



projectart works

Project Art Works Pilot Study

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

Summary of findings

Susan Potter, December 2017

1 Aims of the PAW Pilot Study

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 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.

2 Findings from the online survey

2.1 Issues affecting families, carers and support workers

The online survey was delivered to families, support workers and other professionals via PAW and its partner organisations and completed by 50 individuals. The key issues affecting the lives of families, carers and support workers in supporting individuals with complex and/or additional needs were reported to be systemic, financial and/or social:

- understanding the systems to gain the best support
- understanding the language to gain the best support
- assessments of need
- financial and/or care budget worries or concerns
- feelings of isolation and/or exclusion
- negative professional or public attitudes towards individuals with complex needs
- lack of statutory, professional training for support workers
- lack of mentoring and/or regular supervision for support workers.

2.2 Assistance needed for families, carers and support workers

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

- practical support with financial and/or legal issues
- a template or toolkit for planning individual care plans
- online resources to help understand the language and/or systems
- buddying or mentoring from families with more experience
- financial recognition for support workers
- positive professional attitudes to this field of work
- high quality, standardised professional training, with regular supervision.

3 Findings from interviews and focus group meetings

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.

4 Feedback related to Project Art Works

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. PAW has already begun 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.

5 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.