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Social networks and people with intellectual disabilities: A systematic review

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Abstract

Background: Despite the importance of social networks for health and well-being, relatively little is known about the ways in which adults with intellectual disabilities in the U.K. experience their social networks.

Method: A systematic review was completed to identify research focused on the social networks of adults with intellectual disabilities. Studies published from 1990 to 2019 were identified. Studies were thematically analysed.

Results: Quantitative, qualitative and mixed methods studies were analysed to identify key factors influencing social networks. Experiences of people with intellectual disabilities identified themes of identity, powerlessness, inclusion, family and support. These themes are discussed with reference to theories of stigma and normalisation.

Conclusions: Stigma and normalisation can be used to better understand the needs, desires and dreams of people with intellectual disabilities for ordinary relationships, from which they are regularly excluded. Implications for policy and practice are discussed in relation to building and repairing often spoiled identities.

KEYWORDS
normalisation, policy, relationships, social networks, stigma

1 | BACKGROUND

Social networks can be defined as 'opportunity structures' (Forrester-Jones and Grant, 1997, p. 7) or interpersonal relationships (Sullivan et al., 2016). Social networks can contain a range of people, including partners, family, friends, acquaintances, professionals and neighbours.

Hill and Dunbar (2003) reported typical network size for non-disabled adults as over 100 contacts dispersed across different areas of life. Social network size for adults with intellectual disabilities however is smaller and more restricted; Forrester-Jones et al., (2006) in their study of 213 individuals, finding an average network size of just 22 contacts and 'dense' network membership restricted to mainly other adults using intellectual disability services.

Social networks are key to social identity for adults with intellectual disabilities (Heyman et al., 1997) and social networks are vital for social functioning, self-esteem and quality of life (Bhardwaj, Forrester-Jones & Murphy, 2018). Social networks are also associated with happiness, self-confidence, mental health and leisure activities (Forrester-Jones et al., 2006) and are deemed crucial for facilitating social inclusion (van Asselt-Goverts et al., 2013; White & Forrester-Jones, 2019). Strong, supported social networks can build people's skills and positively impact on the identities of adults with intellectual disabilities (Beadle-Brown et al., 2016). Adults can

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find their relationships are enhanced through much-needed supportive networks (Hall & Kramer, 2009) in diverse situations such as living on locked wards (Fish, 2016); being mothers (Stenfert Kroese et al., 2002); or experiences of older age (McCausland et al., 2018). Social networks can also combat loneliness (Callus, 2017), which itself can have a detrimental effect on health and well-being. For adults with intellectual disabilities and their families, the importance of social networks for positive health, well-being, social inclusion and tackling disadvantage across the life-course cannot be understated (Bele & Kvalsund, 2016). Despite this, non-disabled people rarely consider the importance of social networks for adults with intellectual disabilities (Dunbar, 2015; Emerson & McVilly, 2004; Hall, 2005).

An examination of relevant theories can aid our understanding of the lack of inclusion adults with intellectual disabilities experience. Goffman (1990, p. 15), for example defined stigma as, 'an attribute that is deeply discrediting', and pointed out that when considering the ways in which the self can be presented in society and the social 'norms' that are created in relation to a sense of 'usual' self, identity, institutions and societies, 'it should be seen that a language of relationships, not attributes, is really needed'. In his consideration of human relationships, broadly from the perspective of symbolic interaction, he showed that the power inherent within stigma and labelling can be dynamic and have significant negative impacts on the lives of those who are stigmatised (Goffman, 1991). One critique of Goffman's work is the need to focus not only on what causes this situation, but also on how it can be overcome, in particular when social networks and relationships which, 'emphasise acceptance of differences' are formed between disabled and non-disabled adults (Bogdan & Taylor, 1987, p. 33). One such principle which is used to try to develop positive relationships with self and others is normalisation, developed by Wolfensberger et al. (1972). They suggested that perceived social deviance identified adults with intellectual disabilities in several specific ways: as sub-human organisms; as threatening; as menacing; as objects of pity; as holy innocents; and as eternal children. They proposed that a focus on supporting adults with intellectual disabilities in 'ordinary' day-to-day places, with 'ordinary' adults was more likely to succeed in reducing stigma and tackling the perceived social deviance of adults with intellectual disabilities. This in turn would lead to the opening up of possibilities for adults with intellectual disabilities to build and maintain wider, reciprocal social networks, with a broader range of people. Critiques of normalisation suggest that its absence from sociological and ideological agendas render it inadequate. Challenges include possible gender-bias (Williams & Nind, 1999) and that disability-specific spaces can be used to celebrate disabled identities and resist social discourse around what constitutes ordinary vs stigmatised locations. Chappell (1992) suggested normalisation reflects the views of powerful (non-disabled) professionals and their understanding of typical ways of behaving rather than the views of disempowered and impoverished people with intellectual disabilities. A lack of clarity of concept among policymakers and practitioners and of empirical evidence are important concerns, though could be argued to be less important

than understanding inclusion as a human rights issue (Culham & Nind, 2003). Despite their flaws, using the concepts of normalisation and stigma highlights that social networks can therefore either protect against or entrench the effects of stigma and segregation for adults with intellectual disabilities. Using these theories adds to our understanding of the possible reasons for a lack of focus on the social networks of adults with intellectual disabilities.

While previous research has considered the effects of poor social networks on the health and well-being of groups of adults with intellectual disabilities, to our knowledge no systematic literature review and synthesis exists that considers the social networks of adults with intellectual disabilities in the U.K. Institutional closures in the 1980s and 1990s, day services closures in the 2000s and austerity policies since 2008 may have impacted the nature of social networks for adults with intellectual disabilities. The aims of this study are therefore to investigate the nature of the social networks of adults with intellectual disabilities and to analyse the reported experiences of adults with intellectual disabilities in relation to those networks.

2 | METHOD

2.1 | Search strategy and eligibility criteria

This review took place in November 2019. The method used for review aligns with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). Databases used were Scopus, Web of science (Social Sciences Science citation index), International Bibliography of the Social Sciences (IBSS) and PsycINFO. Inclusion criteria were that articles must be published in peer-reviewed academic journals; written in English; empirical using the responses of adults with intellectual disabilities, or their families or formal care providers; had adults with intellectual disabilities as the focus; were carried out in the U.K.; and were focused on the social networks of adults with intellectual disabilities. No start date was set; the earliest study was published in 1990 and the last in November 2019. U.K.-only studies were included in order to identify studies which took account of shifts in U.K. policy such as community rather than institutional care, and more recently, policies of austerity unique to the U.K. Due to the wide timeframe, some early papers did not include specific information regarding their study's ethical procedures. Where findings formed part of a larger study, sometimes ethical review had already been reported in allied publications and so were absent in the reviewed article. Studies were excluded if they did not differentiate between children, young people and adults with intellectual disabilities; included autistic participants or those with mental health conditions without intellectual disabilities as their focus; or were undertaken outside of the U.K. Keywords used in the electronic search were as follows:

- (Social networ*) OR (Social support networ*) AND
- (Intellectual and Developmental Disabilit*) OR (learning disabilit*) OR (mental retardation) OR (subnorma*) OR (mental handicap) OR (developmental disabilit*) AND

- (famil*) OR (family support) OR (informal support)
- OR (Identity)
- OR (friend*)
- OR (relationship*)

The asterisk symbol was used to account for possible suffix variation in keywords. Although several of these terms are considered disrespectful currently, they were included so as not to inadvertently exclude relevant studies published when these terms were considered appropriate or those which were conducted in the U.K. but the terminology changed for publishing in international journals based outside the U.K.

2.2 | Study selection

In the first stage, 687 results were found of which 78 were duplicates. The remaining 609 records were screened by the first author with 550 excluded by title, abstract or type. In the second stage, the first and second authors independently reviewed the remaining 59 articles against the inclusion and exclusion criteria, which the Centre for Reviews and Dissemination (2009) suggest is good practice. There was an inter-rater agreement of 56/59 (94.9%). Differences were discussed and agreed. Both authors then independently agreed the exclusion of 32 articles. The remaining 27 articles made up the systematic review and synthesis (see Figure 1).

2.3 | Quality assessment

The methodological quality of studies was assessed using Sirriyeh et al. (2012) Quality Assessment Tool for Studies with Diverse Designs (QATSDD). The QATSDD had good reliability and validity and included a range of questions designed to judge the quality and rigour of research and therefore make judgements on whether it should be included (Fenton et al., 2015). The thirteen included papers were rated against QATSDD quality criteria on a 4-point scale from 'not at all' (0) to 'complete' (3). Percentage scores were calculated using the actual score and the maximum total score of 42 for qualitative or quantitative studies, and 48 for mixed methods studies. Papers scoring over 75% were rated as being of 'high' quality, those between 50% and 74.9% as of 'good' quality, 25%–49.9% as 'moderate' and below 24.9% as 'poor'. Five papers were scored as being of high quality, 18 papers as good, three as moderate and one as poor.

Seven papers (25.9%) were randomly selected and scored by the second author to determine the inter-rater reliability of the use of QATSDD for the 27 included papers. Overall inter-rater reliability for quality was 97.94%.

2.4 | Data analysis

Quantitative studies were analysed for information regarding the reported size and structure of participants' social networks. Influencing factors were also noted. These are reported in Table 1.
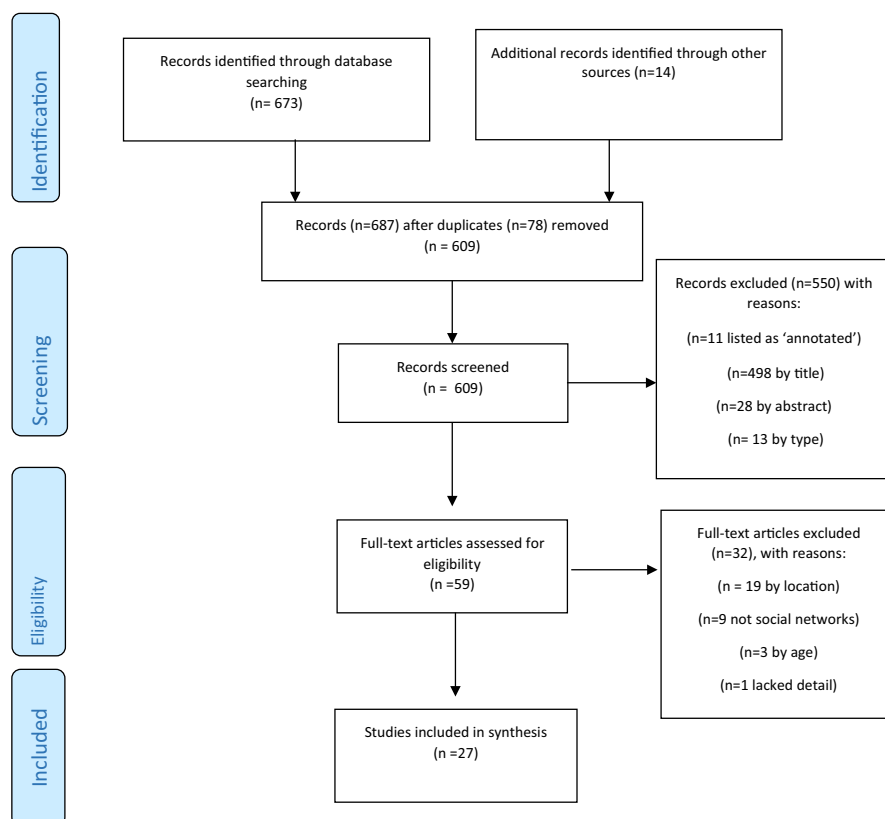
FIGURE 1   PRISMA (2009) Flow Diagram indicating records included and excluded at each stage

TABLE 1 Indicating the nature of social networks over time as reported in quantitative data

Quantitative article	Relevant policy for the timeframe of the study	Network size	Network characteristics
Bhardwaj et al. (2018)	Community care, The Care Act 2014	Mean = 2	n = 47 consisting 27 men (15 white, 12 South Asian) and 20 women (10 white, 10 South Asian) in day service settings. South Asian participants' networks were more likely to contain members of different ethnic groups and be made up of mainly family. White participants had networks which included more service users and staff. Both groups had the largest number of networks members from extended family, then day services.
Cooper (1998)	Community care: Care homes for older people	Older people (aged 65 years+) living in care homes saw 27 people in the previous 7 days. Younger people (aged 20–64 years) living in learning disability homes saw 16.5 people.	Older people tended to have social networks made up of more people with whom they lived. Day services for older people provided less opportunities for wider social network development than for younger people. Younger people had networks made up of more relatives and friends. Differences may be accounted for in lack of living relatives, and type of accommodation (care home vs learning disability home).
Dagnan and Ruddick (1997)	Community care: Participants had moved from an institutional setting to small, staffed houses	Mean = 3.1	n = 52 people aged 40+ years. 8% of participants had no social network. 52% of participants listed family as part of their networks. 52% of participants listed co-residents, 42% listed friends with a learning disability, and 29% listed other people without a learning disability, 12% of whom were advocates. The most common type of support was personal and emotional.
Donnelly et al. (1997)	Community care: Less mixed economy of care in Northern Ireland than in the rest of the U.K. meant lack of accommodation choices.	On average people were in contact with 2 family members and 2 friends.	n = 283 people discharged from institutional settings and a 40% sample followed up after 3 and 6 years. Mixed economy of care was limited so most homes were large private residential homes. Visits from others were infrequent, most people had no friends outside their place of residence. Little choice or opportunity to maximise their potential socially or economically.
Emerson et al. (2000)	Community care: Community-based residential supports compared with residential campuses for people with severe and complex disabilities	People living in dispersed housing had larger networks z = 3.30 than those in residential campuses (z not reported).	n = 40 (20 in residential supports and 20 in residential campuses. Family contact was greater for those living in residential campuses, but social network size and composition was greater for those living in dispersed housing. Participants in dispersed housing had people in their networks who were not staff, family or other people with intellectual disabilities. Participants in residential campuses reported none.
Emerson et al. (2001)	Community care: Supported living residences compared with small group homes, and large group homes.	7.4 in supported living residences, 8.3 in small group homes, and 6.1 in large group homes.	n = 270 people in three types of accommodation. The networks of participants in Supported living accommodation appeared to be larger only because they lived with larger numbers of people with intellectual disabilities. Participants in large group homes had the least number of staff in their networks. Participants in small group homes had the largest number of networks members who were not family, staff or other people with intellectual disabilities.
Emerson and McVilly (2004)	Community care: Supported accommodation	Friendship activities were measured. 65.3% of activities with friends were with network members with intellectual disabilities. 25.3% of friendship activities were undertaken with people who did not have intellectual disabilities.	The public sphere was a more likely location for friendship activities to take place than a person's home. Greater levels of adaptive behaviour were linked to greater numbers of friendship activities.

TABLE 1 (Continued)

Quantitative article	Relevant policy for the timeframe of the study	Network size	Network characteristics
Emerson (2004)	Community care: Cluster housing compared with dispersed housing	Not measured	People living in cluster housing have less social and friendship activities than those in dispersed housing.
Forrester-Jones et al. (2004)	Supported employment	Average social network size increased over time from 36 to 42 members.	The most common type of support provided was providing company, invisible support, confiding and support with decision-making. All types of support rose from colleagues significantly after time in an employment setting. Networks were more diverse than is typical for this group.
Forrester-Jones et al. (2006)	Community care: Resettlement from long-stay hospitals to small group homes, residential and nursing homes, supported accommodation, and hostels.	Average network size 22.	Accommodation type made a difference to the social networks of participants. Those in smaller services were more likely to experience close and companionable relationships than those in residential or nursing homes, but also more likely to experience aspects of relationships that were critical. Relationships also tended to be dense.
Grant (1993)	Community care	At baseline: family: 6, friends and neighbours: 1	n = 78 family carers over 2 years. Increased involvement by professionals was linked to policy development and accompanied a decrease in family contacts, usually due to deaths, moves and loss of capacity to provide care. Mothers were most typically the main carer.
Hulbert-Williams et al. (2011)	Community care	Median network size 8	38 participants. Participants reported 1.13 median members who criticised them and 2.3 median members with whom they were close. Social networks did not positively impact on ability to manage life events. Criticism was associated with higher levels of anxiety.
Lippold and Burns (2009)		Mean = 11.67 members.	N = 30. Family members made up 40.28%, friends (mainly with intellectual disabilities) made up 28% and staff 21.14%. Participants undertook community activities in groups with staff which affected opportunities for integration.
Perry et al. (2011)	Community care	Size not measured.	After moving, social contact in the previous month rose with neighbours, but no change found in contacts with friends.
Robertson et al. (2001)	Community care	Mean size 2 people excluding staff.	n = 500. 83% of participants reported a staff member as part of their network, 72% a family member, 54% another person with intellectual disabilities and 30% had members which did not fit into these categories. Staff provided most practical, emotional, informational and close support. Friends with intellectual disabilities provided the most bi-directional reciprocity and were significantly more likely to have been known by the participant for more than 5 years. Networks are affected by the personal characteristics of the person with intellectual disabilities, the types of accommodation, staff ratios, Institutional climate and whether 'active support' is used.
Robertson et al. (2007)	Person-centred support	Not measured	Increased social network was associated with having a small network before PCP training was delivered and with living in an area of deprivation. Living closer to family did not link with having more contact with family.

The review of the qualitative aspects of the literature was undertaken using a thematic synthesis approach, as advocated by Thomas and Harden (2008) using Braun and Clarke's (2006) six-step analysis process. This process was also used to consider the process of understanding and coding themes and subthemes. Articles were read repeatedly, preliminary descriptive codes were assigned, patterns and themes were identified across articles, themes were reviewed in line with article content and themes were defined and named. Coding was based on the research question, 'How do people with intellectual disabilities experience social networks?'. The one article

TABLE 2 Characteristics of included articles

References	Title	Study sample	Sample approach	Design and methodology
Bhardwaj et al. (2018) QATSSD score: Good	Social networks of adults with an intellectual disability from South Asian and White communities in the United Kingdom: A comparison	n = 47 consisting 27 men (15 white, 12 South Asian) and 20 women (10 white, 10 South Asian)	Day services in Kent and London were approached. Samples were similarly matched in terms of age and gender.	Quantitative. Adaptive behaviour Scale and Social Network Guide were used in interviews.
Cooper (1998) QATSSD score: High	A population-based cross-sectional study of social networks and demography in order compared with younger adults with learning disabilities	n = 207 consisting n = 134 aged 65+ n = 73 aged 20–64	n = 134 was a population-based study. n = 73 was a random sample	Quantitative Demographic, Interview Measure of Social Relationships, Vineland Adaptive Behaviour Scale
Dagnan and Ruddick (1997) QATSSD score: Poor	The Social Networks of Older People with Learning Disabilities living in staffed community-based homes.	n = 52 people aged 40+	Not clear. Participants live in small staffed house in Solihull with support provided by one service. All had previously lived in an institutional setting.	Quantitative. Wessex Scale and Social Network Questionnaire (Krauss and Erickson, 1988)
Donnelly et al. (1997) QATSSD score: Good	A 3–6 years follow-up of former long-stay residents of mental handicap hospitals in Northern Ireland.	n = 283 people discharged from institutional settings and a 40% sample followed up	Quantitative data collected about all 283 people discharged. 40% followed up with additional measures were selected randomly in proportion to the type of community setting.	Quantitative measures of quality of life covering material, emotional and social well-being; development and activity; and service receipt.
Emerson, E., Robertson, J., Gregory et al. (2000) QATSSD score: Good	The Quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities	Quantitative data n = 40 (20 in residential supports and 20 in residential campuses.	Purposive sampling from a larger parent study (N = 414).	Cross-sectional design, range of quantitative measures, some using observation.
Emerson et al. (2001) QATSSD score: Good	Quality and costs of supported living residences and group homes in the United Kingdom	Quantitative data on n = 270 people in three types of accommodation	270 people from a target sample of 300 (10 samples of 30 adults supported by 10 agencies, randomly selected)	Cross-sectional design to establish characteristics of people and costs of services. Range of measures used.
Emerson and McVilly (2004) QATSSD score: Good	Friendship Activities of Adults with Intellectual Disabilities in Supported Accommodation in Northern England	n = 1542	Random and non-random sampling by local managers	Range of quantitative measures
Emerson (2004) QATSSD score: Good	Cluster housing for adults with intellectual disabilities	n = 910 of which n = 741 lived in dispersed housing and n = 169 lived in cluster housing.	Sampling strategies defined by locality managers across 10 geographical areas.	Cross-sectional using a range of quantitative measures.
Forrester-Jones et al. (2004) QATSSD score: Good	Supported Employment: A Route to Social Networks.	n = 18	First 20 people to use the employment agency service	Social Network Guide, Adaptive Behaviour Scale, Life Experiences Checklist

Key findings	Ethics?	Theories	Limitations identified by authors
Social networks differed between white and South Asian participants. Social network size for both groups was 32. Impact of age on network size. South Asian participants more likely to have networks made up of mainly family.	University of Kent	Social networks.	More in-depth or a more ethnographic study needed.
Most older people lived in residential care and had more restricted social networks than younger people, and spent less time in enjoyable social interactions. Older people saw more people than the younger cohort, but these were limited to the residential home. Current services do not meet the needs of older people with ID.	Leicestershire Ethical Research Committee.	Quantitative population-based comparison research.	Cross-sectional design so younger and older group not matched
Older people have less family and so less family contact. 92% (*n* = 48) of participants has at least one person in their social network. Mean number was 3.1 (SD = 2.1).	None discussed.	Social networks.	A range of people filled out the questionnaires. More men than women in the sample.
Few opportunities for choice and disadvantage economically and socially continued. Poor social networks and no new or ordinary daytime activities took place in the new services. On average people were in contact with 2 family members and 2 friends. Normalisation and a mixed economy of care have limited success.	University of Kent.	Quality of life.	No baseline data. No comparison group. Possible bias towards those with higher levels of communication skills.
Small community-based homes provided better quality of life than larger new-built campuses, but at greater cost. Family contact was greater for those living in residential campuses, but social network size and composition was greater for those living in dispersed housing.	Not discussed but consent was gained from a range of sources.	Quality and cost correlations	None identified.
People living in smaller homes had greater choice, did more community-based activities and had larger and more diverse social networks. They were also more likely to have their homes vandalised and were considered at greater risk of exploitation.	None given but consent procedures used and research staff from King's College London were involved.	Quality and costs correlations	Organisations were not randomised or stratified. Few agencies involved. No random allocation re residential supports. Defined supported living as described by care providers.
Low levels of friendship activity within supported accommodation, most people with ID were more likely to undertake activities with other people who had ID, the public sphere was a more likely location for friendship activities to take place.	Not discussed	Friendship activities and supported accommodation	Not possible to determine the response rate or representativeness of the sample.
Cluster housing does not provide the connected community that is often assumed. People living in cluster housing have less social and friendship activities than those in dispersed housing.	Not discussed.	Quality and cost correlations	Sample size may not be representative. No within-study check was made on the reliability or validity of data collection. Analysis and reporting of results may be better based on measures of effect size and confidence limits rather than alpha levels.
Average social network size increased over time from 36 to 42 members. Higher social network size was linked to higher quality of life satisfaction.	Tizard Centre, University of Kent	Social networks and employment	Carers presence may have affected responses. Social networks size was already larger than average. Like for like comparisons are difficult.

(Continues)

TABLE 2 (Continued)

References	Title	Study sample	Sample approach	Design and methodology
Forrester-Jones et al. (2006) QATSSD score: Good	The Social Networks of People with Intellectual Disability Living in the Community 12 years after Resettlement from Long-Stay Hospitals	n = 213	n = 272 participants from a previous study. n = 213 agreed to participate.	Social Network Guide
Grant (1973, 1993) QATSSD score: Moderate	Support Networks and Transitions over 2 years among adults with a mental Handicap	n = 78 family carers over 2 years	From a wider study of n = 100	Quantitative measure in semi-structured interviews
Gregory et al. (2001) QATSSD score: Good	Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports	N = 96 people with IDD. 45 in village communities, 51 in residential support	Parent project used consultation with interest groups identified as 'good practice services'. Participants chosen at random.	Cross-sectional mixed methods
Hamilton et al. (2017) QATSSD score: Good	'There's a lot of places I'd like to go and things I'd like to do': the daily living experiences of adults with mild to moderate intellectual disabilities during a time of personalised social care reform in the United Kingdom	N = 26 people with IDD plus n = 13 support workers	Purposive sampling	Focus groups using qualitative methods. Critical realist approach to data analysis.
Head et al. (2018) QATSSD score: Good	Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital	N = 11 people with both IDD and Mental Health conditions	A total of 11 participants were recruited through the local multi-disciplinary Transforming Care team. Participants were identified by members of the team and invited to approach the main researcher if they were interested in taking part. 11 additional people participated as Key Support Persons including parents, a social worker, a support worker, a nurse and a home manager.	2 different types of qualitative interview

Key findings	Ethics?	Theories	Limitations identified by authors
Average network size 22. Accommodation type made a difference to the social networks of participants. Those in smaller services were more likely to experience close and companionable relationships than those in residential or nursing homes, but also more likely to experience aspects of relationships that were critical. Relationships also tended to be more dense rather than dispersed.	Not stated but detailed consent information.	Social network size and type in relation to accommodation type.	Fewer than half of the participant answered all questions. Participants may overstate their network size. Participants had mild to moderate ID.
Mothers tend to be main carers, as they age, other network members or agencies may not step in to provide support. Relationships with people with ID are reciprocal. Earlier intervention and greater information could support mothers to see transferring the care role more positively. Changes in networks happen independently of changes to the needs of people with ID.	Not discussed	Transitions in support networks	2 years is a short time period in which to consider change. People with ID not included.
In village communities people are more satisfied with friendships and relationships than people living in residential, but all are happier with accommodation and day services than with friendships. All satisfaction with friendships is 'far from optimal' which may link to isolation, harassment and institutional constraints. More hours of support relates to more satisfaction with friendships. More people with IDD in a network relates to greater satisfaction with friendships. Structural and process factors affect friendship formation. Proximity to people without IDD does not tackle the issues relating to making friends with people without IDD. 'We' like people who are like 'us', 'so' people with IDD express greater satisfaction if they have more people with IDD in their networks. People are happier having regular hours and days for day activities.	No information	Satisfaction, Quality of life, friendships and relationships.	Quality of life may not be representative as organisations chosen were chosen for their better practice. Quality of life satisfaction measured once in brief interview, high number of statistical comparisons using two-tailed alpha level of $p < .05$ which leads to high level of type 2 error.
Links reduced eligibility with austerity and the fragmentation of social networks and reduced quality of life, including increased risk of isolation and exclusion.	York St John University Ethics Committee.	Social capital	Small sample from 1 Local Authority area, study did not capture the most excluded people, no statistically generalisable trends.
People reported that their relationships with other people, including friends, family and staff, played a significant role in how they experienced the move. Moving was also an opportunity for people to shift their ideas about who they were as a person and opened up a wider array of stories about their identity. A number of recommendations are discussed, relevant for staff working in this field to support positive transitions out of hospital.	NHS	Social constructionist, Grounded Theory	No information

(Continues)

TABLE 2 (Continued)

References	Title	Study sample	Sample approach	Design and methodology
Heyman et al. (1997) QATSSD score: Good	Alone in the crowd: How adults with learning difficulties cope with social networks problems	*N* = 32 people with IDD were interviewed, *n* = 6 case studies are used in this paper.	Through services and researchers' networks, people with IDD who had some verbal communication ability.	Grounded theory using case studies and qualitative interviews
Hulbert-Williams et al. (2011) QATSSD score: Good	Self-reported life events, social support and psychological problems in adults with intellectual disabilities	*n* = 38	Recruited from 4 counties across N. Wales via social services departments and voluntary organisations.	A range of quantitative measures
Jahoda et al. (1990) QATSSD score: Good	Moving out: An opportunity for friendship and broadening social horizons?	*n* = 25 people with IDD, plus 12 mothers and 33 members of staff.	Via multi-disciplinary team and ATC managers. 8 hospital leavers, 7 home leavers and 10 people who stayed living at home were chosen and interviewed twice, 8–9 months apart, before and after moving. Similar levels of ability.	Mixed methods empirical
Lippold and Burns (2009) QATSSD score: Good	Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability	*N* = 30 with mild ID and *n* = 17 with physical impairments (PD).	Recruitment from specialist day services in same geographical area, age 18–60, not in full-time employment.	Quantitative comparison study, hypothesising that people with PD have wider social circles and better quality of life.
McConkey et al. (2003) QATSSD score: Moderate	Moving from long-stay hospitals: The views of Northern Irish patients and relatives.	*N* = 39 people with IDD and *n* = 34 relatives	All participants had been resettled from a long-stay hospital in NI. Inclusion criteria was ability to give informed consent.	Mixed methods empirical study, but specific questionnaires used are not clear.
Murphy et al. (2017) QATSSD score: Good	Offenders with intellectual disabilities in prison: what happens when they leave?	*N* = 38 men	Healthcare organisations and prisons identified 88 people due to be released from prison.	Mixed methods empirical.
Perry et al. (2011) QATSSD score: Good	Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living	19 people with ID who moved from institution to community living.	All participants who were moved minus 1 who died and 1 whose next of kin refused consent.	Quantitative quality of care and Lifestyle indicators assessed at 4 time periods before, during and after resettlement.

Key findings	Ethics?	Theories	Limitations identified by authors
People with IDD accept fatalistic roles or non-conforming roles in relation to the stigmatising situations in which they find themselves. Many suggestions for change but lack of optimism for change. Self-advocacy as the way forwards.	No information	Social Identity, fatalism	It is unsafe to generalise from small studies such as this, or to extrapolate findings from research with people with IDD to other groups.
Social support does not impact psychological life events. Having people being critical of participants was associated with higher levels of psychological problems.	University of Wolverhampton and Bangor University.	Social support and psychological problems.	Participants struggled with quantitative judgements, with judgements that involved time, carers assistance was required with significant events and with financial questions. Questions about sexual abuse were removed.
4 types of activities were identified, including inside and outside activities. Poor opportunities to make new friends in any of the 3 participant groups. Little contact with people who do not have IDD. Additional activities tacked on to organised activities. Families important. In hospital little or no contact with family, which did not change when leaving hospital. Lack of daily occupation. Lack of money was the single most limiting factor in the development of social lives. Living more independently in the community does not mean integration with non-disabled people. Wish for sense of belonging. Lack of acceptance by non-disabled people. Type of residence influences the nature of social opportunities. Degree of satisfaction with social lives and social networks is central to sense of identity. Staff need to create opportunities for social activities. Friendship schemes could be set up. Benefits should be increased so people can socialise. Parents should encourage greater financial independence. Education of general public to foster integration and be more accepting of people with IDD.	No information given	Links satisfaction with social life.	None listed
Type of 'disability' matters. People with PD have wider social circles while people with ID do more activities. People with ID have more contact with family and have fewer friends. Higher numbers of friends does not equate to 'better' relationships. For people with ID, more important than making new friends is support to maintain and foster current relationships.	None given	Quality of life	None given
A failing of resettlement schemes is the inability to create social networks for the person with IDD. Staff satisfaction with services outweighs other disadvantages of different settings. There is a need to recruit and retain high calibre staff.	Project steering group.	Evaluation of resettlement outcomes.	Study 'was not able to' collect data re increases in adaptive behaviours and in contacts with the community and family
Men were under-occupied and had limited networks (M = 29.1) rising to M = 45.2 for those in large secure units. Positive outcomes where services are joined-up.	NHS and NOMS.	Quality of Life. Evidence is required for policy to be effective.	Recruitment was difficult, there was no non-disabled control group, possibility of lost participants at later follow-up.
Quality of life remained the same or improved over time. Improvement in particular was found in greater family contact and in a reduction in staff-reported challenging behaviour.	Multi-centre Research Ethics Committee.	Evaluation of resettlement outcomes.	Improvements within hospital before moving may be due to staff training and awareness. More time is needed to review staff training outcomes.

(Continues)

TABLE 2 (Continued)

References	Title	Study sample	Sample approach	Design and methodology
Power and Bartlett (2019) QATSSD score: Good	Ageing with a learning disability: Care and support in the context of Austerity.	N = 21 over 2 studies. 1st study n = 4. 2nd study n = 17.	1st study purposive, 2nd study via local advocacy service.	Qualitative. 1st study semi-structured interviews and photo-elicitation, 2nd study semi-structured interviews.
Prosser and Moss (1996) QATSSD score: Moderate	Informal Care Networks of Older Adults with an Intellectual Disability.	N = 32 (carers of 32 people with ID).	Part of a wider study identifying older disabled people in a borough of NW England.	Qualitative, semi-structured interview schedule
Robertson et al. (2001) QATSSD score: High	Social networks of people with mental retardation in residential settings	N = 500 people with ID across village communities, NHS campuses and community-based homes.	This study provides greater detail on social networks from previously reported from a larger project. Sampling was random within setting type.	Quantitative comparison study.
Robertson et al. (2007) QATSSD score: High	Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities.	N = 93 over 2 years.	Purposive sampling of organisations. The first 25 people with ID to agree in each area, were included.	Quantitative study of the effectiveness of PCP after training.
Sango and Forrester-Jones (2018) QATSSD score: High	Spirituality and social networks of people with intellectual and developmental disability.	N = 36	Purposive across two different services (one faith-based, one not).	Exploratory, mixed methods (surveys, semi-structured interviews and observation), empirical.
The Money, Friends, and Making Ends Meet Research Group c/o Tilly. L. (2012) QATSSD score: High	Having friends - they help you when you are stuck from money, friends and making ends meet research group	N = 11 to start and n = 7 by the end of the research	All members of the group were invited to be participants	Social model of disability, action research, grounded theory approach using qualitative individual and group interviews.

rated as poor and the three rated as moderate were used as secondary rather than primary sources when themes were considered. Themes were checked by the second author.

3 | RESULTS

3.1 | Description of studies

Sixteen of the studies reported on quantitative research, six on qualitative and five were mixed methods studies (see Tables 1 and 2). All but two studies (Emerson, 2004; Emerson & McVilly, 2004) measured network size, but often in different ways. Other studies used social networks to evaluate interventions (Donnelly et al. 1997; Hamilton et al., 2017; Robertson et al., 2007); mental health (Hulbert-Williams et al., 2011); the needs and views of caregivers (Heyman et al., 1997; Prosser & Moss, 1996); or compared people who had intellectual disabilities with people who had physical disability (Lippold & Burns, 2009). A consideration of the factors which influenced social networks is now presented. Firstly, quantitative

studies will be examined, including the quantitative aspects of the mixed methods studies. These are followed by a thematic analysis of the qualitative studies, including the qualitative aspects of the mixed methods studies.

3.2 | Quantitative studies: key findings

Key findings from an examination of the quantitative data within this review are presented below. These findings relate to network size and characteristics, accommodation and location, and activities.

3.2.1 | Network size and characteristics

Network size in the 11 quantitative studies which measured this specifically, ranged from 0 (Dagnan & Ruddick, 1997) to a mean of 42 members (Forrester-Jones et al., 2004). Average network size reported in the quantitative studies was 12,059 members. Across

Key findings	Ethics?	Theories	Limitations identified by authors
Retreating welfare state, absence of kin, variable neighbourhood support, limited opportunities and spaces for friendships to flourish.	University of Southampton.	Geographies of disability and care.	Sample is not diverse, not necessarily generalisable. Austerity affected the shaping of the research.
Parents are main carers for most tasks, with siblings taking less responsibility. Proximity to family does not equate to additional support.	No details	Policy does not adequately recognise the importance of carers.	None given.
People with ID are excluded and marginalised. Social networks contain mainly other people with ID. Personal, structural and care environment structure all impact on social networks. Active support is linked to positive outcomes.	No details	Descriptive personal and environmental factors affecting social network size and composition.	Sample of organisations was not random, small number of organisations used, where participant had severe ID, proxy responses may not be accurate.
The efficacy of person-centred practice (PCP) is affected by participant characteristics, contextual factors and elements of the PCP process.	None given	Person-centred Planning	Small sample sizes affected the ability to calculate bivariate and multivariate analyses.
People in faith-based services had larger networks than those in non-faith-based services (m = 78 vs m = 44). Both groups had staff as largest component of their networks. Participants in faith-based services had more social acquaintances, more friends without IDD and more employers or colleagues in their networks.	NHS Ethics committee	Spirituality and social well-being	Relatively small sample, researcher bias, faith was restricted to Christian, not necessarily transferrable.
Links austerity and social networks. People with IDD define 'friends' and what it is like to have no money. No work, no money, few friends and limited confidence means we feel we live very limited and unfulfilled lives.	None given.	Austerity and social networks	Difficulty of some people to concentrate for long periods, conflicts of personality within the group.

the almost 30 years of this review, staff, family and other adults with intellectual disabilities most typically made up the majority of people's network membership, with other people without intellectual disabilities being in a minority. Those studies which measured networks in other ways, such as number of people seen in the previous seven days (Cooper, 1998), or number of activities undertaken with other people in the last four weeks (Emerson & Mcvilly, 2004) also found that networks were typically limited to these three groups. In Dagnan & Ruddick's, 1997 study, where mean network size was 3.1 members, the authors suggested that low numbers of non-disabled people in networks could be as a result of only recently moving from an institutional setting. In the most recent quantitative study, Bhardwaj et al. (2018) found the same three groups made up the bulk of adults' networks, with higher than average network size possibly linked to health, age and level of socially inclusive activities. Network size in all studies though remained significantly lower and less diverse than non-disabled people's networks.

3.2.2 | Accommodation and location

A key positive influence on social network size and/or satisfaction with social network members was accommodation type and location, which were usually inter-linked, most often as a result of U.K. Community Care policies which resulted in the closure of long-stay hospitals or other institutional settings. Studies found that larger settings, such as large residential homes, related to larger numbers of contacts with other adults with intellectual disabilities (Cooper, 1998), with few or no friends reported outside of the home (Donnelly et al., 1997). Cluster housing was reported to be related to smaller network size than accommodation which was more dispersed (Emerson, 2004). Smaller homes based in the community related to networks which were less dense (Dagnan & Ruddick, 1997; Emerson et al., 2000) and more likely to be considered close and companionable (Forrester-Jones et al., 2006). Grant (1973/1993) found that when adults with intellectual disabilities lived with parents, networks were typically small (six family and one friend or neighbour) with mothers providing most

care. The structure of networks in this study changed over 2 years as policies were introduced which led to professional workers becoming more involved in the lives of adults with intellectual disabilities and their parent carers. This tended to replace the one friend or neighbour with one professional worker, leaving network size unchanged. Perry et al. (2011) offered an alternative view of the influence of accommodation and location. In their study of adults moving from institutions into community settings, they found that staff training may have been an influencing factor in the higher number of activities undertaken by adults before they left the institutional setting. Hospital staff knew that adults were going to be moving into community settings, and the institution day service closed; suggesting that while important, smaller community-based accommodation could be even further enhanced. Robertson et al. (2001) similarly found that while accommodation was a clear factor in network size and structure, personal characteristics, staff ratio, institutional climate and the use of 'active support' also affected these aspects of the social networks of adults with intellectual disabilities.

3.2.3 | Activities

Over the timeframe of these studies, it was suggested that public spaces where friendship activities were found to be more likely to occur (Emerson & McVilly, 2004). Forrester-Jones et al., (2004) findings concurred; they concluded that being employed was a significant factor in increasing social network size and diversity. Day services, where these were available and accessed, were spaces where adults with intellectual disabilities could engage with others outside their home environment, but networks remained small overall (Bhardwaj et al., 2018; Cooper, 1998). Many studies highlighted that even though policies with their basis in normalisation principles, such as community care and person-centred planning, had had a beneficial impact on the lives and networks of adults with intellectual disabilities, the aim of full inclusion in terms of community presence and relationships that early authors had argued for had yet to be achieved (Cooper, 1998; Donnelly et al., 1997; Robertson et al., 2001, 2007). They found that although activities had shifted location from institutional to community settings, these were still segregated from 'ordinary' activities enjoyed by non-disabled people. Activities often took place as a group of adults with one staff member all undertaking the same necessary household activity such as shopping, or took place in day service settings. Both these types of activity, while important, provided adults with limited opportunity to create relationships or build networks as they were unlikely to either meet new people, or to meet a diverse range of people (Lippold & Burns, 2009). Contacts with new neighbours did not necessarily lead to inclusion (Perry et al. 2011); and adults with intellectual disabilities remained criticised by others across settings and by different network members (Forrester-Jones et al., 2004, 2006; Hulbert-Williams et al., 2011). Where networks increased significantly and included higher numbers of non-disabled members, this was in a workplace setting and networks took time to develop as familiarity grew (Forrester-Jones et al., 2004).

Summary

An examination of the quantitative data has suggested that social network size and structure can be affected by policy. Policies based on normalisation from the 1990s led to adults with intellectual disabilities being moved from institutional to a range of community settings. This provided opportunities for social networks to be developed and maintained. Differences in social networks were found between accommodation type and location, and activity type. Networks remained smaller than that of the wider non-disabled population and were typically comprised of other people with intellectual disabilities, staff and family.

3.3 | Qualitative studies: key themes

Forrester-Jones et al. (2006) highlight the importance of allowing individuals with intellectual disabilities to report on their own social lives, rather than relying on staff accounts; individuals being the best judge of who is included in their social network. Gregory et al.'s (2001) study found participants valued relationships which were friendly, where people got on with one another and did 'ordinary' activities together, such as shopping, working and conversing with neighbours. In that vein, supportive relationships, where they existed, were recognised and valued by people with intellectual disabilities (Bhardwaj et al., 2018). This could be seen in people with intellectual disabilities' definitions of friendships particularly. For example,

> We say that a friend is someone who is there for you when you are stuck, and someone who is gentle, kind and helpful. You can tell your friends things you do not want other people to know. It is also about having people to spend time with and do things together.
>
> (The Money, Friends and Making Ends Meet Research Group, 2012, p. 130)

Using thematic analysis to consider the experiences of adults with intellectual disabilities from their own perspective, an aspiration for ordinariness, of 'normality' was found throughout the qualitative literature, yet opportunities for the development of broader social networks were often thwarted (Hamilton et al., 2017; Jahoda et al., 1990). This was the main theme which emerged in the analysis of the qualitative data. The following subthemes were also identified: networks and identity; networks and power; networks and inclusion; networks and family; and networks and support services (see Figure 2). These are presented in turn below.

3.3.1 | Networks and identity

The ways in which people with intellectual disabilities made meaning of their experiences were directly affected by how they understood themselves in terms of their relationships with others (Heyman et al.,

FIGURE 2 Diagram of the theme and subthemes indicated by qualitative data
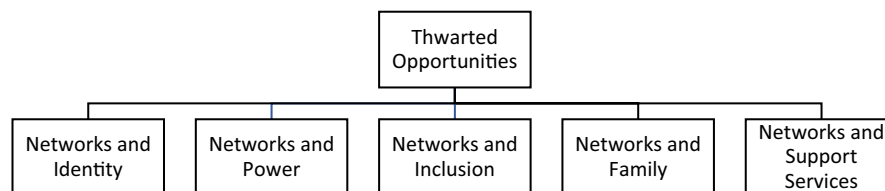
1997; Head et al., 2018). This could be confusing (Dagnan & Ruddick, 1997; Head et al., 2018) and work both positively and negatively for individuals. The dichotomy that adults with intellectual disabilities experienced was knowing that even while striving to be ordinary, they were being treated as other than ordinary, which could also negatively impact one's sense of self and one's relationships (The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012).

Positive relationships and networks were found to be essential for the formation of a positive sense of identity (Gregory et al., 2001; Heyman et al., 1997; Jahoda et al., 1990). A negative social identity could equally be created through negative relationships and networks. Hulbert-Williams et al.'s (2011) study for example noted the relationship between some psychological problems and higher levels of criticism by others. The creation of positive social networks and identities included the need for support from others which should be multi-dimensional in order to be effective. This included support to understand social norms which societies create around forming and maintaining relationships and the ways in which identity can be affected by deviance from those norms (The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012). Support could be from a variety of sources which should include self-advocacy (Gregory et al., 2001; Heyman et al., 1997). Without support, lack of social networks and valued identities could be thwarted and could lead to vicious cycles within relationships and networks, where people with intellectual disabilities had devalued social identities and could deal with the frustration this caused through fatalistic acceptance of those spoiled identities, often experiencing depression, anxiety, hostility or anger (Hulbert-Williams et al., 2011). Robert for example explained how his lack of networks affected his sense of self, 'I have a bottle of vodka, big massive bottle of vodka on own and drink it. I said "nobody wants me"' (Hamilton et al., 2017, p. 301).

3.3.2 | Networks and power

Thwarted opportunities also related to power, especially the powerlessness experienced by adults with intellectual disabilities.

When relationships with staff worked well, this could outweigh many other disadvantages people experienced within their new services, especially when people moved out of institutional care (McConkey et al., 2003). A lack of control in relationships with staff was particularly apparent though when people spoke about their experiences of relationships in institutional settings. Abusive relationships with staff could have subsequent negative effects on sense of self (Head et al., 2018). As a participant in Gregory et al.'s study

(2001, p. 287) explained, 'They're quite all right here, as long as you do what you're told'.

People also experienced little power over ending of relationships, especially when decisions about where they live, with whom, and whether and when they move were made at short notice, often without information or their input. Often the importance of maintaining relationships was thwarted by staff who were nevertheless ideally placed to support that maintenance (Jahoda et al., 1990; McConkey et al., 2003). When relationships, which often helped people to feel safe, were so frequently ended (especially relationships with staff), people were left feeling bereaved as they knew and were known by so few people (Hamilton et al., 2017; Head et al., 2018).

People reported finding a range of systems difficult or impossible to negotiate (Power & Bartlett, 2019). Many people did not have access to digital systems and many could not read or write, so needed support from people in their networks without intellectual disabilities in order to access and negotiate systems which are vital for well-being (such as welfare benefits, housing and finances). When this was lacking, people could easily experience a slide into debt and crisis without the social networks and relationships which could slow or stop the slide into powerlessness (The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012).

Policies introduced to promote adults with intellectual disabilities as employers of their own staff, in principle appeared to afford the opportunity to move into more powerful roles. Yet people still experienced stigma and powerlessness even in these relationships (Hamilton et al., 2017), thereby thwarting possible opportunities for social network development.

3.3.3 | Networks and inclusion

The composition of people's social networks was far from inclusive of non-disabled people, with most people with intellectual disabilities having very few close relationships of any kind and of those, most being people with intellectual disabilities.

People who had moved from institutional life to living in communities were often, 'deeply disappointed' (Jahoda et al., 1990, p. 138) with their lack of integration into 'ordinary' community life and their lack of expected friendships with non-disabled people. Sadly, lower expectations were indicative of people's higher satisfaction with their move (Gregory et al., 2001; Head et al., 2018). Lack of community acceptance appeared to occur irrespective of a person's previous or current accommodation (Murphy et al., 2017).

Lack of meaningful daytime activity was also an issue (Murphy et al., 2017) and when staff attempted to involve people with intellectual disabilities in their communities through activities, these

tended to be activities delivered to groups of people with intellectual disabilities rather than as part of wider communities. The effects of the double stigma of having intellectual disabilities and having segregated activities affected individuals and their sense of self, 'Makes me feel that size, (the participant made a gesture towards the ground indicating how small he felt) as though I could just crawl into a hole and curl up' (Jahoda et al., 1990, p. 139).

This stigma was also seen in 'ordinary' activities and spaces. Adults with intellectual disabilities and the people who supported them were aware of often erroneous reasons for resistance from employers for example (Hamilton et al., 2017; Murphy et al. 2017), even when people performed above the standard of non-disabled colleagues (Hamilton et al., 2017).

Much of the literature suggested the need for not only individualised approaches to the training of people with intellectual disabilities and their staff, but also wider tackling of the social stigma attached to negative perceptions about people with intellectual disabilities. This stigma thwarted opportunities for social network development. Authors suggested tackling stigma could begin to dismantle barriers and negative stereotypes, which otherwise may have prevented non-disabled people from considering friendships with people with intellectual disabilities (Forrester-Jones et al., 2004; Head et al., 2018; Heyman et al., 1997; Jahoda et al., 1990; McConkey et al., 2003).

3.3.4 | Networks and family

Most studies highlighted that a key relationship in many people's lives was the relationship they had with members of their family. As with other relationships in the literature, family relationships (and their lack) could have an empowering or disempowering effect in people's understandings of themselves and their network development.

When people with intellectual disabilities received positive regard from people in their social networks, particularly family, (sometimes described as, 'best friend' (Bhardwaj et al., 2018, p262)), it boosted their self-esteem and self-image. Being close to family both figuratively and literally could improve the way people with intellectual disabilities felt about themselves (Head et al., 2018; Heyman et al., 1997; Jahoda et al., 1990). Conversely, physical and emotional distance or abuse could have devastating effects (Power & Bartlett, 2019; Grant, 1973/1993).

While families could be a source of valuable and valuing support, Murphy et al. (2017, p. 964) warned professionals not to make assumptions about family settings equating to positive solutions, as when family were perceived as overprotective or abusive (Power & Bartlett, 2019) people experienced limitations in the rest of their relationships and network (Grant, 1973/1993; Bhardwaj et al., 2018), thwarting opportunities to develop supportive networks.

Just as authors suggested that policies based in normalisation, such as personalisation and community care, could be perceived as mere rhetoric when not backed by resources, families too were fearful of their family members falling through the gaps in any policy

delivery (Prosser & Moss, 1996; Grant, 1973/1993), so strived to protect them from the 'irresponsible' 'drive towards increased independence and choice' at any cost (Hamilton et al., 2017, p. 295).

In situations where family were absent, the importance of being connected socially, including being connected to charitable services, became essential for well-being, relationships, social justice and rights (Hamilton et al. 2017; The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012). These adults with intellectual disabilities were often reliant on a Social Worker or Care Manager to make decisions on their behalf, making their struggle harder than for those who had family support (Hamilton et al., 2017; Power & Bartlett, 2019).

Both people with intellectual disabilities and their (often older-aged) parents could feel trapped in situations where their own expectations around coping were unrealistically high yet support for improvement was desperately needed but either not trusted or not forthcoming, leading people with intellectual disabilities and their wider family members to crisis point (Prosser & Moss, 1996). Policies which promoted the far earlier intervention by professionals, respected the reciprocal nature of care, and had a psychological understanding of the functioning of families and social networks, could better enable the development of wider social network structures and community participation (Grant, 1973/1993).

3.3.5 | Networks and support services

Where Local Authorities had reduced or removed the services they provided, often voluntary sector groups had been a vital source of support. Despite positive policy developments, when experiencing cuts to their services people with intellectual disabilities appeared thwarted in their lives and opportunities for relationships without significant additional support from others (Power & Bartlett, 2019; The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012). Adults with intellectual disabilities needed support not only to access social activities and networks but also to access a range of support services (Sango & Forrester-Jones, 2018).

Negative impacts of cuts to services on existing networks were reported. Lack of money and irregular hours of support led to reports of boredom (Power & Bartlett, 2019; The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012), isolation and harassment by strangers or neighbours. Hamilton et al. (2017) and The Money Friends and Making Ends Meet Research Group c/o Liz Tilly (2012) suggested that any positives of the Personalisation agenda were greatly diminished by significant cuts to social care budgets. As Michael explained, 'they're trying to stretch people as far as they can without spending any money to give people support' (Hamilton et al., 2017, p. 294).

Proactive support and reciprocal social network relationships were required to prevent problems occurring in the first instance, with for example reading letters, paying essential bills, shopping, accessing food banks and budgeting on very limited or zero finances

until benefits were available (The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012).

As austerity policies continued, relationships and meaningful networks were perceived as being unimportant in the eyes of funders (Hamilton et al., 2017, p. 301). It was therefore unsurprising that people with intellectual disabilities could feel, 'Sometimes it seems like we are always in a battle' (The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012, p. 131).

4 | DISCUSSION

When considering the experiences of adults with intellectual disabilities highlighted by this literature review it is possible to illuminate the results further by synthesising Goffman's theory of stigmatisation and Wolfensberger's concept of normalisation.

In this way, it is possible to begin to consider not only the ways in which people with intellectual disabilities are perceived by societies more widely, but also the effects this could have on people's sense of identity, their social networks and their experience of relationships.

The construction of an ordinary identity through social networks can be viewed and understood from the perspective of symbolic interactionism. Using this approach, various aspects of self, such as self-worth, are linked to the ability to understand and play valued social roles, in socially accepted ways (Goffman, 1990a, 1990b). Crucially, the understanding of self and identity is created in one's social interactions with others and is therefore significantly impacted by one's social networks, or their lack. Yet this study has shown that the opportunity structures Forrester-Jones and Grant suggested in their study in 1997 do not appear to have developed into wider interpersonal relationships which authors argued enhance the identities of people with intellectual disabilities (van Asselt-Goverts et al., 2013; Sullivan et al., 2016). The desire for an ordinary identity can be at least partially explained by an awareness that one both is and is not perceived by others as ordinary (Wolfensberger et al., 1972); this review has highlighted that little has changed in terms of opportunities for this ordinariness to be reflected in social networks (Gregory et al., 2001). There were clear links to Goffman's consideration of stigma as a tool to identify socially constructed deviance and to ensure identity creation is embedded in the understandings of both stigmatisers and those being stigmatised (), which has been highlighted throughout the timespan of this literature review (Hamilton et al., 2017; Jahoda et al. 1990). Wolfensberger et al. (1972) argued that this understanding required people with intellectual disabilities to be immersed in, rather than isolated from communities. The creation of identity then can be understood as a joint, symbiotic activity; identity becomes both a verb and a noun in the context of social networks. Yet adults with intellectual disabilities reported deep disappointment with a lack of community acceptance and engagement which did not appear to change over time (Jahoda et al., 1990; Murphy et al., 2017).

Without the support of social networks, extreme marginalisation could further affect people's poor sense of self, which could be devastating (Goffman, 1990a, 1990b; Hamilton et al. 2017;

Hulbert-Williams et al., 2011; Wolfensberger et al., 1972). Yet typical service approaches to integration, which are assumed to lead to wider networks including friendships and relationships with non-disabled people and therefore address the power imbalances of societies, often did not deliver positive change, as Wolfensberger et al. (1972) warned and both Robertson et al. (2001) and The Money Friends and Making Ends Meet Research Group c/o Liz Tilly (2012) re-iterated. In addition to experiencing powerlessness in their relationships and networks, stigma is also experienced by people with intellectual disabilities in their desire for ordinary patterns of behaviour such as being employed (Goffman, 1990a, 1990b). A range of policies and programmes highlight the opportunities provided by employment (Parkin et al., 2020) which could build a less-stigmatised self-identity; but this too remained a dream rather than a reality for many people with intellectual disabilities (Hamilton et al., 2017).

In terms of inclusion, Goffman (1990) explained that often people are aware of the stigmatised characteristic they embody and can feel shame, as Jahoda et al.'s (1990) study showed. Stigma could extend to the places and spaces individuals with intellectual disabilities inhabit and despite critiques of normalisation (Donnelly et al., 1997) and stigma, this did not appear to change over time (Gregory et al., 2001; Heyman et al., 1997). Just as actors in a drama must maintain an image of self which they feel will be accepted by their peers and society more widely, so people with intellectual disabilities could feel they must hide their true 'selves' by managing their spoiled identities and adapting their behaviours (Emerson & McVilly, 2004). Stigma therefore created a negative dynamic relationship which also thwarted social network creation; this too did not appear to change over time (Head et al., 2018; Jahoda et al., 1990).

Expectation was an important consideration for people with intellectual disabilities and their families but was only part of the story in a stigmatising society where identity, networks and relationships can be spoiled (Goffman, 1990a, 1990b; Heyman et al., 1997). This can apply in all relationships and can be particularly complex and nuanced in families, who can often experience the effects of courtesy stigma from others. Family members of people with intellectual disabilities can also internalise the stigma they experience, blaming themselves for their family member's condition and situation (often known as affiliate stigma). As this review has shown, unrealistic expectations of and by families could lead to parents taking on the caring 'burden' and being unwilling to share that for many reasons (Prosser & Moss, 1996; Grant 1973/1993; McConkey et al., 2003). Often the opportunity for family members to create and maintain what Goffman (1991) referred to as 'ordinary' social identities as individuals rather than the 'virtual' stigmatised identities they inhabit was not available, especially in settings where segregation and isolation were the norm, creating additional pressure for everyone involved. This too did not appear to change over time (Bhardwaj et al., 2018; Emerson, 2004; Jahoda et al.,1990; Power & Bartlett, 2019).

Until the stigmatising perceptions of people with intellectual disabilities were challenged and addressed, with a strong emphasis on advocacy, Wolfensberger et al. (1972) argued that they would persist unchecked leaving people with intellectual disabilities to exist

as one-dimensional, devalued citizens with devalued social roles. Wolfensberger et al. (1972) went on to argue that support could lead to the benefits inherent in being part of an inclusive society which encourages social support networks, relationships and support systems between people with and without intellectual disabilities. In a time of austerity policies leading to significant cuts to services, less statutory support is available for people with intellectual disabilities, and the voluntary sector is being relied upon to provide the most basic of support (NIHR SSCR, 2020). Yet support is needed to access the voluntary sector, making social networks even more essential; and the sector itself is experiencing cuts to the services it can provide. This study suggests this has affected the ability of voluntary sector organisations to act as part of meaningful networks which 'catch' those falling through the net of statutory support and to support advocacy (Power & Bartlett, 2019; The Money, Friends, & Making Ends Meet Research Group c/o Liz Tilly, 2012).

Many people with intellectual disabilities had dreams and aspirations of ordinariness which were thwarted by their spoiled identities and their lack of power, inclusion and support. That this was a theme across decades is illustrated by William for example, who explained there were, 'a lot of things I'd like to do, but I can't'; asked what made him happy, William replied, 'when you can do what you want' (Heyman et al., 1997, p. 49). Susan, in Hamilton et al.'s study 20 years later, echoes this experience almost word for word, 'There's a lot of places I would like to go and things that I would like to do and I don't have anyone that I can go with and I would never go by myself' (Hamilton et al., 2017, p. 302).

This literature review and synthesis has shown that the voices and experiences of people with intellectual disabilities, parent carers and staff can illuminate the ways in which the day-to-day effects of policy were experienced in terms of social networks. It is this holistic approach which is needed in order that policy can be informed, created, funded and implemented more effectively, benefitting not only people with intellectual disabilities, but communities and societies also, so that an 'ordinary' life with supportive social networks can be grasped and embraced (Cooper, 1998; Emerson & McVilly, 2004; Sango & Forrester-Jones, 2018).

4.1 | Limitations

There are limitations to this review. Firstly, studies dating back as far as 1990 reflect the relationships and policies of the closure of large institutional hospitals of the time, which while relevant, have now been superseded. Secondly, some articles focused on cost rather than social networks specifically, some studies measured social relationships in different ways, and some did not include the views of people with intellectual disabilities directly. Different search terms or databases may have provided different results. Lastly, there are a number of theories which could have been used as a lens to illuminate the results of this study instead of stigma and normalisation, which may have suggested different interpretations of the experiences of people with intellectual disabilities.

5 | CONCLUSIONS

This systematic literature review and thematic analysis has highlighted the lack of published research in the U.K. which considers the social networks of people with intellectual disabilities and includes the voices or experiences of people with intellectual disabilities, their families and/or carers. While globally the voices of people with intellectual disabilities are beginning to be reported more widely, only 27 U.K.-based articles across the last 29 years met the search criteria for this study and have been thematically reviewed and synthesised in this way.

Synthesising the results of the review with Goffman's theory of stigmatisation, and Wolfensberger's concept of normalisation enabled a consideration of the ways in which adults with intellectual disabilities were perceived by societies more widely, and the effects this could have on people's sense of identity, their social networks and their experience of relationships. People with intellectual disabilities need support in order to have access to meaningful, valued relationships and roles. Policies which affected people with intellectual disabilities could benefit their social networks but were bound by current financial constraints.

Suggestions for ways to enhance rather than thwart the dreams of an ordinary life are suggested. The need for appropriate policy which is adequately funded and takes full account of the desires of people with intellectual disabilities has been demonstrated. The need for funded support to make, develop and maintain relationships and social networks has been highlighted. Training for people with intellectual disabilities, families and staff should tackle not only people's own abilities in creating and maintaining social networks but also wider social stigma which so often thwarts dreams of ordinariness and creates negative environments where identities are spoiled, often despite the efforts of staff and families. Further U.K.-based research regarding the significance of support for social networks in and on the lives of people with intellectual disabilities is needed.

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