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"*I need to talk, to talk to people*": a qualitative study of service user and carer views and priorities for social functioning in schizophrenia-spectrum disorders

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Abstract

Improving social functioning for people with schizophrenia-spectrum disorders is a priority for service users, carers and broader society. While many face challenges with social functioning, a proportion do obtain a job, a partner, and other valued social goals. Informal carers are key stakeholders, support recovery and may support service users' social functioning, though some research suggests carer and service user priorities may differ. Research suggests item content in measures of social functioning may not fully capture people's social world. The aim of this study was to explore service user and carer understandings of social functioning and what they value most, to inform intervention and measurement approaches. Semi-structured interviews were conducted with twelve service users and eight carers and audio recorded. Reflexive thematic analysis was conducted on anonymized transcripts with input from a multidisciplinary team and a carer with lived experience. One overarching theme, 'Fitting in and being accepted' reflected service user and carer participants' emphasis on integration and belonging beyond any particular social functioning outcome. Four themes were generated from the analysis: 'the value in performing everyday activities', 'communication and sociability as connection to the world', 'close relationships as central to social functioning and wellbeing' and 'the paradox of work: highly valued but a potentially risky endeavour'. Having a job was considered important but was out of reach for many. Revised expectations meant that service users who had more challenges with social functioning valued basic independence and achieving this helped them feel integrated in society. Service users and carers had broadly similar priorities and expectations for social functioning, with some exceptions including expectations around romantic relationships. Digital communication served as an important means of low pressure connection to others. People with schizophrenia need more social opportunities that fit their circumstances including developing relationships and accessing work. Instruments that measure social functioning may not reflect what service users find meaningful about social functioning, such as feeling accepted and fitting in and their use of digital communication.

Keywords Psychotic disorders · Caregivers · Social functioning · Qualitative research

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Background

Schizophrenia-spectrum disorders affect about 1% of the population and account for 1.5-3% of healthcare costs in developed countries (Altamura et al., 2014; Knapp et al., 2004). Symptoms typically include a combination of hallucinations, delusions, and disorganised speech or behaviour which impact perception, affect, thinking and behaviour (McCutcheon et al., 2020; Patel et al., 2014). Challenges with social functioning are common for people with schizophrenia-spectrum disorders, are one of the main drivers of the global burden of disability (Insel, 2008), and are part of the diagnostic criteria for schizophrenia in the major diagnostic manuals (American Psychiatric Association, 2022; World Health Organization, 2019). While the term social functioning is widely used in clinical and research contexts, recovery oriented literature often focuses on related, holistic concepts such as social engagement, participation and community belonging, which are less deficit focused, but are not currently widely used (Wood & Alsawy, 2018). There is no agreed-upon definition of social functioning, but instruments which assess it generally capture specific roles (work, parental, household, family), social contact and interaction with others, leisure activities and general interests, and integration within society and participation in the community (Burns & Patrick, 2007). The International Classification of Functioning framework defines functioning more broadly, as an interaction between the individual, their bodily functions, activities, participation and their context (World Health Organization., 2001), though this framework has not been widely adopted in psychiatry research due to its complexity and lack of specificity for schizophrenia spectrum disorders (Álvarez, 2012). As such there is no widely-used framework or consensus of understanding of social functioning, which results in considerable variation in approaches to measurement (Long et al., 2022).

Limited research has explored the lived experience of social outcomes in schizophrenia spectrum disorders, which is a significant gap given recent estimates that 63% of people with severe mental health disorders experience social isolation (Hajek et al., 2025). Social isolation exacerbates symptoms (Fett et al., 2022; Giacco et al., 2012), predicts worse physical functioning (Chen et al., 2024), and there is some evidence that isolation may have broader negative health impacts, including increasing the risk of mortality (Holt-Lunstad et al., 2010). A related issue is that few instruments have incorporated the perspectives of people with schizophrenia spectrum disorders in instrument development (Long et al., 2022).

Longitudinal data suggest there is marked heterogeneity in social functioning outcomes (Velthorst et al., 2017), and a sub-group of people have good social functioning and attain valued social outcomes (Cohen et al., 2017). Fewer challenges with social functioning are related to fewer positive and negative symptoms (de Winter et al., 2022; Galderisi et al., 2014; Handest et al., 2023), better cognitive functioning (Cowman et al., 2021) and higher levels of social support (Gonzalez-Blanch et al., 2015). Social support is often provided by informal carers (hereafter 'carers'), who are friends/family members who provide crucial practical, emotional and economic support (Caqueo-Urízar & Gutiérrez-Maldonado, 2006). Carer attitudes to illness are related to the social functioning of their loved one (Pérez et al., 2021), and carers make important contributions to service user recovery processes (Estradé et al., 2023), but little is known about how carers support social functioning. Priorities for social functioning varies between stakeholders; carers prioritise independence, role functioning and reaching life milestones (Lloyd et al., 2017), while service users prioritise improving cognition, communication, social skills and sedation (Roy et al., 2009). The little research in this area suggests that perceptions and expectations for social functioning among people with the disorders vary considerably (Shepherd et al., 2012), though it is unclear if there is similar variation in carer perceptions.

Differences in priorities and expectations for social functioning are reflected in the heterogeneity of item content across measurement instruments of social functioning (Burns & Patrick, 2007). Recent reviews suggest that many instruments are limited as they do not capture aspects of a changing social world, including Internet use - that people with schizophrenia-spectrum disorders and their carers may prioritise (Bjornestad et al., 2019; Long et al., 2022).

Exploring carers and service user views and priorities for social functioning, and differences between service users and carers is important for identifying targets for future interventions, aiding healthcare professionals tasked with working with service users and carers to provide recovery-oriented care, as well as informing the measurement of social functioning.

Aim

This study aimed to explore how people with schizophrenia-spectrum disorders and carers understand social functioning, and which aspects of social functioning they value most.

Methods

Methods are reported according to COREQ guidelines (see Appendix 1). Ethical approval was granted in Northern Ireland (HSC Northern Ireland REC, 19/NI/0086), which is

accepted by the research governance body in England, the Health Research Authority (HRA), where the study took place. All participants provided written informed consent.

Study Design

A critical realist framework was adopted and issues of reflexivity within the team were carefully considered during analysis, which included researchers with backgrounds in psychology, psychiatry, social work and lived experience of caring with someone with a diagnosis of schizophrenia spectrum disorders. Semi-structured qualitative interviews and reflexive thematic analysis were considered appropriate to explore participants' experiences and views of social functioning, to understand what aspects of daily life, relationships, and community participation they consider important. This approach allows for capturing rich, lived experience perspectives while maintaining continuity with existing instruments and literature.

Participants

Eligibility criteria included that service users should be aged 18 years and over with a confirmed diagnosis of a schizophrenia-spectrum disorder and have current or previous use of antipsychotic medication (i.e. rather than prescription alone); and carers aged 18 years and over who provided five hours per week or more of unpaid practical or emotional support (Carmichael & Charles, 1998) to a service user with a diagnosis of a schizophrenia-spectrum disorder. Diagnoses were confirmed verbally by carers during the consent process. Participants were identified from secondary care mental health services from a single public healthcare Trust in England, which serves communities in urban and suburban localities. Service users and carers were not necessarily dyads. Carers were recruited through service user participants, clinicians and community groups across London. Service users were purposively sampled for diversity among both social outcomes (clinician-judged social functioning) and sociodemographic (gender, ethnicity) factors. Clinician judgement of social functioning directed the sampling of service users in the study. Clinicians classified potential participants as 'low' 'mid-range' and 'high' social functioning according to their professional judgement. The Objective Social Outcomes Index (the SIX, (Priebe et al., 2008), a six-item index of social functioning, was administered to service users after consent and served as a means of describing the social functioning in the sample. The SIX has reasonable construct validity (Priebe et al., 2008) and was chosen as it is quick to administer and combines domains which are considered to be objective indicators of social functioning into a single index. As an index it does not capture the complexity of social functioning, but can support its assessment.

Information Power

Information power (Malterud et al., 2015) provides a framework to plan the sample size in qualitative research and uses the following guiding principles: whether the research aim is broad or narrow; how relevant the sample is to the study aim; whether theory exists in the study area; the quality of the interview dialogue; and the type of analysis, namely whether the analysis is cross-case or case. Alongside this, studies investigating similar topics (functioning, recovery), a similar population (schizophrenia spectrum disorders), and two respondent groups (Nimmons et al., 2023; O'Keeffe et al., 2022) were reviewed. This resulted in a plan to interview 10–15 service users and 10–15 carers. After eight service user interviews, the coding framework and sample characteristics revealed that participants were fairly diverse in terms of distribution among clinician judgements of social functioning and demographics; and accounts of social functioning began to converge around a shared set of broad understandings, congruent with domains identified in prior literature. Review after three carer interviews revealed that rich, detailed data had been collected, which primarily (although not entirely) converged with service user accounts. After this review, the carer recruitment strategy was focused away from carer groups and towards clinical services to capture perspectives of carers who were less involved in caring. After a further two interviews were conducted and no new ideas were introduced, it was decided to stop recruitment after all carers who had already been invited to take part had been interviewed.

Procedures

Semi-structured topic guides were developed (and piloted) with a person with lived experience of psychosis and a carer of a person with a schizophrenia-spectrum disorder diagnosis. Questions were also informed by a systematic review of item content of measures of social functioning (Long et al., 2022). Open-ended questions explored views, priorities and aspirations for social functioning, and the impact of antipsychotic medication on social functioning. Data on the impact of antipsychotic medication on social functioning will be published elsewhere. Social functioning was both defined by the participant and probed across domains drawn from the review (Long et al., 2022). Participants were not previously known to the researcher. After a phone call introducing the study, participants received information sheets on the aims of the research and gave written informed consent. Interviews took place in NHS

offices, at the interviewee's home, telephone or using video-conferencing software and were audio recorded, before being transcribed. All identifying details were removed and transcripts were checked for accuracy. ML (MSc) conducted the interviews as part of her doctoral studies and received training in qualitative interviewing, analysis and NVivo. Field notes were made after each interview. Participants were asked an opening question "Researchers often talk about the 'functioning' or 'social functioning' of people with mental health conditions like psychosis. What does the phrase 'social functioning' mean to you?" about their understanding of social functioning to elicit individual accounts in their own words. Demographic information was collected from both service users and carers, and carers also provided the demographics of the person they cared for. The SIX was administered to both groups; carers provided objective social information on the person they cared for. The topic guides can be viewed in Appendix 2.

Data Analysis

Data were analysed using reflexive thematic analysis (Braun and Clarke 2019, 2021a, b) and manged in NVivo. Two coders independently coded five transcripts to develop an initial coding framework, which was discussed among the team, including a carer and service user with lived experience. During this meeting the overarching theme of 'fitting in and being accepted' was identified. The framework was refined and applied to the rest of the data by ML. Codes were grouped to generate preliminary themes which were refined during critical discussion in team meetings. Themes were then iteratively reviewed and the final set of themes were agreed after further input from lived experience perspective.

Results

Between April 2019 and December 2021, 20 participants took part, of whom 12 were service users and eight were carers. Full demographics can be viewed in Table 1. Service users were on average aged 45 years old. Two service user participants whom clinicians identified as having low social functioning and were living in supported accommodation were less able to articulate and reflect on their experiences, possibly due to experiencing more negative symptoms, antipsychotic medication side effects or may reflect a lack of trust or fluency in social situations. Twelve interviews were conducted before the national restrictions introduced by COVID-19 came into effect ($n=7$ service users, $n=5$ carers). Eight interviews were conducted once national restrictions were lifted in July 2021. Interviews were on average 65 min. Service users' quotes are labelled 'P', carer quotes are labelled 'C'. One dyad was interviewed. An overarching theme of 'fitting in and being accepted' was generated, along with four themes: (1) importance of independence in performing everyday activities, (2) communication, sociability and connection to the world, (3) relationships as a feature of and a threat to social functioning, and (4) the paradox of work: highly valued but a risky endeavour. Overlap between sub-themes reflects the interconnected nature of different aspects of social functioning.

Overarching theme: Fitting in and Being Accepted

Most participants were not familiar with the phrase social functioning but spontaneously developed their own definitions. Reflections on what constitutes good and poor social functioning naturally followed. Across accounts, participants expressed that social functioning was connected to being ideas of social integration and being accepted. Carers compared the social lives and activities of the person they care for with a perceived 'normal'. While service users did not directly draw on social norms in the language they used, they did report social functioning to be connected to being like others and fitting in. Both service user and carer narratives reflected on implicit comparison of service user functioning against perceived social standards or norms. For some, perceptions of normal had shifted in line with revised expectations for someone with a severe mental health condition. Being in work was for most an indication of normal life.

Theme 1 The value of independence in performing everyday activities.

Several participants expressed that on the most basic level, social functioning was characterized by independence and autonomy, as manifested in the ability to undertake everyday tasks and responsibilities such as cooking and shopping. Completing everyday tasks was important for service users with different levels of functioning, but for service users who faced more challenges with social functioning it was particularly important and helped them define what was 'normal'. This was sometimes contrasted with the dependence thought to characterize schizophrenia. Completing daily tasks signified personal productivity in the absence of structured occupation.

> *"[For] someone with a [psychotic] diagnosis… it might be difficult to get on with everyday life sort of thing… I'm still going out every day and doing stuff, and cooking and cleaning and whatever else." (P06, male 30s).*

Table 1 Demographics of service user participants, carer-reported demographics of the cared-for person with a diagnosis and carer participants

Characteristic	Service user (service user reported) ($n=12$)	Cared-for person with schizophrenia spectrum disorder diagnosis (carer reported) ($n=8$)	Carers (carer reported) ($n=8$)
Primary diagnosis			
Schizophrenia	6	7	--
Other psychosis	6	1	--
Gender			
Female	4	4	4
Male	8	4	4
Relationship type			
Parent	--	--	5
Spouse	--	--	2
Sibling	--	--	1
Age			
<30	2	2	2
30–39	3	1	3
40–49	3	4	3
50–59	4	1	4
Ethnicity			
White British	10	4	5
White non-British	0	1	1
Black British	1	1	0
Asian British	1	2	2
Employment status			
Employed	3	0	2
Unemployed	6	7	1
Voluntary	1	1	0
Looking after home or family	0	0	1
Retired	0	0	3
Clinician judgment of social functioning			
Low	3	--	--
Middle	5		
High	4		
SIX score			
0	1	0	--
1	0	0	--
2	1	0	--
3	4	5	--
4	2	3	--
5	1	0	--
6	3	0	--
Antipsychotic polypharmacy			
Yes	4	2	--
No	8	6	--
Mental health service contact (years)			
<4	0	1	--
4–10	4	2	--
11–15	1	1	--
16–20	2	1	--
20+	4	3	--
Marital status			
Long term relationship/married	3	1	6
Single/unmarried	9	7	1
Age left full-time education			
Before the age of 15 years	0	--	0

Table 1 (continued)

Characteristic	Service user (service user reported) ($n=12$)	Cared-for person with schizophrenia spectrum disorder diagnosis (carer reported) ($n=8$)	Carers (carer reported) ($n=8$)
At the age of 15 or 16 years	4	--	3
Between the age of 17 and 20 years	6	--	1
After the age of 20 years	2	--	4

Some participants focused on appearance and adhering to certain standards of behaviour.

> *"Enjoying your own company first and foremost and looking after yourself… High standards, cleanliness, the wardrobe that you've got of clothes and shoes and trainers and that." (P12, male 40s).*

Some carers reported that good social functioning did not include behaving in antisocial or problematic ways, which was mentioned less by service users.

> *"He was lost in some of the neighbours' gardens […] It's not harmful but it's disturbing other people and it's involving the police […] this is very stressful." (C03, father to son, 20s).*

Several participants described difficulties making decisions or solving problems in everyday life, which inhibited independence and may suggest problems with cognitive functioning. Carers described providing significant support with daily activities and responsibilities, and this was linked to fears of the person they care for becoming homeless, losing welfare support and ultimately with lowered expectations for independence for their loved one.

> *"The idea of people living independently is a farce. I sort out X's bills and they're always going wrong […] all these things that happen." (C03, mother to son, 40s).*

One spousal carer maintained high expectations for their partner despite their need for support with daily activities, such as travelling to new places and paranoid thinking. In providing support, the person they cared for was able to maintain paid part time employment.

> *"Things have to happen regularly at certain days … new stuff, you know, really frightens her…. You have to go through the process of explaining it and likening it to things that we've done in the past too… there are challenges everyday but it's important that when she does think negatively you don't ignore it" (C08, spouse to female, 50s).*

Theme 2 Communication and sociability as connection to the world.

Participants expressed that an important feature of social functioning was communication and sociability, and this offered connection to the world and others, was described as a human need, important for identity and mental health, and a foundation to the success of other areas of social functioning such as gaining employment. Nearly all participants expressed that being among others was an unmet need for themselves or their loved ones. One participant reflected on how for social functioning, symptom-management with antipsychotic medication was not sufficient, and social contact provided an important adjunct for wellbeing.

> *"I need to talk, to talk to people. It's not only the tablet, the medication, it's for me to engage with people and not be on my own, alone" (P07, female, 40s).*

Data suggested that this was underpinned by social ability and communication skills, opportunity, interest and motivation, confidence in the self, trust in others and clear thinking. Table 2 includes these six elements with indicative quotes from the data. Familiarity was an important precursor to connection because of difficulties with trust. Even carers described

Table 2 elements of sociability important to social functioning in schizophrenia-spectrum disorders with indicative quotes

Element of sociability	Evidence from data
Communication skills and abilities	"Able to socialize, mix with people… make eye contact." C04
Confidence in self	"[Being] comfortable with family and friends and that I'm happy in the way I interact… that I'm confident in social situations" P10
Interest and motivation	"I would like for him to discover what he likes and that's it… if he would like to connect with other people or not." C03
Clear thinking	"Ability to fit in with society based on having reasoned thought processes." P09
Trust	"When I meet people I'm a bit wary of them because I can't trust them because I don't know them." P11
Opportunity	"Everything to do with being sociable isn't it. I mean, when the music centre was going on … although he hesitated it was somewhere from him to go to socialize" C05

difficulties communicating with the person they cared for at times, and some were fearful of having personal conversation in case this exacerbated mental health difficulties.

> *"[I] have to gauge whether it's worth me asking at that particular time because she might not want to talk… I don't want to trigger her off into a negative response or into negative feelings, or her feeling sad or withdrawn again. So I, as in, I don't want to be the cause of her going into depression" (C06, brother to sister, 30s).*

Accounts suggested that participants judged as having higher or middling social functioning generally had the requisite skills, abilities, interest and trust to communicate and connect with others. They were also able to create opportunities for themselves to do so, some with the of services (e.g. support workers accompanying service users to community activities). Symptoms of psychosis challenged clear thinking, confidence and trust in others, but once these passed, service users were able to re-connect in ways that suited them. Participants facing more challenges with social functioning, on the other hand, reported a greater lack of trust in others, as well as limited opportunities to interact and engage. One participant described a more profound sense of social exclusion:

> *"I have a non-existent social life… it's communicating with other people that sometimes becomes a problem for me… I think sometimes I feel guilty [about event in past]. That comes back to me… I'll go to the lounge [of his residential home]… and see people. They probably talk to each other all the time and I'll be there like a gooseberry." (P01, male, 50s).*

Carers perceived their loved ones as stuck in a reenforcing cycle of fear, isolation and disconnection. They portrayed their loved ones as living in a fragile reality, which was threatened by interactions with others, limiting sociability, which in turn limited the development of self and self-esteem. Paranoia and difficulties with social interaction may induce or exacerbate feelings of mistrust in others, which may fuel the cycle.

> *"He's happy with his own little space and his own bubble and he doesn't want that bubble to break. I don't know what he's scared of or what fear does he have. He feels safe at home with the people whom he knows… I think this illness has caused trust issues, and er, if he knows you he'll talk to you or smile but if not, he'll shut down, he won't talk to strangers" (C04, mother to male, 20s).*

Participants described digital communication, including the use of messaging applications, social media and forums, as a means of connecting to others on their own terms. Social media and messaging apps were used by most of the service user sample across gender and age groups, and in some cases most socialising was conducted online. Digital communication was important for most participants, regardless of whether they were interviewed before or after the COVID-19 pandemic, though the national restrictions may have led to increased use. The low pressure and non-demanding nature of digital communication was helpful when experiencing symptoms, or when confidence, motivation or trust in others was low. For some digital communication provided a sense of belonging, appeared to support social functioning and was perceived to help prevent a relapse in mental state.

> *"I do go on Facebook. I have friends, virtual friends… I just don't want to be [laughs] alone. I believe if I'm on my own and thinking, I don't want to go to the hospital anymore." (P07, female, 40s. interview conducted 2019).*

Most carers in the sample felt that digital communication enabled social functioning, however, some carers questioned the merits of using it as a sole method of communication, felt their loved one was potentially vulnerable to people online and felt that digital communication may create a false sense of connection.

> *"They text each other all the time. Right, OK. But you know, but she doesn't see her, but she texts her all the time…. X lives in this world where they're all her friends, but a friend to me is somebody who makes time for somebody. You know?… It's not a normal friendship, where your mates pop round to see how you are, or you pop round." (C07, father to female, 40, interview conducted in 2021).*

Digital communication helped service users make and maintain connections and relationships in specific ways. Relationships was another area commonly mentioned across accounts.

Theme 3 Close relationships as central to social functioning and wellbeing.

Close personal relationships were considered both a feature of good social functioning and also a means of achieving better social functioning through the support they offer. Attaining close personal relationships were also linked to improvements in overall mental health.

"When I was younger… I didn't have hardly any friends and stuff and I felt really isolated. And that, that can have a massive impact on your mental health." (P04, male, 30s).

Service users with partners greatly valued their romantic relationships for the support and stability that these relationships provided. Many service users not in a romantic relationship were resigned to remaining single, and this was observed across age groups. For some service user participants, including some younger service users, difficulties around decision-making, lack of experience, uncertainty around others' intentions, and difficulties navigating interpersonal difficulties in general were linked to a resigned acceptance to remain single.

"I don't really want to get in conversations [with strangers]… you don't really get anywhere with that… the thing is it's [dating] so out of my depth anyway, that I don't really know what's good for me and what's not…I suppose I just have to leave it like that." (P03, female, 20s).

Several younger service users reported attempting to meet potential romantic partners using dating websites and apps, which they viewed as pressurized and impersonal. Service users found it difficult to make judgements about others and felt at risk when sharing details about themselves with strangers.

"If there's someone I know from the past I'll contact them through the internet, but overall I've really given up on the internet and dating apps… it just doesn't seem very real… you don't really know what they're like at all… I wouldn't approach if it was a complete stranger." (P08, male, 30s).

There was some evidence in the data that obtaining a romantic relationship may be more valued by some with certain cultural and religious backgrounds. For British South Asian and Muslim participants in the sample ($n=3$), the family unit constitutes the main structure of support and social identity, and obtaining a romantic relationship and marriage were important norms. One participant reflected on the sadness he felt in not being able to achieve a relationship.

"In Asian culture we are very extremist in love, extremist and emotional…. Over there we give our life to another person…. It's a necessity. The age I am now, it's not an age to be living like a bachelor life. I have to have a woman in my home, we go together for shopping and outing and all that… it's very important because I have no other activity in my life. I don't drink, I don't smoke, I don't gamble. I have no social life." (P02, male, 50s).

Most parental carers expressed ambivalent feelings around their loved one establishing a romantic relationship, with vague hopes as well as sadness and resignation that this may be not realistic or achievable. Participants linked establishing a family unit to increased independence and some thought this would have beneficial effects on mental health and recovery. For carers of older participants this hope was generally diminished, and expectations were revised due to long duration of illness, perception of a lack of interest from their loved one and perceived discrimination.

"What girl today would want to be with someone that's got a mental disability like him?… It's got to be a pretty good person to do that." (C05, mother to son, 40s).

Friendships were considered important for many service users, and both carers and service users expressed the need for age-matched friendships, which some younger service users in the sample found difficult to develop and maintain. The two service users in full-time work in the sample found it difficult to build new friendships.

"I think it's hard to meet new people now… that things [are] like… set in stone. It's like when I was younger I used to meet new people all the time … I don't really seem to be able to extend that friendship." (P09, male, 20s).

Peer friendships were particularly important for some as these relationships provided a space of acceptance where service users could not only discuss difficulties related to their illness without the fear of stigma, but also take part in social activities together which have normalising effects.

"It's a good dynamic between that particular group of men [a community service user group] and so that was X's first point of social contact probably and he knows he can go and be accepted and have a chat and a few cups of coffee with people…it probably makes him feel normal… [it] makes him feel good about himself that people like him enough to want to spend time with him" (c02, mother to son, 40s).

Theme 4 The paradox of work: highly valued but a potentially risky endeavour.

For nearly all participants, including those who were not working, paid work was considered one of the most important features of social functioning, as well as a means of improving overall mental health and wellbeing.

> *I: "If. X could have been offered one thing that would've helped what, what would it be do you think? P:"…A job! Most people need to be employed in order to live…there needs to be an emphasis… people with mental illnesses need to be given an opportunity… that can resolve a lot of issues." (C08, spouse to female, 50s).*

However, both service users and carers expressed muted expectations around work, with full-time work not considered feasible for many. Expectations were modulated by age, with younger service users and carer participants of younger people with schizophrenia spectrum disorders more likely to express desire for working, albeit in positions with limited responsibility.

> *"I'm not thinking of anything major, but at least a little bit hands on job." (C04, mother to son, 20s).*

> *"I'd like to be busier which is where a little job could come in… I could have a much busier and much happier life." (P06, male, 30s).*

An exception to this were two younger service users who despite reporting few ongoing symptoms, expressed that engaging in work would expose them to stressful situations. Exposure to stress was perceived as threatening their fragile stability due to their sensitivity to socially demanding situations, suggesting a fear of relapse. Some participants ultimately felt their condition and the impacts of antipsychotic medication were incompatible with keeping a job.

> *"I'm not interested in work… my medication is [lists antipsychotic medications] and obviously that does affect me, and I need to stay away from stressful situations and that's really the biggest reason for me not to get a job, it's because of the stress that it could potentially give." (P08, male, 30s).*

Older working-age unemployed service users did not feel capable of work. Resigned acceptance of their circumstances did not mitigate the sadness they felt and loss of belonging and integration with the rest of society.

> *"It was a great big part of my life because I was earning good money and I was socialising, and I could pay my own way… [working was] very important. Because you meet people don't you, you feel more better, that you're doing something… [I feel] very sad… that I can't earn my own money" (P11, male, 50s).*

Data suggested that for a sub-sample of these service users, having better social functioning in other areas such as close personal relationships compensated for their lack of integration through work. For those in employment, work was described as a structured environment which helped establish routine, was important for identity and facilitated purpose and belonging.

> *"Work is my main… gets me out, gets me in a routine, gets me functioning. Erm, my social life is very limited really." (P05, female, 40s).*

Work was valued and service users were deeply motivated to remain in work, but paradoxically the workplace also presented significant challenges and stressors, including issues with performance, progression, and concerns around the disclosure of their mental health problems to colleagues. For some, volunteering was considered a low pressure and preferred alternative to the stress of paid work.

> *"My [volunteering] work? It's a huge… if I didn't do that at the moment, I wouldn't have much going on so… it's a huge deal. It's one of the best things I've ever done." (P06, male, 30s).*

For others, volunteering was less positive, and some described experiences that did not seem suitable or beneficial in terms of improving opportunities for gaining competitive employment. Some described being passed over when job openings arose in volunteering placements.

> *"I've done voluntary work and then they've asked me to do cleaning… they make you do things that other people don't want to do… I've done various things, but it's never really led to any paid work… I suppose you could say it's a bit of a dead end." (P03, female, 20s).*

Discussion

Overall Findings

To the best of our knowledge, the present study is the first to explore social functioning in people with

schizophrenia-spectrum disorders from both a service user and carer perspective, while taking account of differences in the social functioning circumstances of service users. Findings revealed that across service users and carers of people with differing social circumstances, social functioning is about social integration and being able to fit in. Perceptions of good social functioning were broadly similar in people across social circumstances, but there were some differences between service users and carers in terms of expectations. Many service users consider having a job or relationships important, but some consider attaining them a risk to their stability. Faced with not achieving desired social goals, some service users found a new 'normal' by revising their expectations for themselves, potentially reflecting the realities of living with the condition, but also self-stigma and discrimination which are common in schizophrenia-spectrum disorders (Fond et al., 2023), and negatively associated with social functioning (Shehata & Abd El Aziz, 2015). Adjusting to revised expectations for social functioning appeared to be harder to accept for carers than service users, with carers expressing more sadness in their accounts, in particular around their loved one not attaining a romantic relationship.

Basic Independence

A portion of the sample had significant challenges with social functioning (reflected in clinician judgements and SIX scores). Conceptual understandings of social connectedness focus on the subjective feelings of belongingness in social relationships (Hoffman et al., 2023). The present findings suggest that enabling people with schizophrenia-spectrum disorders to maintain independence in activities of daily living may contribute to feelings of belongingness and connection even when they have few or no social relationships. Striving for some social functioning goals including a job or a relationship were often perceived as risky to their mental health or recovery, and instead, exercising autonomy and independence in their activities of daily living helped service users redefine social functioning on their terms. Carers and others may overlook the importance of these small achievements in functioning which may contribute considerably to service users' quality of life. Carer participants reported providing support with the basic independence by mitigating the impact of issues with decision-making and organisation, possibly related to negative symptoms, social difficulties inherent to the disorder, or to the effects of antipsychotic treatment, adding to the evidence that carers support the social functioning and recovery of the people they care for (Estradé et al., 2023). Understanding more about how the right kind of social support facilitates social functioning may inform intervention development. While service users and carers broadly prioritised similar aspects of social functioning, carers expressed more concern over the potential for reemergence of disordered behaviour, in line with other research (Lloyd et al., 2017), likely linked to carer fear of relapse and difficult experiences while caregiving (Shiraishi & Reilly, 2019), and may result in known caregiving responses such as monitoring and hypervigilance (Allan et al., 2020).

Relationships and Digital Communication

While carers reported sadness and a sense of loss that the person they care for had not established a romantic relationship in line with other literature (Lloyd et al., 2017), many single service users reported resignation and acceptance. This pattern was reported across service user participants with different social circumstances. Service users' resignation, may be linked to factors such as stigma, discrimination, fear of rejection and the impact of antipsychotic medication side effects, for example lack of confidence due to weight gain, as reported elsewhere (White et al., 2021). However, it may also represent an adaptive revision of expectations so that service users can prioritise performing day to day activities. In contrast, carers' sadness may be understood in the context of grief for an imagined future they had anticipated for their relative. Carers often report difficulties with communication with the person they care for (Estradé et al., 2023), and discrepancies in expectations within the caregiving dyad found in this study may contribute to and exacerbate these tensions. Participants from South Asian backgrounds were less satisfied for themselves and the person they care for to remain single, suggesting a cultural difference potentially related to the differential value collectivist communities place on relationships and the group over the individual (Chadda & Deb, 2013; Hampson et al., 2020; Markus & Kitayama, 1991). We had small numbers of South Asian participants ($n=3$) in our sample, so we cannot draw general conclusions from these findings. Interventions targeting romantic relationships are feasible and acceptable for people with schizophrenia spectrum-disorders (Hache-Labelle et al., 2021), but there are no known effective interventions (Barnett et al., 2022), suggesting a significant gap.

Consistent with other research, we found that service users wish for more social connection but find it difficult (Mote & Fulford, 2020). Some participants described a reenforcing cycle of fear of interacting with others, isolation, disconnection and negative feelings about the self. Many service users used digital means of communication (messaging applications, social networking sites and online forums) to connect with others as a low-pressure alternative to in-person social interactions, and some described digital communication protecting their mental health. Digital communication may increase socialisation in people with schizophrenia (Miller

et al., 2015), and social networking sites and forums may offer a low-pressure context for targeted interventions. A review found that using a purpose-built social networking platform had no effect on social outcomes or quality of life (Thelwell et al., 2024). This study suggests that harnessing existing networks may be more acceptable.

While digital communication was popular for non-romantic social interactions, young, single service users reported abandoning online dating, in part due to low levels of trust in others. In the general population, online dating is emerging as the predominant means of meeting a potential new partner (Rosenfeld et al., 2019), at the same time as spaces for people with schizophrenia spectrum disorders to socialise in person are diminishing (Xanthopoulou et al., 2022). This suggests a need for further research to understand the needs of people with mental health problems who are seeking romantic relationships to prevent further social exclusion.

Employment

For many participants, employment was described as the most important indicator of social functioning and was linked to mental wellbeing and purpose, in line with other literature (Gühne et al., 2021; Marwaha & Johnson, 2005). Work generated a sense of purpose for service users in full time work, but some were not able to capitalise on workplace social networks to extend them beyond work (Boardman et al., 2022). Participants reported anxieties around disclosing mental health challenges to colleagues, likely linked to stigma, self-stigma and discrimination (Hampson et al., 2020). A study of employed service users found that many reported not feeling close to another person in the past week (Cohen et al., 2017), suggesting more support is needed for this group to gain broader social inclusion.

Fear of stress appeared to influence perceptions and expectations across social functioning domains. In terms of employment, fear of stress and relapse influenced both the belief for some service users that paid employment was not compatible with their condition, and the preference for jobs with few responsibilities for those who felt capable of work. Fear of relapse may directly impact social functioning expectations or may be mediated by other negative psychological outcomes such as low self-esteem, which has been found to be associated with fear of relapse in other research (Zukowska et al., 2022).

Recovery-oriented services should consider these factors alongside other established barriers to work including stigma and discrimination (Hampson et al., 2020). Developing workplace cultures free of discrimination that aim to reduce stigma and offer support to people with schizophrenia-spectrum disorders is needed.

Participants in this study reported mixed experiences of volunteering. In line with research in a general severe mental illness sample (Pérez-Corrales et al., 2019), volunteering helped people feel more socially integrated where the setting matched job aspirations or previous experience and involved positive relationships. Experiences were less positive where the placement did not align with the person or their work goals, in line with research in a non-clinical sample (Hoskins et al., 2020).

Two participants reflected on the role and impact of antipsychotic medication on their social functioning, including employment. For one, antipsychotic medication was perceived to increase vulnerability to stress and limit the feasibility of employment, while the other emphasized that although antipsychotics were necessary for symptom management, it was social engagement that enabled wellbeing. The limited qualitative evidence on the impacts of antipsychotics on social functioning suggests that for some, antipsychotics are perceived to improve social functioning, provided its use is personalised to optimise individual functioning (e.g. taking medication at certain time or reducing the dosage). For others, long-term antipsychotic medication use can have a negative impact on agency, increase stigma and hence limit social integration, in part because of adverse side effects, including weight gain and sedation (Bjornestad et al., 2020; Thompson et al., 2020). The present study findings highlight the importance of exploring service users' perceptions of antipsychotic medication and the impact of antipsychotic medication on social integration, though further research is needed to explore this in more detail.

Instruments and Rating Scales of Social Functioning

Scores on instruments of social functioning are largely anchored to individual capacity for different activities or behaviour including the number, type or time spent on activities and objective outcomes, such as employment or relationship status (Long et al., 2022). The present study findings complicate this view by suggesting that for people with schizophrenia-spectrum disorders (and carers), social functioning is understood within a subjective framework, where a sense of belonging is broadly prioritized over specific behaviours or outcomes. Measurement instruments that do not take the subjective experience of the service user into account in terms of perceived connectedness or belongingness, may miss important information on the subjective psychological experience of inclusion and integration which constitute meaningful social functioning. Subjective social outcomes are important predictors of quality of life (Nevarez-Flores et al., 2022), and are more strongly associated with risk for mortality (Holt-Lunstad et al., 2010) than objective social outcomes, which suggests the importance of

subjective outcomes more broadly. Optimal assessment of social functioning should be multidimensional and include both objective and subjective indicators.

The present study suggests that for many service users, regardless of age or gender, digital communication may be an important means of connections to others. Digital communication does not feature in many commonly-used social functioning measures (Bjornestad et al., 2019; Long et al., 2022), suggesting social functioning instruments should be adapted to ensure they are valid in this population and capture the different digital mediums used for social interaction.

Implications

This research supports personalised approaches to recovery that focus on helping service users feel accepted and socially integrated on their own terms, such as that which is offered in psychiatric rehabilitation services. Evidence suggests that psychiatric rehabilitation services that take a recovery approach result in increased rates of successful transition to independent living (Killaspy et al., 2020). Helping people to maintain their abilities in basic activities of daily living, such as hygiene, cooking and shopping is important to enable people to have a sense of pride when they feel they cannot achieve more ambitious goals such as working. Recovery goals should be person-centred and consider an individual's capacity, and clinicians should be attentive to service users' perceived barriers to social functioning, with the potential for more ambitious recovery goals to develop over time as barriers are overcome (Leamy et al., 2011). Despite efforts for service delivery to be genuinely recovery-oriented, clinical outcomes such as treatment adherence may be prioritised in current service structures (Speyer et al., 2025). The present findings add to existing literature which suggests that a focus on symptom management may be insufficient without also considering social integration. Carers are key stakeholders and partners in care and research should explore how services could better work with carers to support service users' independence and functional goals. Carers should be enabled to provide support to service users with social functioning in daily activities, decision-making and problem solving while limiting their burden and the established negative impacts of caregiving.

Future Research

People with schizophrenia-spectrum disorders need more social opportunities including opportunities to develop relationships, and this may be more valued by some social and cultural groups than others. Further understanding is needed about the variation in priorities and expectations for social functioning between ethnic groups. Understanding more about dating attitudes and behaviour including online dating in a large representative sample of people with schizophrenia-spectrum disorders, including minoritised groups, could inform intervention development. Understanding the link between social interaction online, broader social functioning outcomes and mental wellbeing could also inform future development of interventions. Work is important for many with schizophrenia spectrum disorders but is perceived as inaccessible. Research should seek to understand the contribution of fear of stress and relapse on employment expectations and indicators as well as factors such as stigma and discrimination (Hampson et al., 2020). Research is needed to understand the barriers and facilitators to social functioning, as understood by service users and carers on their own terms, including the role of antipsychotic medication. Understanding the barriers and facilitators to positive volunteering experiences may help shape interventions and delivery of employment support services. New measures or rating scales of social functioning should be developed, or existing measures adapted, which fully capture digital communication to ensure they are ecologically valid. Future research should explore social functioning among people with schizophrenia-spectrum disorders not on antipsychotic medication.

Strengths and Limitations

Purposive sampling enabled the inclusion of participants (and carers of people) with schizophrenia spectrum disorders across a range of social functioning circumstances (low, mid, high), as identified by clinicians, allowing for exploration of experiences associated with differing social circumstances. We acknowledge that such classifications may oversimplify individuals' lived experiences, but reflect how social functioning is conceptualised in clinical practice. Service user participants were distributed across the full range of SIX scores (0–6). In contrast, carer-reported SIX scores for the person they care were concentrated within a narrower mid-range of social functioning (scores 3–4). This difference may reflect sampling differences between the groups, as carers were likely reflecting on individuals with higher support needs, whereas service user participants were drawn from a broader range of social functioning circumstances. The clustering of carer-reported scores may also reflect the scoring structure of the index, whereby respondents receive the maximum score for items related to living in independent housing (i.e. not sheltered or supported accommodation), and living with family. The SIX does not constitute a comprehensive assessment of social functioning and may have limited sensitivity to subtle differences (Priebe et al., 2008). Therefore, findings may not be transferable across all social functioning circumstances.

Only one service user-carer dyad was interviewed, which limited the ability to compare of service user and carer perspectives within the same caregiving relationship. The analysis therefore explores themes across the service user and carer groups rather than exploring experiences within dyads.

Recruitment from carer community groups helped to balance out the representation of carer experiences. Service users facing more challenges with social functioning may be more reluctant to take part in an individual interview, and this may challenge the transferability of these findings to this group. Twelve of the interviews were conducted before COVID-19, and 8 were conducted after the final lockdown in July 2021. Changes to patterns in socialising may have impacted accounts of the latter group, though this not was apparent during analysis. Recruitment in a single Trust in urban and semi urban areas with a predominantly White ethnic make-up may limit transferability of findings to rural areas or people from minority backgrounds. People with the fewest challenges with social functioning may have less time to participate in research, and are often not served by secondary care services who offer support to those with the highest need. Data on living situation or accommodation status were not systematically collected as part of the study, limiting the ability to situate the findings in this context. All service user respondents and loved ones of carer respondents were taking antipsychotic medication. Sense checking of findings was not conducted with participants as this was not considered compatible with the use of reflexive thematic analysis (Braun & Clarke, 2022). However, an expert by experience of caring for someone with a schizophrenia spectrum disorder was involved in the interpretation of findings.

Conclusion

Service users and carers understand social functioning as social integration and acceptance and despite employment not being seen as realistic by many, perceive it as the most important indicator of functioning. For service users with more challenges with social functioning, independence in daily activities can help them feel more integrated. This is in line with care provided in psychiatric rehabilitation services. Service users and carers prioritise many of the same aspects of social functioning including work and independence, but carers also prioritise the person they care for establishing a romantic relationship and not exhibiting disordered behaviour. Commonly used instruments of social functioning may have limitations in terms of their validity if they do not capture the subjective psychological nature of social functioning or digital communication, which is an important means of connection for service users with different demographic profiles. Future research should explore dating attitudes in schizophrenia spectrum disorders and whether digital interaction translates to broader improvements in social functioning and quality of life.

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Data Availability Due to the nature of this research, the data are not available due to their containing information that could compromise the privacy of research participants.

Declarations

Ethics Approval The study was approved by NHS Research Ethics Committees Northern Ireland (19/NI/0013, 13/03/2019) and performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments.

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Competing Interests The authors declare no competing interests.

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