CENTRE FOR MENTAL HEALTH

IMPROVING SUPPORT FOR PEOPLE WITH COMPLEX MENTAL HEALTH DIFFICULTIES

Susan Mizen, Felicitas Rost and Frederico Cardoso

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ANCILLARY DOCUMENTS

A range of ancillary documents are discussed throughout this report. They can be accessed at **https://tinyurl.com/yzzk9wdh** or by scanning the QR code below.

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DEFINING COMPLEX MENTAL HEALTH DIFFICULTIES

People with complex mental health difficulties may be given a range of diagnoses, including but not limited to 'personality disorders' (sometimes referred to as 'complex emotional needs'), eating disorders, persistent (sometimes described as 'medically unexplained') physical symptoms, and substance use. These often co-occur, including with neurodivergence, so that people with these diagnoses do not fit easily into existing specialist services or classifications of need. Many have experienced significant lifetime traumas, and too many encounter entrenched negative attitudes and discrimination, including from health and other public services.

ABOUT THE TALKING THERAPIES TASK FORCE

The Talking Therapies Task Force (TTTF) was convened in 2015 as a collaboration between psychotherapy organisations to promote development of a national programme of psychological therapies for patients with the most complex mental health difficulties. The aim is to provide parity of provision with NHS Talking Therapies services (formerly known as IAPT- Improving Access to Psychological Therapies) for people with mild to moderate mental health problems (see **briefing doc**). The six founding organisations included the Medical Psychotherapy Faculty at the Royal College of Psychiatrists (RCPsych), The British Psychoanalytic Council (BPC), The Association for Psychoanalytic Psychotherapy in the Public Sector (APPP), The British Association for Counselling and Psychotherapy (BACP), The United Kingdom Council for Psychotherapy (UKCP) and The Society for Psychotherapy Research, UK Chapter (SPR UK). TTTF has been joined by the Centre for Quality Improvement (CCQI) at RCPsych, the Knowledge and Understanding Framework (KUF) and the British Association for Behavioural and Cognitive Psychotherapies (BABCP).

RESEARCH COLLABORATIONS

The Health Economics And Relational Disorder (HEARD) study (see **study protocol**) was undertaken with the support of Devon Partnership NHS Trust, who funded parts of the data analysis, and in collaboration with the Peninsula Collaboration for Health Operational Research (PenCHORD) and Whole Systems Integrated Care (WSIC) in West London. Participating organisations included North Devon Healthcare Trust, Royal Devon and Exeter NHS Foundation Trust, Devon County Council and North West London NHS Trust. NHS ethics was obtained (IRAS 262622) and all ethical and research governance adhered to.

The TTTF commissioned Centre for Mental Health to conduct the economic analysis and write this health economic report of the HEARD study findings.

EXECUTIVE SUMMARY

People with some of the most complex mental health difficulties are poorly served by existing mental health, physical health and social care provision. In the absence of appropriate psychotherapeutic pathways of care in the community, many end up in long-term placements in hospitals locally or sometimes far from home, stranded there because they are not getting the necessary therapeutic support to recover.

Until now the experiences of this group of people have remained 'hidden' for two reasons. They are highly stigmatised, including within health and social care services, and they are overlooked in routine data collection as many will be given several different simultaneous diagnoses and are excluded from symptom-specific services that do not meet their needs and thus become invisible to the system. As a result they have been neglected in national health and care strategies, their clinical outcomes are poor, and both they and their carers have poor experiences of the support they are offered.

Not only are people's needs, experiences and outcomes 'hidden' but so is the cost of treatment. We estimated the cost of treating people with the most complex needs in local hospital beds to be between £480 million and £785 million each year nationally, while out-of-area placements cost a further £135 million. Funds currently used in this way could be better spent providing specialist therapeutic support that actually meets people's needs, closer to home.

Using health and social care data on service use and costs allowed us to identify a small proportion (around 1.5%) of people with complex mental health difficulties who account for approximately one-third of the cost. The majority of these costs were incurred in inpatient mental health services. Because appropriate psychotherapeutic treatment is not available in these settings, the costs are high and clinical outcomes poor. Our study shines a light on the unacceptably poor experiences and outcomes people in this group face. The findings of the study presented here confirm that the financial costs are unsustainable and the human costs unacceptable.

The data further shows that a person who gets multiple referrals from community mental health teams to other community-based services is likely to end up in a protracted hospital admission if their needs are not adequately met. In the absence of pathways tailored to the therapeutic needs associated with their multiple diagnoses, people are not helped sufficiently by existing teams which are not able to meet their needs holistically.

These insights can help integrated care boards (and health boards in Scotland and Wales) and providers of mental health services to find ways to offer better support that meets people's needs and upholds their right to equitable and effective treatment.

A local service in Devon has offered an alternative to long-term hospitalisation with community intensive day and outpatient therapeutic treatment. This new service significantly reduced the number and duration of hospital admissions both locally and out of area, reduced emergency service attendance, and provided a better experience for service users and their families. This approach could be extended to a series of demonstrator sites in other areas, with a view to informing a longer-term national strategy to improve outcomes and provide better support to people with the most complex mental health difficulties.

INTRODUCTION

People with complex mental health difficulties face a high risk of being admitted to hospital for long periods locally or far from home, in elective, rather than emergency, 'out-of-area placements'. Many find themselves dislocated from their community and sometimes face protracted stays in inpatient care, simply because their needs cannot be met by local services.

Their needs cannot usually be met either in generic mental health inpatient settings, in community services, or by specialist services that focus on single diagnostic categories, such as personality disorder services, eating disorder services or substance misuse services. But because this is a comparatively small, highly stigmatised and heterogeneous group of people, their needs have been overlooked, both nationally and locally in most parts of the country. Consequently, hospital admissions become extended and care pathways characterised by different services referring people between them. In generic inpatient settings, their risks may be managed but they are unlikely to receive evidence-based psychotherapeutic treatment, leading to long admissions with poor therapeutic outcomes.

This invisibility extends to NHS England's programme to eliminate 'inappropriate' out-of-area hospital admissions, which focuses on preventing these for people with symptoms of psychosis (CQC, 2018; Kalidindi, 2022). As a result, data about their admissions is not routinely collected, and therefore the number of people with these diagnoses in out-of-area placements is unknown.

To look for evidence of the human and financial cost, the Talking Therapies Task Force (TTTF) part-funded the HEARD study (see **study protocol**). The aim was to identify the characteristics, patterns of service use and costs associated with people with the most complex mental health difficulties in one urban and one rural area, and to evaluate the impact on service use of a psychotherapeutic service designed specifically to meet their needs. Centre for Mental Health was commissioned to carry out the health economic data analysis.

The research questions were:

- What health and social care services do individuals with the most complex mental health difficulties use and what is the average annual cost of these?
- What are the clinical and service use predictors which would facilitate identification within public sector services to establish service need and resource allocation to therapeutic pathways?
- Does intervention from the Devon Specialist Personality Disorder Service (SPDS) reduce the cost and intensity of service use for these individuals?

The HEARD study is the first study to examine health and social care data in England in order to explore how many people experience the most complex mental health difficulties, the nature and location of the services they are offered, and the associated cost. The study prioritised involvement of experts by experience who informed the study throughout, and included detailed interviews with people who have used these services and their families. While this research did not include data from the devolved UK nations, the themes and implications are likely to be similar in all four. The responsible agencies and application of effective solutions will, however, be distinct in each nation.

HOW MANY PEOPLE WITH COMPLEX MENTAL HEALTH DIFFICULTIES ARE IN HOSPITAL OUT OF AREA?

As there is no data available for people with complex mental health difficulties who are in hospital out of area, we have used data for people labelled as having 'personality disorders' or 'complex emotional needs' to provide the closest estimate. We first looked at the report by the British and Irish Group for the Study of Personality Disorder (BIGSPD) who undertook a Freedom of Information (FOI) request to 191 Clinical Commissioning Groups (CCGs) to find out how many people with these needs were in out-of-area beds between 2017 and 2019. Their report (Zimbron *et al*., 2022) highlights a lack of transparency in that only 22 CCGs provided diagnostic information. Based on this data, 11% of placements were for people with complex mental health difficulties.

In December 2023, we identified providers who advertised inpatient facilities for people given a diagnosis of personality disorder. We found NHS England commissioned 50 specialist inpatient NHS beds for people given this diagnosis in 2013. Given the high demand, local integrated care boards (ICBs) commissioned further beds from private providers. Private units are described as either "personality disorder specialist inpatient services" (with 431 beds) or "High Dependency Inpatient Rehabilitation" (HDIR) services accommodating a range of diagnoses. The number of people with complex mental health difficulties in HDIR services can only be estimated. In the absence of robust national data, we carried out an internet search of four of the many private sector providers, which provided an estimate of 160 such beds. This gives a total of 641 beds in England. We acknowledge this is an estimate and would wish to see routine data providing information of this kind to improve transparency and accountability.

The median cost of a night in one of these beds is £575 (NHS England, 2024). This equates to an annual cost across England of £135 million. In the absence of a strategic plan, specialist services are not located evenly across the country. They are provided by the private sector and located where high rates of bed occupancy can be secured.

THE HUMAN COSTS OF INADEQUATE CARE

We interviewed six service users and three family members to gain insight into their experiences of health and social care pathways locally, culminating in an out-of-area placement. They described examples of good practice, but the overwhelming impression was that services were not meeting their needs. As a consequence of the disunited system of care, people with experiences of early childhood adversity described finding services to be traumatic and that family relationships which were already under strain were further disrupted. The main themes they identified have been summarised into one typical fictional service user journey (Sam) in Figure 1. Some quotes from the interviews are included.

Figure 1: Example service user journey

THE MONETARY COST OF INADEQUATE CARE

To identify the characteristics, patterns of service use and costs relating to the current services provided to people with complex mental health difficulties, the HEARD study collected data from clinical and local authority electronic patient records from one rural setting (Devon) and one urban setting (north west London) between 2015 and 2018. Search criteria for inclusion in the data set involved meeting Health of the Nation Outcome Scales (HoNOS) Clusters 7 and 8[1] and specific International Classification of Diseases (ICD) diagnostic codes. For this study, people with a psychosis diagnosis were not included. To capture the characteristics and cost of those with complex mental health difficulties, we identified those whose service use fell outside three standard deviations from the mean of the whole sample. In other words, we explored data from the 3% of people whose pattern of service use was furthest above the average of the group as a whole. We compared this group with all others in this cohort.

Activity and cost data were analysed separately for each site. We wanted not only to find out how many diagnoses people were given and what services they used over the three years, but also what variables predicted the total amount spent on a person, and to identify patterns of service use which predicted the greatest likelihood of going on to incur the highest-cost service use. To that effect we used regression analysis.

Below is a summary of the main findings. More details of the method and results can be found in the health economic analysis.

SUMMARY OF OVERALL NUMBER OF PEOPLE AND SERVICE COSTS

Extracted data between 2015 and 2018 from research sites identified a total cohort of 29,189 people with the ICD codes mentioned above. This included the health and social care records for 4,751 people in Devon and 24,438 people in London.

The total system-wide service use cost per annum for the whole cohort in Devon was £24.8m and in London was £60.8m. The annual service costs for the group with complex mental health difficulties was £8.1m in Devon and £14.5m in London. The annual cost for the remainder of the cohort was £16.7m in Devon and £46.3m in London. Overall, the study found that the most complex 1.8% of the cohort accounted for 32.6% of the total cost in Devon, and 1.1% accounted for 23.9% of the total cost in London.

1 Cluster 7 ("enduring non-psychotic disorders"): "This group suffers from moderate to severe disorders that are very disabling. They will have received treatment for a number of years and although they may have improvement in positive symptoms considerable disability remains that is likely to affect role functioning in many ways" and "likely primary diagnosis of depressive episode, OCD, phobic anxiety." Cluster 8 ("non-psychotic chaotic and challenging disorders"): "This group will have a wide range of symptoms and chaotic and challenging lifestyles. They are characterised by moderate to very severe repeat deliberate self-harm and/or other impulsive behaviour and chaotic, over dependent engagement and often hostile with services" and "likely primary diagnosis of personality disorder."

PATTERN AND COST OF SERVICE USE

Devon

In Devon, our analysis identified 4,751 people using mental health services with the relevant ICD codes. On average they had 3.2 ICD diagnoses and 3.6 HoNOS clusters. Of these, 85 (1.8%) had service costs which were three standard deviations above the mean for the whole cohort. These 1.8% accounted for 32.6% of the annual total cost, namely £8.1m out of 24.8m.

They had twice as many diagnostic codes in their medical records as the rest of the sample (average of 3.2 compared with 1.5). Between 2015 and 2018, they had almost five times as many A&E attendances (7.3 compared with 1.5); an average of 11.9 bed days in a physical health hospital, compared with 6.5; 186.2 bed days in mental health inpatient care, compared with 3.7; and six times as many contacts with community mental health services (69.5 compared to 11.6 average number of contacts).

As a result, the average cost per person each year was many multiples higher for people with complex mental health difficulties, at £95,122, compared with £3,582.

Patterns of service use were markedly different between the two groups. For those with 3 standard deviations above the mean, 25% of the cost was attributed to NHS community mental health services, 32% to inpatient mental health beds, 29% to out-of-area inpatient beds, 12% to social care and 2% to physical care (see Figure 2 below).

The regression analysis revealed two significant non-monetary predictors of total spent: the number of community mental health service referrals (explaining 58% of the variation) and the number of acute inpatient physical health bed days (explaining 14% of the variation). We used these findings to calculate the total system-wide cost of £24.6m. Most importantly, it allowed us to identify a referral rate at which the cost becomes markedly increased: between five and seven community mental health service referrals. The proportion increased ten-fold for people referred to more than six community mental health teams.

North west London

In north west London, 272 people out of a sample of 24,438 were found to have service costs three standard deviations above the average between 2015 and 2018. 1.1% of people with complex mental health difficulties accounted for 23.9% of total costs, at an annual cost of £14.5m out of a total of £60.8m.

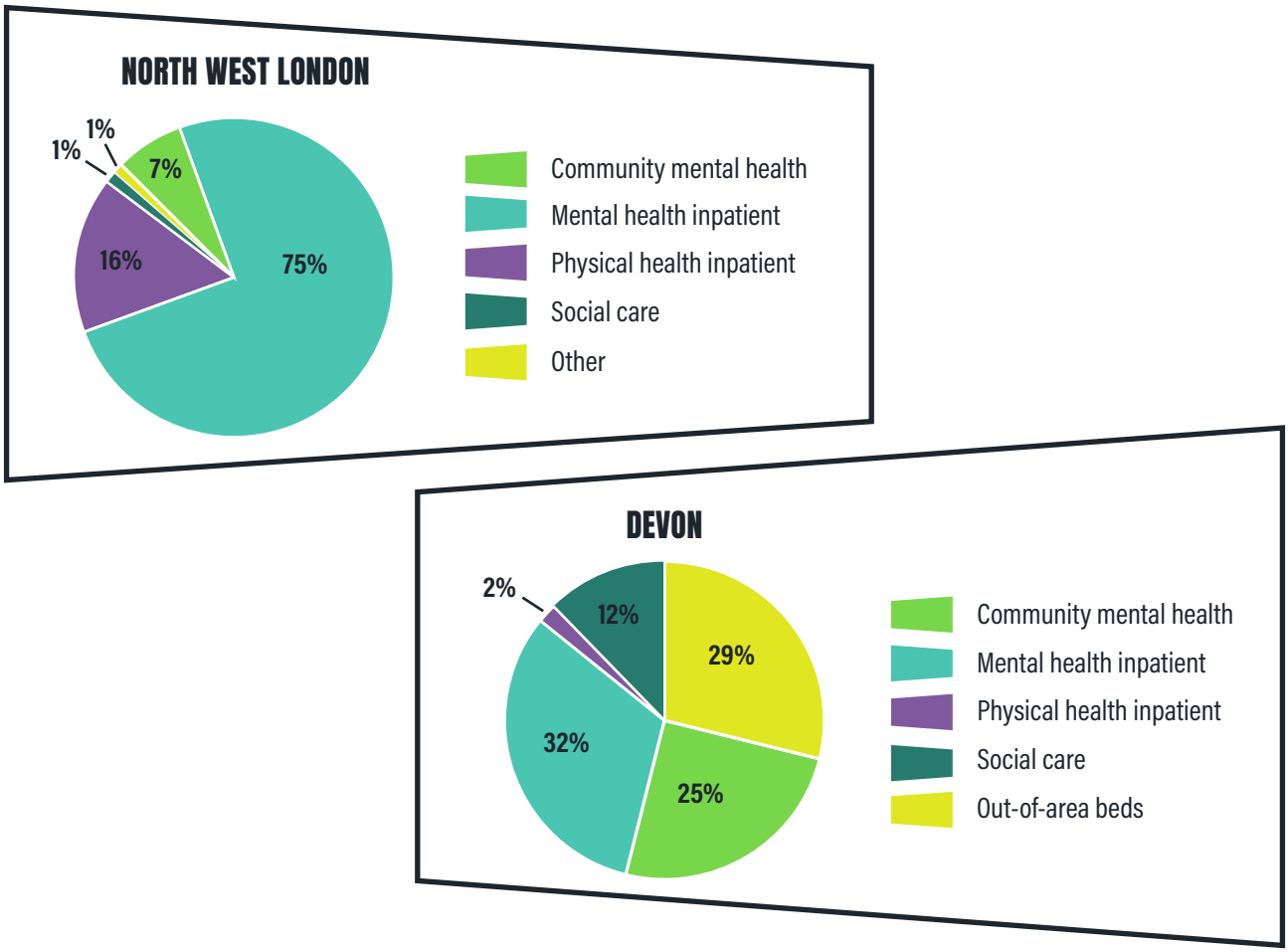
Unlike in Devon, this group did not have more diagnostic codes but had more than twice as many HoNOS clusters (average of 3.4 compared with 1.2). Over the three-year period, people in this group attended A&E more frequently (10 times compared with 1.2 times) and had a higher number of bed days in both physical health hospitals (206.6 compared with 3.7) and mental health inpatient services (202.3 compared with 1.1).

As such, like in Devon, the mean annual cost per individual in this group was equally high at £160,164 compared with £5,743. The proportion of spending on mental health inpatient services was much higher for people with complex mental health difficulties (75% versus 10%). A total of 207 people spent over 100 bed days in hospital each, at a total cost of £35 million.

As highlighted in Figure 2 below, the largest expenditure category was mental health inpatient care (76%). Unlike in Devon, out-of-area placements (1%) were not frequent. Costs for physical health care accounted for 16% and costs for community mental health care accounted for 7%.

Finally, regression analysis revealed several significant predictors of the total spend, including number of diagnoses, A&E attendance, physical and mental health inpatient bed stays. The best explanatory variable is mental health inpatient days.

Figure 2: Percentage of service use in north west London and Devon



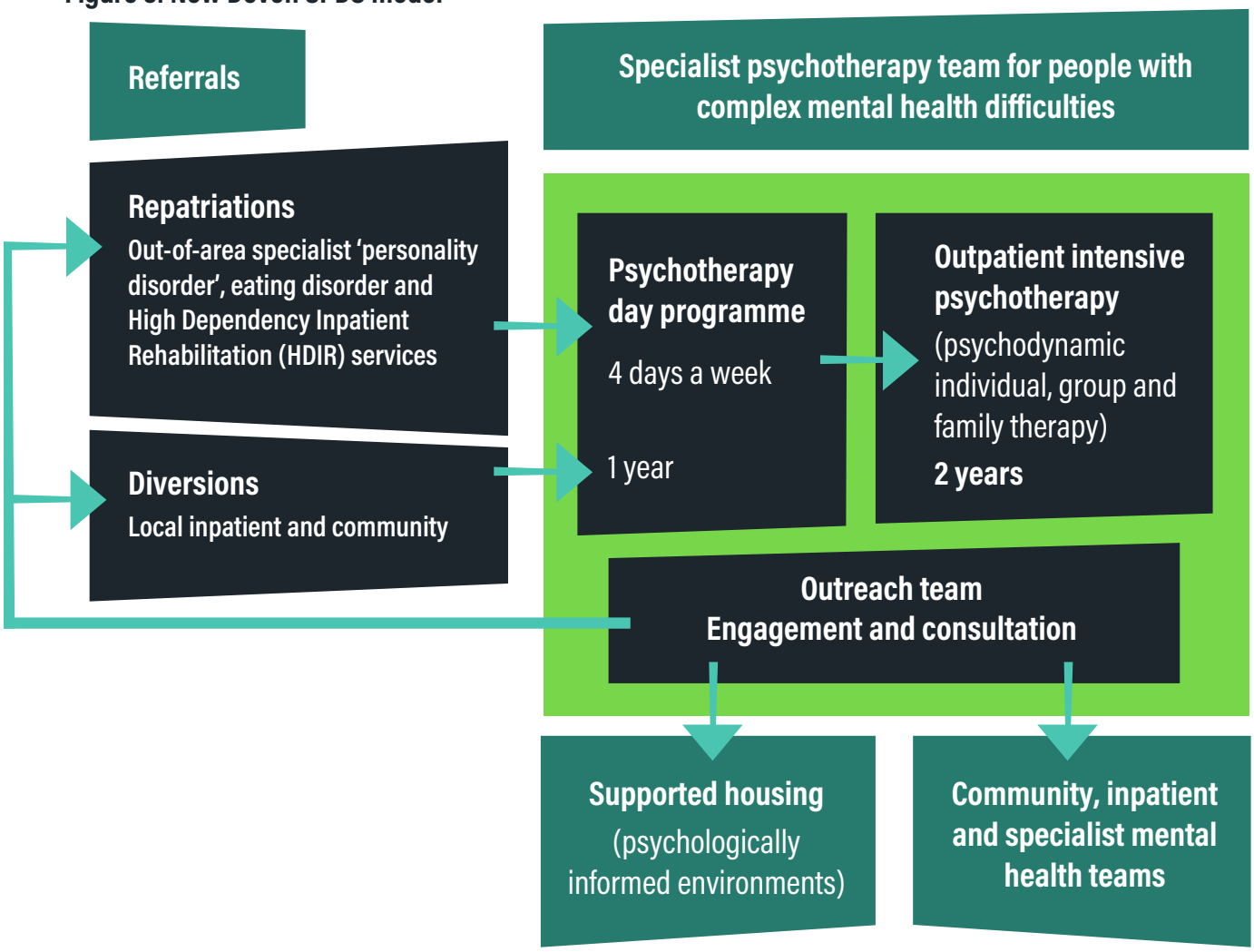
A LOCAL ALTERNATIVE TO OUT-OF-AREA PLACEMENTS AND HOSPITALISATION

A new psychotherapeutic pathway was commissioned in Devon in 2011 to reduce out-of-area placements. The Devon Specialist Personality Disorder Service (SPDS) was available to people who met the clinical threshold for a Tier 4 personality disorder hospital admission (see NHS England, 2014). People offered this service had been given an average of 15 diagnoses, compared with 2.6 diagnoses, including that of 'personality disorder', in other local mental health services.

The cost to provide the Devon SPDS was £1.4 million a year. The pathway is summarised in Figure 3. It provided outreach and assessment to those at risk of, or already in, an out-of-area placement. Those able to use the local pathway were provided with intensive psychotherapy, including a year-long, four days a week psychodynamic therapeutic community day programme adapted to their transdiagnostic presentations (Mizen, 2015). This was followed by weekly outpatient psychodynamic therapy and family therapy as needed. For those unable to use psychotherapy, support and consultation to teams was offered. People discharged from hospital were offered high support accommodation alongside the day programme where appropriate. The accommodation providers were supported by the team to deliver a psychologically informed environment (Haigh *et al*., 2012). Between 2012 and 2020 the service worked with around 300 people.

At any one time, one-third of people using the service were receiving therapy; one-sixth were offered consultation with the team rather than a therapeutic intervention. The remaining half were getting assertive outreach support, often while they were in hospital, to prepare for therapy. Assertive outreach support included monthly visits from the SPDS team, for example to plan for their discharge from hospital or to make arrangements for them to return to therapy when they are ready and willing for it.

Figure 3: New Devon SPDS model



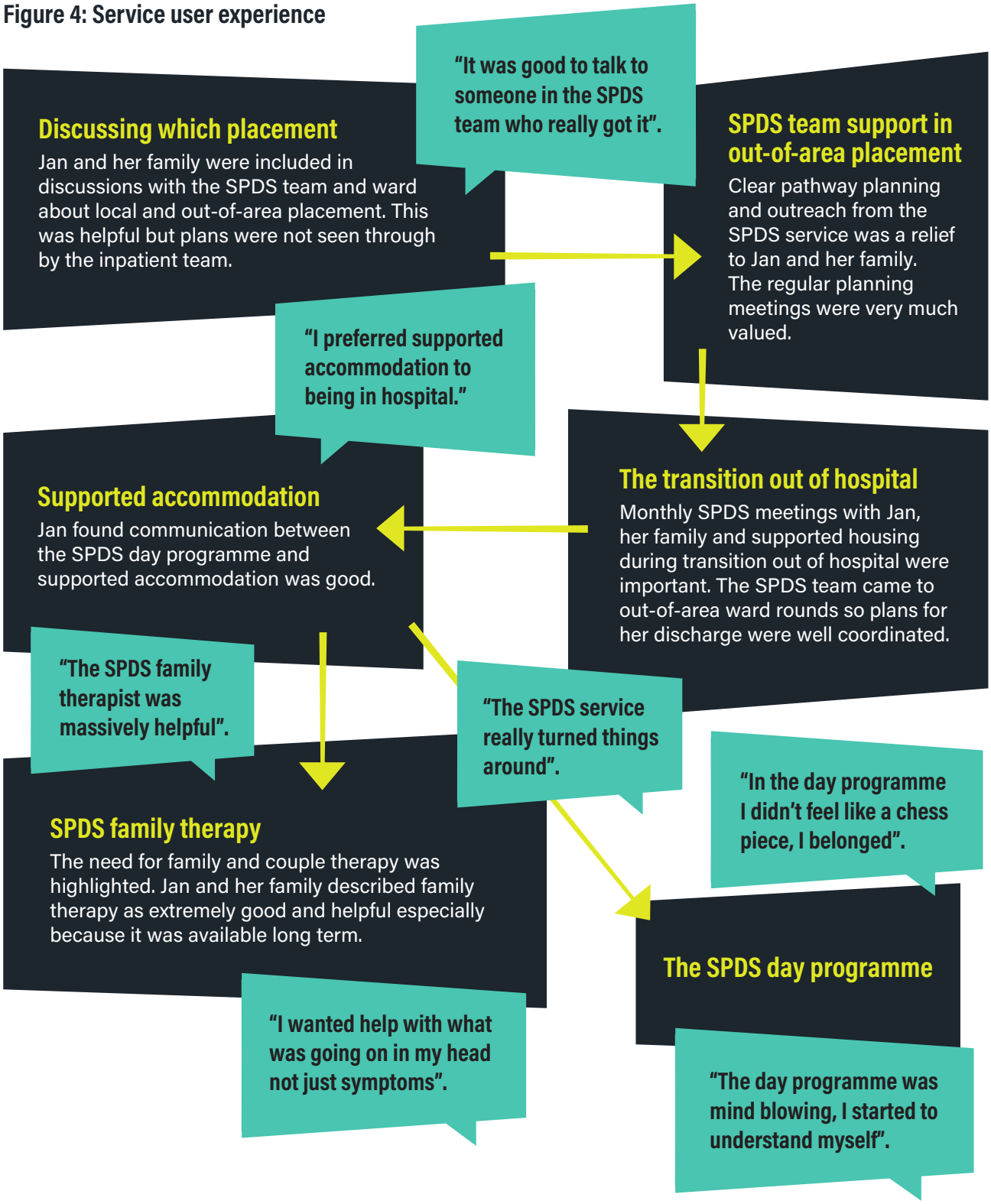
OUTCOMES FROM THE SPDS

People were referred to inpatient services out of area less after the SPDS service opened than before. Both the number and duration of out-of-area placements in specialist personality disorder and High Dependency Inpatient Rehabilitation services reduced: in 2012, there were 27 such placements; from 2014 to 2020 this fell to 13. Mean length of stay fell from 951 days to 406. And the costs of such placements therefore reduced too, from an average per case of £90,487 to £35,947 (Mizen, Jones and Howson, 2024). The use of funding that would have gone into an out-of-area placement meant that twice as many people received therapeutic treatment (122 compared with 57 previously) and 39 were able to access local supported accommodation, compared with just 7 before the service opened. Although the service cost £1.4m per year, it saved 15% per year in real terms in the cost of out-of-area placements alone during the first eight years.

Further to this, the HEARD study data confirmed a significant reduction in number of admissions and length of stay in local mental health inpatient beds following the SPDS therapeutic intervention. Use of emergency services also fell during this period: at the outset, 98% of attendees needed help from emergency services, while after therapy this fell to 46%.

People using the service and carers interviewed for this report were asked to comment on their experience of the new service. Their responses are summarised in a description of a fictional patient, Jan (Figure 4).

Figure 4: Service user experience



FUTURE SERVICE PROVISION FOR PEOPLE WITH COMPLEX MENTAL HEALTH DIFFICULTIES

The survey undertaken for this report underlined the importance of coordinating a system-wide response across health and social care and emergency services. This requires a collaborative approach to commissioning pathways to ensure people get more consistent care and to manage transitions between services when they are necessary. The survey highlighted the importance of working therapeutically with families, adopting a compassionate relational therapeutic approach, and consistency of therapy across inpatient and community settings.

From literature on the topic, the limited evidence available suggests that for most people with complex mental health difficulties, intensive psychotherapeutic services in a community setting provide a more local and effective alternative to inpatient care far from home (Galante, Humphreys and Molodynski, 2019; Royal College of Psychiatrists, n.d.). However, this cannot be achieved through existing community mental health services including existing 'personality disorder' services. Amongst those with complex mental health difficulties who could use more intensive community psychotherapeutic services are a small minority of people who have difficulties that are too high risk, or co-occurring conditions that are too complex, for treatment in the community at all in the first instance. They require therapeutic programmes in an inpatient setting. An optimal model may be one that flexibly combines inpatient and community therapeutic care (Beecham *et al*., 2006). As integrated care systems cover larger populations than previous NHS commissioning structures, this may offer the scale to facilitate the implementation of this model.

Studies highlighted the importance of resourcing inpatient and community therapeutic programmes adequately to deliver the full evidence-based therapeutic model. Without this, both the clinical and cost benefits are unlikely to be realised (Bohus *et al*., 2016).

At present, the evidence for effective interventions and pathways is not robust enough to inform a national strategy. A next step towards this would be the development of a new set of demonstrator sites to implement a range of therapeutic pathways and models. Based on the evidence available, the following organisation of therapeutic pathways is proposed as a suitable model for pilot sites.

A pragmatic solution would be to develop flexible provision between specialist inpatient psychotherapeutic services located not more than 70 miles from home and local specialist services in community settings. Pilot pathways could be established between specialist inpatient and community settings with a robust outreach function to ensure the pathway operates coherently. Intensive local psychotherapeutic provision may be offered through partial hospitalisation (as a day programme) or within supported accommodation providers.

While this pilot phase is taking place, the NHS nationally and locally can take steps to prepare the ground for a coherent national strategy to provide better support to people with complex mental health difficulties. This would include:

- A review of the number and location of specialist personality disorder and High Dependency Inpatient Rehabilitation (HDIR) beds out of area. These must be included in the national data collection system already in place to monitor progress towards eliminating inappropriate out-of-area placements (Department of Health & Social Care, 2016)
- Writing a service specification for inpatient specialist services to include competence to work with the common co-occurring conditions of people diagnosed with personality disorder, people with eating disorders, persistent physical symptoms, and substance misuse
- Reconfiguring existing NHS England and integrated care board commissioned specialist personality disorder inpatient services and a proportion of HDIR services to establish regional specialist units not more than 70 miles from home in all regions of the UK
- Developing a workforce and training strategy to be included in the next iteration of the NHS Long-Term Workforce Plan.

Integrated care boards (in England) and health boards in Scotland and Wales can work with local partners to:

- Identify the people with complex mental health difficulties in their locality, their patterns of service use and costs
- Reconfigure the resources currently invested in those patients to improve care pathways and invest in local therapeutic services
- Integrate these services with reconfigured regional specialist inpatient services
- Identify training needs for the specialist workforce and system-wide training requirements for non-specialist health and social care professionals
- Routinely collect data on patterns of service use and therapeutic outcomes before and during therapeutic intervention and at follow up.

KEYS TO SUCCESS

FOCUS ON SUPPORTING PEOPLE WITH THE GREATEST NEEDS

People with complex mental health difficulties deserve skilled psychiatric and psychotherapeutic support. On the basis of the evidence presented in this report, providing highly specialised care and support will result in both better clinical outcomes and improved value for money. Achieving this requires a commissioning focus on system-wide change in pathways and on building up well trained and resourced specialist teams.

LISTEN TO PEOPLE'S LIVED EXPERIENCE

As with any other area of mental health support, drawing on expertise by experience is fundamentally important to improving the accessibility and quality of services. Coproduction and co-design are essential for all mental health services, recognising and valuing the lived experience of people who have used services and their carers in order to improve what is offered and evaluate its effectiveness.

NATIONAL AND LOCAL DATA COLLECTION

Identifying and monitoring progress towards reducing out-of-area placements, and providing care closer to home, are essential to success nationally. Routine data collection across regional and local specialist teams will allow clinical outcomes to be monitored and reported at a national level. The Talking Therapies Task Force reviewed available frameworks for data collection. Their recommendations can be found in the outcomes framework.

INPUT FROM MULTIPLE AGENCIES IN LOCALITIES

Given the scale of change required to find local solutions and deliver effective treatment pathways, active interest and involvement from CEOs of participating organisations in ICBs is essential to success. This should encourage pooled funding and a commitment to integrated care and support that meets people's needs holistically – without the stigma and discriminatory processes and attitudes, and punitive approaches, that for too long have been attached to people with complex mental health difficulties.

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