (66.7% (4)) for the non-SLD/PMLD group (Figure 16).

Effects of secondary trauma on the participant

The most regularly occurring effect of trauma on the respondent for the SLD/PMLD group was 'Depression', 'Anxiety and fearfulness' and 'Personality change (i.e., difficulty trusting others)', each being voted for by 66.67% (2) participants (Figure 17). The most common regular trauma effect for the non-SLD/PMLD group varied, but 'Guilt' and 'Disagreement with friends/family members' were the most popular, being voted for by 66.67% (4) respondents (Figure 18). Although the responses varied, every respondent in both groups reported experiencing effects as a result of their relative's traumatic experience.

Effectiveness of trauma support in the Black Country

Participants identified that CAMHS, Early help and counselling phone calls had been offered to them by professionals, but of those who answered the question 50% (3) said nothing had been offered to them. Participants who sought their own support stated that they used (or are on the waiting list for) Healthy Minds, CBT, and a family counsellor, although one participant stated they "*just got on with it*" in response to seeking trauma support. Two participants in the SLD/PMLD group stated that they were not aware that further support was available. Participants identified 'We Love Carers', 'Voice 4 Parents' and an early help worker as individuals or organisations that they felt understood their experiences and were useful in providing support. Additionally, two people (66.67%), one from each group, claimed that the trauma support received was helpful, with one in the SLD/PMLD group claiming it made no change.

When asked what existing trauma support participants are aware of that exists in the Black Country, respondents in both groups indicated that there is minimal support available "*There is very little support*", "*None*", whist one non-SLD/PMLD group respondent mentioned that they are aware of a "*Family counsellor*". The SLD/PMLD group highlighted that better access would improve support in the Black Country "*More access or better well known and signposted*", "*More details provided. Easy access.*". Non-SLD/PMLD responses included "*Provide some support to families and make is accessible*", "*Coaching for the family member to understand coping mechanisms for the child as well as how to respond to situations and adapt things*" and "*Everything*".

See Appendix 3 Table 5 for full secondary trauma response information.

Key points

- 90.9% of SLD/PMLD and 44.44% of non-SLD/PMLD respondents either knew or unsure whether their relative had experienced a traumatic event, the most common traumatic experience was 'loss of familiar routines, environment, people'
- SLD/PMLD respondents indicated that depression, anxiety and fearfulness, and personality change were the most regularly occurring effect of trauma. For non-SLD/PMLD this was guilt and disagreement with friends/family members
- Respondents identified services that they received trauma support from, however half of the respondents were not offered professional trauma support. Most found professional support helpful
- Respondents said there was minimal trauma support available, and families could benefit from better access to support and more accessible support

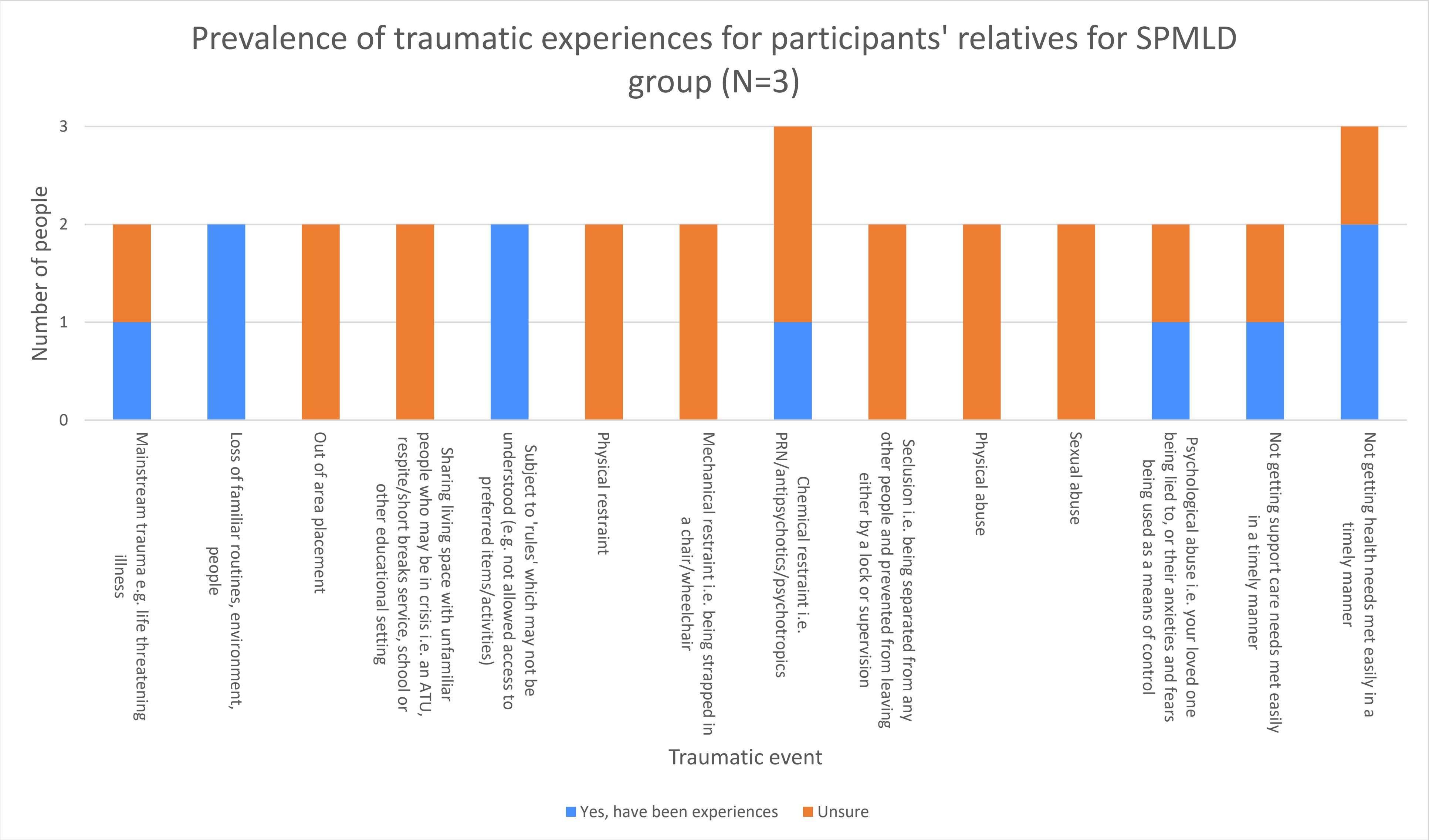

Figure 15 – A graph to show the frequency of traumatic events across SLD/PMLD respondents relatives in the Black Country

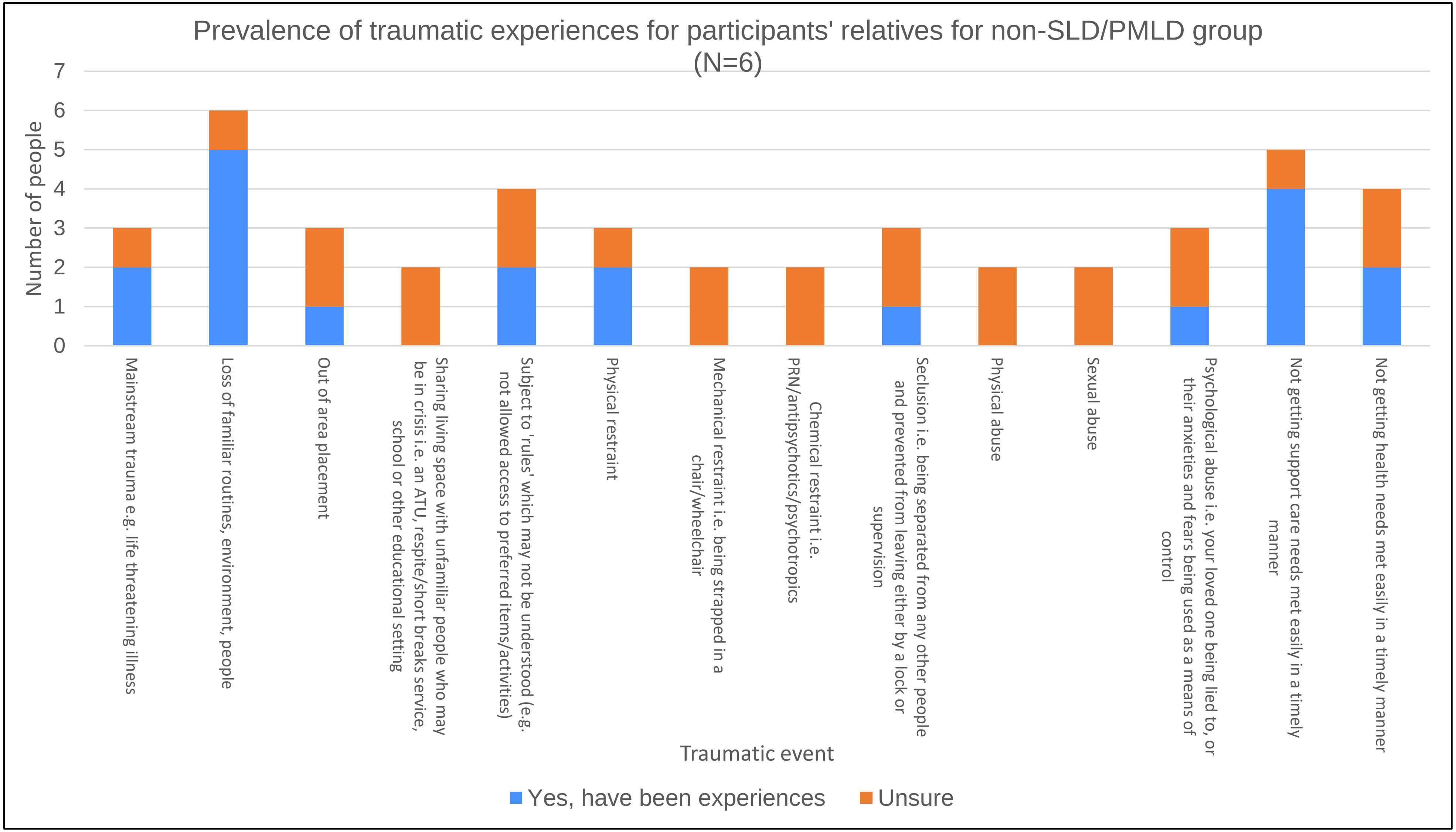

Figure 16 – A graph to show the frequency of traumatic events across non-SLD/PMLD respondents relatives in the Black Country

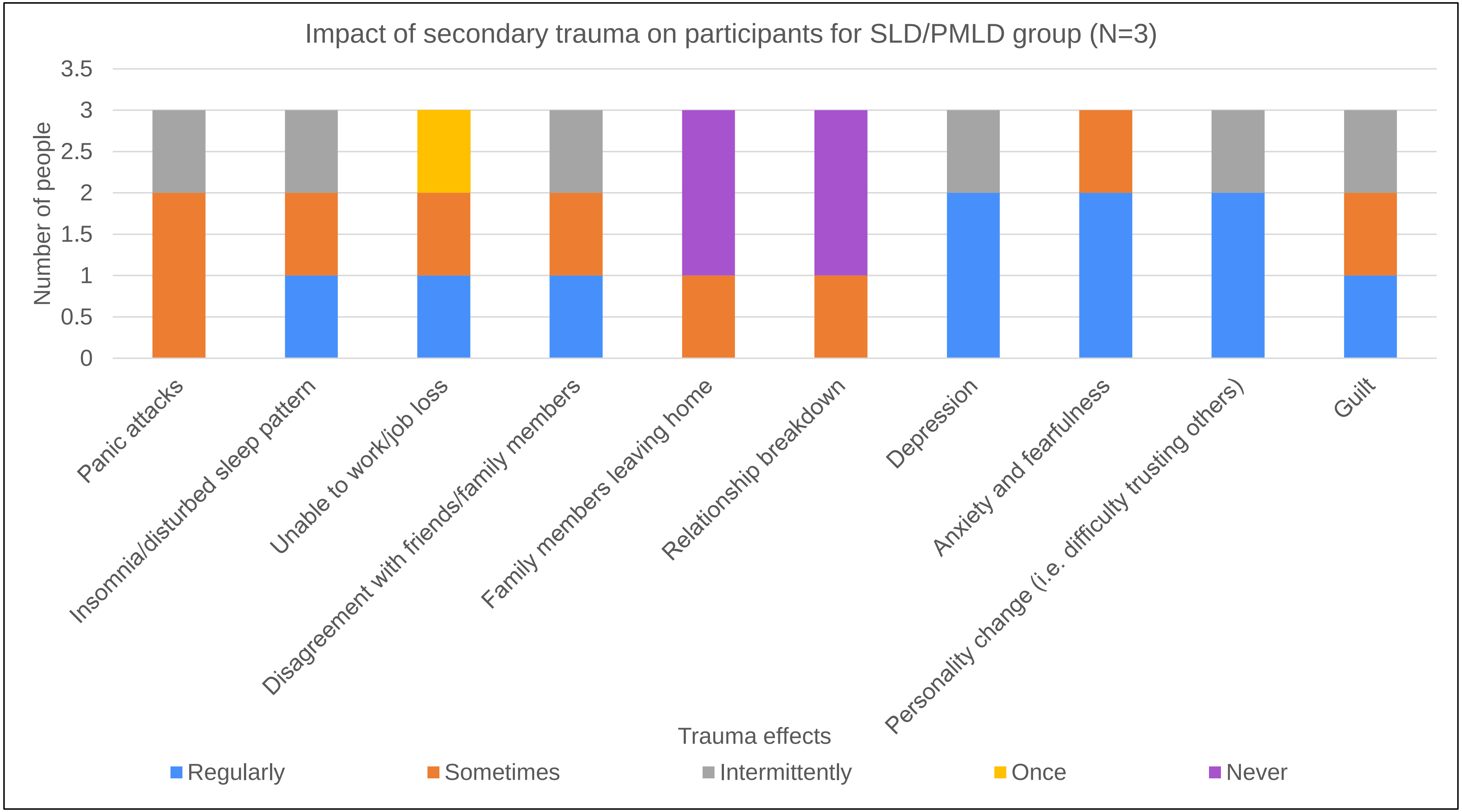

Figure 17 – A graph to show the impact of secondary trauma on participants in the SLD/PMLD group

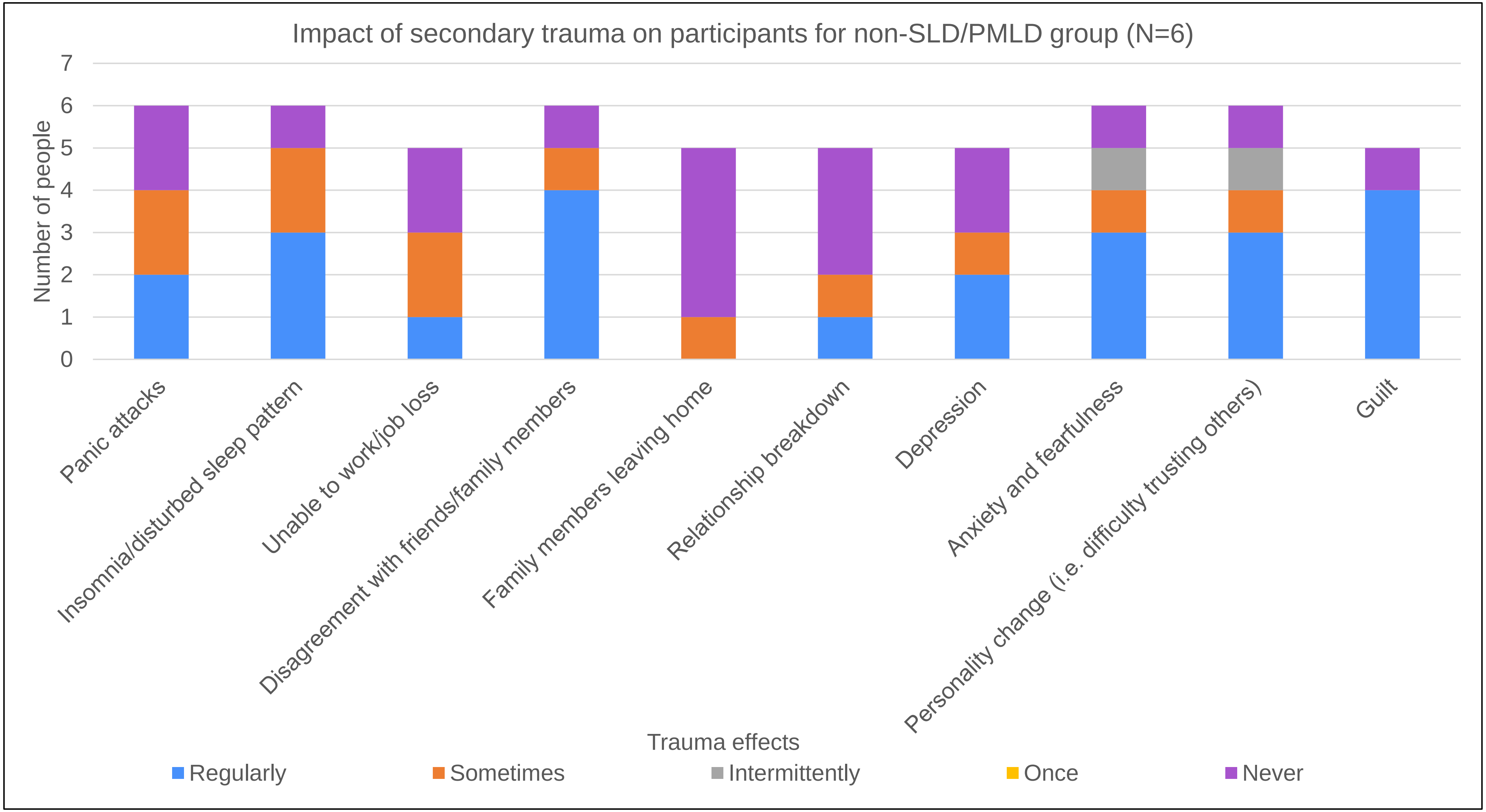

Figure 18 – A graph to show the impact of secondary trauma on participants in the non-SLD/PMLD group

Appendices

Appendix 1 - Getting it Right in the Black Country survey

Getting it Right in the Black Country

Thank you for taking part in this survey on the needs of family carers in the Black Country. We are keen to hear from parents and other family carers of children and young people aged 0-25 with a learning disability whose behaviours challenge.

'Challenging behaviour' is how we talk about a range of behaviours which some people with learning disabilities may display to get needs met. Behaviours might be things like: Hurting others, self-injury, destructive behaviours, eating inedible objects, etc.

To take part you can be anyone who lives in the Black Country and provides unpaid care to a child or young person aged 0-25 years with a learning disability even if they currently live elsewhere. Whether you are a grandparent, sibling, foster carer or parent we want to hear your views.

Your responses will inform a project called "Getting it Right" led by family-led UK charity The Challenging Behaviour Foundation (CBF) in collaboration with Black Country NHS Healthcare Trust. The project team is committed to listening to family carers and learning about services you value and those that could be improved. We want to use this information to improve services in the Black Country for families caring for a loved one with challenging behaviour.

By taking part in this survey your information will remain completely confidential and will be stored securely. You will not be identified in relation to any information you share with us. The survey should take around 30 mins to complete but you do not have to complete it all in one go, if you attempt to re-access the survey using the same link on the same device, you will be able to pick up where you left off.

The last section of questions in this survey focuses on trauma, you can skip this section if you want to. We want to understand how well families are supported to recover from trauma in your area, so we can plan to improve services. Access to support information will be made available at the start of the section on trauma, as well as at the end of the survey.

Questions about you

The following questions relate to you, the person completing the survey.

Q1. What is your relationship to the child or young person you have caring responsibilities for?

Answer Choices
My child
My sibling
My grandchild
My niece or nephew
My foster child
Other (please specify)

Q2. Please select the area of the Black Country that you live in

Answer Choices
Dudley
Wolverhampton
Sandwell
Walsall

Q3. What is your age?

Open text box

Q4. What is your ethnic group? Select one option to best describe your ethnic group or background

Answer Choices
English/Welsh/Scottish/Northern Irish/British
Irish
Gypsy or Irish traveller
White and Black Caribbean
White and Black African
Indian
Pakistani
Bangladeshi
Chinese
African

Caribbean
Arab
Other (please specify)

Q5.
Do you have caring responsibilities for another member of your family or household? Please select all that apply

Answer Choices
I care for an older parent or grandparent
I care for another child under 5
I care for another child over 5
I care for another member of my household or family with a disability
I have no other caring responsibilities

Q6. Please select all of the following statements which apply to the disabled child or young person you care for. My relative has …

Answer Choices
been diagnosed with a mild or moderate learning disability
been diagnosed with a severe learning disability (little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe, have difficulties with social skills, need life-long support)
been diagnosed with profound and multiple learning disabilities (profound intellectual and multiple disabilities, very severe communication problems, often extreme physical and/or sensory disabilities, and complex health needs)
a suspected learning disability (but no diagnosis)
been diagnosed with autism (including aspergers syndrome)
suspected autism (but no diagnosis)
a complex additional physical health condition
Other (please specify)

Information about your relative
The following questions relate to you relative that you care for.

Q7. How old is your relative?

Open text box

Q8. Is your relative

Answer Choices
Male
Female

Q9. How does your relative communicate? Select all that apply

Answer Choices
Verbally, using speech
Using own gestures or a signing system like Makaton
Using a picture system like Picture Exchange Communication or photobook
Using objects of reference (e.g., using a cup to indicate thirst or getting shoes if they want to go out)
Body language
Other (please specify)

Q10. Does your relative

Answer Choices
Live at home
Live away from home (please specify where in the box below)
Do a mixture of both (please specify where in the box below)
Please specify

Behaviour

This section relates to questions about your relative's behaviour.

Q11. Does your relative behave in ways that challenge you or others around them? (These behaviours might be things like hurting others, self-injury, destructive behaviours, eating inedible objects etc.)

Answer Choices
Never
Sometimes (e.g., every month or so)
Most weeks
Once or twice a week
Daily

Q12. Have you asked for and received support for your relative's behaviour?

Answer Choices
Yes, I asked for behaviour support and received it
I have asked for behaviour support but have not received it
I received behaviour support after being referred by professionals
No, I have not asked for, nor received behaviour support

Q13. Who did you receive behaviour support from? Select all that apply

Answer Choices
Portage
Nursery/school/college
GP
Specialist CAMHS-LD/Challenging behaviour team
Community learning disability team
Early Intervention Team working with and Early Help Plan
Paediatrician
Health Visitor
Social Communication Team
Autism West Midlands
Inclusion Support/Inclusion Support Early Years
Adoption Support Service
Local Family Carer Groups (e.g., Sandwell Parents Voices United, Triple P Positive Parenting)
Keyworker connection
Social worker
Inclusive Learning Services
Other (please specify)

Q14. How long did you have to wait to receive behavioural support most recently?

Answer Choices
Under a month
1-6 months
6 months to a year
1-2 years
2-3 years
Over 3 years

Q15. How happy were you with the support you received?

Answer Choices
Very happy
Happy
No strong feelings either way
Unhappy
Very unhappy

Q16. What tools and behaviour strategies do you use? Select all that apply

Answer Choices
None
A Positive Behaviour Support plan
A visual timetable
Putting in place a regular routine
Sensory play
Specialist communication tools like PECS
Other (please specify)

Q17. If you do not use any of these tools or approaches, can you tell us the main reasons why? Select all that apply

Answer Choices
They don't meet my relative's needs
I haven't been offered them
I don't know enough about them to understand how they might work for my relative
I am not confident in how to use them
Other (please specify)

Q18. What impact (in terms of physical or emotional difficulties) does your relative's behaviour have on them?

Answer Choices
Very negative impact
Negative impact
Some impact
No impact

Q19. What impact does your relative's behaviour have on your ability to access services in your community (such as school, leisure services, GP appointments)?

Answer Choices
Very negative impact
Negative impact
Some impact
No impact

Q20. How easy is it for you to access information on the following?

Not able to access at all	Information is hard to find	I can find some information	Information is fairly easy to find	There is a lot of information very easily accessible	Not relevant

Supporting a child or young person with learning disabilities
Supporting a child or young person with autism
Supporting a child or young person who displays challenging behaviour
Financial support for disabled children and young people and their family
Practical support for families of disabled children and young people
Keeping in touch with other families
Looking after my own needs as a carer
My rights and the rights of the child or young person I care for

Q21. If you have accessed information on the following, how would you rate its quality?

Very poor quality	Poor quality	Reasonable quality	Good quality	Very good quality	Not relevant

Supporting a child or young person with autism
Supporting a child or young person who displays challenging behaviour
Financial support for disabled children and young people and their family
Practical support for families of disabled children and young people
Keeping in touch with other families
Looking after my own needs as a carer
My rights and the rights of the child or young person I care for

Q22. How do you prefer to access information? Select all that apply

Answer Choices
Websites
Facebook
Printed materials/leaflets

Email
Over the phone
Face to face from other families
Face to face from professionals
Local Parent Support Groups
Other (please specify)

Q23. Does your relative (outside of the Covid-19 restrictions) attend a nursery, school, or college?

Answer Choices
Yes
We are awaiting a placement
We home educate
No

Q24. Which nursery, school or college does your relative attend? (this information will not be used to identify them)

Open text box

Q25. Does your relative's behaviour negatively impact their nursery, school, or college attendance?

Answer Choices
Yes
No

Q26. Select all of the following that have been barriers to your relative's attendance, or include any additional barriers

Answer Choices
Reduced timetable offered by the nursery/school/college
Lack of suitable transport
Exclusion from school transport
Exclusion from nursery/school/college
Awaiting placement
Home-schooling due to lack of an appropriate placement
Lack of reasonable adjustments by the school/nursery/college in response to my relative's needs
Fear or anxiety around attending nursery/school/college
Other (please specify)

Q27. How well do you think the nursery, school or college supports your relative's behaviour?

Answer Choices
Very well
Quite well
No strong feelings either way
Less well than hoped
Not well at all

Q28. How well does the nursery, school or college listen to and work with you as a carer to address your relative's behaviour?

Answer Choices
Very well
Quite well
No strong feelings either way
Less well than hoped
Not well at all

Q29. If you responded 'Less well than hoped' or 'Not well at all' for either of the two previous questions, please explain how your relative's nursey, school or college could work with you more effectively to address their behaviour

Open text box

Q30. As a carer, have you contributed suggestions for developing and improving your relative's nursery, school, or college services?

Answer Choices
Yes
No

Q31. How have you contributed to developing and improving your relative's nursery, school, or college services? Select all that apply or add any other methods

Answer Choices
Engaging in discussion with professionals
Being involved in steering groups or advisory groups
Being involved in focus groups

Completing surveys
Other (please specify)

Q32. As a carer, have you contributed suggestions for developing and improving your relative's health care services?

Answer Choices
Yes
No

Q33. How have you contributed to developing and improving your relative's health care services? Select all that apply or add any other methods

Answer Choices
Engaging in discussion with professionals
Being involved in steering groups or advisory groups
Being involved in focus groups
Completing surveys
Other (please specify)

Q34. As a carer, have you contributed suggestions for developing and improving your relative's social care services?

Answer Choices
Yes
No

Q35. How have you contributed to developing and improving your relative's social care services? Select all that apply or add any other methods

Answer Choices
Engaging in discussion with professionals
Being involved in steering groups or advisory groups
Being involved in focus groups
Completing surveys
Other (please specify)

Services in the Black Country

The questions in this section are about specific services within the Black Country.

Q36. Have you heard of the SEND Local Offer?

Answer Choices
Yes
No

Q37. Have you browsed the SEND Local Offer website?

Answer Choices
Yes
No

Q38. How useful do you find the information offered by the SEND Local Offer?

Answer Choices
Extremely useful
Very useful
Somewhat useful
Not so useful
Not at all useful
Add any additional comments here.

Q39. Have you heard of the Inclusive Learning Service?

Answer Choices
Yes
No

Q40. Have you used the services of the Inclusive Learning Service?

Answer Choices
Yes
No

Q41. How useful do you find support offered by the Inclusive Learning Service?

Answer Choices
Extremely useful
Very useful
Somewhat useful
Not so useful
Not at all useful
Add any additional comments here.

Q42. Have you heard of the Child and Adolescent Mental Health Service (CAMHS) or the Child and Adolescent Mental Health Service for children and young people with Learning Disabilities (CAMHS-LD)?

Answer Choices
Yes
No

Q43. Have you used the services of CAMHS or CAMHS-LD?

Answer Choices
Yes
No

Q44. How useful do you find the support offered by CAMHS or CAMHS-LD?

Answer Choices
Extremely useful
Very useful
Somewhat useful
Not so useful
Not at all useful

Q45. Have you heard of the Disabled Children's Team?

Answer Choices
Yes
No

Q46. Have you used the services of the Disabled Children's Team?

Answer Choices
Yes
No

Q47. How useful do you find the support offered by the Disabled Children's Team?

Answer Choices
Extremely useful
Very useful
Somewhat useful
Not so useful

Not at all useful
Add any additional comments here.

Q48. What would improve these services (SEND Local Offer, Inclusive Learning Service, CAMHS, CAMHS-LD, Disabled Children's Team) to support you better in the future?

Open text box

Q49. Have you heard of local Parent Support Groups (e.g., Sandwell Parent's Voices United, Triple P Positive Parenting)?

Answer Choices
Yes
No

Q50. Have you joined a local Parent's Support Group, or used any of their services or support?

Answer Choices
Yes
No

Q51. How useful do you find the services and support provided by local Parent Support Groups?

Answer Choices
Extremely useful
Very useful
Somewhat useful
Not so useful
Not at all useful
Add any additional comments here.

Q52. How connected do you feel to the local Parent Support Groups?

Answer Choices
Very connected
Quite connected
Somewhat connected
Somewhat isolated
Quite isolated
Very isolated

Q53. What changes, if any, could be made to help you feel more connected to other family carers in your community?

Open text box

Transition

These questions are about your relative's transition from child to adult services.

Q54. Please select the age bracket that your relative comes under

Answer Choices
Under 13
13-17
18-25

Q55. How easy is it for you to access information and support on your relative's transition within the following areas?

Not able to access at all	Information is hard to find	Some information is fairly easy to find	There is a lot of information very easily accessible	Not relevant

Transition from child to adult social care

Transition from child to specialist health services (learning disability or mental health)

Transition within education and training beyond school

Transition from returning from an out of area residential placement

Q56. If you are supported by a professional regarding your relative's transition, how would you rate the quality of this support for each of the following areas?

Very poor quality	Poor quality	Reasonable quality	Good quality	Very good quality	Not relevant

Transition from child to adult social care

Transition from child to specialist health services (learning disability or mental health)

Transition within education and training beyond school

Transition from returning from an out of area residential placement

Q57. How well informed and supported do you feel about your relative's transition to the next stage of services?

Very well informed	Somewhat informed	Neither informed nor uninformed	Somewhat unprepared	Very unprepared	Not relevant

Transition from child to adult social care
Transition from child to specialist health services (learning disability or mental health)
Transition within education and training beyond school
Transition from returning from an out of area residential placement

Q58. If you indicated feeling unprepared in the previous question, please describe any specific worries you have regarding your relative's transition

Open text box

Q59. What would help reduce this anxiety or any worries about relevant services? Please select all that apply, or include any additional answers

Answer Choices
Access to better information
Access to better information
Agreements on funding for my relative's transition
Planning well in advance of my relative's transition
Better communication with relevant services
Add any additional answers here.

Q60. Please think back to when your relative was transitioning from child to adult services. How easy was it for you to access information and support on your relative's transition within the following areas?

Not able to access at all	Information was hard to find	Some information was fairly easy to find	There was a lot of information very easily accessible	Not relevant

Transition from child to adult social care
Transition from child to specialist health services (learning disability or mental health)

Transition within education and training beyond school
Transition from returning from an out of area residential placement

Q61. If you were supported by a professional regarding your relative's transition, how would you rate the quality of this support for each of the following areas?

Very poor quality	Poor quality	Reasonable quality	Good quality	Very good quality	Not relevant

Transition from child to adult social care
Transition from child to specialist health services (learning disability or mental health)
Transition within education and training beyond school
Transition from returning from an out of area residential placement

Q62. How well informed and supported did you feel about your relative's transition to the next stage of services?

Very well informed	Somewhat informed	Neither informed nor uninformed	Somewhat unprepared	Very unprepared	Not relevant

Transition from child to adult social care
Transition from child to specialist health services (learning disability or mental health)
Transition within education and training beyond school
Transition from returning from an out of area residential placement

Q63. If you indicated feeling unprepared in the previous question, please describe any specific worries you have regarding your relative's transition

Open text box

Q64. What would have helped reduce this anxiety or any worries about relevant services? Please select all that apply, or include
any additional answers

Answer Choices
Support from a keyworker
Access to better information
Agreements on funding for my relative's transition
Planning well in advance of my relative's transition

Better communication with the relevant services
Add any additional answers here.

Secondary trauma

Trauma can be defined as a response to a situation (single or ongoing) where a person feels that he/she or someone they love is in a situation that is dangerous (physically or emotionally). As a result, the person feels helpless or overwhelmed and the world no longer feels like a safe place. They may continue to find it harder to trust people, feel permanently on edge or anxious, it may be more difficult to concentrate or sleep, and they may have less patience on a daily basis.

We recognise that experiences of services and support can vary greatly and that some family carers may relive difficult experiences whilst completing the survey. If you would like to discuss any concerns as a result of completing the survey please visit: https://www.blackcountryhealthcare.nhs.uk/contact-us/help-crisis for details on support in the Black Country.

Alternatively, you can contact the Challenging Behaviour Foundation's Family Support Team on: 0300 666 0126 or email on support@thecbf.org.uk if your relative has a severe learning disability.

If you are worried about the safety of someone with a learning disability, you can visit https://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/ for more information

Q65. Please select this box if you DO NOT want to answer questions related to trauma

Answer Choices
I would like to skip this section

Information about your relative

The questions in this section relate to the relative that you care for.

Q66. Has your relative experienced any events that they felt was traumatic? (e.g., restraint, seclusion, abuse, separation from family etc.)

Answer Choices
Yes
No
Unsure

Q67. Has your relative experienced any events that they felt was traumatic? (e.g., restraint, seclusion, abuse, separation from family etc.)

Yes	Unsure

Mainstream trauma e.g., life threatening illness
Loss of familiar routines, environment, people
Out of area placement
Sharing living space with unfamiliar people who may be in crisis i.e., an ATU, respite/short breaks service, school, or other educational setting
Subject to 'rules' which may not be understood (e.g., not allowed access to preferred items/activities)
Physical restraint
Mechanical restraint i.e., being strapped in a chair/wheelchair
Chemical restraint i.e., PRN/antipsychotics/psychotropics
Seclusion i.e., being separated from any other people and prevented from leaving either by a lock or supervision
Physical abuse
Sexual abuse
Psychological abuse i.e., your loved one being lied to, or their anxieties and fears being used as a means of control
Not getting support care needs met easily in a timely manner
Not getting health needs met easily in a timely manner

Information about you

The questions in this section relate to you, as a carer.

Q68. What impact did the event(s) (indicated in the previous question) have on you as a carer?

Regularly	Sometimes	Intermittently	Once	Never

Panic attacks
Insomnia/disturbed sleep pattern
Unable to work/job loss
Disagreement with friends/family members
Family members leaving home
Relationship breakdown
Depression
Anxiety and fearfulness
Personality change (i.e., difficulty trusting others)

Guilt
If you experience any symptoms not mentioned here, please feel free to write them in this space

Q69. Please identify all forms of trauma support, if any, that have been offered to you by professionals

Open text box

Q70. If no trauma support was offered to you by professionals, please identify all forms of support, if any, that you sought out

Open text box

Q71. If you were offered support or sought support yourself but did not access it, please identify the reasons why. Please select all that apply

Answer Choices
Time commitment not possible
Waiting list too long
Sessions offered were not at appropriate times
Support too far away/not accessible
Fees
Inappropriate support type offered
Other (please specify)

Q72. Of the trauma support that you received (either offered to you, or that you sought out yourself); was there any professional individual, group, or organisation that you felt understood your experience and were useful in helping to support you? If so, please indicate which professional individual, group or organisation that was

Open text box

Q73. How helpful was the trauma support you received? (Either offered to you, or that you sought out yourself)

Answer Choices
Very helpful
Helpful
No change
Not helpful
Detrimental

Add any additional comments here

Q74. What existing trauma support are you aware of that is available to family carers in the Black Country?

Open text box

Q75. Based on your experience, what could be improved about the existing trauma support for the families of people with learning disabilities and/or autism in the Black Country. Please provide details

Open text box

Getting it Right in the Black Country.

Thank you.

Thank you for taking the time to complete this survey. Your information will be kept anonymous but if you would like to leave your details below, you can choose to stay in touch with out project and enter our prize draw to win a £50 Amazon voucher.

Your responses will inform a project called “Getting it Right” led by family-led UK charity The Challenging Behaviour Foundation (CBF) in collaboration with Black Country NHS Healthcare Trust. Once the report is published, you will be able to find it here: https://challengingbehaviour.org.uk/what-we-do/projects-and-research/support-and-services/getting-it-right/

If you have any questions, please contact the Challenging Behaviour Foundation on: 01634 838739, or email on info@thecbf.org.uk.

We recognise that experiences of services and support can vary greatly and that some family carers may relive difficult experiences whilst completing the survey. If you would like to discuss any concerns as a result of completing the survey please visit: https://www.blackcountryhealthcare.nhs.uk/contact-us/help-crisis for details on support in the Black Country.

Alternatively, you can contact the Challenging Behaviour Foundation's Family Support Team on: 0300 666 0126 or email on support@thecbf.org.uk if your relative has a severe learning disability.

If you are worried about the safety of someone with a learning disability, you can visit https://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/ for more information

Please click 'Done' at the bottom, to ensure your response is recorded.

Q76. To enter our prize draw to win a £50 Amazon voucher, please enter your name and email address

Answer Choices
Name
Email address

Appendix 2 - Getting it Right in the Black Country logic model

Logic model- Getting It Right in the Black Country 2021- 2022

CONTEXT: In Black Country, existing services need to be strengthened and the offer to families broadened. A particular need for improvements in support and services for the transition age group has been identified.

The CBF have experience and knowledge of supporting local authorities and CCGs and linking health with social care, education and employment.

AIMS AND OBJECTIVES: Children and young people *(with a focus on the transition age group 14-25*) with severe learning disabilities at risk of behaviours that challenge will receive the right support, in the right place and at the right time, from well informed professionals and staff so they can live a happier and more inclusive life in their community.

(In this logic model 'Families' refers to families of children and young people with severe learning disabilities whose behaviour challenges.)

INPUTS	PROCESSES	OUTPUTS	OUTCOMES
Specific project inputs National Lottery Community Funding Getting It Right project time from staff at CBF and Black Country Children and Young People's Policy lead at the CBF Policy Officer at the CBF Black Country steering group Black Country project lead? Black Country Family-Carer lead Independent evaluation Existing service provision in Black Country - Summary (refer to Keyworker's scoping of services): Keyworker pilot Short breaks (varied across localities) Adult CLD team Existing adult IST and developing child IST CAMHs TC focus on autistic children	Getting It Right steering group meetings To inform delivery plan: 1 x family carer focus group Black Country stakeholder (professionals and family carers) event Online survey of family carers about their needs and service provision, with a focus on transition support, in BC. CBF write up findings in report and co-produce delivery plan with Black Country. To develop families' skills and confidence in PBS: 2 sets of 2 positive behaviour support workshops with follow-up drop-in	Co-produced plan for sustainable improvements in support (including for transition age group) in Black Country Provision of specialist training and sharing of best practice with families, professionals, and commissioners in Black Country. New self-sustaining networks established to support families, informed by focus groups/survey. Families have opportunities to share their experiences/ be listened to by services and each other. Presentation on project findings by BC colleagues at Challenging Behaviour - National Strategy Group Meeting.	KEY OUTCOME: **Families feel more connected, confident and able to contribute.** **Confident**: Families have the knowledge and confidence to use PBS techniques to understand and respond appropriately to challenging behaviour. Families who have been on PBS workshops find a reduction in the prevalence/ severity of challenging behaviour and positive changes to the whole family dynamic. **Connected**: Families feel well informed about useful services and support in Black Country and know how to access them. Families feel less isolated and better connected to local support networks. **Able to contribute**: Families are routinely involved as valued co-producers in developing and improving services and support. Professionals learn from families (through this project and beyond) and use learning to strengthen support and services they are offering. **Trauma:** Local professionals/ leaders understand prevalence of secondary trauma amongst family carers Local professionals/ leaders have a good knowledge base around provision of existing services and support for families with secondary trauma **Transition:** Local professionals understand gaps and barriers in current provision in support and services around transition.

Appendix 3 – Survey response information

Table 1 – Demographic response information

All respondents

	Number of respondents
What is your relationship to the child or young person you have caring responsibilities for?	
My child	56
My sibling	1
My grandchild	1
My niece or nephew	0
My foster child	2
Other	1
Other responses include: "Special Guardian and Grandparent"	
Total respondents	**61**
Please select the area of the Black Country that you live in	
Dudley	18
Wolverhampton	25
Sandwell	6
Walsall	13
Total respondents	**62**
Age of participants	
0-19 *	6
20-29	0
30-39	19
40-49	23
50-59	6
60-69	2
Total respondents	**56**
What is your ethnic group? Select one option to best describe your ethnic group or background	
English/Welsh/Scottish/Northern Irish/British	45
Irish	0
Gypsy or Irish traveller	0

White and Black Caribbean	1
White and Black African	1
Indian	3
Pakistani	6
Bangladeshi	1
Chinese	1
African	2
Caribbean	0
Arab	0
Other	1
Other responses include: “Other”	
Total respondents	**61**
Do you have caring responsibilities for another member of your family or household? Please select all that apply	
I care for an older parent or grandparent	6
I care for another child under 5	9
I care for another child over 5	24
I care for another member of my household or family with a disability	12
I have no other caring responsibilities	17
Total respondents	**59**
Please select all of the following statement which apply to the disabled child or young person you care for. My relative has …	
Been diagnosed with a mild or moderate learning disability	18
Been diagnosed with a severe learning disability (little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe, have difficulties with social skills, need life-long support)	22
Been diagnosed with profound and multiple learning disabilities (profound intellectual and multiple disabilities, very severe communication problems, often extreme physical and/or sensory disabilities, and complex health needs)	9
A suspected learning disability (but no diagnosis)	1

Been diagnosed with autism (including aspergers syndrome)	33
Suspected autism (but no diagnosis)	9
A complex additional physical health condition	6
Other (please specify)	11
Other responses include: “Pda. Asd.adhd.”, “Hyper active, challenging behaviour,, no sense of danger,, runner.”, “ADHD”, “Adhd hearing loss”, “Cromes deletion”, “Harlequin Ichthyosis”, “ADHD”, “Complex needs”, “Adhd”, “Suspect ADHD no diagnosis”, “Brain abnormality, partial sight”	
Total respondents	**58**
Age of relative	
0-4	3
5-9	18
10-14	27
15-19	10
20-24	2
Total respondents	**54**
Relative’s gender	
Male	42
Female	12
Total respondents	**54**
How does your relative communicate? Select all that apply	
Verbally, using speech	40
Using own gestures or a signing system like Makaton	8
Using a picture system like Picture Exchange Communication or photobook	13
Using objects of reference (e.g., using a cup to indicate thirst or getting shoes if they want to go out)	10
Body language	18

Other (please specify)	9
Other responses include: “Grid player”, “Few words and pulling and pushing towards things”, “None”, “Written via text/messenger”, “Some single words”, “No”, “Uses a Little bit of everything to form 3 words”, “Facial expression. Noises.”, “Two or three word sentences”	
Total respondents	**57**
Does your relative…	
Live at home	53
Live away from home	1
Do a mixture of both	0
Please specify	2
Other responses include: “Residential school”, “No”	
Total respondents	**55**

* These figures were excluded from the average age calculation as it is presumed participants input their relative’s age

Table 2 – Behaviour response information

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
Does your relative behave in ways that challenge you or others around them?		
Never	0	6
Sometimes (e.g., every month or so)	2	5
Most weeks	0	2
Once or twice a week	4	3
Daily	17	16
Total respondents	**23**	**32**
Have you asked for and received support for your relative's behaviour?		
Yes, I asked for behaviour support and received it	8	6
I have asked for behaviour support but have not received it	7	12
I received behaviour support after being referred by professionals	4	2
No, I have not asked for, nor received behaviour support	3	4
Total respondents	**22**	**24**
Who did you receive behaviour support from? Select all that apply		
Portage	0	0
Nursery/school/college	4	1
GP	0	1
Specialist CAMHS-LD/Challenging behaviour team	8	5
Community learning disability team	1	0
Early Intervention Team working with and Early Help Plan	1	1
Paediatrician	4	1
Health Visitor	0	1
Social Communication Team	0	0
Autism West Midlands	1	0

Inclusion Support/Inclusion Support Early Years	1	0
Adoption Support Service	0	0
Local Family Carer Groups (e.g., Sandwell Parents Voices United, Triple P Positive Parenting)	0	0
Keyworker connection	1	0
Social worker	4	1
Inclusive Learning Services	1	0
Other	1	1
Other responses include:	"PEGS"	"CAMHS non-learning difficulties",
Total respondents	**11**	**8**
How long did you have to wait to receive behavioural support most recently?		
Under a month	2	2
1-6 months	5	4
6 months to a year	2	1
1-2 years	1	1
2-3 years	0	0
Over 3 years	1	0
Total respondents	**11**	**8**
How happy were you with the support you received?		
Very happy	1	1
Happy	5	1
No strong feelings either way	2	5
Unhappy	3	0
Very unhappy	0	0
Total respondents	**11**	**7**
What tools and behaviour strategies do you use? Select all that apply		
None	2	2
A Positive Behaviour Support Plan	5	7
A visual timetable	11	13
Putting in place a regular routine	15	18
Sensory play	11	12

Specialist communication tools like PECS	4	1
Other (please specify)	3	6
Other responses include:	“Nothing set as yet”, “Sensory snacks, reinforcing speech with makaton to help aid communication”, “Sensory ladder”,	“Rewards/Treats”, “Triple P, rewards and sanctions” “Water strategies”, “Communication”, “Base 23”, “Lots of talking about what will happen. Answering questions. Usually this is repeated continuously”,
Total respondents	**21**	**24**
If you do not use any of these approaches, can you tell us the main reasons why? Select all that apply		
They don’t meet my relative’s needs	0	0
I haven’t been offered them	2	1
I don’t know enough about them to understand how they might work for my relative	1	3
I am not confident in how to use them	1	5
Other	0	2
Other responses include:		“I don’t now” “You have not told me the techniques”
Total respondents	**2**	**8**
What impact (in terms of physical or emotional difficulties) does your relative’s behaviour have on them?		
Very negative impact	5	6

Negative impact	11	9
Some impact	3	7
No impact	0	3
Total respondents	**19**	**25**
What impact does your relative’s behaviour have on your ability to access services in your community (such as school, leisure services, GP appointments)?		
Very negative impact	8	4
Negative impact	8	4
Some impact	2	9
No impact	0	8
Total respondents	**18**	**25**

How easy is it for you to access information on the following?														
	Not able to access at all		Information is hard to find		I can find some information		Information is fairly easy to find		There is a lot of information very easily accessible		Not relevant		**Total**	
	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	**SLD/ PMLD**	**Non-SLD/ PMLD**
Supporting a child or young person with learning disabilities	2	3	5	10	8	6	3	0	0	2	1	3	**19**	**21**
Supporting a child or young person with autism	4	3	2	4	11	10	1	0	1	1	0	4	**19**	**19**
Supporting a child or young person who displays	5	3	3	10	9	6	1	0	1	1	0	2	**19**	**19**

challenging behaviour														
Financial support for disabled children and young people and their family	3	0	4	10	9	6	2	0	0	1	1	4	**19**	**21**
Practical support for families of disabled children and young people	5	6	8	11	6	3	0	0	0	2	0	3	**19**	**19**
Keeping in touch with other families	3	1	6	8	9	7	1	0	0	2	0	4	**19**	**21**
Looking after my own needs as a carer	6	3	8	12	4	5	1	0	0	1	0	2	**19**	**20**

My rights and the rights of the child or young person I care for	2	0	9	14	7	8	0	0	0	1	0	1	**18**	**24**
If you have accessed information on the following, how would you rate its quality?														
	Very poor quality		Poor quality		Reasonable quality		Good quality		Very good quality		Not relevant		**Total**	
	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	**SLD/ PMLD**	**Non-SLD/ PMLD**
Supporting a child or young person with learning disabilities	3	4	4	6	8	8	1	1	0	0	3	5	**19**	**24**
Supporting a child or young person with autism	4	4	4	2	7	10	2	1	0	0	2	7	**19**	**24**

Supporting a child or young person who displays challenging behaviour	5	4	5	9	7	6	0	1	0	0	2	3	**19**	**23**
Financial support for disabled children and young people and their family	3	2	4	6	5	9	4	2	0	0	3	5	**19**	**24**
Practical support for families of disabled children and young people	4	5	7	8	4	6	2	1	0	0	1	4	**18**	**24**
Keeping in touch with	3	1	5	5	8	8	2	2	0	0	1	7	**19**	**23**

other families													
Looking after my own needs as a carer	6	5	6	8	2	4	2	1	0	0	3	5	**19**	**23**
My rights and the rights of the child or young person I care for	6	4	7	5	4	9	1	1	0	0	1	4	**19**	**23**

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
How do you prefer to access information? Select all that apply		
Websites	16	21
Facebook	8	14
Printed materials/leaflets	7	13
Email	10	14
Over the phone	8	8
Face to face from other families	9	9
Face to face from professionals	9	14
Local Parent Support Groups	8	6
Other	0	1
Other responses include:		"Parent carer forums"
Total respondents	**19**	**24**
Does your relative (outside of Covid-19 restrictions) attend a nursery, school or college?		
Yes	19	24
We are awaiting a placement	0	0
We home educate	0	0
No	0	1
Total respondents	**19**	**25**
Does your relative's behaviour negatively impact their nursery, school or college attendance?		
Yes	9	10
No	10	14
Total respondents	**19**	**24**
Select all of the following that have been barriers to your relative's attendance, or include any additional barriers		
Reduced timetable offered by nursery/school/college	3	4
Lack of suitable transport	3	2
Exclusion from school transport	1	2
Exclusion from nursery/school/college	1	3
Awaiting placement	0	0

Home-schooling due to lack of an appropriate placement	0	1
Lack of reasonable adjustments by the school/nursery/college in response to my relative’s needs	3	3
Fear or anxiety around attending nursery/school/college	6	9
Other	0	2
Other responses include:		“Now in an appropriate school but had to fight and a lack of support from education in getting the right placement previously”, “Anxiety resulted in panic attacks. Reduced timetable has actually helped us access education more effectively”
Total respondents	**7**	**10**
How well do you think the nursery, school or college supports your relative’s behaviour?		
Very well	7	8
Quite well	6	7
No strong feelings either way	4	4
Less well than hoped	1	3
Not well at all	0	2
Total respondents	**18**	**24**
How well does the nursery, school or college listen to and work with you as a carer to address your relative’s behaviour		
Very well	8	7

Quite well	4	9
No strong feelings either way	3	3
Less well than hoped	3	2
Not well at all	0	3
Total respondents	**18**	**24**
If you responded ‘Less well than hoped’ or ‘Not well at all’ for either of the two previous questions, please explain how your relative’s nursery, school or college could work with you more effectively to address their behaviour		
Responses included:	“strategies are not supported across settings. too many mixed messages/boundaries”, “Not all staff understand my sons disability”, “He’s not getting right help according to his needs.”, “I don’t get told about how my kids have coped in school only get told the negative of they have been naughty”, “I feel the school doesn’t listen to me”	“Would be better to sit down with them to discuss triggers, what does ot not work, has been better since moving from mainstream to specialist but still issues arise”, “They could listen”, “Send us emails letters tell us who my child’s learning coach is. Answer emails I have sent”, “Adhere to EHCP”, “They put him in isolation which he loves”, “More communication with me , less relaxed with his behaviour, more support with my son”

		“I have attached private diagnosis and because the school very rarely see this behaviour they are pinning it all on me”, “Now in the right placement this is all ok. Previously in mainstream school they did not put in place adjustments that met his needs unless pushed to or demanded everything has been fought for”,
Total respondents	**5**	**8**
As a carer, have you contributed suggestions for developing and improving your relative’s nursery, school or college services?		
Yes	13	12
No	5	12
Total respondents	**18**	**24**
How have you contributed to developing and improving your relative’s nursery, school or college services? Select all that apply or add any other methods		
Engaging in discussion with professionals	10	11
Being involved in steering groups or advisory groups	4	5
Being involved in focus groups	1	3
Completing surveys	8	4
Other	2	2
Other responses include:	“Spoke to the manager”,	“Parent led EHCP”,

	“Na”	“Contacted sendiass”,
Total respondents	**13**	**12**
As a carer, have you contributed suggestions for developing and improving your relative’s health care services?		
Yes	9	8
No	9	17
Total respondents	**18**	**25**
How have you contributed to developing and improving your relative’s health care services? Select all that apply or add any other methods		
Engaging in discussion with professionals	9	8
Being involved in steering groups or advisory groups	6	3
Being involved in focus groups	1	1
Completing surveys	6	4
Other	1	0
Other responses include:	“Working with school to devise coping strategies”	
Total respondents	**9**	**8**
As a carer, have you contributed suggestions for developing and improving your relative’s social care services?		
Yes	7	8
No	11	16
Total respondents	**18**	**24**
How have you contributed to developing and improving your relative’s health care services? Select all that apply or add any other methods		
Engaging in discussion with professionals	7	6
Being involved in steering groups or advisory groups	4	1
Being involved in focus groups	3	1
Completing surveys	4	4
Other	0	0
Total respondents	**7**	**7**

Table 3 – Services in the Black Country response information

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
Have you heard of the SEND Local Offer?		
Yes	11	12
No	7	12
Total respondents	**18**	**24**
Have you browsed the SEND Local Offer website?		
Yes	8	6
No	3	7
Total respondents	**11**	**13**
How useful do you find the information offered by the SEND Local Offer		
Extremely useful	0	0
Very useful	0	0
Somewhat useful	4	4
Not so useful	2	1
Not at all useful	2	0
Any additional comments	0	1
Other responses include:		“Difficult to find information on it. Info isn’t in there.”
Total respondents	**8**	**5**
Have you heard of the Inclusive Learning Service?		
Yes	0	2
No	18	22
Total respondents	**18**	**24**
Have you used the services of the Inclusive Learning Service?		
Yes	0	1
No	0	1
Total respondents	**0**	**2**
How useful do you find the support offered by the Inclusive Learning Service?		
Extremely useful	0	1
Very useful	0	0

Somewhat useful	0	0
Not so useful	0	0
Not at all useful	0	0
Any additional comments	0	0
Total respondents	**0**	**1**

		Number of SLD/PMLD respondents	Number of non- SLD/PMLD respondents
Have you heard of the Child and Adolescent Mental Health Service (CAMHS) or the Child and Adolescent Mental Health Service for children and young people with Learning Disabilities (CAMHS-LD)?			
Dudley	Yes	5	4
	No	0	0
Wolverhampton	Yes	9	8
	No	2	2
Sandwell	Yes	1	4
	No	0	0
Walsall	Yes	1	5
	No	0	1
Total respondents		**18**	**24**
Have you used the services of CAMHS or CAMHS-LD?			
Dudley	Yes	4	3
	No	1	2
Wolverhampton	Yes	7	5
	No	2	3
Sandwell	Yes	1	3
	No	0	1
Walsall	Yes	1	5
	No	0	0
Total respondents		**16**	**21**
How useful do you find the support offered by CAMHS or CAMHS-LD?			
Dudley	Extremely useful	1	0
	Very useful	2	0

	Somewhat useful	1	1
	Not so useful	0	1
	Not at all useful	0	1
Wolverhampton	Extremely useful	1	0
	Very useful	3	1
	Somewhat useful	1	2
	Not so useful	2	1
	Not at all useful	0	1
Sandwell	Extremely useful	0	0
	Very useful	0	0
	Somewhat useful	0	0
	Not so useful	1	2
	Not at all useful	0	1
Walsall	Extremely useful	0	3
	Very useful	0	1
	Somewhat useful	1	1
	Not so useful	0	0
	Not at all useful	0	0
Total respondents		**13**	**16**
Have you heard of the Disabled Children’s Team?			
Dudley	Yes	4	4
	No	1	0
Wolverhampton	Yes	7	4
	No	4	6
Sandwell	Yes	1	1
	No	0	3

Walsall	Yes	1	3
	No	0	3
Total respondents		**18**	**24**
Have you used the services of the Disabled Children's Team?			
Dudley	Yes	3	2
	No	1	2
Wolverhampton	Yes	5	1
	No	2	3
Sandwell	Yes	1	0
	No	0	1
Walsall	Yes	1	1
	No	0	2
Total respondents		**13**	**12**
How useful do you find the support offered by the Disabled Children's Team?			
Dudley	Extremely useful	0	0
	Very useful	1	0
	Somewhat useful	2	1
	Not so useful	0	0
	Not at all useful	0	1
Wolverhampton	Extremely useful	1	0
	Very useful	0	0
	Somewhat useful	2	0
	Not so useful	1	0
	Not at all useful	1	1
	Additional comments:	"they are not supportive, they just put up blocks to support"	

		"Not much support constantly changing the person who is supposed to help. Mixing up information of my children."	
Sandwell	Extremely useful	0	0
	Very useful	0	0
	Somewhat useful	0	0
	Not so useful	0	0
	Not at all useful	1	0
Walsall	Extremely useful	0	0
	Very useful	0	0
	Somewhat useful	0	1
	Not so useful	0	0
	Not at all useful	1	0
	Additional comments:	"They just talk and never do as they say."	
Total respondents		**10**	**4**

SLD/PMLD respondents	Non-SLD/PMLD respondents
What would improve these services (SEND Local Offer, Inclusive Learning Service, CAMHS, CAMHS-LD, Disabled Children’s Team) to support you better in the future?	
“Information about groups via email” “clearer personalised targets strategies to meet targets reviews of strategies more regular input one person allocated to help support carer to tie all the services together. too much chasing up of professionals. nothing happens until u hit crisis and it takes months even after that.” “Listen to parents/carers the first time , tell it once, be supported from the beginning, prevention of family breakdowns and acting when families reach out for support and not after they have a breakdown , stop parent blaming , stop breaking the law …" “More relevant information” “Information” “Trying to keep one person we have dealt with 5 different people over the last 4 years.” Actually have an appointment” “Access to them!!” “More personalised social care plan and more productive reviews.” “That services are linked up and with better resources to respond in a timely fashion. Long wait times for support”	“To be more accessible” “They need to listen to parents my son is self harming and harming others due to anxiety and difficulties and they are still ignoring him.” “Offer services that support us as a family. Diagnosis given and then left with very little help or flexibility in what was offered. Reduce waiting times for services and provide services for children with autism as there are none unless they have co morbid mental health issues. Gap in service where these children are failed with sensory issues eating issues as some examples. Help with behaviour and managing access to social care.” “A key worker across all services. To be listened to. Not to keep repeating our journey Appropriate leisure Asc accessible services and leisure” “More information and handling about challenging behaviour children” “Information” “more interaction. More information” “They free session center in holiday”

"To be more accessible. To be more understanding and have more empathy for parents." "Cut the long waiting list when children need the services, providing more professional in local area, listening to the parents first because they know their children best." "Things need to move faster when people ask for help. Parents only come for help when they have reached crisis. Then everything takes too long" "Listening to parents the first time rather then years later." "Better communication"	"The waiting for assessments be shorter time" "Finding a way to reduce waiting times for diagnosis of neurological disorders such as ASD, ADHD, ADD etc" "More information about services and how to access them" "Cahms said they couldn't find the right service to help my son so did nothing" "Better access when having issues, more practical support as appears to be medication focussed" "More help around autism" "Shorter waiting lists for families. More sessions" "Applied for support and not been offered anything as we don't have a diagnosis" "Stop affirming girls with ASD as boys help them to feel comfortable 8n their own bodies" "Supporting children for longer not discharging them so fast"
Total respondents: 15	**Total respondents: 17**

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
Have you heard of local Parent Support Groups (e.g., Sandwell Parent's Voices United, Triple P Positive Parenting)?		
Yes	11	9
No	7	15
Total respondents	**18**	**24**
Have you joined a local Parent's Support Group, or used any of their services or support?		
Yes	11	7
No	0	2
Total respondents	**11**	**9**
How useful do you find the services and support provided by local Parent Support Groups?		
Extremely useful	2	3
Very useful	3	1
Somewhat useful	7	2
Not so useful	1	1
Not at all useful	0	0
Any additional comments here	0	0
Total respondents	**11**	**7**
How connected do you feel to the local Parent Support Groups?		
Very connected	3	2
Quite connected	1	3
Somewhat connected	4	4
Somewhat isolated	6	2
Quite isolated	0	3
Very isolated	4	8
Total respondents	**18**	**22**

SLD/PMLD respondents	Non-SLD/PMLD respondents
What changes, if any, could be made to help you feel more connected to other family carers in your community?	
"Career meetings where we can discuss about our special needs kids needs" "more cultural diversity" "A broader range of activities offered, also at times that do not clash with work time." "More awareness of where to go who to see" "Maybe a virtual groups, Facebook groups etc" "Support by other language too(Punjabi) to understand things more clearly" "Instead of specific times have an open timetable" "Not just seating and listening to what they have to say, give parents chance to speak up, change their ideas in different area where they struggle ask questions, how to improve the quality of care of their love one without feeling a lone." "Don't the group" "More support groups and communication"	"Better advertising. More localised meet ups" "More knowledge of local groups available to me" "When child is diagnosed to be given information about groups local to home" "Group in my area as disabled my self don't go out cause there group are not local to me" "More parent/ caret activities, local meet ups,etc." "Meet ups face to face listening ear/befriending service" "We requested training in autism and never received" "More information" "Nothing" "Yes plz 8f could get through"
Total respondents: 10	**Total respondents: 10**

Table 4 – Transition response information

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
Please select the age bracket that your relative comes under		
Under 13	14	16
13-17	4	8
18-25	0	0
Total respondents	**18**	**24**

How easy is it for you to access information and support on your relative's transition within the following areas?								
	Transition from child to adult social care		Transition from child to specialist health services (learning disability or mental health)		Transition within education and training beyond school		Transition from returning from an out of area placement	
	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD
Not able to access at all	2	2	2	3	1	3	1	2
Information is hard to find	2	3	1	2	2	2	1	1
Some information is fairly easy to find	0	0	1	0	1	0	1	0
There is a lot of information very easily accessible	0	0	0	0	0	1	0	0
Not relevant	0	1	0	1	0	0	1	3
Total respondents	**4**	**6**	**4**	**6**	**4**	**6**	**4**	**6**

If you are supported by a professional regarding your relative’s transition, how would you rate the quality of this support for each of the following areas?

	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD
Very poor quality	0	0	0	1	1	1	0	0
Poor quality	0	1	1	0	1	1	0	0
Reasonable quality	1	0	2	1	1	1	1	1
Good quality	0	0	0	0	0	0	0	0
Very good quality	0	0	0	0	0	0	0	0
Not relevant	3	6	1	5	1	4	3	6
Total respondents	**4**	**7**	**4**	**7**	**4**	**7**	**4**	**7**

How well informed and supported do you feel about your relative’s transition to the next stage of services?

	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD	SLD/PMLD	Non-SLD/PMLD
Very well informed	1	0	1	0	0	0	0	0
Somewhat informed	0	0	0	1	1	2	0	0
Neither informed not uninformed	1	1	0	1	0	0	0	1
Somewhat unprepared	1	0	1	0	1	0	1	0
Very unprepared	1	4	2	3	2	3	0	1
Not relevant	0	2	0	2	0	2	3	5
Total respondents	**4**	**7**	**4**	**7**	**4**	**7**	**4**	**7**

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
If you indicated feeling unprepared in the previous question, please describe any specific worries you have regarding your relative's transition		
Responses include:	"Lack of services and placements beyond 19+, uncertain of what the future holds" "We have not been given explanation how it's work, the impact of those changes in his life, outside world. We don't know", "I've not started the process so it's too early to say",	"No communication. no discussion", "How the services differ will they support him how they previously have done"
Total respondents	**3**	**2**
What would help reduce this anxiety or any worries about relevant services? Please select all that apply, or include any additional answers		
Access to better information	4	7
Agreements on funding for my relative's transition	1	4
Planning well in advance of my relative's transition	3	5
Better communication with relevant services	2	4
Add any additional answers here	0	1
Other responses include:		"Lack of information lack of discussion"
Total respondents	**4**	**7**

Table 5 – Secondary trauma response information

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
Has your relative experienced any events that they felt was traumatic? (e.g., restraint, seclusion, abuse, separation from family etc.)?		
Yes	2	5
No	5	1
Unsure	2	5
Total respondents	**9**	**11**

	Number of SLD/PMLD respondents		Number of non-SLD/PMLD respondents	
Has your relative experienced any events that they felt was traumatic?				
	Yes	Unsure	Yes	Unsure
Mainstream trauma e.g., life threatening illness	1	1	2	1
Loss of familiar routines, environment, people	2	0	5	1
Out of area placement	0	2	1	2
Sharing living space with unfamiliar people who may be in crisis i.e., an ATU, respite/short breaks service, school or other educational setting	0	2	0	2
Subject to 'rules' which may not be understood (e.g., not allowed access to preferred items/activities)	2	0	2	2
Physical restraint	0	2	2	1
Mechanical restraint i.e., being strapped in a chair/wheelchair	0	2	0	2

Chemical restraint i.e., PRN/antipsychotics/psychotropics	1	2	0	2
Seclusion i.e., being separated from any other people and prevented from leaving either by a lock or supervision	0	2	1	2
Physical abuse	0	2	0	2
Sexual abuse	0	2	0	2
Psychological abuse i.e., your loved one being lied to, or their anxieties and fears being used as a means of control	1	1	1	2
Not getting support care needs met easily in a timely manner	1	1	4	1
Not getting health needs met easily in a timely manner	2	1	2	2
Total respondents	**3**		**6**	

What impact did the event(s) have on you as a carer?												
	Regularly		Sometimes		Intermittently		Once		Never		**Total**	
	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	SLD/ PMLD	Non-SLD/ PMLD	**SLD/ PMLD**	**Non-SLD/ PMLD**
Panic attacks	0	2	2	2	1	0	0	0	0	2	**3**	**6**
Insomnia/disturbed sleep pattern	1	3	1	2	1	0	0	0	0	1	**3**	**6**
Unable to work/job loss	1	1	1	2	0	0	1	0	0	2	**3**	**5**
Disagreement with friends/family members	1	4	1	1	1	0	0	0	0	1	**3**	**6**
Family members leaving home	0	0	1	1	0	0	0	0	2	4	**3**	**5**
Relationship breakdown	0	1	1	1	0	0	0	0	2	3	**3**	**5**
Depression	2	2	0	1	1	0	0	0	0	2	**3**	**5**
Anxiety and fearfulness	2	3	1	1	0	1	0	0	0	1	**3**	**6**
Personality change (i.e., difficulty trusting others)	2	3	0	1	1	1	0	0	0	1	**3**	**6**
Guilt	1	4	1	0	1	0	0	0	0	1	**3**	**5**

	Number of SLD/PMLD respondents	Number of non-SLD/PMLD respondents
Please identify all forms of trauma support, if any, that have been offered to you by professionals		
Responses included:	“none” “Early help” “Had a few counselling phone calls”	“None” “None” “CAMHS”
Total respondents	**3**	**3**
If no trauma support was offered to you by professionals, please identify all forms of support, if any, that you sought out		
Responses included:	“healthy minds”	“Cbt, anxiety support” “None just got on with it” “Sought support from family counsellor. Also on waiting list for Healthy minds”
Total respondents	**1**	**3**
If you were offered support or sought support yourself but did not access it, please identify the reasons why. Please select all that apply		
Time commitment not possible	0	0
Waiting list too long	0	0
Support too far away/not accessible	0	0
Fees	0	0
Inappropriate support type offered	0	0
Other	2	0
Other responses include:	“Advised no further support available” “not aware of support available”,	
Total respondents	**2**	**0**

Of the trauma support that you received (either offered to you, or that you sought out yourself); was there any professional individual, group or organisation that you felt understood your experience and were useful in helping to support you? If so, please indicate which professional individual, group or organisation that was		
Responses include:	“Voice 4 Parents, early help worker”	“We love carers”,
Total respondents	**1**	**1**
How helpful was the trauma support you received? (Either offered to you, or that you sought out yourself?)		
Very helpful	0	0
Helpful	1	1
No change	1	0
Not helpful	0	0
Detrimental	0	0
Add any additional comments here	0	0
Total respondents	**2**	**1**
What existing trauma support are you aware of that is available to family carers in the Black Country?		
Responses include:	“None”	“Family counsellor based at [redacted] [redacted]”, “There is very little support”,
Total respondents	**1**	**2**
Based on your experience, what could be improved about the existing trauma support for the families of people with learning disabilities and/or autism in the Black Country.		
Responses include:	“More access or better well known and signposted”, “More details provided. Easy access”	“Coaching for the family member to understand coping mechanisms for the child as well as how to respond to situations and adapt things”, “Everything”, “Provide some support to families and make is accessible”,
Total respondents	**2**	**3**

Appendix 4 – Service improvement feedback analysis

Table 1 – What could be done to improve services in the local area feedback

Theme	Example quotes
Information and advice	"More relevant information" "More information and handling about challenging behaviour children" "Information" "More interaction, more information" "Help with behaviour and managing access to social care." "More information about services and how to access them" "Information about groups via email"
Co-ordination of services/continuity	"One person allocated to help support carer to tie all the services together. too much chasing up of professionals." "A key worker across all services. To be listened to. Not to keep repeating our journey" "Trying to keep to one person we have dealt with 5 different people over the last 4 years." "That services are linked up"
Accessibility and inclusivity	"To be more accessible" "Leisure ASC accessible services and leisure" "To be more accessible"
Communication	"Listen to parents/carers the first time, tell it once, be supported from the beginning, prevention of family breakdowns, stop parent blaming" "They need to listen to parents" "To be more understanding and have more empathy for parents." "listening to the parents first because they know their children best."

	“Listening to parents the first time rather than years later.” “Better communication”
Gaps in services	“Offer services that support us as a family. Diagnosis given and then left with very little help or flexibility in what was offered. provide services for children with autism as there are none unless they have co morbid mental health issues. Gap in service where these children are failed with sensory issues eating issues as some examples.” “my son is self-harming and harming others due to anxiety and difficulties and they are still ignoring him.” “Actually have a appointment” “Access to them!!” “Cahms said they couldn't find the right service to help my son so did nothing” “Applied for support and not been offered anything as we don’t have a diagnosis” “Better access when having issues, more practical support as appears to be medication focussed” “More personalised social care plan and more productive reviews.” “More help around autism” “Stop affirming girls with ASD as boys help them to feel comfortable 8n their own bodies” “clearer personalised targets strategies to meet targets reviews of strategies more regular input”
Waiting times	“Nothing happens until u hit crisis and it takes months even after that” “Reduce waiting times for services” “The waiting for assessments be shorter time” “Better resources to respond in a timely fashion. Long wait times for support”

	“Finding a way to reduce waiting times for diagnosis of neurological disorders such as ASD, ADHD, ADD etc” “Shorter waiting lists for families. More sessions” “Cut the long waiting list when children need the services, providing more professional in local area, “Things need to move faster when people ask for help. Parents only come for help when they have reached crisis. Then everything takes too long” “acting when families reach out for support and not after they have a breakdown, stop breaking the law …"
Other	“They free session center in holiday”

Table 2 – Feeling more connected to family carers in the community feedback

Theme	Example quotes
Information, advice and activities	“We requested training in autism and never received" “More information” “A broader range of activities offered” “More awareness of where to go who to see”
Peer-to-peer support and involvement	“Meet ups face to face listening ear/befriending service” “Career meetings where we can discuss about our special needs kids needs” “Not just seating and listening to what they have to say, give parents chance to speak up, change their ideas in different area where they struggle ask questions, how to improve the quality of care of their love one without feeling a lone.”
Accessibility and inclusion	“more cultural diversity” “at times that do not clash with work time.” “Maybe a virtual groups, Facebook groups etc” “Support by other language too(Punjabi) to understand things more clearly” “More localised meet ups” “Instead of specific times have an open timetable” “Group in my area as disabled myself don't go out cause there group are not local to me”
Awareness of support available	“When child is diagnosed to be given information about groups local to home” “Better advertising.”