



projectart works

Project Art Works Pilot Study

Investigating the issues affecting families and support workers in delivering personalised provision to individuals with complex needs

Research Report

Susan Potter, April 2017

“The NHS Commissioning Board’s objective is to ensure that Clinical Commissioning Groups work with local authorities to make sure vulnerable people - particularly those with learning disabilities and autism - receive safe, appropriate, high quality care. Our shared objective is to see the health and care system get to grips with past failings by listening to this very vulnerable group of people and their families, meeting their needs and working together to commission the range of support which will enable them to lead fulfilling and safe lives in their communities.”

NHS Mandate, 2012

“It’s absolutely crucial that whoever is working with an individual - in whatever context - has the understanding, knowledge and skillset but also, the support to maintain that practice. At Project Art Works, everybody comes to the table with the same ethos. When you are working within health or social services, people come from very different backgrounds and you approach things from slightly different angles. So to begin with, we need to ensure that everybody is on that same page to develop a coherent ethos, culture and approach to working, then we need to make sure that is maintained.”

Stakeholder, February 2017

“Project Art Works has really helped me. They lifted me! I come out of there and I feel less isolated. I feel positive and motivated. It makes you feel that you’re not the only one in that situation. I try really hard to not let it drag me down, it’s up to me whether I want to make myself a prisoner in my own mind and I won’t let that happen. Meeting other families is very refreshing, it opens you up to seeing and also, it’s a way of learning from them and how they coped when starting on this journey. Listening to each other and helping each other, inadvertently, in a kind of light touch sort of way.”

Parent, February 2017

Contacts

Kate Adams, Artist and Director

Matthew Pitts, Communications and Creative Programme Manager

Project Art Works

Arch 3

Braybrooke Terrace

Hastings

TN34 1TD

T. 01424 423555

E. kate@projectartworks.org

W. www.projectartworks.org

Susan Potter

Arts Evaluation and Research

17 Grimston Gardens

Folkestone

Kent

CT20 2PU

T. 01303 210369

E. susan.potter55@hotmail.co.uk

Image credits

Cover page images and report images taken during workshops, exhibitions and events delivered by Project Art Works. All images copyright Project Art Works © 2017.

Contents	Page
Executive Summary	6
Acknowledgements	10
1 Context and rationale	11
2 Methodology	14
3 Quantitative findings	16
3.1 Description of participants	16
3.2 Issues affecting families	17
3.3 Issues affecting support workers	18
3.4 Assistance needed for families	19
3.5 Assistance needed for support workers	20
3.6 Responses to open question	21
4 Qualitative findings	22
4.1 Research with families	24
4.2 Research with support workers	27
4.3 Research with stakeholders	30
5 Learning and recommendations	33
5.1 Family related learning	34
5.2 Support worker related learning	35
5.3 Sector related learning	36
5.4 Recommendations	38

Contents	Page
6 Summary and conclusions	40
7 References and bibliography	43
8 List of images	46
9 Appendices	47
i. Preliminary review of studies	
ii. Information Sheet	
iii. Consent Form	
iv. Online Questionnaire	
v. Interview Schedule	
vi. Focus Group Schedule	

Executive Summary

Background

Established in 2004 and based in Hastings, Project Art Works (PAW) is an artist-led organisation working with children, young people and adults who have complex and additional needs alongside their families, carers and professionals, via a wide range of creative projects. PAW works from the basis of the radical model of disability, which in its simplest form moves the focus away from peoples' impairments and towards removing the barriers to inclusion that certain individuals face in everyday life and including:

- Environmental barriers (lack of accessible information)
- Systemic barriers (segregated provision)
- Attitudinal barriers (individuals being seen as expensive, non-contributing or needy).

Aim

In 2016, PAW received a small grant from the Hastings & Rother Reducing Health Inequalities Fund to conduct a six month pilot study to assess current support for independent provisions for people who have complex behavioural support needs, their families and support workers. The project included two distinct strands: a supportive programme of activity delivered to families and support workers; a discrete research study to investigate key associated themes with families, support workers and other professionals working with individuals with complex needs. The project included the following programme of activity:

- Study investigating efficacy/deficits of current support for families/support workers
- Delivery of three peer network group meetings for families
- Delivery of three peer network group meetings for support workers
- Provision of planning and management tools for families in need of support
- Provision of social networking opportunities for families and support workers.

Method

A mixed methods study was conducted from October 2016 to March 2017, engaging with 100 individuals and five stakeholder organisations, comprising four closely interlinking strands:

- Online survey delivered to families, support workers and other professionals
- Focus group meetings with families, support workers and other professionals
- Interviews with individual families and support workers
- Interviews with other professionals and/or key stakeholders.

Quantitative findings

The online survey was delivered to families, support workers and other professionals via PAW and its partner organisations and completed by 50 individuals, with the following characteristics:

- The sample comprised 68% females and 30% males, aged between 21 and 75 years
- 60% respondents were residents of Hastings & St Leonards or the District of Rother
- 80% described themselves as 'White British', 8% as 'White Other' and 8% as BAME
- 36% respondents were 'parents' of a young person/adult with complex needs
- 36% were 'other professionals' involved in service development
- 10% were 'support workers', while 4% were 'family members/friends'.

Issues affecting families/carers

The main issues affecting the lives of families/carers in supporting individuals with complex and/or additional needs were reported to be systemic, financial and/or social issues:

- 80% respondents reported 'understanding the systems to gain the best support' to be always/regularly an issue
- 80% respondents reported 'financial and/or care budget worries or concerns' to be always/regularly an issue
- 64% suggested 'feelings of isolation and/or exclusion' were always/regularly an issue
- 60% respondents noted 'assessments of need' were always/regularly an issue
- 40% respondents reported 'negative professional attitudes' or 'negative public attitudes' towards individuals with complex needs to be always/regularly an issue
- 38% respondents suggested 'understanding the language to gain the best support' to be always/regularly an issue.

Issues affecting support workers

The main issues affecting the lives of support workers in assisting individuals with complex and/or additional needs were reported to be financial, social and/or management issues:

- 58% respondents reported 'financial and/or care budget worries or concerns' to be always/regularly an issue
- 54% respondents reported 'a lack of statutory, professional training' to be always/regularly an issue
- 52% respondents suggested 'a lack of mentoring and/or regular supervision' were always/regularly an issue
- 42% respondents noted 'feelings of isolation and/or exclusion' to be always or regularly an issue
- 36% reported 'negative public attitudes' or 'negative professional attitudes' (32%) towards individuals with complex needs to be always/regularly an issue.

Assistance needed for families/carers

Asked what is needed to best assist families/carers supporting young people/adults in receipt of Direct Payments or Personal Health Budgets, survey respondents suggested the following:

- 87% reported 'practical support with financial and/or legal issues' to be very important/important
- 84% respondents noted 'a template or toolkit for planning individual care plans' to be very important/important
- 80% respondents indicated 'online resources to help understand the language and/or systems' to be very important/important
- 80% respondents suggested 'buddying or mentoring from families with more experience' were very important/important.

Assistance needed for support workers

Asked what is needed to best assist support workers supporting young people/adults in receipt of Direct Payments or Personal Health Budgets, survey respondents suggested the following:

- 90% respondents reported 'financial recognition for this field of work' to be very important/important
- 90% respondents noted 'positive professional attitudes to this field of work' to be very important/important
- 86% respondents indicated 'high quality, standardised professional training' to be very important/important
- 86% respondents suggested 'regular mentoring and/or supervision' to be very important/important.

Qualitative findings

Qualitative research conducted with families, support workers and other professionals concurred with the online survey results, with the following issues reported as affecting families and support staff in enabling fulfilling, choice driven lives for individuals with complex needs:

- Families described financial and/or care budget concerns; understanding and/or navigating the systems of care; mental and/or emotional stress; feelings of isolation and/or exclusion
- Support workers reported financial worries or concerns; a lack of statutory, professional training; a lack of mentoring and/or regular supervision; feelings of isolation and/or exclusion
- Professionals across the sectors of education, health and social care described the need for a more coherent framework; a conflict between agencies and/or services; the negative impacts of continuing austerity measures; a significant mismatch between policy and practice.

Participants in the pilot study regularly attested to the high quality, personalised service delivered by Project Art Works to children, young people and adults with complex and additional needs alongside their families, carers and professionals. Through the pilot study, PAW began to address some of those aforementioned challenges, resulting in positive outcomes for families, support workers and stakeholders alike:

- Improved quality of life for people with complex needs and their families in receipt of services
- Improved communication between families, support workers and other professionals
- Reduced social isolation and improved mental wellbeing for individuals and families
- Advice, supervision and training provided for support workers working directly with families.

Summary of recommendations

Following analysis of the online survey results, focus group and interview data, a number of deliverable recommendations were suggested to assist Hastings & Rother CCG, Project Art Works and other stakeholder organisations in developing meaningful, personalised provision for young people/adults with complex needs. In summary, these are:

- For families, a need for guidance and skills training related to e.g. designing individual care plans; understanding terminology and navigating systems of care; budgeting systems and management of Direct Payments/Personal Health Budgets; the recruitment, employment and retention of support workers
- For support workers, a need for improved working conditions and professional development, including e.g. standardised hourly rates for PAs and/or support workers; high quality, training opportunities to support career development; regular supervision and/or mentoring; peer support groups and/or networks
- For professionals across the sector, a need for greater coordination of services and support for those in need, including e.g. staff training to improve understanding and delivery of personalised provision; a more consistent approach across education, health and social care services; clearer guidelines offered to families seeking Direct Payments/Personal Health Budgets; an online resource bank of care workers with details of skills and experiences.

In the context of a challenging broader economic and social environment, the research findings from the present study are significant and timely. The Project Art Works Pilot Study has provided core evidence to inform the development of a new charity to address the current deficits in service provision and implement a longer term programme of support including: shared budgets; cross sector training and development; informal networking events; improved skills for families and support workers; the sharing of best practice. The proposed charity aspires to work with all stakeholders to provide a peer led support worker agency and family support provision, in partnership with health and social care services. From the findings, it is hoped that the Hastings & Rother Clinical Commissioning Group and Project Art Works - along with those education, health and social care partners - might now work together to develop robust, evidence based strategies, leading to meaningful, individualised support.

Acknowledgements

Project Art Works would like to thank those individuals and organisations who have given their time, skills and resources to this study. Thanks are also due to those numerous pilot study participants, family members, support workers and key stakeholders who have shared their insights and suggestions through the online survey, focus group meetings and individual interviews.

Susan Potter is grateful for the advice and support provided by the following individuals, in the collection of data and preparation of this report:

Kate Adams, Artist, Director of Project Art Works and parent of individual with complex needs

Peter Baker, Clinician and Honorary Senior Lecturer at The Tizard Centre, University of Kent

Sheryll Catto, Director of Action Space and parent of individual with complex needs

Kerry French, Resource Officer with East Sussex County Council Transition Team

Matthew Gibb, Personal Assistant for individuals with complex needs

Yvonne Laatz, Social Worker with East Sussex County Council

Richard Lewis, Strategic Commissioning Manager Learning Disability with East Sussex County Council

Steve Manwaring, Chief Executive of Hastings Voluntary Action

Dan Marshall, Personal Assistant for individuals with complex needs

Ursula Mazur, Clinical Psychologist with Sussex Partnership NHS Foundation Trust

Matthew Pitts, Communications and Creative Programme Manager at Project Art Works

Mandy Rapisarda, Parent of individual with complex needs

Melissa Rowland, Shared Lives provider and sister of individual with complex needs

David Sexton, Parent of individual with complex needs

Doreen Sexton, Parent of individual with complex needs

Angela Simons, Clinical Commissioning Lead for Transforming Care with NHS Hastings & Rother CCG

Sara Weech, Childrens Commissioning Lead (Interim) with East Sussex County Council

The Project Art Works Pilot Study was supported by Hastings & Rother Clinical Commissioning Group



1 Context and rationale

Based in Hastings, Project Art Works (PAW) is the UK's leading artist led organisation working with children, young people and adults with complex and additional needs, alongside their families, carers and circles of support. The people who have shaped PAW share a common purpose in pursuing a vital line of enquiry: to investigate the capabilities of an individual through creative collaborations that foster choice, subjective preference, intuition and non-verbal interaction. In a social and political landscape that is constantly shifting, the work of PAW seeks to address areas of need as they occur. Their artistic approach is as much about an ability to affect positive change in society, as it is to produce artefacts. PAW works from the basis of the radical model of disability, which in its simplest form moves the focus away from peoples' impairments and towards removing the barriers to inclusion that certain individuals face in everyday life and including:

- Environmental barriers (lack of accessible information)
- Systemic barriers (segregated provision)
- Attitudinal barriers (individuals being seen as expensive, non-contributing or needy).

The radical model stresses that disability is not a point of individual or social tragedy but a natural and necessary part of human diversity. The 'tragedy' of disability is not different minds and bodies but oppression, exclusion and marginalisation. In the main it is not the impairment that is the problem, nor the person, rather society's failure to take into account and cater for the diversity of its members. The radical model therefore shifts policy away from a medical, charity, care agenda into a rights led, equalities agenda. With this ethos in mind, PAW provides specialist and holistic support to children, young people and adults with complex needs and behaviours that challenge - including those of learning disabilities and/or autism - working in close collaboration with families and services to improve outcomes in social care.

At a legislative level, individuals with learning disabilities and/or autism and their families have a wide array of rights in law or Government policy through e.g. Disability Discrimination Act, Equalities Act, the NHS Constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, UN's Convention on the Rights of Persons with Disabilities¹. The Care Act 2014 is the most significant reform of publicly funded care and support in England in 60 years. It fundamentally reframes local authorities' statutory duties from one of providing services for specific client groups to promoting wellbeing. It rescinds earlier legislation, including the NHS and Community Act 1990, with the aim of creating a consistent route to establishing an entitlement to publically funded care and support.

The Care Act came into force in April 2015, placing 'personalisation' or 'personalised provision' on a statutory footing for the first time. It provides those who are eligible with a legal entitlement to a personal budget (including Direct Payments and Personal Health Budgets) as part of their care and support plan, regardless of setting. In spite of these requirements, the lived experience of people with learning disabilities and/or autism and their families is frequently reported as very different. Too often they describe feeling powerless, their rights are unclear, they are confused, misunderstood or ignored. In addition, families and support workers suggest there is little emphasis placed upon the dedicated, specialist skills required in supporting individuals with complex needs by policymakers and/or commissioners. The Learning Disabilities Observatory estimates there were 1,087,100 people with learning disabilities and/or autism living in England in 2015, equating to 2.7% of the global population². Recent research also suggests between 16 and 40% of these individuals present behaviours perceived as challenging, resulting in severe negative impacts upon education, employment, physical and mental health³. Through its advocacy work, creative programmes, publications and high profile exhibitions, PAW seeks to address these contradictions, while supporting those individuals with complex needs, their families, care workers and other professionals in delivering truly personalised provision.

During 2015/16, PAW delivered three Peer Network Forums for families with young or adult children who have complex needs. All expressed a need for more structured support in managing Direct Payment provisions, recruiting and retaining support staff. Additionally, support workers expressed a need for more structured management and training in working with people who have behaviours that challenge. Following these events a number of participants convened a Steering Group of stakeholders including support workers, parents and families, clinical psychologist, Dr Peter Baker and Steve Manwaring, Director of Hastings Voluntary Action (HVA). Work has been undertaken with HVA that has resulted in governance documents that are now ready to submit to the Charities Commission.

¹ See bibliography for full list of studies and policy documents

² Learning Disabilities Observatory (2016). *People with learning disabilities in England 2015*. London: Public Health England

³ Community and Mental Health Team Health and Social Care Information Centre (2015). *Learning Disability Census Report: Experimental Statistics*. London: HSCIC

In 2016, PAW received a small grant from the Hastings & Rother Reducing Health Inequalities Fund to conduct a six month pilot study to assess current support for independent provisions for people who have complex behavioural support needs, their families and support workers. The project is exploring different models of support for young people and adults in receipt of Direct Payments or Personal Health Budgets (PHBs) and includes two distinct strands: a supportive programme of activity delivered to families and support workers; a discrete research study to investigate key associated themes with families, support workers and other professionals working with individuals with complex needs. The overarching aims of the PAW Pilot Study are:

- To improve quality of life for people with complex needs and their families in receipt of services
- To reduce behaviours that challenge in people who have autism and learning disability
- To reduce social isolation as a result of behaviours that challenge
- To provide advice, supervision and training to support workers working directly with families.

Between October 2016 and March 2017, Project Art Works delivered a six month pilot study to explore different models of support for children, young people and adults in receipt of Direct Payments or Personal Health Budgets. Through the pilot, PAW has been investigating what kinds of support are already available and/or whether new models of support might be needed to ensure high quality and successful personalised provision. Families, support workers and stakeholders have been invited to take part in the project, which PAW hopes will lead to the establishment of a not-for-profit specialist support worker network and agency. This resource will be made accessible to those who have complex needs and/or behaviours that challenge, alongside their families and support workers.

The PAW Pilot Study engaged with 100 individuals (i.e. parents and carers; PAs and support workers; key stakeholders and other professionals; Project Art Works staff), and five partner organisations (i.e. Hastings & Rother CCG; Hastings Voluntary Action; East Sussex County Council; East Sussex NHS Foundation Trust; The Tizard Centre, University of Kent). The project included the following activities:

- Research study to investigate efficacy/deficits of current support for families/support workers
- Delivery of three peer network group meetings for families
- Delivery of three peer network group meetings for support workers
- Provision of planning and management tools for families in need of support
- Provision of social networking opportunities for families and support workers
- Engaging support of local CLDT and psychology pathway through observation of project activity, attendance at peer network meetings and participation in the research study.

The purpose of this report then is to present the outcomes from the Project Art Works Pilot Study. From the findings, it is hoped that the Hastings & Rother Clinical Commissioning Group and Project Art Works - along with those education, health and social care partners - might work together to develop robust, evidence based strategies, leading to meaningful, individualised support.



2 Methodology

This mixed methods study was conducted between October 2016 and March 2017, engaging with a total of 100 individuals and five stakeholder organisations. The study comprised four separate yet closely interlinking strands:

- Online survey delivered to families, support workers and other professionals
- Focus group meetings with families, support workers and other professionals
- Interviews with individual families and support workers
- Interviews with other professionals and/or key stakeholders.

Through consultation with the PAW Pilot Study Steering Group, a research framework and tools were designed, with a focus upon investigating the following criteria:

- i. The value and use of current services that aim to support people and families in running their own personalised provisions
- ii. The mental and emotional stress experienced by those families working in isolation with children, young people and adults presenting behaviours that challenge
- iii. The support needed for those people working in isolation with children, young people and adults presenting behaviours that challenge, enabling them to progress
- iv. Those issues that affect families and support workers in the delivery of high quality, choice driven lives for people who have complex needs and/or behaviours that challenge
- v. Those issues affecting recruitment of support staff delivering family run provision
- vi. Effective practice in managing and retaining staff, in the delivery of well-rounded provision.

An initial literature search included sources published from a range of web-based knowledge management systems (e.g. JSTOR, MENCAP Online, NHS Online, PsycINFO Online, SCIE Online), while satisfying the areas under consideration for the current investigation: *personalised provision; complex needs; challenging behaviours*. While there is an increasing body of documentation available regarding the benefits and value of 'personalised provision', extensive searches found little published empirical research focusing specifically upon 'personalised provision' for 'individuals with complex needs and challenging behaviours'. Much of the available information is either policy related and/or discussion around policy implementation⁴. However, a small selection of studies with a focus upon: *personalised provision, complex needs, challenging behaviours* was developed for more detailed review⁵. This enquiry aimed to provide a foundation for the research design and tools, while informing the subsequent analyses, discussion and recommendations included in this report.

Drawing from the literature review and the findings of the initial PAW Peer Network Forums, an online questionnaire⁶ was designed and delivered to families, support workers and other professionals via PAW and its partner organisations. This survey was complemented by a series of focus groups and individual interviews⁷. Focus groups were conducted with family members, support workers and professionals engaged in the development of services for individuals with complex needs. In-depth interviews were concurrently conducted with families, support workers and also, key stakeholders representing PAW's education, health and social care partners.

In the quantitative study, SurveyMonkey was employed to support the collection and preliminary analysis of resulting questionnaire data. In the qualitative study, audio-recorded interviews were transcribed and analysed using thematic analysis. The aim was to prioritise the 'lived experience' of participants, while also exploring those themes under investigation, i.e. *personalised provision; complex needs; challenging behaviours*. The design and methods of delivery aimed to ensure the highest levels of health, safety and comfort for all participants. An information sheet was provided in advance⁸ and permission to take part was obtained through consent forms⁹. Personal data was anonymised so that no individual participant could be identified in the reporting. It was anticipated that certain individuals might have found the interviews stressful. With this in mind, interviews were conducted in an inclusive and accessible manner. In addition, data collection methods aimed to be both sensitive and flexible to the specific needs of individual family members, support workers and other professionals.

⁴ See bibliography for full list of studies and policy documents

⁵ Appendix i. Preliminary Review of Studies

⁶ Appendix iv. Online Questionnaire

⁷ Appendices v. and vi. Interview and Focus Group Schedules

⁸ Appendix ii. Information Sheet

⁹ Appendix iii. Consent Form

3 Quantitative findings

3.1 Description of participants

The Project Art Works online survey was delivered to families, support workers and other professional stakeholders between February and March 2017. It was completed by a total of 50 individuals, the larger majority residents of Hastings & St Leonards (20%) or the wider District of Rother (40%), including e.g. Braybrooke, Gensing, Hollington. A lesser number were residents of East or West Sussex, London or other parts of the UK. The sample comprised 68% females and 15% males, aged between 21 and 75 years. As described in Figure 3.1, the larger majority respondents (80%) described themselves as ‘White British’ and were aged 31 to 45 years (32%), or 46 to 55 years (26%). Describing their relationship to individuals with complex needs and challenging behaviours, the larger majority were parents (36%), or professionals (36%) involved in service development; 10% respondents were support workers, while 4% were family members/friends of an individual with complex needs.

Figure 3.1 Description of participants

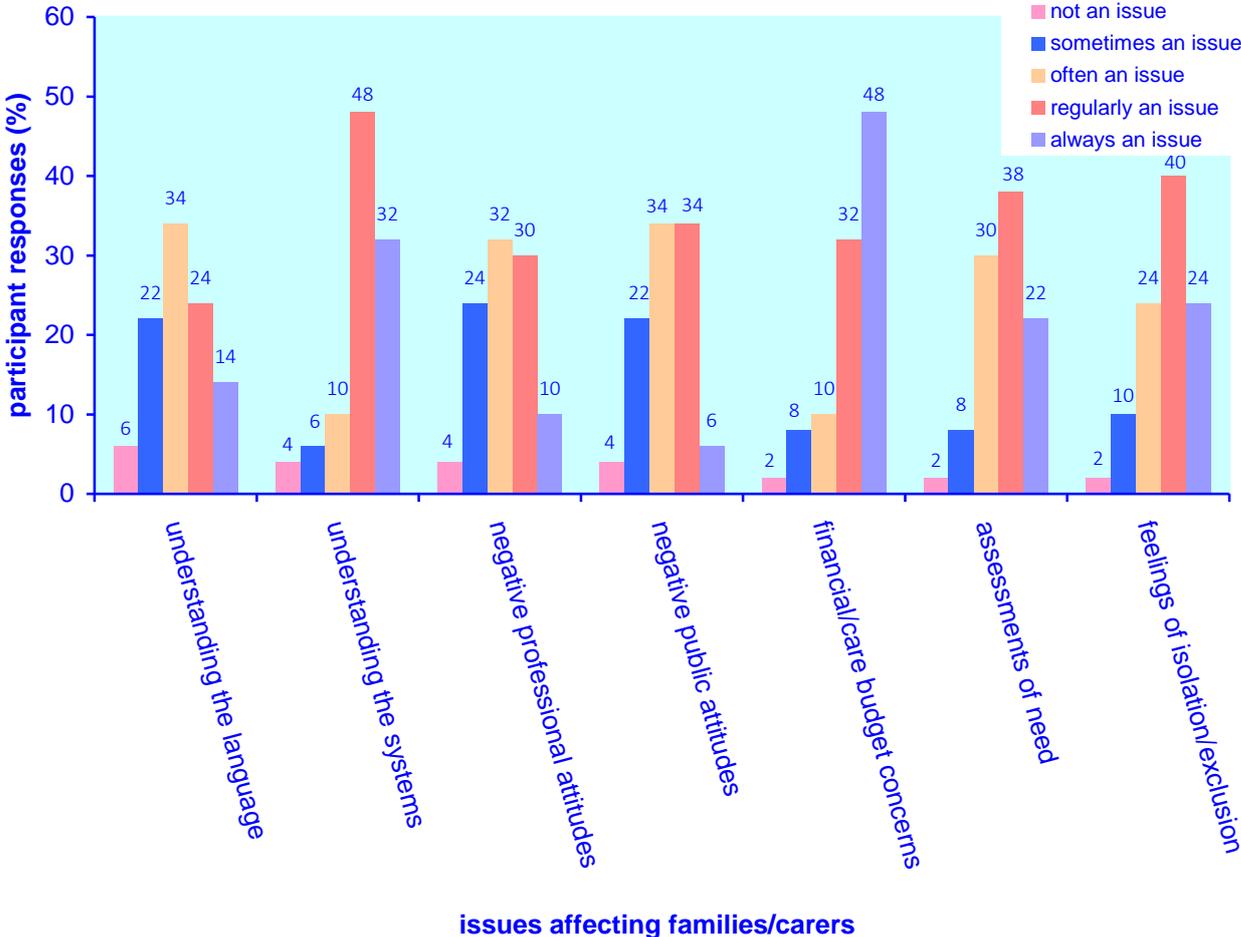
Characteristic	Frequency	Characteristic	Frequency
<i>Gender</i>		<i>Relationship</i>	
Female	34 (68%)	Parent	18 (36%)
Male	15 (30%)	Family member	1 (2%)
Other	0 (0%)	Friend	3 (6%)
Prefer not to say	1 (2%)	Support worker	10 (20%)
		Other professional	18 (36%)
		Prefer not to say	0 (0%)
<i>Age</i>		<i>Home postcode</i>	
Under 21	0 (0%)	Hastings & St Leonards	10 (20%)
21-30 years	4 (8%)	District of Rother	20 (40%)
31-45 years	16 (32%)	East Sussex	8 (16%)
46-55 years	13 (26%)	West Sussex	3 (6%)
56-65 years	5 (10%)	London	4 (8%)
66-75 years	11 (22%)	Wider UK	5 (10%)
Prefer not to say	1 (2%)	Prefer not to say	0 (0%)
<i>Ethnicity</i>			
White British	40 (80%)		
White other	4 (8%)		
Asian or Asian British	1 (2%)		
Black or Black British	1 (2%)		
Chinese or Chinese British	0 (0%)		
Mixed ethnicity	2 (4%)		
Prefer not to say	2 (4%)		

3.2 Issues affecting families

Since a main premise of this study was to investigate those issues affecting families and/or carers in supporting a young person/adult with complex needs and behaviours that challenge, the online survey asked participants ‘what issues affect the lives of families/carers supporting individuals with complex and/or additional needs?’ As described in Figure 3.2 (below), respondents rated items as ‘always an issue’, ‘regularly an issue’, ‘often an issue’, ‘sometimes an issue’ or ‘not an issue’. The following narrative highlights those issues perceived to be *continuous* (i.e. always an issue or regularly an issue), although it is evident that a large number of responses were noted for *intermittent* occurrence (i.e. often an issue), and across many of those items listed.

The far larger majority of respondents (80%) reported ‘understanding the systems to gain the best support’ to be always an issue or regularly an issue, while 80% respondents also reported ‘financial and/or care budget worries or concerns’ to be always or regularly an issue. A high percentage of respondents (64%) suggested ‘feelings of isolation and/or exclusion’ were always an issue or regularly an issue, while 60% respondents noted ‘assessments of need’ were always or regularly an issue. A lesser proportion of respondents reported ‘negative professional attitudes’ (40%) or ‘negative public attitudes’ (40%) towards individuals with complex needs and behaviours that challenge to be always or regularly an issue, while 38% respondents suggested ‘understanding the language to gain the best support’ to be always or regularly an issue affecting families and/or carers.

Figure 3.2 Issues affecting families/carers

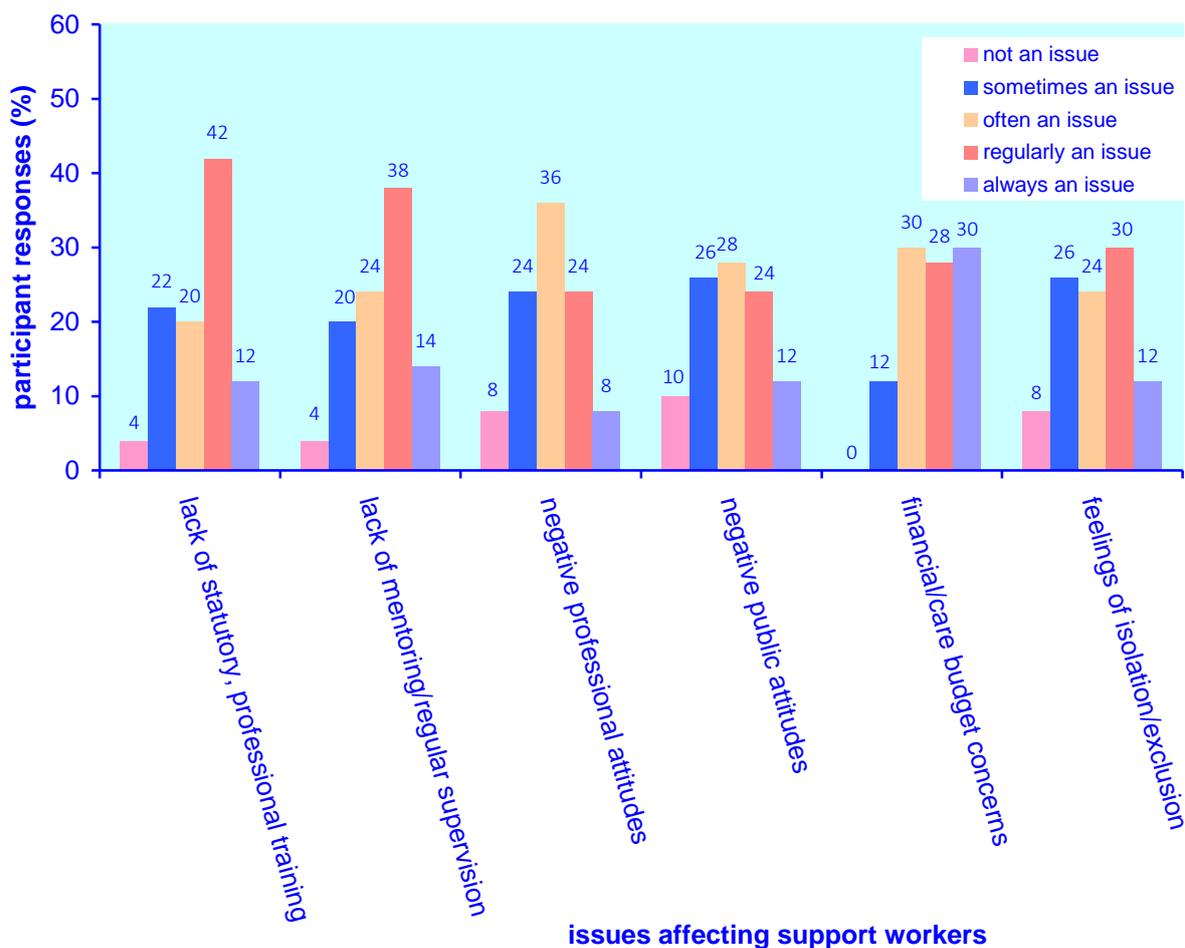


3.3 Issues affecting support workers

Another aim of the present study was to investigate those issues affecting support workers in working with a young person/adult with complex needs and behaviours that challenge. The online survey therefore asked participants ‘what issues affect the lives of support workers working with individuals with complex and/or additional needs?’ As described in Figure 3.3 (below), respondents rated items as ‘always an issue’, ‘regularly an issue’, ‘often an issue’, ‘sometimes an issue’ or ‘not an issue’. As previously, the following narrative focuses only upon those issues perceived to be *continuous* (i.e. always an issue or regularly an issue), although it is once again evident that a large number of responses were noted for *intermittent* occurrence (i.e. often an issue), and across each of those items listed.

The larger majority of respondents (58%) reported ‘financial and/or care budget worries or concerns’ to be always an issue or regularly an issue, while 54% respondents reported ‘a lack of statutory, professional training’ to be always or regularly an issue; 52% respondents suggested ‘a lack of mentoring and/or regular supervision’ were always an issue or regularly an issue, while 42% respondents noted ‘feelings of isolation and/or exclusion’ were always or regularly an issue. A lesser number of respondents reported ‘negative public attitudes’ (36%) or ‘negative professional attitudes’ (32%) towards individuals with complex needs and behaviours that challenge to be always or regularly an issue.

Figure 3.3 Issues affecting support workers

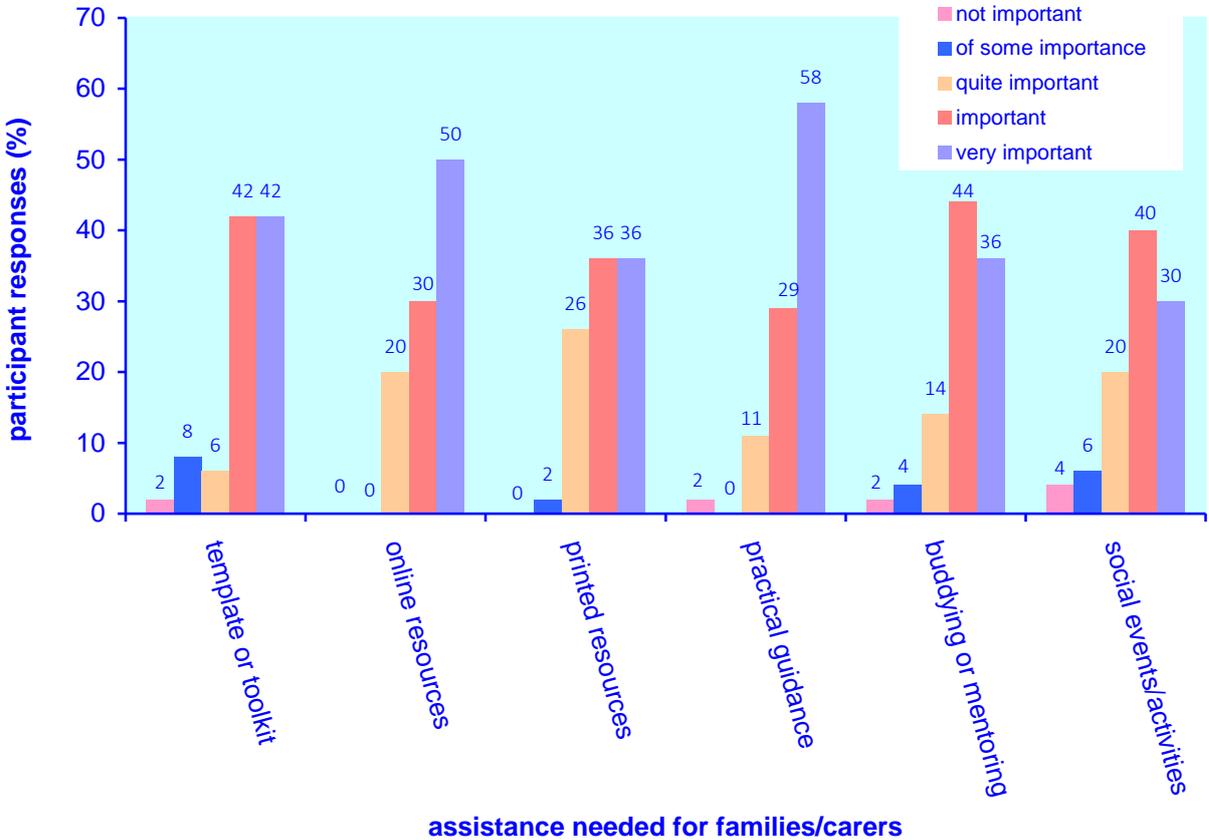


3.4 Assistance needed for families

In addition to investigating those issues most affecting families/carers and support workers in assisting individuals with complex needs and behaviours that challenge, this investigation sought to determine what assistance might be required to improve the quality of life for people with complex needs and their families in receipt of services. The online survey therefore asked participants ‘what is needed to best assist families/carers supporting young people/adults in receipt of Direct Payments or Personal Health Budgets?’ As described in Figure 3.4 (below), respondents rated items as ‘very important’, ‘important’, ‘quite important’, ‘of some importance’ or ‘not important’. The following narrative describes those issues perceived to be of *greatest importance* (i.e. very important or important), although it is evident that respondents felt all items listed to be of importance in supporting those families and/or carers of individuals with complex needs.

The far larger majority of respondents (87%) reported ‘practical support with financial and/or legal issues’ to be very important or important, while 84% respondents also noted ‘a template or toolkit for planning individual care plans’ to be highly important; 80% respondents indicated ‘online resources to help understand the language and/or systems’ as being very important or important and similarly, 80% respondents suggested ‘buddying or mentoring from families with more experience’ was of high importance. A slightly lesser percentage (72%) indicated ‘printed resources to help understand the language and/or systems’ were very important or important and 70% respondents suggested ‘social events/activities with families in a similar situation’ to be of high importance.

Figure 3.4 Assistance needed for families

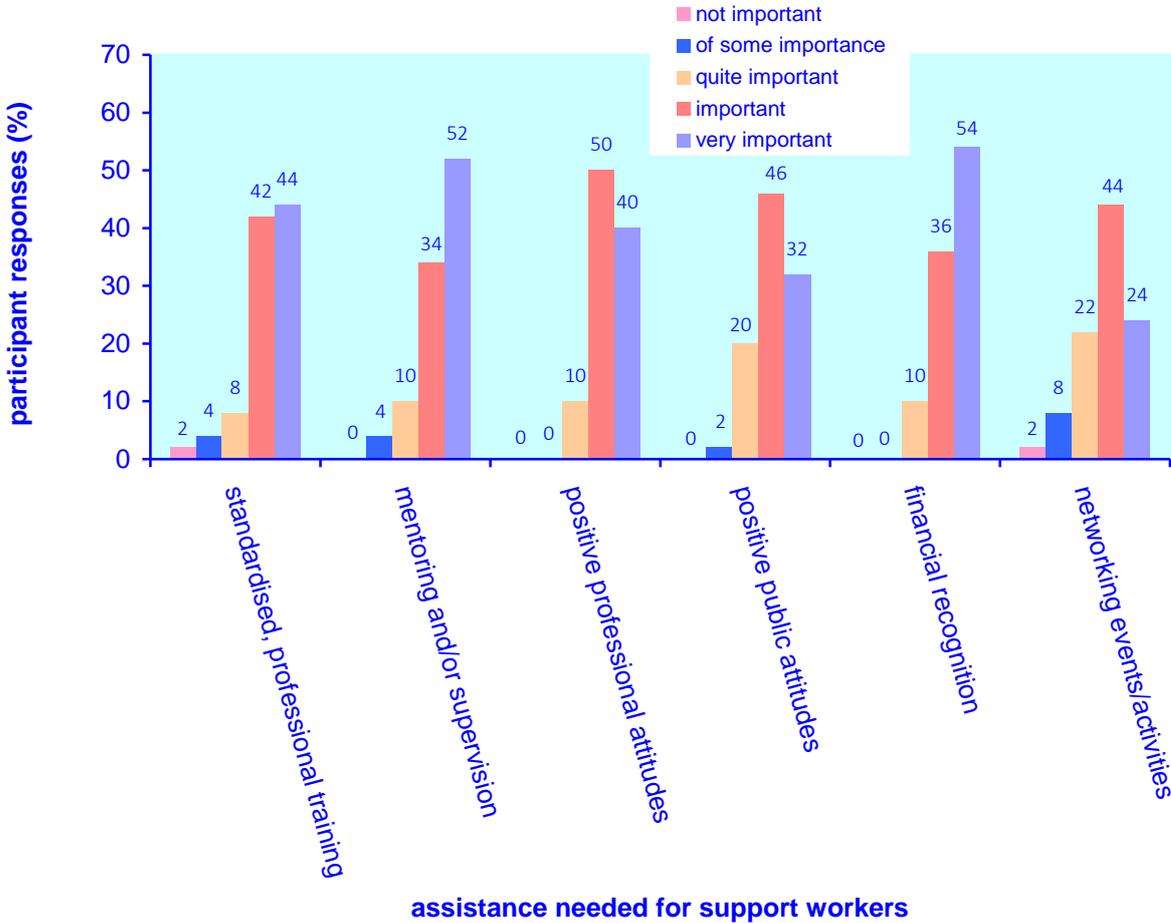


3.5 Assistance needed for support workers

Just as the present study sought to ascertain the support needed for families and/or carers, so another aim was to determine the assistance required for those staff working with children, young people and adults with complex needs and behaviours that challenge, enabling them to progress. The online survey therefore asked participants ‘what is needed to best assist and sustain skilled support workers supporting young people/adults in receipt of Direct Payments or Personal Health Budgets?’ As described in Figure 3.5 (below), respondents rated items as ‘very important’, ‘important’, ‘quite important’, ‘of some importance’ or ‘not important’. As previously, the narrative describes only those issues perceived to be of *greatest importance* (i.e. very important or important), although it is evident that all items were deemed of importance in supporting and sustaining staff working with those individuals with complex needs.

The far larger majority of respondents (90%) reported ‘financial recognition for this field of work’ to be very important or important, while 90% respondents also noted ‘positive professional attitudes towards this field of work’ to be highly important; 86% respondents indicated ‘high quality, standardised professional training’ to be very important or important and similarly, 86% respondents suggested ‘regular mentoring and/or supervision’ was of high importance. A slightly lesser percentage respondents (78%) indicated ‘positive public attitudes towards this field of work’ as being very important or important, while 68% respondents suggested ‘networking events/activities with peers’ to be of high importance.

Figure 3.5 Assistance needed for support workers



3.6 Responses to open question

Finally, the online survey included one open question, asking participants if they had ‘any further suggestions regarding the support needed to ensure high quality and sustainable personalised provision for young people/adults in receipt of Direct Payments or Personal Health Budgets?’ As described in Figure 3.6 (below), responses included a number of recurring themes, closely aligned to the literature reviewed and correlating with the qualitative data collected via focus group meetings and interviews.

Figure 3.6 Responses to open question





4 Qualitative findings

Focus groups were conducted with families, support workers and other professionals engaged with individuals with complex needs and behaviours that challenge. In-depth interviews were concurrently conducted with family members and also, key stakeholders in the development and delivery of services for individuals with complex needs. Focus group meetings and interviews were audio recorded with all resulting data transcribed. As described in Table 4.1 (over) this process was followed by thematic analyses, with themes determined according to their prevalence across each dataset and their relevance to the main research questions. It should be noted however that although time was spent discussing those 'issues' affecting the lives of people living and/or working with individuals with complex needs, the means for 'assisting' those individuals, their families and support staff was explored in some detail and as such, provides endorsement for the subsequent recommendations. Results from the qualitative analyses are presented in relation to findings from each of the three participant groups:

- Research with families
- Research with support workers
- Research with stakeholders.

Table 4.1 Thematic analysis of qualitative data

Overarching Themes	Preliminary Themes	Examples from interview/focus group data	Research Themes
Need for coherent framework Policy versus practice	Continuing austerity measures Conflict between agencies/services Negative focus on assessment of need Articulating 'a good quality of life' Hidden systems of resource allocation	<i>"There are very different cultural models delivered through the different agencies - health, education, social services - that affect the way of approaching an issue. I don't think services are aligned enough, so it leads to inconsistencies which becomes challenging for staff and families alike."</i>	The value and use of services supporting families in running personalised provisions
Need for financial resource Physical and/or emotional exhaustion	Continuing austerity measures Negative focus on assessment of need Lack of confidence/low self-esteem Isolation and/or stigmatisation Lack of support and/or respite	<i>"You really lose your confidence because the people you are talking to are meant to have all of the experience and you believe what they say. It is often quite misleading, what they are saying, but how would you know? It really gets you down at times."</i>	The mental and emotional stress experienced by families of children with complex needs and behaviours that challenge
Need for financial resource Need for professional development	Appropriate salary for this field of work Access to affordable housing/benefits Lack of respect and/or recognition Professional training and supervision Clarity of roles and responsibilities	<i>"Pay is a big issue! You won't get professional people unless you pay them properly. Obviously, they have to be properly qualified and the courses have to be there. They also have to be supported to become qualified. The whole profession needs to be given more status and respect."</i>	Support needed for staff working with individuals with complex needs and/or behaviours that challenge, enabling progression
Need for service coordination Range and quality of service provision	Conflict between agencies/services Navigating systems of care Lack of information/resources Developing individualised care plans Challenge to balance long-term aspirations with short-term gains	<i>"Some parents are extremely knowledgeable about what good quality care looks like - they understand the historical context and legislation, they can manage all of the administration - but not all families have that level of experience and need lots of help."</i>	Issues affecting families/support workers in delivering high quality, choice driven lives for individuals with complex needs and/or behaviours that challenge
Need for financial resource Clarity of roles and responsibilities	Appropriate salary for this field of work Negotiating family/staff relationships Lack of service coordination Lack of public/professional respect Lack of information/resources	<i>"Are we friends, are we entertainers, are we bodyguards? That's what some families think we support workers are! In the absence of clarity of roles and a shared vision, people tend to make up their own rules and that leads to disastrous consequences."</i>	Issues affecting the recruitment, management and retention of high quality staff, in delivering well-rounded family run provision



4.1 Research with families

The qualitative research revealed those issues affecting families in delivering high quality, choice driven lives for individuals with complex needs, while echoing those described in the quantitative research, i.e. financial and/or care budget concerns; understanding and/or navigating the systems of care; mental and/or emotional stress; feelings of isolation and/or exclusion. Those families interviewed frequently described the ‘struggles’ or ‘battles’ in obtaining professional advice, consistent information and/or access to service provision. A ‘conflict’ or ‘mismatch’ between policy and practice was repeatedly noted, with families suggesting many service providers ‘did not understand’ the personalisation agenda, demonstrated ‘a reluctance to embrace change’ and/or had not as yet ‘developed their practice’ to meet policy requirements.

“There’s a huge struggle to receive suitable provision and approval to create individual and tailored packages. It’s totally dependent upon the people involved. It’s all very good on paper but it’s just not being properly put into practice. I don’t think that things have moved on. There are processes and systems that have been created to adapt to the wonderful idea of ‘personalisation’ but for the most part, service providers are continuing in the fashion they are familiar with.”

Parent, February 2017

For those parents/carers of young people with complex needs progressing from children’s to adult services, the transition was described as ‘complicated’, ‘stressful’ and ‘deeply frustrating’. If families had managed this phase and succeeded in gaining Direct Payments and/or Personal Health Budgets, a lack of ‘appropriate’, ‘flexible’ and ‘inclusive’ provision was cited as an additional issue. For families supporting young people/adults with complex needs and challenging behaviours in particular, anxieties regarding an ‘understanding of specific needs’, ‘lack of skills and experience’ and/or the ‘affordability of services’ were frequently cited, especially when seeking activity to support their loved one’s quality of life.

“Once your son or daughter reaches school leaving age they literally fall down into a black hole! It’s very difficult and the quality of service has been really patchy. We have the best range of provision now that we’ve ever had in my son’s life but this is just through finding it and paying for it ourselves. He now does a drumming course once a week - he really likes music - he has three days at college and a day at PAW.”

Parent, February 2017

Across the interview data, families reported the need for increased cohesion across the sectors of education, health and social care, suggesting systems were ‘impenetrable’, ‘lacked structure’ and required a ‘dogged determination’ to develop meaningful, individualised care plans and achieve those positive outcomes described in policy documents. In addition to the skills needed to understand and navigate the ‘elongated processes’ to attain Direct Payments and/or Personal Health Budgets, many parents described the further challenges of taking on the position of employer, with all of the legal and managerial responsibilities included in this new role.

“You have to develop a really good understanding of how personalised provision is intended to work but the important thing missing for most people is this, the understanding of becoming an employer. If you are an employer, then you have all of the responsibilities of an employer, you need all of skills and knowledge required to run a team and to lead people. If you’ve been looking after a disabled child or adult child as a single parent for the last 15 or 20 years, they are not skills you will necessarily have.”

Parent, February 2017

Families regularly described feelings of ‘isolation’, ‘exclusion’ and ‘loneliness’ as a result of supporting young people/adults with complex needs, a factor noted to be more prevalent amongst those parents taking full responsibility for the care of their child, without a partner or spouse. Such feelings were reported to have a negative impact upon social interactions, decreasing parental confidence and self-esteem while increasing the potential for mental health issues, including e.g. anxiety and depression. Interviewees acknowledged the importance of extended family members/friends in providing a ‘circle of support’, ‘a little respite’ and/or ‘some time for us’, yet several parents noted a reluctance to ‘share my worries’ or ‘over burden others’, something they felt might jeopardise their existing relationships.

“I don’t really have any respite. There isn’t anybody for me, you’re in an atomised position. If I meet with other carers, families in a similar situation, it almost escalates things because you are comparing your dire situations. There are a lot of other parents in very difficult situations. I often feel isolated and that gets me down. I do have a few friends but many of my friends are not carers and so there is a limit as to how much you can go on about your own issues. I really don’t want to do that.”

Parent, February 2017

When asked about the service model delivered by Project Art Works, families described the support provided to those families of individuals with complex needs as 'generous', 'inclusive', 'non-judgmental' and 'meaningful'. In addition to the creative programmes aimed at young people/adults in need of support, PAW delivered three peer network group meetings as part of the six month pilot study. These *Connecting Families* events were reported to 'empower' and 'inspire' participant families, while offering 'practical advice' and 'helpful resources' in establishing individualised care plans. Importantly, meeting with other families and sharing - negative and positive - experiences was evidenced to counter the 'downward spiral' or feelings of 'helplessness' described by many of the parents engaged.

"When I read about PAW, I was blown away, I thought it sounded absolutely amazing! We contacted them and they've been fantastic. They have been so supportive! We went to the first Connecting Families event, that was so helpful because they were the people that inspired me. They showed us how to put our goals down and the main thing I came away with, was to first plan for the week ahead, then the month, then three months and where you might like to be in a year or so. That really helped me."

Parent, February 2017



4.2 Research with support workers

Qualitative data captured via interviews and focus group meetings described those issues affecting support workers in delivering high quality, choice driven lives for individuals with complex needs. Once again, findings concurred with those themes described in the quantitative research, including i.e. financial worries or concerns; lack of statutory, professional training; lack of mentoring and/or regular supervision; feelings of isolation and/or exclusion. Support workers repeatedly attested to the need for ‘a decent salary’, ‘better working conditions’ and ‘recognition’ of the skills required to fulfil this often challenging role. Across the data, interviewees suggested the families they worked with were frequently ill-equipped to employ and manage support staff, especially during those initial stages of setting up personalised provision and/or individualised care plans for their child/adult child.

“There’s a real need for basic people management skills training for Direct Payments clients employing PA’s or support workers. More support is needed for families in setting up systems to run personalised provision, with continued mentoring during the initial period. We need improved hourly rates and better working practices for support workers, since these are a significant impediment to providing what would otherwise be a feasible solution to addressing some of the current problems.”

Support Worker, February 2017

Those support staff who had worked with a range of client families and/or in a diversity of settings noted ‘little consistency’ across the sector, with ‘varying rates of pay’ and ‘very few opportunities’ for career development or progression. In spite of their responsibilities in supporting an individual with complex needs, a lack of ‘meaningful communication’ or ‘regular supervision’ with parents and/or other professionals was reported, which they suggested led to them feeling ‘demotivated’ or ‘under-valued’.

“My supervisions happen with the parent. That person is very busy, so sometimes it happens quite sporadically. We do chat a lot but what would be helpful is to have some feedback from the supervisions that we do have. Maybe a summary of what has been said, points that have arisen and often that doesn’t happen which is a bit demotivating. The informal chatting is useful but there is certainly a lack of continuity with regard to supervisions.”

Support Worker, February 2017

In addition to describing a need for assisting parents in interviewing and selecting appropriate staff, support workers suggested more help was required during the induction period, particularly in ‘building relationships’ while ‘establishing boundaries’ within the family home. Interviewees noted that families often found it difficult to ‘step aside’ in the beginning stages, not always trusting and/or recognising the skills and experience of those individuals they were employing to care for their loved ones. A ‘clarity of roles and responsibilities’ was deemed necessary, with support workers requesting a more detailed description of what was and/or was not felt to be appropriate practice (e.g. eating while working; buying sweets for the person in their care; watching television together).

“There is a place here for educating the families. It’s very hard for a support worker to enter a families’ home and work with their child, whatever the age. I think it is equally hard for a parent to step aside in the family home and have somebody work with them. Building that relationship over the years, if you are allowed to have years, it all hangs in that really difficult balance.”

Support Worker, February 2017

Support workers reported the ‘sensitive nature’ of their role, demanding ‘excellent interpersonal skills’ and ‘continuous flexibility’ in developing trusting relationships with the individual in their charge and other family members. For those staff working alone with a family, the role was described as ‘isolating’ or ‘lonely’ at points, especially if the family did not fully acknowledge the support being provided and/or were less experienced in managing staff. Interviewees described the importance of ‘the right fit’ in terms of matching a client with support worker, maintaining ‘open and honest dialogue’ with parents, ‘developing empathy’ and ‘mutual respect’, in aspiring to meet the needs of all parties while preserving the delicate balance of this ever changing dynamic.

“It is very, very difficult to recruit good people to start with but it’s not a constant and it’s not an inherent thing. It needs to be carefully nurtured in an on-going fashion, otherwise that commitment can soon die. Getting the right people is crucial, people who are flexible and understand the need for flexibility. There needs to be empathy on both sides. It really has to be about the individual’s needs with some meeting of minds in the middle.”

Support Worker, February 2017

In terms of the Project Art Works Pilot Study, a key aim was to provide advice, supervision and training to support workers working directly with families. The six month initiative delivered three peer support network meetings to staff engaged in personalised provision, however participation was low. Those individuals able to take part in these meetings described the experience as ‘interesting’ and ‘useful’, allowing time for ‘sharing diverse experiences’ and ‘reflecting on practice’. In spite of a reported need for such provision, support workers suggested ‘finding time’ to attend meetings outside of their working hours resulted in ‘increased pressure’ and felt ‘like more work’. Attendees suggested any future programmes aimed at support staff should ensure sessions are ‘practical’, ‘inclusive’ and ‘enjoyable’ allowing ‘adequate notice’ to take part. The importance of families ‘recognising the benefits’ of enabling support workers to attend was also noted, with staff reimbursed for time (and travel) expenses incurred by participating in such events.

“There’s a real need for that sharing of information and especially for those of us who work in isolation. Meetings like this are really useful. However, with the social networking and other events, it’s important to have rotas that factor in time for people to go and do stuff. If we are warned about what’s going on far enough in advance we can be flexible and swap shifts, but that all needs to be included in our rotas and we really need to be paid for attending such events.”

Support Worker, February 2017



4.3 Research with stakeholders

Telephone interviews were conducted with key stakeholders and other professionals engaged in the development of services for young people/adults with complex needs, including education, health and social care. Interviewees were aware of national Care Act and Transforming Care requirements in supporting individuals with learning disabilities and/or additional needs. However, stakeholders' understanding and experience of 'personalisation' or 'personalised provision' differed from sector to sector, in spite of a recognition that services should now be driven by this agenda. It was acknowledged that service providers were under 'acute financial constraints', lacking 'a stable workforce' and/or 'appropriate resources', resulting in a disparity between policy and practice, with 'continuous challenges' to deliver individualised care plans.

"In the area of Learning Disabilities, personalised provision is essential. If we take it back to Valuing People, everything was about changing the way that we worked and making it person centred. That has been the driver for the last ten to twelve years. My experience is that our services are increasingly person centred and developed around an individual's need. However, the real extent as to how much that happens varies, the extent to which that is able to happen within financial constraints also varies."

Stakeholder, February 2017

Several stakeholders reported a need to revisit the core meaning of 'personalisation', since professionals across the sector had become 'bogged down' by processes and problems, concentrating on what was 'not possible' in terms of service delivery, rather than finding 'creative solutions' focused upon 'positive outcomes' for the individual and their family. In addition, interviewees noted there was little emphasis placed upon ensuring 'a good quality of life', or how that might be articulated, designed and delivered within the limitations of the current systems of care.

“If I’m honest, I hear it talked about a lot but I don’t actually see it happening. I have a feeling that it’s about personalising provision for the individual and the family, so wider than personalised care. I know about the technical in terms of developing personalised care budgets, which has all got a bit process driven. I think it gets too organisationally driven or problem centred, rather than person-centred.”

Stakeholder, February 2017

Across the data, no stakeholder made reference to ‘the house of care’ or coordinated model of care as described by The Kings Fund¹⁰ nor did they describe an integrated or holistic approach to service delivery. Rather, they reported a ‘mismatch’ between education, health and social care, lacking a coherent framework which resulted in conflict across agencies and/or services. This in turn was noted to cause additional ‘confusion and stress’ for those families attempting to navigate the systems of care, with a ‘negative focus’ upon assessment of need. Stakeholders suggested there remained ‘a need for alignment’ across services, to ensure positive outcomes for those individuals in need of support.

“There is potential for conflict if the systems of having the public sector and third sector, if we’re not all working as one in thinking about how an individual or family need help, that creates potential conflict for the support workers, the family and the individual. This will impact upon aiming to get the best outcomes and so I think there is something about aligning all of those things to get the best outcomes with the individual at the heart of any provision and/or decision making.”

Stakeholder, February 2017

Several stakeholders acknowledged the current allocation provided to families was insufficient to deliver individualised provision in the majority of cases. It was noted that Direct Payments and/or Personal Health Budgets were regularly being used for the ‘nuts and bolts’ of care, with little or no flexibility for ‘meaningful daytime activities’ for the individual in need of support.

“In most cases, families have an allocation that really isn’t sufficient. If there is a level of support for meaningful daytime activities, in most cases families are using that for daytime respite or to supplement support because they just don’t have enough support throughout the week. This means it’s much harder for them to pay for any activities. So it really comes down to the level of budget and whether that is realistic.”

Stakeholder, February 2017

Stakeholders suggested that although there existed examples of effective practice across the sector, there were also many areas in need of improvement. The holistic, individualised model delivered by PAW in supporting those young people/adults with complex needs, their families and support staff was frequently commented upon. In considering those wider and/or longer term implications, several interviewees noted the importance of timely identification and assessment of need - alongside early intervention - in supporting those individuals in need of care.

¹⁰ Coulter, A., Roberts, S. and Dixon, A. (2013). *Delivering better services for people with long-term conditions: Building the house of care*. London: The Kings Fund

“We know we have pockets of good practice and likewise, we have areas of deficits, so we need to enhance both community support and case support in those areas. If issues are picked up earlier, they can be supported earlier and those individuals won’t have to go into an in-patient setting. We also need to get far better at earlier identification or diagnosis and then early intervention.”

Stakeholder, February 2017

As previously described, stakeholders repeatedly described the beneficial support provided by PAW to individuals, families and support workers. An invitation to participate in the research strand of the Project Art Works Pilot Study was met with a highly positive response, with many professionals keen to support this important initiative. In addition to their engagement with the Connecting Families and Peer Support Network events, more than a third of the online survey respondents comprised stakeholders and/or other professionals. Having followed the development of PAW and its work over a period of years, several interviewees attested to the organisation’s ‘immense value’ and ‘truly individualised’ approach in working with young people/adults with complex needs, in contrast to those other services currently on offer to families.

“For those individuals with more challenging needs, PAW has enhanced their communication, given them time to be themselves and a place to be accepted for being themselves. That is something you rarely find in other day activities, where it is more about people fitting to the activity. PAW have succeeded in delivering an entirely individualised provision! With those individuals engaged in PAW, it’s meeting their sensory needs on a number of levels, enabling them to be calmer, then enhancing their communication and improving behaviour.”

Stakeholder, February 2017

5 Learning

Findings from the present study concur with those described in the literature reviewed, including i.e. a lack of coherence in providing 'personalised provision' across the sectors of education, health and social care; the predominance of economic, educational and social barriers for individuals with complex needs and behaviours perceived as challenging; the financial and emotional stresses placed upon families and care workers; the need for high quality, standardised training for professionals supporting individuals with complex needs; a need for commissioners to focus upon improving the quality and diversity of community provision. The research also echoes issues presented to those providers of health and social care, local authorities and regulators in the Department of Health's Final Report (2012) into Winterbourne View and its recommended Programme of Action¹¹:

- Commission the right model of care to focus on the needs of individual people, looking to avoid factors which might distress people and make behaviours more challenging, thereby building positive relationships in current care settings
- Listen to people with learning disabilities and their family carers in developing person-centred approaches across commissioning and care
- Only local action can guarantee good practice, stop abuse and transform local services
- Build understanding of the reasonable adjustments needed for people with learning disabilities who have a mental health problem, for them make use of local generic mental health beds
- Focus on early detection, prevention, crisis support and specialist long term support to minimise the numbers of people reaching a crisis which could mean going into hospital
- Work together to plan carefully and commission services for the care of children as they approach adulthood to avoid crises and commission flexible, community-based services.

With the findings of the present study in mind - in addition to those themes recurring throughout the literature - the subsequent recommendations are for the consideration of Hastings & Rother CCG, Project Art Works and all other stakeholders, in order to assist in the processes of reflection, discussion and forward planning. The ensuing list aims to focus upon those issues deemed most critical by the research, in supporting PAW and its partner organisations to establish an order of priorities for developing and delivering robust, evidence based strategies, leading to meaningful, individualised support. Learning outcomes and recommendations are presented as follows:

- Family related learning
- Support worker related learning
- Sector related learning.

¹¹ Department of Health (2012). *DH Winterbourne View Review Concordat: Programme of Action*. London: DoH

5.1 Family related learning

Families engaged in the present study reported a number of critical issues affecting those parents/carers supporting children/adult children with complex needs and behaviours perceived as challenging: financial and/or care budget concerns; understanding and/or navigating the systems of care; mental and/or emotional stress; feelings of isolation and/or exclusion. Participant families also described the assistance needed for them to deliver high quality, choice driven lives for their loved ones with complex needs: practical support with financial and/or legal issues; templates or toolkits for planning individual care plans; online resources to help understand the language and/or systems; buddying or mentoring from families with more experience. Although families referred to those organisations currently commissioned or recommended by East Sussex County Council to provide support (e.g. Amaze, People Plus, Spectrum), parents/carers frequently noted a lack of specialist knowledge and/or skills required to work with individuals with behaviours perceived as challenging. This was described in contrast to the unique service provided by PAW and more specifically, the pilot study programme.

In addition to capturing valuable evidence with which to further develop personalised provision for individuals with learning disabilities and/or autism across East Sussex, the Project Art Works Pilot Study began to address some of the aforementioned challenges for parents/carers aiming to establish and/or manage individualised care plans. For those families of children/adult children with complex needs in need of both practical and emotional support, the PAW Pilot Study was evidenced to result in many positive outcomes, including a greater awareness and understanding of independent provisions. This in turn enabled parents/carers to begin navigating the systems of care, in order to gain the most appropriate services for their loved ones. The Peer Network Forums facilitated connections between families, support workers and professionals from across the sector, providing opportunities for parents to seek advice and raise issues in an inclusive and non-judgemental setting. This mode of delivery was noted to result in a 'levelling' between service users and providers, resulting in increased confidence and self-esteem for families. Importantly, attending the Peer Network Forums was evidenced to reduce social isolation for those family members managing personalised provision alone, specifically lone parents unable to work due to their role as main carer for their loved one with complex needs. Importantly, the support provided by other families experiencing similar issues and/or who had already navigated the systems of care was noted to engender a sense of inclusion, lessening emotional stress and improving mental wellbeing.

Project Art Works aims to continue the delivery of its Family Support Network events in collaboration with all education, health and social care partners from across the county. From the findings of the present study, it is evident this resource is perceived as essential in maintaining the wellbeing of families in need of support, while providing valuable advice and resources related to the management of Direct Payments and/or Personal Health Budgets. Project Art Works has now established an important network of families from across East Sussex, all of whom have attested to the importance of its services in supporting the delivery of individualised care to young people/adults with complex needs.

5.2 Support worker related learning

Support staff participating in the Project Art Works Pilot Study reported a number of significant issues affecting their practice in supporting young people/adults with complex needs and behaviours described as challenging: financial worries or concerns; a lack of statutory, professional training; a lack of mentoring and/or regular supervision; feelings of isolation and/or exclusion. Support workers also described the assistance needed for them to deliver high quality, choice driven lives for those individuals with complex needs in their charge: financial recognition for their work; positive professional attitudes towards this field of work; high quality, standardised professional training; regular mentoring and/or supervision. In addition to capturing evidence regarding those issues affecting the recruitment of support staff delivering family run provision, the PAW Pilot Study began to explore some of those challenges in managing and retaining staff, in the delivery of well-rounded personalised care.

One key aim of the pilot study was to provide advice, supervision and training to support workers working directly with families. The six month initiative delivered three Support Worker Network meetings to those staff engaged in personalised provision, however participation was low. The new network was intended to provide advocacy, on-going support, training and encouragement to support workers working with families in receipt of Direct Payments and/or Personal Health Budgets. The network was identified as a need - by support workers and families - to address those countywide challenges in recruiting and retaining support staff, resulting in negative impacts upon children, young people and adults in need of Personal Assistants and/or other specialised support. In spite of the difficulties experienced in engaging substantial numbers during the past months, the pilot study has enabled PAW to explore those reasons for non-attendance:

- Support staff do not as yet identify as a recognised professional group or workforce
- Long and unsociable working hours, resulting in little time for additional meetings or events
- Support staff do not realise the potential professional development provided by such events
- Many families do not recognise the value of advocacy and support for their staff in sustaining commitment and developing practice.

Project Art Works aims to continue to develop the Support Worker Network in collaboration with its education, health and social care partners. This new initiative is likely to require time to engender increased support and momentum, as potential participants gain an understanding of how such a network might provide support. PAW has already engaged with a core group of support staff who contributed to the pilot study and have since established a dedicated Facebook page. This will enable support workers to share information and articulate the group's further ideas and/or suggestions. In these ways, it is hoped a valuable local resource will be developed, with the needs of support workers at its heart.

5.3 Sector related learning

The Government and leading organisations across the health and care systems are committed to transforming care for people with learning disabilities and/or autism with challenging behaviours. In recognition of the deficits, NHS England commissioned Sir Stephen Bubb to investigate how the transformation required by individuals with learning disabilities, their families and support staff might be hastened. Since the Bubb report was published in 2014¹², NHS England, the Department of Health (DH), the Local Government Association (LGA), the Association of Directors of Adult Social Services (ADASS), the Care Quality Commission (CQC) and Health Education England (HEE) have pledged to strengthen the Transforming Care delivery programme, building on the work of the last five years since the Winterbourne View Hospital Serious Case Review and accelerating progress where it has been slow.

These stakeholders aim to reinforce the Transforming Care delivery programme by creating a new delivery board, bringing together the 'senior responsible owners' from each organisation. The work to be taken forward through this programme is described as 'wide-ranging, co-designed and co-produced' with people with learning disabilities and/or autism, their families, clinicians, commissioners, service providers, national organisations in the health and care system (e.g. Skills for Care, Skills for Health, Public Health England) and other stakeholders. The Bubb report sets out those actions to have been taken in 2015, transforming care for the most vulnerable members of society:

- Empowering people and families: the needs and wishes of people who require support, their families and carers are listened to, are at the heart of planning and delivery of care
- Getting the right care in the right place: ensuring the current care system works for clients and families, designing and implementing individualised changes for the future
- Regulation and inspection: tightening regulation and inspection of providers, strengthening providers' corporate accountability, responsibility and management, to improve quality of care
- Workforce development: improving care quality and safety through raising workforce capability
- Data and information: underlying all the aforementioned work streams will be a focus on ensuring the right information is available at the right time to those people who need it.

At a local level and in response to the national Transforming Care agenda, the East Sussex Better Together (ESBT) programme was established in August 2014¹³, to support the transformation of health and social care services across the county. It is led by the two local NHS Clinical Commissioning Groups (i.e. Eastbourne, Hailsham and Seaford CCG and Hastings & Rother CCG), East Sussex County Council, East Sussex Healthcare NHS Trust and Sussex Partnership NHS Foundation Trust. The ESBT Alliance has been developed to better integrate the systems of: primary prevention, primary and community care, social care, mental health, acute and specialist care, demonstrating how an annual budget of £850m might best meet the health and care needs of all people across East Sussex.

¹² Winterbourne View: Time for Change. Transforming the commissioning of services for people with learning disabilities and/or autism (2014). Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb

¹³ East Sussex Better Together: A guide (2015). East Sussex County Council with Sussex Partnership NHS Foundation Trust

The ambition is to develop a fully integrated health and social care system in East Sussex by 2018, ensuring every patient or service user enjoys 'proactive, joined up care' that supports them to live 'as independently as possible' and achieve 'the best possible outcomes'. Progress has been made in certain areas but service providers acknowledge there remains much work to be done. Professionals working in the sectors of education, health and social care who participated in the Project Art Works Pilot Study reported significant, persistent issues affecting their practice in supporting young people/adults with complex needs and challenging behaviours: continuing financial constraints and budget reductions; a lack of political support; a conflict between agencies and/or services; a negative focus on assessment of need; the challenge to articulate 'a good quality of life'; a lack of continuity in staff and/or services; a lack of workforce capability and/or development; a lack of high quality service providers.

Transforming care for people with a learning disability and/or autism requires commissioners from local government and the NHS to work together to reshape services, with oversight and support from Health and Wellbeing Boards. NHS England, the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS) should be working together to support commissioners to do so in a coordinated way. However, in order to successfully deliver this integrated programme of care, there clearly needs to be adequate financial and professional support. At a time when the political agenda is focused upon improving public services - particularly for those in greatest need - councils are being subjected to year on year funding cuts. Their capacity to deliver positive change is being reduced exactly when it is most needed. Although total gross expenditure for social care during 2015-16 saw an 18% increase in cash terms to £14.36 billion, in real terms this sum equates to a 2% decrease.

Budget restrictions have naturally impacted upon Adult Social Care expenditure across East Sussex, leading to a year on year funding gap of £6 million and resulting in a 30% cut in monies available for care packages, with voluntary sector expenditure reduced even further¹⁴. In addition, those professionals interviewed for the current study suggest social care provision for those young people/adults with complex needs and behaviours that challenge may be considered as 'low on the political agenda', due to the small numbers in need of support, as compared with the total population. If the ESBT Alliance aims to transform the care of those individuals, while meeting the requirements of the Care Act in delivering meaningful, personalised provision by 2018, immediate action is required. The challenge to deliver truly individualised care to those young people and adults in need of support cannot be tackled by health and social services alone. Innovative solutions that do not cost more than current services are therefore required. Working in close collaboration with user-led organisations or 'experts by experience' such as those represented in the current study are to be recommended, in order to develop meaningful, respectful relationships and improved, sustainable services.

¹⁴ East Sussex County Council (2014). *Financial Strategy and Budget Summary*. Lewes: ESCC

5.4 Recommendations

5.4.1 Short term

- Project Art Works is recommended to disseminate the findings of the present study to all participants and funders, in order to stimulate dialogue regarding the best ways forward; such discussions will be of support in establishing a new charitable user led organisation, while continuing to develop the valuable work begun during the pilot phase.
- A high profile presentation event is recommended, in order to share findings of the Project Art Works Pilot Study with the widest range of stakeholders including: steering group members; participant families and support workers; education, health and social care service providers.
- Project Art Works should invite the East Sussex Learning Disability Partnership Board, the Direct Payments Peer Support Group and Continuing Healthcare Team to both review and discuss the findings of the present study. Early consultation with these key stakeholders will be of value in developing and improving personalised provision across the county.

5.4.2 Medium term

- Project Art Works and its stakeholder organisations are recommended to take account of the issues and needs raised by research participants, in developing the work begun by the pilot study and improving personalised provision for all young people/adults with complex needs and behaviours that challenge:
 - Guidance for families in establishing e.g. individual care plan, circle of support, deputyship
 - Skills training for families in the recruitment and employment of care workers
 - Skills training for families in budgeting systems and management of Direct Payments/PHBs
 - Mentoring scheme for families regarding the management of PA's and/or support workers
 - Videos and/or visual guides for families to use as induction tool for support staff.
- Project Art Works and its stakeholder organisations are recommended to take account of the issues and needs raised by research participants, to ensure the successful recruitment and retention of support staff working with young people/adults with complex needs and behaviours that challenge:
 - Improved and standardised hourly rates for PA's and/or support workers
 - High quality, professional training opportunities to support career development
 - An online resource bank of care workers with details of skills and experiences
 - Apps for communicating the day to day experiences of clients with complex needs
 - Networking opportunities for support staff to share skills and experiences.

- Project Art Works and its stakeholder organisations are recommended to take account of the issues and needs raised by research participants, to ensure health and social care professionals are adhering to the legal requirements of national policies related to young people/adults with complex needs and behaviours that challenge:
 - One continuous professional adviser to be allocated to each client and family
 - Improved coordination of both information and resources across the sector
 - Clearer guidelines offered to families seeking Direct Payments/Personal Health Budgets
 - A more consistent approach across the sectors of education, health and social care
 - Training for professionals to improve understanding and delivery of personalised provision.

5.4.3 Longer term

At a national level, the Care Act (2014) sets out the duties for local authorities and partners, with new rights for service users and carers. The statutory principle of ‘individual wellbeing’ underpins the Act and is the driving force behind care and support. Findings from the Project Art Works Pilot Study suggest that service providers remain some distance from placing the wellbeing of clients, families and/or carers at the heart of service delivery. At a local level, the Sussex Transforming Care Partnerships Plan (May 2016) for people with learning disability and/or autism details how Sussex will transform care for individuals with complex needs and behaviours that challenge, implementing the new service model by March 2019. The plan acknowledges that while there has been considerable engagement with stakeholders across Sussex to date, there remains much work to be done in this area.

Stakeholders engaged in the Project Art Works Pilot Study suggest they are committed to ensuring that people with learning disabilities and their families are effectively involved in the development of health and social care services. However, the experience of families participating in the research study describes a significant mismatch between policy and practice. With reference to the aims of the Transforming Care Partnerships Plan and the Care Act, alongside those findings from the current study, the following longer term recommendations are therefore advised:

- Increased and improved consultation with families, support workers and other professionals
- More rigorous monitoring and evaluation of current service specifications and provision
- Reconfiguration of health, social care and education services to include more effective transition from children’s to adult services
- The further development of peer-to-peer links and support networks
- Mapping exercise to investigate alternative approaches to personalisation across the UK
- More rigorous outcome focussed studies investigating diverse models of personalised provision
- Increased centralised support that does not rely entirely upon Local Authorities.



6 Summary and conclusions

Since 2004, Project Art Works has supported children, young people and adults with complex and additional needs alongside their families, carers and professionals, via a wide range of art focused projects. In addition to its creative programmes, PAW has extensive expertise in specialist systems of support including personalisation, total communication, positive behaviour support. PAW artists work intensively with participants on an individual basis, supporting each to engage with materials and processes, thereby enabling a freedom and sense of purpose not dictated by disability or impairment.

In 2016, Project Art Works received a small grant from the Hastings & Rother Reducing Health Inequalities Fund to conduct a six month pilot study to assess current support for independent provisions for people who have complex behavioural support needs, their families and support workers. Through the pilot project, PAW has been investigating what kinds of support are already available and/or whether new models of support might be needed to ensure high quality and successful personalised provision. The aim of this report then has been to present findings from the Project Art Works Pilot Study, as described by participant parents, support workers, carers and other professionals supporting young people/adults with complex needs.

The call for a more personalised, better co-ordinated approach to managing care for people with long-term conditions and/or disabilities has been embraced by numerous advisory bodies, advocacy groups, governments and agencies from across the UK during the past decade. However, this requires making the perspective of the patient/service user the organising principle of integrated care. In 2012, a report by the Richmond Group of Charities and The King's Fund¹⁵ outlined the service components needed to achieve this aim:

¹⁵ Richmond Group of Charities and The King's Fund (2012). *From vision to action: making patient-centred care a reality*. London: The Kings Fund

- Patients engaged in decisions about their care
- Supported self-management
- Co-ordinated care
- Prevention, early diagnosis and intervention
- Emotional, psychological and practical support.

The Government's Mandate for NHS England¹⁶ requires it to 'ensure the NHS becomes dramatically better at involving patients and their carers, empowering them to manage and make decisions about their own care and treatment' (Department of Health, 2012). This includes the aspiration that individuals with a long-term condition, including those with disabilities and/or mental health issues, should be offered a personalised care plan that reflects their preferences and agreed decisions. However, only through a development of community provision might services achieve these ambitions. A mandatory national commissioning framework is required that delivers expansion, pooled budgets, and with a focus upon individual needs rather than system boundaries. The role of user led, community based organisations that both advocate for and provide services for people with learning disabilities and/or autism is critical to fulfilling these aims, as are the individuals themselves, their families, carers, clinicians, managers and professionals across the health service and in local councils, who need to work together to achieve this rapid turnaround. In tackling this challenge, Sir Stephen Bubb (2014) suggests a major extension of community delivery models is required, driven by improved commissioning and crucially, the empowerment of people with learning disabilities and/or autism and their families.¹⁷

Through its advocacy work, creative programmes, publications and high profile exhibitions, Project Art Works seeks to confront these issues, while supporting those individuals with complex needs, their families, care workers and other professionals across the sector in delivering truly personalised provision. This investigation has been the first step in providing an understanding of those critical issues affecting families, support workers and other professionals in delivering high quality, choice driven lives for individuals with complex needs. The findings have described many challenges for both individuals and organisations, including e.g. continuing financial constraints and budget reductions; a lack of political support; conflict between agencies and/or service providers; a serious mismatch between policy and practice. The research process has also afforded time for discussion and reflection between families, support workers and service providers. Importantly, it has encouraged stakeholders to assess the value of work delivered by Project Art Works to children, young people and adults with complex needs and behaviours perceived as challenging.

¹⁶ Department of Health (2012). *DH Winterbourne View Review Concordat: Programme of Action*. London: DoH

¹⁷ Bubb, S. (2014). *Time for Change: Transforming the commissioning of services for people with learning disabilities and/or autism*. London: Transforming Care and Commissioning Steering Group

In the context of a challenging broader economic and social environment, the research findings from the present study are therefore significant and timely. The Project Art Works Pilot Study has provided core evidence to inform the development of a new charity to address the current deficits in service provision and implement a longer term programme of support including: shared budgets; cross sector training and development; informal networking events; improved skills for families and support workers; the sharing of best practice. The proposed charity aspires to work with all stakeholders to provide a peer led support worker agency and family support provision, in partnership with health and social care services. This potential organisation would also be eligible for a wider range of funding opportunities, thereby extending costs across a broad income stream.

Within the confines of the present study, the surface has been lightly scratched - at least in terms of research - and has naturally prompted more questions than it may have answered. However, through a review of the literature, findings from the online survey, interviews and focus groups, it is hoped this investigation has provided at least some insight into those issues concerning the delivery of personalised provision to young people/adults with complex needs and behaviours perceived as challenging. Importantly, it has provided a rich source of data for discussion and reflection, leading to a greater understanding of the challenges apparent for families, support workers and other professionals in working towards a truly integrated and individualised model of care.

“Project Art Works offers something, rather than nothing! I feel supported for the first time, since my daughter has had to come out of education because of her challenging behaviour. Supported because of being with families who are going through the same issues and also, because Kate has experienced it with her own son. It’s the first time I’ve been to anything like this for a long time. It feels positive and now I feel a bit more able to tackle the challenges!”

Parent, February 2017

7 References and bibliography

- Bauer, A. (2015). *The economic case for early and personalised support for parents with learning difficulties*. PSSRU Discussion Paper, London School of Economics. London: LSE
- Bennett, S. (2016). *Integrated Personal Commissioning and Personal Health Budgets: Emerging Framework*. London: NHS England
- Brown, H., Orlowska, D. and Mansell, J. (1996). From complaining to campaigning, in J. Mansell and K. Ericsson (Eds.), *Deinstitutionalisation and Community Living* (pp. 225-240). London: Chapman & Hall
- Bubb, S. (2014). *Time for Change: Transforming the commissioning of services for people with learning disabilities and/or autism*. London: Transforming Care and Commissioning Steering Group
- Centre for Workforce Intelligence (2013). *Big picture challenges for health and social care Implications for workforce planning, education, training and development*. London: CFWI
- Clement, T. and Bigby, C. (2009). *An evaluation of an exemplary residential support service for people with severe intellectual disability and challenging behaviour*. School of Social Work and Social Policy, La Trobe University, Melbourne
- Community and Mental Health Team Health and Social Care Information Centre (2015). *Learning Disability Census Report: Experimental Statistics*. London: HSCIC
- Cornes, M., Mathie, H., Whiteford, M., Manthorpe, J. and Clark, M. (2015). *The Care Act, Personalisation and the New Eligibility Regulations. A discussion paper about the future of care and support services for homeless people in England*. LSE/Kings College London/University of Liverpool
- Coulter, A., Roberts, S. and Dixon, A. (2013). *Delivering better services for people with long-term conditions: Building the house of care*. London: The Kings Fund
- DCLG (2013). *The Cost of Troubled Families*. London: HMSO
- Department of Health (2014). *Transforming Primary Care Safe, proactive, personalised care for those who need it most*. London: Department of Health
- Department of Health (2013). *Understanding personal health budgets*. London: Department of Health
- Department of Health (2012). *DH Winterbourne View Review Concordat: Programme of Action*. London: Department of Health
- Department of Health (2010). *Improving the health and well-being of people with long term conditions*. London: Department of Health
- Department of Health (2009). *NHS and Community Act*. London: Department of Health
- Department of Health (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities 'Making it happen for everyone.'* London: Department of Health
- Department of Health (2008). *Making a strategic shift to prevention and early intervention: a guide*. London: Department of Health
- Department of Health (2007). *The Mental Health Act*. London: Department of Health
- Department of Health (2007). *Services for People with learning disabilities and Challenging Behaviour or Mental Health Needs*. London: Department of Health
- Department of Health (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs*. London: Department of Health
- Department of Health Commissioning and System Management Directorate (2009). *Improving the health and wellbeing of people with learning disabilities*. London: Department of Health.
- Disability Rights Commission (1995). *Disability Discrimination Act*. London: HMSO

Dowling, S., Manthorpe, J. and Cowley, S. (2006). *Person-centred planning in social care: A scoping review*. London: Joseph Rowntree Foundation

East Sussex County Council (2015). *East Sussex Better Together: A guide*. East Sussex County Council/Sussex Partnership NHS Foundation Trust

East Sussex County Council (2014). *Financial Strategy and Budget Summary*. Lewes: ESCC

East Sussex County Council (2002). *Integration Project: Proposal for Establishment of Health and Social Care Community Learning Disability Teams*. Lewes: ESCC

Emerson, E. and Robertson, J. (2008). *Commissioning person-centred, cost-effective, local support for people with learning disabilities*. London: Social Care Institute for Excellence

Fitzpatrick, J. (2010). *Personalised Support: How to provide high quality support to people with complex and challenging needs - learning from Partners for Inclusion*. Sheffield: The Centre for Welfare Reform

Fulton, K. and Winfield, C. (2008). *Person-centred commissioning now: a pathway approach to commissioning learning disability support*. London: Improvement and Development Agency

General Assembly of the United Nations (1948). Universal Declaration of Human Rights

Gitsham, N., Reynolds, T., Bottomley, S., Crosby, N. and Nicoll, T. (2015). *Personal health budgets and young people with complex needs*. West Midlands: In Control

Goldbart, J. and Caton, S. (2010). *Communication and people with the most complex needs: What works and why this is essential*. Research Institute for Health and Social Change, Manchester Metropolitan University (MMU)

Government Equalities Office (2010). *Equality Act*. London: HMSO

Government Equalities Office (1995). *Disability Discrimination Act*. London: HMSO

Gridley, K. (2010). Good support for people with complex needs: What does it look like and where is the evidence. NIHR School for Social Research

Harflett, N., Turner, S. and Bown, H. (2015). *The impact of personalisation on the lives of the most isolated people with learning disabilities: A review of the evidence*. Bath: National Development Team for Inclusion

Hastings and Rother Clinical Commissioning Group (2016). *Healthy Hastings and Rother: Working together to improve health and wellbeing*. East Sussex Better Together/NHS Hastings and Rother CCG

Hussein, S., Rapaport, J., Manthorpe, J., Moriarty, J. and Collins, J. (2006). Paying the piper and calling the tune? Commissioners' evaluation of advocacy services for people with learning disabilities, in *Journal of Intellectual Disabilities*, 10, 75-91

Learning Disabilities Observatory (2016). *People with learning disabilities in England 2015*. London: Public Health England

Legislation.gov.uk. (2014). *Care Act 2014*. [online] Available at: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

Legislation.gov.uk. (2014). *Children and Families Act 2014*. [online] Available at: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

Lewington, W. and Clipson, C. (2004). *Advocating for Equality*. London: Scope

Lingard, J. (2012). *Personalisation for People with Learning Disabilities & Behaviour Described as Challenging: 2011/12 Project Report*. Chatham: Challenging Behaviour Foundation

McGill, P., Cooper, V. and Honeyman, G. (2010). *Developing better commissioning for individuals with behaviour that challenges services - a scoping exercise*. Canterbury/Chatham: Tizard Centre/Challenging Behaviour Foundation

- McGill, P., Papachristoforou, E. and Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour, in *Child: Care, Health and Development*, 32(2), 159-165
- Morris, J. (2011). *Rethinking Disability Policy*. London: JRF
- NDTI (2013). *Supporting staff working with people who challenge services. Guidance for employers*. Bath: NDTI
- NHS England (2016). *Personalised care and support planning handbook: The journey to person-centred care*. Person Centred Care/Coalition for Collaborative Care/Medical directorate. London: NHS
- NHS England (2015). *The NHS Constitution for England*. London: NHS
- NHS England (2015). *Transforming Care for People with Learning Disabilities: Next Steps*. London: NHS
- NHS England (2015). *Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. Service model for commissioners of health and social care services*. London: NHS
- NHS England (2014). *Meeting needs and reducing distress. Guidance on the prevention and management of clinically related challenging behaviour in NHS settings*. London: NHS
- NHS England (2014). *Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges*. London: NHS/Local Government Association
- NHS England (2007). *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*. London: NHS
- Nunkoosing, K. and Haydon-Laurelut, M. (2011). Intellectual disabilities, challenging behaviour and referral texts: a critical discourse analysis in *Disability & Society*, 26:4, 405-417
- Rankin, J. and Regan, S. (2004). *Meeting Complex Needs: The Future of Social Care*. London: Turning Point
- Richmond Group of Charities and The King's Fund (2012). *From vision to action: making patient-centred care a reality*. London: The Kings Fund
- Rosengard et al (2007). *A literature review on multiple and complex needs*. Edinburgh: Scottish Executive Social Research Council
- Sussex Partnership NHS Foundation Trust (2016). *Sussex Transforming Care Partnerships Plan for people with learning disability and/or autism*. Worthing: Sussex Partnership NHS Foundation Trust
- Townsley, R., Marriott, A. and Ward, L. (2009). *Access to Independent Advocacy: An Evidence Review*. London: Office for Disability Issues
- Turner, S. and Giraud-Saunders, A. (2014). *Personal Health Budgets: Including people with learning disabilities*. Bath: NDTI
- United Nations (2006). *UN Convention on the Rights of Persons with Disabilities*
- West, K. (2013). The grip of personalisation in adult social care: Between managerial domination and fantasy in *Critical Social Policy*, 33 (4) 638-657
- Wodehouse, G. and McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? in *Journal of Intellectual Disability Research*, 53, 644-653
- Wolfson, P., Holloway, F. and Killaspy, H. (2009). *Enabling recovery for people with complex mental health needs: A template for rehabilitation services*. Faculty of Rehabilitation and Social Psychiatry of the Royal College of Psychiatrists

8 List of images

Cover page images (from top):

Project Art Works Open Day, John Cole 2016

Tuesday Studios at Hastings Pier, Project Art Works 2016

Project Art Works Open Day, John Cole 2016

Art Breaks at Ore Valley Adventure Playground, Project Art Works 2015

Art Breaks Saturdays, Project Art Works 2016

Report images:

P11 Tuesday Studios at Hastings Pier, Project Art Works 2016

P14 Art Breaks Saturdays, Project Art Works 2016

P22 Art Breaks at Ore Valley Adventure Playground, Project Art Works 2015

P24 Tuesday Studios, Project Art Works 2014

P27 Project Art Works Open Day, John Cole 2016

P30 BBC South East Today Interview, Project Art Works 2016

P40 Art Breaks at Ore Valley Adventure Playground, Project Art Works 2015

i. Preliminary Review of Studies

Report/Study	Design	Key findings	Comments
<p><i>“Personalisation for People with Learning Disabilities and Behaviour Described as Challenging: 2011-12 project report.”</i></p> <p>Lingard, J. (2012). The Challenging Behaviour Foundation</p>	<p>The project’s aim was for 26 people with learning disabilities and behaviour described as challenging to have a personalisation plan for all aspects of their life in place by the end of the project. The project also wanted to learn about what barriers and solutions there were to developing personalisation plans, in particular, to see how people could access housing, what might be stopping this and how the barriers could be overcome. A further aim was to see if better quality outcomes could be achieved at a lower cost than some of the high cost services typically being commissioned.</p> <p>Qualitative methods included:</p> <ul style="list-style-type: none"> - Project team had regular contact with 10 care managers and in-depth contact with seven - Positive behavioural support consultant carried out in-depth analyses of service users’ behaviour for care managers, providing detailed reports - Aim to advise care managers as to whether the commissioned service was delivering the sought outcomes, whether it could be supported to deliver improved outcomes or whether a different service was needed. 	<p>Project designed and agreed through the East Midlands JIP in 2010 before cuts were made in public sector spending. Many involved in discussions to commission project had left by time project started in summer 2011. This was after first major round of local authority and NHS management reductions, leaving many managers unsure what their jobs were or whether they would lose them in next round of cuts.</p> <p>There was very little evidence of person-centred planning in relation to the futures of people referred to the project. It was not possible to provide consultancy around future housing and support arrangements when this had not taken place, as it would have meant assuming that people should move without being clear why (what was not working about the existing situation) and what for (what different outcomes were sought from a different lifestyle). Project resources were already committed and not able to be diverted for person-centred planning.</p>	<p>The Personalisation Project was run by the Challenging Behaviour Foundation (CBF) from summer 2011 to summer 2012. It was commissioned by the East Midlands regional Joint Improvement Partnership and Strategic Health Authority in the East Midlands. Funding from the Department of Health enabled inclusion of families living in other parts of the country.</p> <p>However, a lack of continuity in staff and a lack of resources resulted in delivery problems. This in turn impacted upon outcomes for participants and the project as a whole. Further research in this area is suggested by the project team.</p> <p>The CBF will review its information resources and update these to ensure they help families and professionals in search of personalisation for individuals, with additions to the website. Families are invited to explore the existing resources which are available free to all families and which can be found on the Challenging Behaviour Foundation’s website.</p>

Report/Study	Design	Key findings	Comments
<p data-bbox="114 256 573 352"><i>“Developing better commissioning for individuals with behaviour that challenges services - a scoping exercise.”</i></p> <p data-bbox="114 440 573 536">McGill, P., Cooper, V. and Honeyman, G. (2010). Canterbury/Chatham: Tizard Centre/Challenging Behaviour Foundation</p>	<p data-bbox="616 256 1111 352">Scoping exercise to map issues ‘from a distance’ and determine where future work was likely to be most useful</p> <p data-bbox="616 384 1111 448">In-depth consultations with the families of six individuals with behaviour that challenges</p> <p data-bbox="616 480 1111 608">Interviews with eight local authority/health commissioners, to identify obstacles and consider support needed to help service development</p>	<p data-bbox="1160 256 1637 320">Families reported significant barriers to personalised service development/delivery:</p> <ul data-bbox="1160 352 1702 624" style="list-style-type: none"> - Lack of professional expertise in understanding or responding to challenging behaviours - Access to services extremely difficult other than at times of crisis - Lack of support/training for carers, with detrimental effects on physical/mental health - Families not included as essential partners in planning for relatives/loved ones. <p data-bbox="1160 655 1666 719">Commissioners reported significant barriers to personalised service development/delivery:</p> <ul data-bbox="1160 751 1702 1230" style="list-style-type: none"> - No evidence of local work to implement the recommendations of revised Mansell Report - Continuing lack of coordination between adult/children’s services - Lack of systematic commissioning framework based on quantity and/or nature of local need - Lack of confidence in ability of locally available providers to deliver high quality support to people perceived as challenging - Continuing difficulties between local authorities and NHS in coordinated and integrated working - Lack of collaboration and understanding (in some areas) between commissioners and clinical support services. 	<p data-bbox="1727 256 2130 320">National recommendations and support for commissioners included:</p> <ul data-bbox="1727 352 2157 1086" style="list-style-type: none"> - Programme of nationally-coordinated work should be developed to support local commissioners (in every region) to implement existing guidance - Programme should include attention both the development/redevelopment of personalised support and the more systematic commissioning of provision which has capacity to prevent and intervene earlier with challenging behaviour and mental health problems - Programme of dissemination activities centred on a new website should be developed to share lessons with all commissioners, collate evidence and examples of good practice in a manner accessible to commissioners, and encourage the development of specialist networks within the commissioning community.

Report/Study	Design	Key findings	Comments
<p><i>“The impact of personalisation on the lives of the most isolated people with learning disabilities: A review of the evidence.”</i></p> <p>Harflett, N., Turner, S. and Bown, H. (2015). National Development Team for Inclusion</p>	<p>Evidence review to investigate impacts of personalisation for the most isolated people with learning disabilities in the UK</p> <p>Systematic searches conducted using academic search engine, Social Care Online database and websites of relevant organisations</p> <p>Overview of findings from c.20 studies reporting evidence on impact of specific mechanisms including personal health budgets, direct payments and person-centred planning</p>	<p>Three isolated groups of people with learning disabilities without access to personalisation: those with complex needs; those in residential care or out of area placements; those without families. Commissioners reluctant to offer self-directed support to those deemed incapable of managing own support due to severity of needs.</p> <p>Significant inequalities regarding which people likely to receive a person-centred plan. Those with learning disabilities and/or behavioural problems, autism or health problems less likely to attain person-centred plan and/or appropriate level of benefit. Also less likely to benefit in areas of social networks, contact with friends/family, hours and range of community activities.</p>	<p>Review highlights lack of research in the field, specifically in relation to individuals with complex needs and behaviours described as challenging.</p> <p>Findings highlight that personalisation can produce positive outcomes for some of the most isolated people with learning disabilities and behaviours described as challenging. NDTi are planning further work to address this gap in knowledge bank.</p>
<p><i>“An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties.”</i></p> <p>McConkey, R., Bunting, B., Ferry, F., Iriarte, E. and Stevens, R. (2013). Genio Trust and University of Ulster, N. Ireland</p>	<p>Evaluation of 20 projects in 2010/11 to facilitate personalised housing and support arrangements for 200 people with intellectual disabilities, mental health issues and physical impairments. Study included: those moving from congregated settings to personalised arrangements; those moving from congregated settings to community group homes; those who continued to live with families.</p> <p>Interviews at three time points with people supported by projects, their relatives and key workers. Additional information gathered on costs, use of community and hospital services and social security benefits claimed.</p>	<p>Comparisons made across domains reflecting service arrangements and quality of life over 20 month period, during 2010-11.</p> <ul style="list-style-type: none"> - Improved quality of life for individuals - Congregated settings most expensive - People living with families have best support, leading to better outcomes over time - Group homes do not offer personalised accommodation or support - It takes at least a year to see positive change - Community engagement/social relationships need intensive support - Building community links takes time and should be seen as essential part of support provided. 	<p>Diverse projects had varied success in relocating people over time period of evaluation. This resulted in a complex evaluation which despite the sizeable number of people studied, along with variations among people and settings made it difficult to draw definitive conclusions as to the impact of new living arrangements on people’s lives.</p> <p>A range and variety of personalised housing provision means individual needs can be better met. Longer-term follow-up is needed particularly to identify the sustainability of changes.</p>

Report/Study	Design	Key findings	Comments
<p data-bbox="114 256 521 355"><i>“The economic case for early and personalised support for parents with learning difficulties.”</i></p> <p data-bbox="114 443 562 539">Bauer, A. (2015). Personal Social Services Research Unit, London School of Economics</p>	<p data-bbox="616 256 1122 496">This document presents evidence of the costs and economic consequences linked to earlier and personalised support for parents with learning difficulties. It consists of economically relevant information gathered from projects that provide this kind of support as well as of information from the literature.</p> <p data-bbox="616 528 1122 624">Economic information included about the costs and cost-effectiveness of interventions as well as long-term impacts if support not available.</p> <p data-bbox="616 655 1122 783">Literature review to identify evidence on the costs and economically relevant outcomes of person centred interventions that support parents with learning disabilities.</p> <p data-bbox="616 815 1122 911">Semi-structured questionnaires delivered to practitioners working for projects as part of Working Together With Parents Network.</p> <p data-bbox="616 943 1122 1007">In-depth case studies to describe diverse family situations, experiences and outcomes.</p>	<ul style="list-style-type: none"> <li data-bbox="1158 256 1664 352">- Cost of care packages as part of long-term personalised support ranged from £32,427 to £47,738 over 12-18 month period <li data-bbox="1158 384 1686 552">- Expected return-on-investments for advocacy, Shared Lives and intensive family interventions for parents with learning difficulties ranged from 1.8 to 3.0 (i.e. for every £1 spent the return was between £1.8 and £3) <li data-bbox="1158 584 1686 679">- These return-on-investments referred to short-term government savings; it meant that costs were likely to be offset in the short-term <li data-bbox="1158 711 1686 839">- Less is known about services that follow a community asset based approach although they appear to achieve a wide range of positive health and wellbeing outcomes <li data-bbox="1158 871 1686 1038">- Short-term interventions concerned with training and education specifically designed for parents with learning difficulties can be effective in improving their knowledge and skills and might achieve cost savings <li data-bbox="1158 1070 1686 1166">- Group-based adult learning programmes for mothers with learning difficulties achieves range of positive health and wellbeing outcomes <li data-bbox="1158 1198 1686 1294">- Intervening earlier in child safeguarding processes can save costs to the government and prevent negative child outcomes. 	<p data-bbox="1727 256 2134 568">These findings have to be interpreted in the context of a highly limited evidence base. Studies in this area typically have many limitations in particular because they are based on very small numbers. Methods that have been used to evaluate these complex and diverse support often lack robustness.</p> <p data-bbox="1727 600 2134 831">The findings suggest that interventions in this area might lead to potential cost savings. It is important to carry out evaluative studies that examine the long-term (cost-) effectiveness of personalised support for parents with learning difficulties.</p>

Project Art Works Pilot Study

In July 2016, Project Art Works was awarded a small grant from the Hastings and Rother Clinical Commissioning Group (CCG) to deliver a brief pilot study. The project will explore different models of support for young people and adults in receipt of Direct Payments or Personal Health Budgets (PHBs). Through the pilot study, we want to investigate what kinds of support are already available and/or whether new models of support might be needed to ensure high quality and successful personalised provision.

Project Art Works has now commissioned researcher Susan Potter, to support the pilot study and write a report of our findings. The study will include four separate but closely interlinking strands:

- Short online survey for families/support workers/key stakeholders
- Three focus group meetings with families/support workers/key stakeholders
- Six interviews with individual families/support workers
- Six interviews with key partners and/or stakeholder organisations.

Data collection will take place during February 2017. All data will then be analysed and the findings will be included in a report written during March 2017. This report will be used to make the case for more specialised support for vulnerable people and families running direct payment provisions and PHBs. The findings will also be fed back to families, support workers, regional and national agencies. The research will be available for all to read on the Project Art Works website.

We invite you to take part in this important piece of research, which we hope will lead to the establishment of a not-for-profit specialist support worker network and agency. This resource will be able to be accessed by those who have complex needs and/or behaviours that challenge.

If you would like further information about the research study and/or the work of Project Art Works, please contact Kate Adams, Director of Project Art Works (T. 01424 423555; E. kate@projectartworks.org) or Matthew Pitts, Communications and Creative Programme Manager (T. 01424 423555; E. matthew@projectartworks.org).

Project Art Works Pilot Study: Participant Consent

If you are happy to help us with the Project Art Works Research Study, please read each of the following sections and circle the responses:

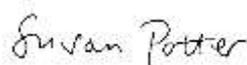
- | | | |
|--|-----|----|
| I would like to help with the Project Art Works Research Study | yes | no |
| I am happy to be interviewed by researcher Susan Potter | yes | no |
| I am happy to have my comments used in the research report | yes | no |
| I understand that anything I say will be used anonymously, while my personal details will not be used at any point | yes | no |
| I understand that all data collected will be recorded, stored safely at all times and used only for this study. | yes | no |

Participant's Name:

Participant's Signature:

Researcher's Name: Susan Potter

Researcher's Signature:



Date:

Project Art Works Pilot Study: Online Survey

In July 2016, Project Art Works was awarded a small grant from the Hastings and Rother Clinical Commissioning Group (CCG) to deliver a brief pilot study. The project will explore different models of support for young people and adults in receipt of Direct Payments or Personal Health Budgets (PHBs). We want to investigate what kinds of support are already available and/or whether new models of support might be needed to ensure high quality and successful personalised provision.

We invite you to take part in this important piece of research, which we hope will lead to the establishment of a not-for-profit specialist support worker network and agency. This resource will be able to be accessed by those who have complex needs and/or behaviours that challenge. Please note that all survey responses will remain anonymous in our final report and will be used for this study only.

If you would like further information about the study or the work of Project Art Works, please contact Kate Adams, Director of Project Art Works (E. kate@projectartworks.org) or Matthew Pitts, Communications and Creative Programme Manager (E. matthew@projectartworks.org).

We thank you for your time and support with this important pilot study.

Section A: Please tell us about yourself

1 Are you?

- Female
- Male
- Other
- Prefer not to say

2 What is your age group?

- Under 21
- 21 – 30
- 31 – 45
- 46 – 55
- 56 – 65
- 66 – 75
- Over 75
- Prefer not to say

3 What is your ethnic background?

- White British
- White Other
- Asian or Asian British
- Black or Black British
- Chinese or Chinese British
- Mixed Ethnicity
- Other ethnic group (*please describe*)
- Prefer not to say

4 What is your home postcode?

.....

5 How would you best describe yourself?

- Parent of young person/adult with complex needs
- Family member of young person/adult with complex needs
- Friend of young person/adult with complex needs
- Support worker for young person/adult with complex needs
- Other professional working with young people/adults with complex needs
- (*please describe*)
- Other
- (*please describe*)

Section B: Please tell us about your experience

- 6 What issues affect the lives of families supporting young people and/or adults with complex needs and behaviours that challenge?**
(Scale: not an issue; sometimes an issue; often an issue; regularly an issue; always an issue)

Understanding the language to gain the best support
Understanding the systems to gain the best support
Negative professional attitudes towards challenging behaviours
Negative public attitudes towards challenging behaviours
Financial worries and/or concerns
Assessments of need
Feelings of isolation and/or exclusion

- 7 What issues affect the lives of support workers working with young people and/or adults with complex needs and behaviours that challenge?**
(Scale: not an issue; sometimes an issue; often an issue; regularly an issue; always an issue)

A lack of statutory, professional training
A lack of mentoring and/or supervision
Negative professional attitudes towards this field of work
Negative public attitudes towards this field of work
Financial worries and/or concerns
Assessments of need
Feelings of isolation and/or exclusion

- 8 What is needed to best support families/carers supporting young people/adults in receipt of Direct Payments or Personal Health Budgets?**
(Scale: not important; of some importance; quite important; important; very important)

A template or toolkit for planning individual care plans
Online resources to help understand the language and/or systems
Printed resources to help understand the language and/or systems
Practical support with financial and/or legal requirements
Buddying/mentoring from families with more experience
Social events/activities with families in a similar situation

9 What is needed to best assist and sustain skilled support workers working with young people/adults in receipt of Direct Payments or Personal Health Budgets?

(Scale: not important; of some importance; quite important; important; very important)

- High quality, standardised professional training
- Regular mentoring and/or supervision
- Positive professional attitudes towards this field of work
- Positive public attitudes towards this field of work
- Financial recognition for this field of work
- Networking events/activities with other families and/or support workers

10 Do you have any further suggestions regarding the support needed to ensure high quality and sustainable personalised provision for young people/adults in receipt of Direct Payments or Personal Health Budgets?

.....

.....

.....

.....

.....

v. Interview Schedule

projectart works



Hastings & Rother Clinical Commissioning Group

Project Art Works Pilot Study: Interview Schedule

A Introduction (10 mins)

- Introduction to study and interview format
- Confirmation of participant consent

B Interview (45 mins)

- 1 What is your role and interest in this piece of research?
- 2 What is your experience of 'personalised provision' or 'personalisation'?
- 3 What issues affect your life and/or work in supporting children, young people and/or adults with complex needs and behaviours that challenge?
- 4 What support is needed for families/support workers working with children, young people and/or adults with complex needs and behaviours that challenge?
- 5 How might we ensure the successful recruitment, training and retention of support staff engaged in family run provisions?
- 6 What features contribute to models of 'best practice' in personalised provision?

C Next steps for research study, thanks and goodbye (5 mins)

Project Art Works Pilot Study: Focus Group Schedule

A Introduction (10 mins)

- Introduction to study and focus group format
- Confirmation of participant consent
- Introductions of participants
- Cloud blanks and pens circulated for capturing thoughts

B Discussion (45 mins)

- 7 What is your experience of 'personalised provision' or 'personalisation'?
- 8 What issues affect your life and/or work in supporting children, young people and/or adults with complex needs and behaviours that challenge?
- 9 How might we best support families/support workers working with children, young people and/or adults with complex needs and behaviours that challenge?
- 10 How might we ensure the successful recruitment, training and retention of support staff engaged in family run provisions?
- 11 What features contribute to models of 'best practice' in personalised provision?

C Next steps for research study, thanks and goodbye (5 mins)