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Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews

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Abstract

Adults on the autism spectrum are affected by health disparities which significantly reduce life expectancy and experience barriers to accessing healthcare. Social prescribing is a holistic approach that diverts patients from primary care to health-enhancing activities in communities. However, there has been a lack of research attention to how autistic people navigate the social prescribing pathway and the ability of these approaches to address existing disparities. This mapping review aimed to synthesise features of non-medical, community-based interventions for autistic adults to assess their suitability for a social prescribing approach. A systematic search and screening process was used to identify literature reviews from medical databases (Embase, Medline, PsycINFO, CINAHL and Cochrane reviews) and grey literature. We extracted data from 26 reviews and 21 studies including types of services, participants, outcomes, settings and procedures. A narrative and visual synthesis is used to map the variety of services and interventions identified, the outcome measures used, and the barriers and facilitators to progression through services in relation to a realist social prescribing framework. The review found that there has been minimal evaluation of holistic, low intensity services for autistic adults, such as those offered in social prescribing approaches. Outcome measures remain focused on features of autism and reveal less about the effects of interventions on health and wellbeing. Aspects of the social prescribing model were identified in the features of service pathways, but findings also suggested how social prescribing could be adapted to improve accessibility for autistic people.

Key Words:

Primary Healthcare; Health Services; Autism; Access to Health Care; Community Participation; Social Prescribing

What is known about this topic

- Autistic people experience health disparities including preventable physical and mental health concerns
- Social prescribing may align with the need for community-based support for autistic adults
- There is a lack of literature investigating outcomes and processes of social prescribing for this population

What this paper adds

- Many features of services for autistic adults that enabled navigation through the service pathway shared features of the social prescribing approach
- Services should consider a broader range of outcomes to identify improvements in health and wellbeing

- A flexible and creative approach to social prescribing may be needed to accommodate the needs of autistic adults

Background

Autistic people represent at least 1% of the UK population (Brugha et al., 2011; note identity-first phrasing is accepted terminology – see Kenny et al., 2016; Bottema-Beutel et al., 2020). Although the characteristics of autism, which include differences in communication, social interaction and sensory processing (Barber, 2017; World Health Organization, 2018) can be disabling in many contexts, autism is not a pathology that causes degeneration or illness. Despite this, autistic people experience health disparities including higher mortality and shorter life expectancy than the general population, and a high prevalence of preventable physical and mental health concerns (Hirvikoski et al., 2016; Woolfenden et al., 2012; Hudson et al., 2019; Kinnear et al., 2019).

In the UK, a diagnosis of autism alone does not qualify for input by mental health or learning disabilities (LD) services (Barber, 2017; Department of Health, 2014). Inconsistencies in recording of autism diagnoses may also impact on how preventative healthcare, such as annual health checks, can be targeted (Sharpe et al., 2019). The UK Government's Autism Strategy (Department of Health, 2014) has highlighted a need for low-level services for autistic adults delivered within communities to reduce inpatient admissions, promote social inclusion and assist individuals ineligible or unknown to other services in order to improve outcomes for this population.

Social prescribing is a distinct referral pathway which involves linking individuals who present to primary care with socially derived or long-term health problems to local, community-based activities such as art groups, exercise clubs and outdoor activities (Chatterjee et al., 2018). Social prescribing delivery typically involves a referral from a GP directly to a service based in the community, or to a link worker, who connects the patient to a service or activity that will meet their presenting needs through a process of joint decision-making (Kimberlee, 2015). Social prescribing offers an alternative model to traditional healthcare through its holistic approach (Polley et al., 2017), and furthermore is already established within primary care networks in the UK and being increasingly prioritised and funded (NHS, 2019).

It is argued that social prescribing has the potential to attend to multiple health and wellbeing needs and promote long-term health management, with studies finding positive impacts of social prescribing programmes and activities on mental health outcomes, subjective wellbeing, self-esteem, social isolation and physical activity in general population groups (Kimberlee, 2016; Foster et al., 2020; Boyce et al., 2018). Autistic people are also disadvantaged by social factors which underlie health inequalities in society (Marmot, 2010), including lower educational attainment, high rates of un- and under-employment, housing disparities and social isolation (Brugha et al., 2011; National Autistic Society, 2016; Orsmond et al., 2013). Social prescribing may help to mitigate some of these social determinants of health (South et al., 2008; Parkinson et al., 2015; Jani et al., 2020); for example, by addressing financial issues, which can impact on multiple areas of health including emotional wellbeing, stress and social relationships; facilitating the development of skills that lead to employment; and providing opportunities for social inclusion and long-term health maintenance.

Single studies of community-level interventions including recreational activities, low-intensity support services (e.g. advice hubs) and social support groups designed for autistic adults have shown reductions in perceived loneliness and improvements in life satisfaction, stress, communication, coping, skill development, quality of life and physical and emotional wellbeing in autistic adults (Billstedt et al., 2011; García-Villamisar & Dattilo, 2010; Macleod, 1999; Southby & Robinson, 2018; Spain & Blainey, 2015). However, many studies have been characterised by high heterogeneity, small effect sizes and lack both active control groups and long-term follow-up.

While coproduced research with autistic people has identified mental health and quality of life as priority areas for addressing emotional wellbeing (Benevides, Shore, Palmer et al., 2020), many interventions and services for autistic people typically focus on reducing core traits of autism (Provenzani et al., 2020), suggesting wellbeing outcomes may currently be overlooked. Self-determination, employment, social support, personal development, coping, self-advocacy, and physical and emotional wellbeing are relevant indicators of quality of life for this population (Burgess & Gutstein, 2007; Kim, 2019; Schalock, 2000; Shattuck et al., 2012), however research has been limited by the use of mental health measurement scales that have not been validated in autistic samples and a lack of measurement of quality of life outcomes (Provenzani et al., 2020). Furthermore, the disparities in physical health for this population suggest physical health may also be an important outcome for services for autistic adults.

These types of interventions also represent only the end point of the social prescribing pathway. Alderwick et al. (2018) highlight the need for evaluation into service pathways and referral routes to assess how patients access and navigate between clinical and community services. As autistic adults report barriers accessing healthcare (Christou, 2016; Raymaker et al., 2017; Mason et al., 2019), leading to delays in treatment and poorer outcomes (Doherty et al., 2020), exploration of service pathways may be important for evaluating how social prescribing can be optimised for this group. Realist studies suggest that factors such as the quality of a relationship with a GP, the accessibility and location of services and the quality of staff training can influence the outcomes of social prescribing to community-based advice and activities at stages of enrolment (referral), engagement (initial uptake) and adherence to a social prescribing intervention (Husk et al., 2019; Bertotti et al., 2018). However, the influence of such factors on access to services and their outcomes for people on the autism spectrum remains underexplored.

Approaches relevant to social prescribing, such as art therapy, physical activity and music therapy, appear to have high acceptability for autistic people, who have identified a preference for such interventions to be available and accessible at the community level as a means of improving wellbeing (Benevides, Shore, Palmer et al., 2020). As a low-level intervention designed to be accessible and available at the local community level, social prescribing aligns well with the goals of the Autism Strategy and may be worthy of consideration as a route for improving health and wellbeing outcomes.

Objectives

Due to the scarcity of literature on social prescribing as a specific approach for improving health outcomes of autistic adults, this review will synthesise the results of reviews of similar community-based or non-medical support services for autistic adults. This review aims to identify gaps in knowledge around the provision, evaluation and mechanisms of these services through a mapping approach. It also aims to explore what these gaps reveal about the suitability of a broad range of existing support types for social prescribing approaches, to address community participation, social inclusion and wider determinants of health in autistic people, in line with UK health policy and the Autism Strategy (NHS, 2019; Department of Health, 2014).

Prior reviews have been carried out on studies of this type of support for autistic adults (e.g. Lorenc et al., 2018; Shattuck et al., 2012) but without the focus on social prescribing. This review will address the following research questions:

1. What is the nature and variety of non-medical, community-based support for autistic adults that has been reviewed?
2. Which outcomes are measured for these services and how do they align with the wellbeing priorities of autistic adults?
3. What can existing research reveal about the characteristics of referral pathways underlying services and their contributions to the access to and success of services?

Methods

We undertook a systematic mapping review of the evidence for non-medical interventions for autistic adults. Mapping reviews do not aim to answer a specific research question or appraise the evidence, but represent an exploratory approach to describe the nature of the evidence base, highlight gaps and identify trends in relation to a broad research question (James et al., 2016; Snilstveit et al., 2016). The process involves rigorous systematic searching and data extraction methods, with a visual and narrative synthesis of the findings. The methodological approach is detailed below.

Scoping and Search Strategy

We used a comprehensive, systematic search process to identify relevant literature. Search strategies were developed in collaboration with an information specialist and drew from the relevant expertise of the review team. Search terms were informed by scoping the existing literature yielding medical subject headings and free text terms pertaining to autism, community-level interventions (e.g. “community referral”; “third sector”) and typical activities and services offered within social prescribing schemes (e.g. “exercise”; “gardening”; “advice”) (Chatterjee et al., 2018). Literature on interventions for autism, health-related quality of life and peer support within the Cochrane library of systematic reviews was searched to identify additional search terms, as well as using PubReMiner.

The final search strategy was developed using Embase, with changes made to how terms were combined and filtered as a result of the amount of relevant hits and further search terms added as these emerged from literature identified through trial searches. The health-evidence.ca filter recommended by Lee et al. (2012) was used to limit results to previous reviews. Additional terms were added to the search strategy to identify further types of review including scoping reviews and rapid reviews. The finalised search strategy is available in Appendix 1. The search strategy was applied to the following databases: Cochrane Database of Systematic Reviews, Embase, Medline, Psycinfo and CINAHL. Searches were run simultaneously on 6 December 2019, and repeated for an update of the review in January 2021.

We manually searched reference lists of accessed literature, personal collections, and websites of interest to identify further relevant literature. Including grey literature in a review can allow for the identification of non-academic sources, increasing the evidence base and reducing publication bias (Adams et al., 2016) and in reviews of complex interventions may obtain more valuable results than medical databases alone (Cooper et al., 2017).Therefore, EThOS, ProQuest Dissertations and Theses Global were used to identify academic theses, and Google and OpenGrey were used to identify further grey literature. Google searches comprised a broad web search with combinations of terms of the systematic search strategy, as well as focused searches of web addresses ending ".gov.uk", ".org.uk", ".nhs.uk" and ".ac.uk". At least 20 pages of results for each search were scanned for relevant literature. Searches were also performed on The King's Fund database (health and social care topics) (https://koha.kingsfund.org.uk/) and Social Care Online (https://www.scie-socialcareonline.org.uk/). Searching for grey literature and hand-searching took place over a longer period beginning on 11 December 2019, and again repeated in January 2021. All records were extracted to and organised using EndNote X8.

Inclusion Criteria

Types of Studies.

We included:

- Any type of review using recognised methods (systematic, scoping, mapping, rapid and realist reviews) to synthesise quantitative, qualitative and mixed methods studies and service evaluations;
- Policy documents or reports, which used a systematic search process with inclusion and exclusion criteria to identify relevant studies and a set protocol for data extraction.

We included reviews using any recognised type of synthesis (e.g. narrative; meta-analysis). Narrative literature reviews or any review, report or evaluation which did not use a systematic search process were excluded.

Participants

We included reviews where at least 50% of participants were adults (aged 16 or over) with a reported diagnosis of autism or suspected autism without learning disability, defined as either "autism", "Asperger's syndrome" (a former diagnosis for what is now considered to be autism), "autistic disorder", "autism spectrum disorder" or "autism spectrum condition". Where IQ but not LD diagnosis was specified, studies were excluded if over 50% of participants had an IQ lower than 70, which is a commonly used cut-off for learning disability (National Institute for Health and Care Excellence, 2018). Where this was not reported in reviews, this information was discerned from the studies contained within reviews.

Interventions and Context

Included reviews needed to have evaluated at least one non-medical intervention. This could be categorised as any of the social prescribing models described by (Chatterjee et al., 2018) (arts, bibliotherapy, adult education, exercise, ecotherapy, healthy living interventions, information referral (including community hubs), supported referral, and/or time banks). Interventions designed to support social skills, employability (including volunteering), befriending and mentoring were also included if relevant to the population of interest. We also included reviews of psychosocial, mind-body, animal-assisted and occupational therapies if delivered outside of primary or secondary care models as further non-medical services that could potentially be targeted at the population of interest. Reviews from any country could be accepted but only those reported in English.

Outcomes

Outcomes could be qualitative or quantitative, and could either be self-reported, parent/caregiver/support worker rated, administrative or observational.

Review Selection

One reviewer (CF) deduplicated results using EndNote. For literature identified through the databases, titles and abstracts for all records were screened independently by two reviewers (CF & RAS) against inclusion and exclusion criteria using Rayyan (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016). Full text was accessed for studies which were included or where inclusion remained unclear. These were screened by two reviewers (CF & RAS) and disagreements were resolved through consultation with a third reviewer (KH). Studies identified through grey literature searching were screened at the full text stage by two reviewers (CF & RAS).

Data Extraction

Meta-data relating to reviews were extracted and organised in tabulated format adapted from the Joanna Briggs Institute data extraction form for umbrella reviews (Aromataris et al., 2017) (see Appendix 2). Data were extracted by one reviewer (CF) and verified by another (RAS).

We coded outcomes of studies included in reviews into the domains of: mental health (e.g. anxiety, depression, self-esteem); physical health (e.g. physical activity level, physical disability); quality of life and adaptive functioning (e.g. quality of life, executive functioning, self-efficacy/self-determination); autism-related outcomes (e.g. diagnostic tools, empathy/theory of mind, behavioural, cognitive); wider health correlates as summarised by Marmot (2010) (e.g. employment; social support); intervention characteristics (e.g. satisfaction, cost-effectiveness, maintenance, generalisation); other outcomes (e.g. academic outcomes, social interaction quality/quantity, ADHD symptoms); and qualitative findings. Some reviews did not summarise the results for all outcomes of their included studies. Snilstvelt et al. (2016) recommend that evidence mapping approaches synthesise data from previous reviews and original studies to ensure both breadth and depth of the evidence. The extraction and synthesis of primary studies was also essential for extracting sufficient data to address the third research question. We therefore extracted data from primary studies in the included reviews but due to the quantity of previous research contained in reviews, and the relevance of our review to UK policy, limited these to studies evaluating

UK-based services. However, the findings may be generalisable to other contexts. Extracting studies from existing reviews also enables access to previous evaluation of the quality of included studies to maintain rigour in investigating an underexplored area, and the inclusion of pre-synthesised literature across many disciplines ensures relevance to the holistic approach of social prescribing.

Data Synthesis

Data from reviews and the extracted UK studies relating to types of intervention, setting, participants and outcome measures were summarised using charts. Study quality assessment was extracted from previous reviews where available.

The extracted primary studies comprised quantitative and qualitative research articles, reports and policy documents. Quantitative outcome data from primary studies were coded according to the same outcome domains identified in reviews; colour coding was used to signify if outcomes were observed to have a positive, mixed/unclear, or adverse effect (Aromataris et al., 2015) and effect sizes, statistical significance and measures used were noted. Coding was carried out by one reviewer (CF) supervised by a further two (RAS & KH).

For qualitative data, all full text articles of the UK studies were uploaded into NVivo which we used to extract descriptive information on study methods and context and qualitative results. Quotes were coded into themes using an inductive method. We adopted an essentialist philosophy and so data were coded at face value. Initial examples of themes were shared and verified by the other reviewers. Service pathway characteristics were coded into facilitators and barriers and organised according to the framework described by Husk et al. (2019) (Enrolment, Engagement and Adherence) (see Background section).

Results

Search Results

The search strategies identified a total of 4536 hits through database and grey literature searches. 4443 were excluded at title and abstract screening, leaving 93 to be screened at full text. A descriptive summary and flow diagram in Figure 1 details the search process and results and indicates the number of studies identified and excluded at each stage of the process.

Figure 1

Screening Process

[Fig.1]

We identified 26 reviews that met the inclusion criteria and data were extracted from 24 of these. The remaining two reviews (Anderson et al., 2017 and Walsh et al., 2017) were items identified later via hand searching. Both concerned vocational interventions, a topic that had been included in ten previous reviews, and neither evaluated any UK studies, so a joint decision was made not to extract further data from these due to saturation and limited benefit from their inclusion. Included reviews comprised systematic, scoping and narrative reviews with a systematic search process. Reviews were published between 2006-2020 (Figure 2). and included between 5-134 studies (M=22). Appendix 2 summarises the included reviews and the UK-based studies identified therein, including the appraisal ratings assigned to studies by the authors of originating reviews.

Figure 2

Number of Reviews by Year

[Fig.2]

Extraction of Primary Studies

Twenty-nine studies originating from the UK were identified in reviews and one study was unobtainable. We excluded review articles, studies which did not aim to evaluate outcomes of a specific service or intervention (e.g. cohort surveys) and one study where all participants were under the age of 16. The remaining 19 studies included in the synthesis were published between 1999-2017. One article reported the results of two studies (Golan & Baron-Cohen, 2006). The study included in most reviews was Howlin et al. (2005). Four studies, spanning 1999-2014, evaluated the same service, a supported employment intervention (‘Prospects’), delivered by the National Autistic Society (Mawhood & Howlin, 1999; Nesbitt, 2000; Howlin et al., 2005; Mavranezouli et al., 2014). Quality appraisal by previous reviewers was available for nine studies; of these, two were found to be strong (Mavranezouli et al., 2014; Russell et al., 2013), two were of moderate quality (Nesbitt, 2000; Ridout, 2011), three were weak (Howlin & Yates, 1999; Spain et al., 2017; Macleod & Johnston, 2007), and two had inconsistent ratings between reviews (Howlin et al., 2005; Mawhood & Howlin, 1999).

Quantitative synthesis

Types of Interventions and Services

Reviews were categorised by topic. Nine reviews were concerned with psychosocial support and interventions, eight with vocational interventions, one with dance-based interventions (categorised as exercise), one with educational interventions for post-secondary students and five were generic reviews of a variety of services. Most studies were conducted in the US, UK, Australia, Canada and Western European countries.

The extracted UK studies evaluated cognitive behavioural therapy (CBT) (Holgate, 2012; Newey, 2002; Spain et al., 2017; Russell et al., 2013), social skills interventions (Ashman et al., 2017; Howlin & Yates, 1999; Golan & Baron-Cohen, 2006), the Prospects supported employment service (Mawhood & Howlin, 1999; Nesbitt, 2000; Howlin et al., 2005; Mavranezouli et al., 2014), holistic community approaches (Ridout et al., 2011; National Audit Office, 2009), academic interventions (Lambe, 2015; Macleod & Green, 2009), mentoring (Milton et al., 2017), a peer support group (Macleod & Johnston, 2007) and a stress management intervention (Gracey, 2011). Most services described in the primary studies were delivered in a community setting (Figure 3).

Figure 3

Intervention Types and Service Settings from Primary Studies

[Fig.3]

Six UK studies did not describe their processes for obtaining informed consent. All other studies sought consent directly from participating individuals except in individuals aged under 16, where parental consent was sought.

Participants

Where reported, participant age range for the reviews was 13-70 with means between 19-30 years for reviews and for UK studies age ranged between 14-61 with means between 18 and 36. Where gender ratios were reported, the proportion of male participants ranged from 56% to 91% for reviews and from 55-100% for UK studies, except for case studies involving single female participants. The majority of participants were of Caucasian ethnicity, though ethnicity was a seldom reported characteristic.

In 18 of the 19 UK studies synthesised, participants comprised autistic adults and in one study, participants were employers (Nesbitt, 2000). No studies reported the socioeconomic status of participants. More participants were unemployed than employed, and this remained the case after excluding students and participants of employment support services. Education level of study participants ranged from no formal education to completion of postgraduate education. All studies required clients to have a diagnosis, or be pre-diagnosis, of autism, Asperger Syndrome or high functioning autism.

Outcomes

The outcomes included in reviews and studies are shown in Figure 4. They are categorised according to the domains identified during data extraction.

Figure 4

Outcomes Evaluated in Reviews and Studies

[Fig.4]

Service Pathways

Figure 5 illustrates the synthesis of characteristics of the service pathways at the stages of enrolment, engagement and adherence. Characteristics of interventions that facilitated enrolment of participants into services included the effective and timely identification of needs, matching participants with staff based on goals, and managing expectations of participants and partner organisations. Methods of identification included databases held by existing services, the targeting of gaps in services, and accepting self-referral or referral from a family member or another service. Early identification of problems was important for preventing escalation; where participants did not perceive themselves to require the service, this presented a barrier to timely support. An initial meeting between an individual and the service or intervention provider to clarify expectations and alleviate anxiety was found to lead to greater enrolment in some cases. Some studies reported that participants and partner organisations sometimes had unrealistic expectations for what services would provide and their personal goals.

Collaboration with other services was a mechanism to engagement. This led to a sharing of expertise that extended beyond that of the main provider as well as helping to educate partner organisations, such as employers involved in the Prospects service, about autism. A mentoring service also included autistic adults in the design and delivery of training, which mentors reported as a benefit of the service. Another mechanism for engagement was opportunities for social interaction, which helped to build confidence in social situations and encouraged a sense of belonging to a group. However, some participants found group activities disagreeable, leading to disengagement, so there is a degree of individual preference and a need for flexibility around this. Barriers to accessibility, including transport, anxiety and limited communication options to allow for the rescheduling of appointments, also led to disengagement. Practical issues around the design or provision of a service or intervention, such as technical difficulties, affected acceptability to participants. Claiming to forget or not have time to complete part of an intervention, which applied to several studies, also suggested a lack of acceptability or practicality. It was also important for measurement tools to be acceptable to participants; participants in one study disengaged where they perceived an outcome measure to be patronising.

The synthesis identified factors facilitating adherence to a service. The skills and qualities of staff delivering services influenced participants' enjoyment of an intervention and the provision of an effective service. These included professional qualifications, level of supervision and reliability. Participants were less satisfied where they perceived a lack of training or expertise. Where there were no standards or a precedent which staff could follow for their service, this created a challenge to providing skilled support. It was also challenging for providers to collaborate with other services in which staff lacked knowledge about autism or the aims of the intervention.

Tailoring was a feature of several services at the adherence level; this was achieved through incorporation of participants' interests and goals, titrating the level of support according to participants' changing levels of need and involving family members. Reinforcement included providing homework and materials which could be revisited in a range of accessible formats, such as visual diagrams, and opportunities for spontaneous, unstructured learning. The duration of an intervention may also contribute to opportunities for reinforcement, with one intervention speculated to have been too brief to lead to measurable improvement. Resources utilised by services to deliver support included suitable venues, existing service models, staff training and technology; however, a lack of tangible resources such as staff or funds, long waiting times and systems that were insufficient, led services and staff to become overwhelmed. It was not always possible for services to address all challenges participants faced in their daily lives, which created a barrier to adherence and achieving a positive outcome. Individual differences identified as affecting levels of enrolment, engagement and retention included age, IQ, motivation, risk aversion, adaptive functioning levels, cultural background and technical skills.

Supporting quotes for the themes outlined above are shown in Appendix 3.

Figure 5

Characteristics of Service Pathways

[Fig.5]

Discussion

This review synthesises current research around the variety of non-medical services which have been evaluated for autistic adults, the outcome measures used to assess their effectiveness and the features of service pathways. This discussion will position the synthesis in the context of social prescribing for autistic adults, which has lacked research attention as a distinct model of healthcare for addressing health disparities in this population.

Types of Services and Outcome Measures

The increasing number of reviews identified by year reflects overall increases in prevalence of autism research relating to adults (Kirby & McDonald, 2021). Our findings demonstrate that studies on employment support and psychosocial interventions have been comprehensively evaluated in reviews. There have been fewer reviews and studies evaluating support services more typical of social prescribing (e.g. information services and holistic approaches, see Chatterjee et al., 2018). The majority of outcomes identified across all studies and reviews related to autism, including communication, behaviour and mentalising. These measures are selected to demonstrate improvement in a targeted behaviour or reduced autism presentation. Provenzani et al. (2020) have emphasised the importance of including outcome measures beyond those targeting core autistic traits, as there is no evidence that gains in these areas generalise to overall improved health, wellbeing, quality of life or daily functioning (Alvares et al., 2019; Burgess & Gutstein, 2007; Khanna et al., 2014; Lorenc et al., 2018; Marriage et al., 2009; Shattuck et al., 2012). Furthermore, suppression of autistic traits may be damaging to emotional wellbeing (Cassidy et al., 2015; Hull et al., 2017) and sense of identity (Wilkenfield & McCarthy, 2020; Hull et al., 2017), which highlights the importance of measuring emotional wellbeing concurrently where interventions target autism presentation due to the potential for stigma (Scott et al., 2019) and promoting strengths-based interventions (Huntley et al., 2019). In contrast, social prescribing has been shown to lead to improvements across a range of outcomes and can promote social connections and community participation by facilitating integration within a diverse group of people (Bhatti et al,. 2021). This, along with the person-centred and tailored nature of social prescribing, aligns with a more strengths-focused approach, which may help to alleviate the stigma associated with deficits-focused models (Huntley et al., 2019). Many studies in the present synthesis included primary or secondary outcomes that were categorised as relating to mental health, quality of life, and the wider correlates of health such as employment, although these were less prevalent than autism-related outcomes. While previous reviews showing narrower outcome priorities have been dominated by studies of children

(Provenzani et al., 2020), it may be that interventions targeting adults have paid more attention to outcomes identified as important to autistic people including anxiety, depression and quality of life (Benevides, Shore, Palmer et al., 2020). However, the outcomes selected can sometimes have low generalisability; Shattuck et al. (2012) noted that the skills targeted by employment interventions to prepare individuals for working in a prescribed role were often not generalisable to other jobs, suggesting a lack of practical application.

The quality of life dimensions of self-advocacy, community empowerment and human rights set out by Schalock (2000) and Kim (2019) were less evident, which was also observed by Shattuck et al. (2012), suggesting interventions could go further to address these aspects of quality of life which affect autistic people disproportionately (McConachie et al., 2018). Self-determination and self-efficacy were considered in some reviews but none of the identified service studies. Social prescribing has been found to facilitate many domains of self-determination (Bhatti et al., 2021), so could be an appropriate route to promoting this outcome in autistic adults but this requires evidence.

Only one review (Benevides, Shore, Andresen et al., 2020) and none of the extracted studies considered physical health as an outcome of importance, despite the disparities autistic people experience. This may be because most services did not target physical health, including a review of dance-based interventions which evaluated the impact on differences in eye contact and theory of mind (DeJesus et al., 2020). Further to this, the physical health outcomes extracted were highly specific including skin-picking behaviour and in-hospital recovery from an acute respiratory episode. However, autistic people experience disparities across a range of physical health concerns including cardiac conditions, epilepsy, gastrointestinal problems, hypertension and sleep disorders (Hirvikoski et al. 2016, Croen et al., 2015). It was also notable that no studies or reviews considered the sensory aspects of autism as an important autism-related outcome despite the impact sensory processing can have on emotional wellbeing and quality of life for people on the autism spectrum (MacLennan et al., 2020; McConachie et al., 2018). There is, therefore, a gap in the evidence on the impact of these types of interventions on generalised physical health or managing the challenges of sensory processing.

Pathways Through Services and Implications for Social Prescribing

Through analysis of the descriptive and qualitative content of studies, we identified barriers and facilitators relevant to progression through service pathways. None of the UK studies described themselves as a social prescribing model, which can include a variety of service models involving direct or mediated referral to community-based activities. All services identified in this review were designed exclusively for autistic adults rather than an integrated group; however, the factors identified may give an indication of how features of the social prescribing pathway might facilitate or hinder its accessibility for autistic adults as a route to improving health outcomes.

Referral to a service makes up part of an individual's enrolment into social prescribing programmes (Husk et al., 2019). In the present review, effective and timely identification of needs was identified as a facilitator to enrolment; the present gap in service provision for autistic adults has been highlighted as a barrier to accessing suitable support for managing wellbeing through failing to identify people who could benefit from support (Sharpe et al., 2019; Brugha et al., 2009). Social prescribing models use referral methods ranging from signposting to link worker referral (Husk et al., 2019), which redirect patients from primary care settings to community settings. However, autistic people report barriers to accessing primary care including limitations of telephone booking systems, emotional barriers, communication difficulties and inaccessible environments, causing delays to seeking appropriate healthcare (Raymaker et al., 2017; Christou, 2016; Charlton et al., 2020; Mason et al., 2019; Doherty et al., 2020), which could impact on enrolment in social prescribing.

The results of the present review suggest services should use creative methods to overcome this. One method used by studies in the synthesis was the identification through records and databases, although this relies on patients having a diagnosis of autism, which may not be accessible for all those who may benefit from it (Lewis, 2017). It also reveals little about individual differences in needs and preferences (Hudry et al., 2020). It may be that self-referral directly to a link worker or activity could be considered. However, studies reported that individuals were not always able to identify their own needs until these had escalated to an unmanageable level, so self-referral may be ineffective to address the access barriers. Self-referral can also place additional demand on services, leading to lower efficiency, long wait times, and reduced quality of consultations (Bertotti et al. 2018). Further consideration may be needed as to how to strike a balance between these limitations to best identify those who may benefit from social prescribing.

In contrast to findings by Husk et al. (2019), the present review did not identify supported referral, such as a phone call or buddy system, as a facilitator of engagement. Charlton et al. (2020) suggested that support from link workers or family members would help autistic adults to navigate transition points in the pathway and mitigate uncertainty, and previous research on social prescribing generally has found that withdrawal of link worker support may lead to disengagement from services (Foster et al., 2020). While more general samples may benefit from telephone support alone (Husk et al., 2019), the reliance on telephone is frequently reported as a barrier to healthcare access in autistic samples (Doherty et al., 2020). Additional forms of communication may need to be considered when supporting autistic people through service pathways, such as service passports that summarise individuals' profiles of needs (Charlton et al., 2020).

Previous research has shown that a barrier to the successful delivery of social prescribing services involves the complexity of patients referred to link workers and activity providers (Wildman et al., 2019), who do not typically receive training on specific conditions. Where patients and referrers involved in social prescribing programmes have perceived both link workers and activity leaders to have good knowledge and interpersonal skills, this facilitated engagement and overall success within services (Husk et al., 2019; Tierney et al., 2020; Holding et al., 2020). The present review found that participants had more negative perceptions of services where staff were inexperienced or untrained, such as students, which impacts on adherence to services. Collaboration utilising the expertise of other organisations and individuals, including autistic adults, enabled engagement and positive attitudes about services. This suggests building strong collaborations may lead to improved accommodations, more effective rapport building and complete gaps in link workers' knowledge about autism (Charlton et al., 2020). The collaborative nature of social prescribing also optimises local, community-relevant resources and a joined-up approach to healthcare (Jani et al., 2020; Kimberlee, 2013), which aligns with some of the Autism Strategy aims (Department of Health, 2014).

It was important for providers to manage the expectations of clients and third-party collaborators such as employers, to allay anxiety and intervene where expectations were not realistic. In social prescribing, link workers are able to offer longer consultations than standard general practice appointments, which allows patients to discuss their preferences, barriers and beliefs about the ability of the service to meet their presenting needs and to build a trusting relationship (Husk et al., 2019; Bertotti et al., 2018; Tierney et al., 2020). However, Charlton et al. (2020) emphasise that definitions of success and goals in social prescribing for autistic adults must meet the preferences of the individual rather than imposing assumptions or norms. Features of tailoring identified in the present review, such as adaptation of intervention content and materials to clients' interests and needs, to facilitate adherence to a service, reflect this person-centred approach. Tailoring a service to both individual and local community needs is a key component of social prescribing, and a barrier when this is lacking (Holding et al., 2020; Foster et al., 2020; Wildman et al., 2019). Opportunities for social interaction were seen to be important for engagement: these opportunities helped validate clients' experiences and evoke a sense of belonging, but feeling overwhelmed by social demands also led to disengagement by some individuals, suggesting services should be flexible and person-centred around this accessibility need. Charlton et al. (2020) suggest that including adaptations such as a quiet area or breakout room may further enable flexibility allowing social interaction to fit the preferred level of the individual. A further possible mechanism to the success of social interactions identified from previous research is when participants perceive other members to be similar to themselves (Crane et al., 2020), which was reflected in these findings.

Limitations

As in previous reviews which have found overrepresentation of males and younger adults (Shattuck et al., 2012; Provenzani et al., 2020), sample limitations mean the present findings may reveal less about what works for autistic older adults, women and individuals from minority ethnic backgrounds, who will experience compounding health factors and healthcare access issues that intersect with autism (Michael, 2016; Hirvikoski et al., 2016; Bishop-Fitzpatrick & Kind, 2017). It is also important to note that this review synthesised only a small number of services that had been included in previous literature reviews and that many of the primary studies were assessed by reviewers as being of poor quality or had not been subject to quality assessment. Data extraction for the pathways synthesis depended upon the amount of descriptive information included about each service, which was highly varied. There may also be services that have not been reviewed or formally evaluated which could reveal further barriers and facilitators to progression through social prescribing service pathways for autistic adults, but were outside the scope of this review.

Implications for Future Research and Practice

There is a lack of development and testing of interventions to address physical health in autistic adults. Studies evaluating outcomes of community-based interventions for autistic people should include a wide range of outcome measures beyond autism-related outcomes, including physical and mental health and quality of life. They should also examine how individual differences may affect outcomes so that support can be tailored. Findings on barriers and facilitators through the referral pathways suggest autistic people may benefit from the link worker appointments and the person-centred and collaborative approach of social prescribing. Ensuring skilled and approachable staff trained in understanding autism, as well as flexible opportunities for social interaction and providing a range of communication options could enable existing social prescribing services to be more accessible to autistic people and increase engagement. It may also be worthwhile to use creative and flexible methods for early identification and referral of autistic people to services, however this needs to be delivered in a way that does not strain service resources. Making accommodations for people who do not have a formal diagnosis of autism may also help more people to access services in communities.

Further investigation with autistic adults enrolled in self-described social prescribing programmes would be beneficial to examine if these mechanisms are supported in the context of existing social prescribing pathways and activities, which may differ from the services evaluated here as they often serve a diverse population instead of being services designed specifically for autism.

Conclusion

In conclusion, this review has demonstrated how a variety of services for autistic adults are delivered and has identified and critiqued the outcome measures used to evaluate these. The review identified a small number of holistic, low intensity and community-based approaches which reflect those offered through social prescribing approaches. Reviews and previous studies focus strongly on outcomes related to autism which is more characteristic of targeted interventions than of the holistic approach of social prescribing, but have also considered outcomes relating to mental health and quality of life. There was a lack of measurement of the impact of services on physical health outcomes relevant to the population. Many of the barriers and facilitators present across the referral pathway had relevance to established social prescribing practice and could be used to identify areas where social prescribing may require adaptation to increase its reach to this population as a potential part of addressing disparities in health and wellbeing.

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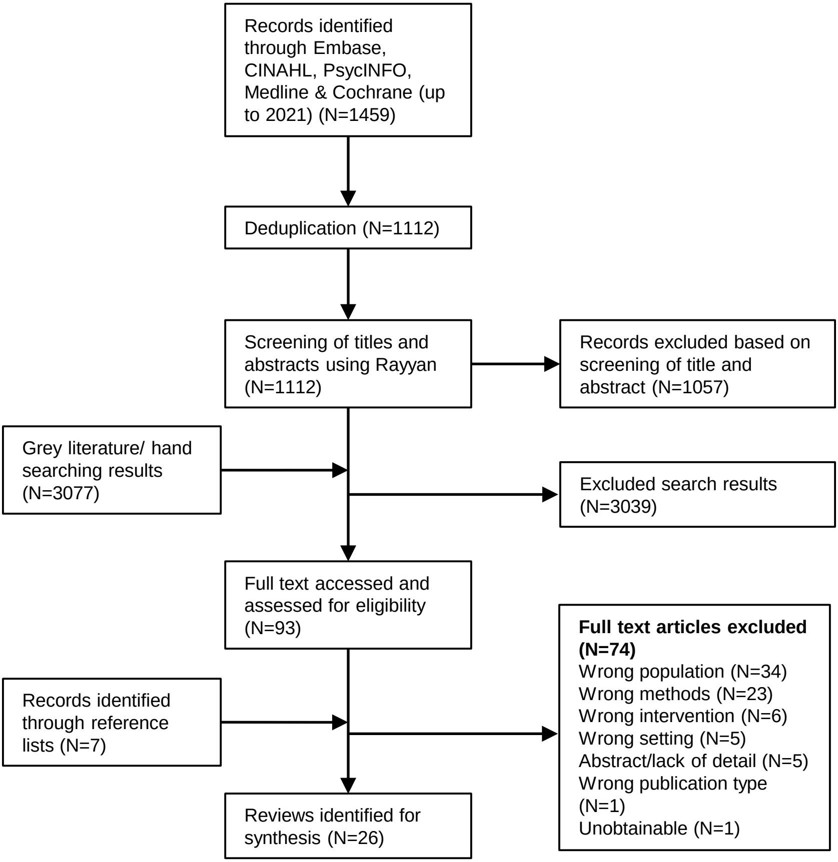
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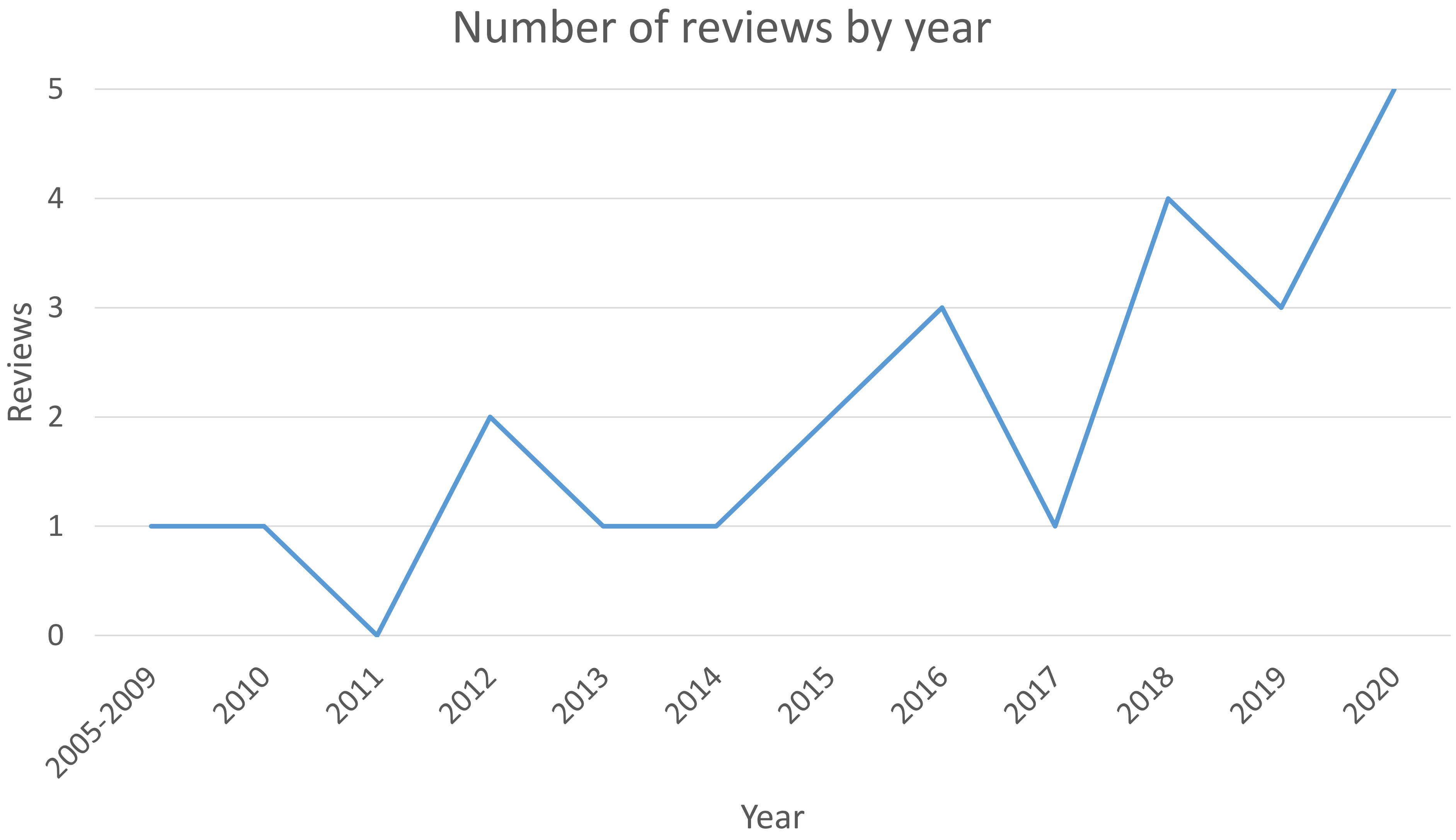
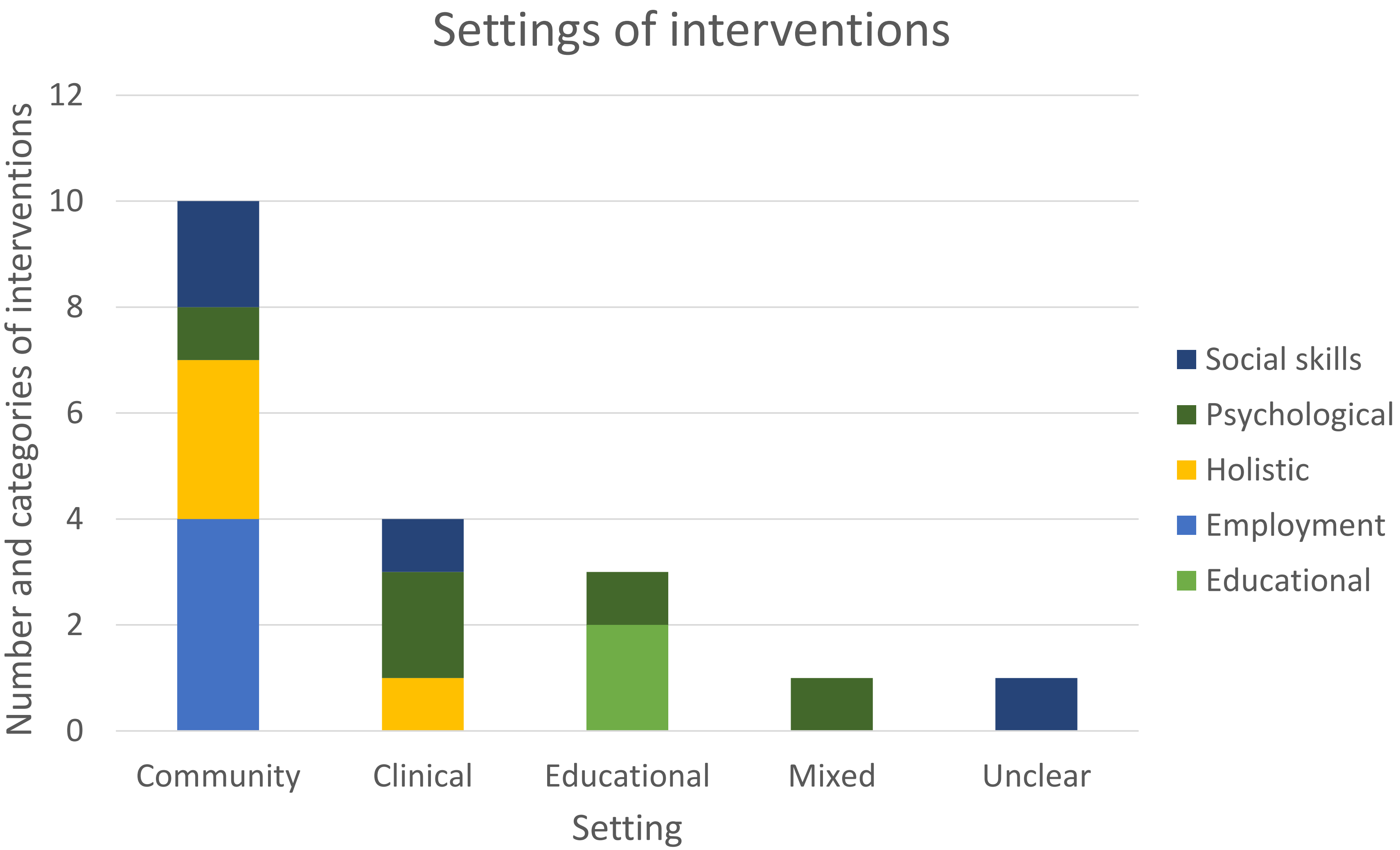
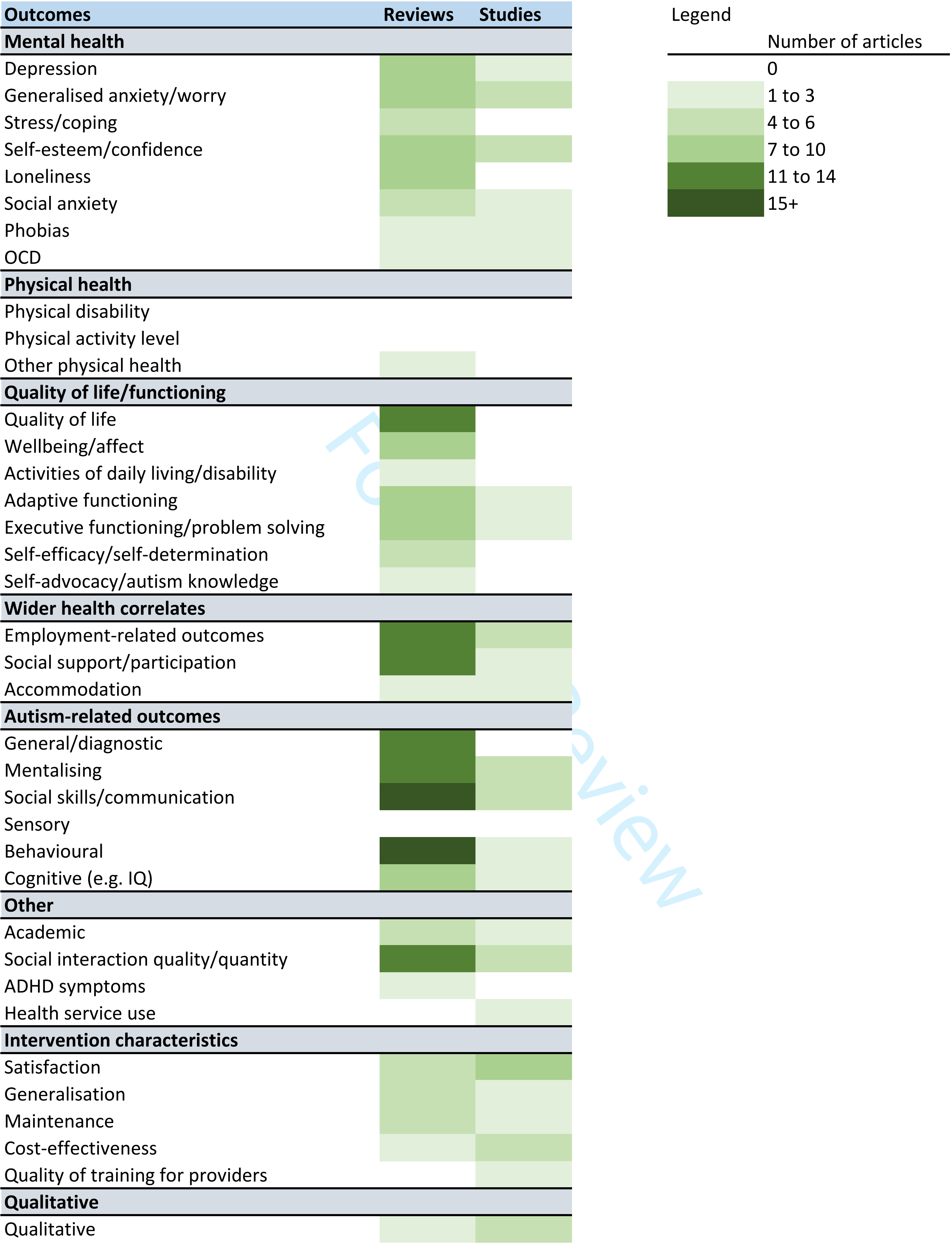
Deduplication (N=1112)
Screening of titles and abstracts using Rayyan (N=1112)
Records excluded based on screening of title and abstract (N=1057)
Grey literature/ hand searching results (N=3077)
Excluded search results (N=3039)
Full text accessed and assessed for eligibility (N=93)
Full text articles excluded (N=74)
Wrong population (N=34)
Wrong methods (N=23)
Wrong intervention (N=6)
Wrong setting (N=5)
Abstract/lack of detail (N=5)
Wrong publication type (N=1)
Unobtainable (N=1)
Records identified through reference lists (N=7)
Reviews identified for synthesis (N=26)


Number of reviews by year
Reviews
5
4
3
2
1
0
2005-2009
2010
2011
2012
2013
2014
2015
2016
2017
2018
2019
2020
Year

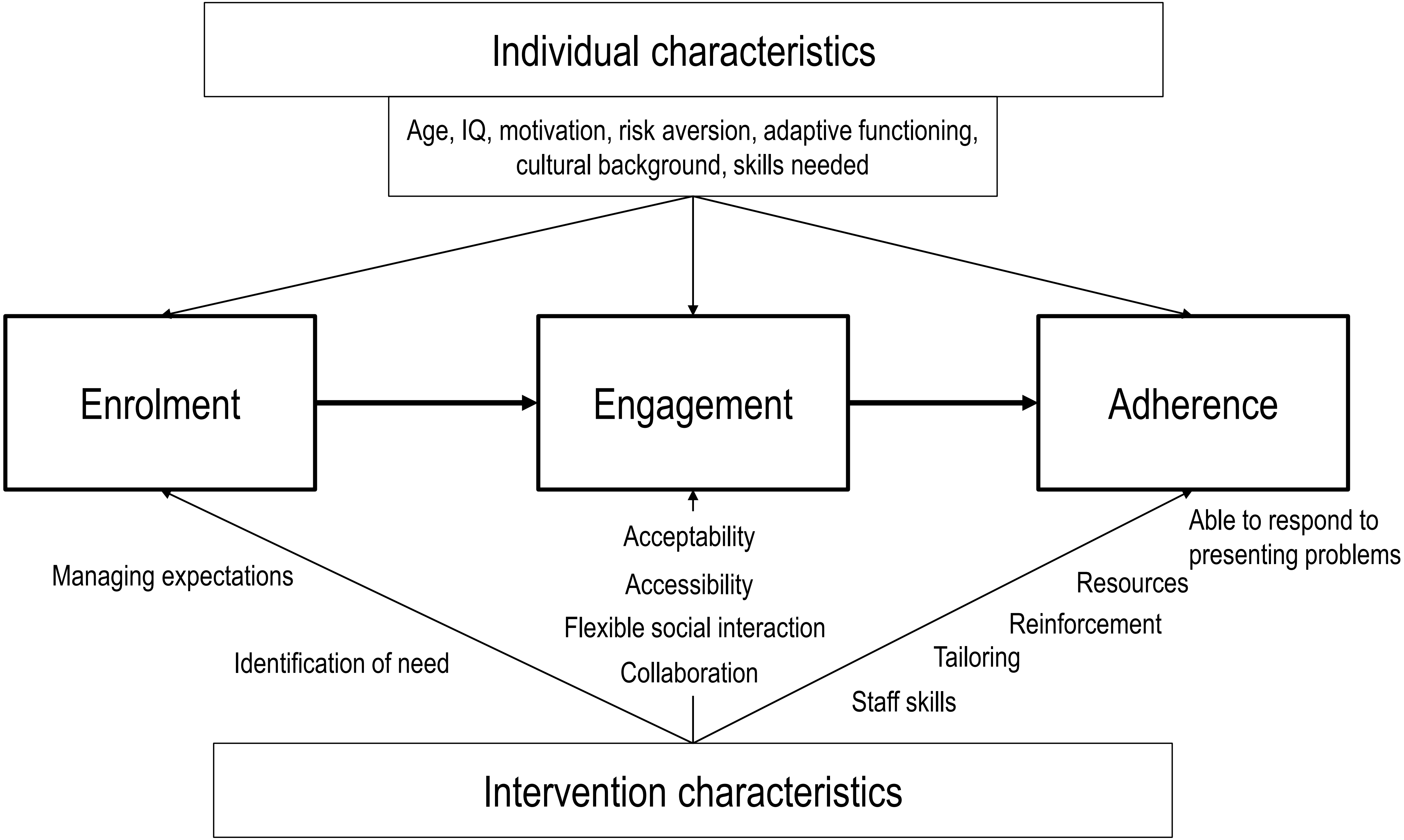

Settings of interventions
Number and categories of interventions
0
2
4
6
8
10
12
Community
Clinical
Educational
Mixed
Unclear
Setting
Social skills
Psychological
Holistic
Employment
Educational



Outcomes	Reviews	Studies
Mental health		
Depression	7 to 10	1 to 3
Generalised anxiety/worry	7 to 10	4 to 6
Stress/coping	4 to 6	0
Self-esteem/confidence	7 to 10	4 to 6
Loneliness	7 to 10	0
Social anxiety	4 to 6	1 to 3
Phobias	1 to 3	1 to 3
OCD	1 to 3	1 to 3
Physical health		
Physical disability	0	0
Physical activity level	0	0
Other physical health	1 to 3	0
Quality of life/functioning		
Quality of life	11 to 14	0
Wellbeing/affect	7 to 10	0
Activities of daily living/disability	1 to 3	0
Adaptive functioning	7 to 10	1 to 3
Executive functioning/problem solving	7 to 10	1 to 3
Self-efficacy/self-determination	4 to 6	0
Self-advocacy/autism knowledge	1 to 3	0
Wider health correlates		
Employment-related outcomes	11 to 14	4 to 6
Social support/participation	11 to 14	1 to 3
Accommodation	1 to 3	1 to 3
Autism-related outcomes		
General/diagnostic	11 to 14	0
Mentalising	11 to 14	4 to 6
Social skills/communication	15+	4 to 6
Sensory	0	0
Behavioural	15+	1 to 3
Cognitive (e.g. IQ)	7 to 10	1 to 3
Other		
Academic	4 to 6	1 to 3
Social interaction quality/quantity	11 to 14	4 to 6
ADHD symptoms	1 to 3	0
Health service use	0	1 to 3
Intervention characteristics		
Satisfaction	4 to 6	7 to 10
Generalisation	4 to 6	1 to 3
Maintenance	4 to 6	1 to 3
Cost-effectiveness	1 to 3	4 to 6
Quality of training for providers	0	1 to 3
Qualitative		
Qualitative	1 to 3	4 to 6

Legend

	Number of articles
	0
🟩	1 to 3
🟩	4 to 6
🟩	7 to 10
🟩	11 to 14
🟩	15+


Individual characteristics
Age, IQ, motivation, risk aversion, adaptive functioning, cultural background, skills needed
Enrolment
Engagement
Adherence
Managing expectations
Identification of need
Acceptability
Accessibility
Flexible social interaction
Collaboration
Able to respond to presenting problems
Resources
Reinforcement
Tailoring
Staff skills
Intervention characteristics

Appendix 1: Embase Search Strategy

1	exp autism/	69285
2	exp "pervasive developmental disorder"/	69285
3	autis*.ti,ab,kw.	63548
4	asperger*.ti,ab,kw.	3406
5	"pervasive development* disorder*".ti,ab,kw.	3195
6	1 or 2 or 3 or 4 or 5	80024
7	adults/	6277617
8	adults.ti,ab,kw.	748353
9	7 or 8	6633693
10	6 and 9	17179
11	MEDLINE.tw.	145386
12	exp systematic review/ or systematic review.tw.	298415
13	meta-analysis/	189080
14	intervention$.ti.	198525
15	or/11-14	613835
16	((systematic or rapid or mapping or scoping or realist or exploratory) adj (review$1 or overview$1)).tw.	218920
17	15 or 16	625469
18	10 and 17	682
19	communit*.ti,ab,kw.	692254
20	(community adj3 intervention*).ti,ab,kw.	12588
21	community care/	53995
22	"social prescri*".ti,ab,kw.	179
23	(communit* adj3 refer*).ti,ab,kw.	4113
24	"non-medical".ti,ab,kw.	9053
25	"link worker".ti,ab,kw.	47
26	exp voluntary worker/	5053
27	exp public sector/	2051
28	exp non-profit organization/	34230
29	"non-profit".ti,ab,kw.	3705
30	"local government".ti,ab,kw.	4642
31	"peer group"/	23214
32	(peer adj3 (led or run)).ti,ab,kw.	1672
33	(lay adj3 (led or run)).ti,ab,kw.	159
34	(user adj3 (led or run)).ti,ab,kw.	345
35	mentors/	4583
36	mentor*.ti,ab,kw.	21089
37	"support group".ti,ab,kw.	5770
38	support*.ti,ab,kw.	1973041
39	program development/	23942
40	program evaluation/	14713
41	"advice service".ti,ab,kw.	179
42	(advice or advis*).ti,ab,kw.	166648
43	exp wellbeing/	82371
44	wellbeing.ti,ab,kw.	25267
45	exp lifestyle/	129219
46	lifestyle.ti,ab,kw.	128703
47	creative.ti,ab,kw.	17797
48	art therapy/	3889
49	music therapy/	6917
50	music.ti,ab,kw.	20427
51	sensory.ti,ab,kw.	222331
52	bibliotherapy/	243
53	exp occupational therapy/	21552
54	(nature adj3 based).ti,ab,kw.	2465
55	(conservation adj3 activit*).ti,ab,kw.	503
56	animal-assisted therapy/	559
57	(animal adj3 therap*).ti,ab,kw.	3390
58	outdoor$.ti,ab,kw.	30087
59	gardening/	1640
60	horticultural therapy/	108

61	garden*.ti,ab,kw.	14225
62	exercise.ti,ab,kw.	355959
63	exercise therapy/	29285
64	sports/	45073
65	(team adj3 sport*).ti,ab,kw.	3039
66	cooking.ti,ab,kw.	17054
67	(health* adj2 eating).ti,ab,kw.	11580
68	employment.ti,ab,kw.	71099
69	mindfulness.ti,ab,kw.	10111
70	meditation.ti,ab,kw.	7057
71	yoga.ti,ab,kw.	6885
72	exp mind-body therapies/	57202
73	group therapy/	18815
74	club.ti,ab,kw.	12957
75	class.ti,ab,kw.	521398
76	exp health education/	320382
77	hobbies/	33149
78	adult education/	271
79	advoca*.ti,ab,kw.	94322
80	coach*.ti,ab,kw.	18800
81	games.ti,ab,kw.	18608
82	gaming.ti,ab,kw.	4371
83	fitness.ti,ab,kw.	84911
84	wellness.ti,ab,kw.	13999
85	intervention study/	45384
86	vocational.ti,ab,kw.	14103
87	holistic.ti,ab,kw.	30472
88	service.ti,ab,kw.	345389
89	befriend*.ti,ab,kw.	399
90	"drop in".ti,ab,kw.	34992
91	"drop-in".ti,ab,kw.	34992
92	"low level".ti,ab,kw.	77760
93	"low-level".ti,ab,kw.	77760
94	leisure.ti,ab,kw.	20299
95	recreation*.ti,ab,kw.	34116
96	"community-based".ti,ab,kw.	76448
97	exp health program/	131193
98	group.ti,kw.	174612
99	psychosocial.ti,ab,kw.	131511
100	exp social competence/	4452
101	*social interaction/	6800
102	"social skills".ti,ab,kw.	7102
103	(social adj3 skills).ti,ab,kw.	10047
104	or/19-103	5172968
105	18 and 104	355

Appendix 2:

Identification of Reviews and Studies

Author(s)	Category/Title	Number of studies included	Appraisal tools used (where stated)	UK studies identified/ Author-rated appraisal (where stated)	Number of UK studies included in mapping review	Reasons for exclusion of UK studies
Anderson et al. (2018)	Academic: “A Systematic Literature Review of Empirical Research on Postsecondary Students with Autism Spectrum Disorder”	24	RCTs: Leong, Carter & Stephenson (2015) checklist Quasi-experimental designs: Preston & Carter checklist (2009)	Holgate (2012) Lambe (2015)	2	
Atkinson-Jones et al. (2008)	Psychosocial: “Do group interventions help people with autism spectrum disorder to develop better relationships with others? A critical review of the literature”	9		Ashman et al. (2017) Howlin & Yates (1999)	2	
Balderaz et al. (2020)	Psychosocial: “Social Skills Interventions for Adults with ASD: A Review of the Literature”	6		Ashman et al. (2017) Spain et al. (2017)	2	
Benevides, Shore, Andresen	General: “Interventions to address health outcomes among	19	Cochrane criteria	Russell et al. (2013) (6/7 criteria	1	

et al. (2020)	autistic adults: A systematic review”			met for low risk of bias)		
Bishop-Fitzpatrick et al. (2013)	Psychosocial: “A Systematic Review of Psychosocial Interventions for Adults with Autism Spectrum Disorders”	14		Golan & Baron Cohen (2006)	1	
DeJesus et al. (2020)	Exercise: “Dance promotes positive benefits for negative symptoms in autism spectrum disorder (ASD): A systematic review”	5				
Hedley et al. (2017)	Vocational: “Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature”	60		Howlin et al. (2005) Mawhood & Howlin (1999)	2	
Hendricks (2010)	Vocational: “Employment and adults with autism spectrum disorders: Challenges and strategies for success”	Not stated		Howlin et al. (2005) Mawhood & Howlin (1999)	2	
Ke et al. (2018)	Psychosocial: “Social Skill Interventions for Youth and Adults With Autism Spectrum Disorder: A Systematic Review”	42	Cooper (2017) guidelines Evaluative method for determining evidence-based practices in autism (Reichow, 2011)	Golan & Baron-Cohen (2006) Mitchell et al. (2006)	1	Participants under 16 (Mitchell et al., 2006)
Lorenc et al. (2018)	General: “Support for adults with autism spectrum disorder	32	EPHPP Quality Assessment Tool	Howlin & Yates (1999)	4	

	without intellectual impairment: Systematic review”			Mawhood & Howlin (1999) Gracey (2011) Newey (2002)		
Lorenc et al. (2016)	General: “Preventative co-ordinated low-level support for adults with high-functioning autism”	37	Quantitative: EPHPP Quality Assessment Tool Economic: CRD handbook Qualitative: Hawker et al. (2002)	Howlin & Yates (1999) (Low quality) Mawhood & Howlin (1999) (High quality) Macleod & Johnston (2007) (Poor) Ridout et al. (2011) (Fair) National Audit Office (2009) (Not rated) Marwick & Tait (2007) (Poor)	5	Unobtainable (Marwick & Tait, 2007)
Lounds Taylor et al. (2012)	Vocational: “A Systematic Review of Vocational Interventions for Young Adults With Autism Spectrum Disorders”	5	Agency for Healthcare Research and Quality Effective Health Care Program’s Methods Guide for Effectiveness and Comparative Effectiveness Reviews	Howlin et al. (2005) (Poor) Mawhood & Howlin (1999) (Poor)	2	

Nicholas et al. (2015)	Vocational: "Vocational support approaches in autism spectrum disorder: A synthesis review of the literature"	10		Howlin et al. (2005) Mawhood & Howlin (1999)	2
Pallathra et al. (2019)	Psychosocial: "Psychosocial Interventions Targeting Social Functioning in Adults on the Autism Spectrum: a Literature Review"	41	RCTs: American Academy of Cerebral Palsy and Developmental Medicine scale Quasi-experimental designs: Gersten et al. (2005) quality indicators Non-controlled experiments: Sackett (1989) scale	Howlin & Yates (1999) (Weak) Spain et al. (2017) (Weak)	2
Robertson & Emerson (2006)	Vocational: "A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with Autistic Spectrum Disorder"	Not stated		Howlin et al. (2005)	1
Schall et al. (2020)	Vocational: Competitive integrated employment for youth and adults with autism: findings from a scoping review	25	Johns Hopkins Nursing Evidence Based Practice Rating Scale 2005	Howlin et al. (2005) (Level 2 research – medium quality)	1

Scott et al. (2019)	Vocational: “Factors impacting employment for people with autism spectrum disorder: A scoping review”	134	Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004) Joanna Briggs Institute (2014) JBI levels of evidence and grades of recommendation	Griffith et al. (2011) (Good) Howlin (2000) (Limited) Howlin et al. (2004) (Strong) Howlin et al. (2005) (Strong) Howlin & Moss (2012) (Limited) Lopez & Keenan (2014) (Adequate) Mavranezouli et al. (2014) (Strong) Nesbitt (2000) (Adequate) Richards (2012) (Adequate) Walsh & Hall (2012) (Limited)	7	Review article (Howlin, 2000; Howlin & Moss, 2012; Walsh & Hall, 2012) Phenomenological qualitative study (Griffith et al., 2011; Richards, 2012) Survey/cohort study (Howlin et al., 2004; Lopez & Keenan, 2014)
Seaman et al. (2016)	Vocational: “Vocational Skills Interventions for Adults with Autism Spectrum Disorder: A Review of the Literature”	20				
Shattuck et al. (2012)	General: “Services for Adults With an Autism Spectrum Disorder”	23		Howlin et al. (2005) Macleod & Green (2009)	2	
Shattuck et al. (2020)	General: “Services for Adults With Autism Spectrum Disorder: A Systems Perspective”	52		Mavranezouli et al. (2014)	2	Secondary analysis/ cohort study (Mukherjee et al., 2018)

				Milton et al. (2017) Mukherjee et al. (2018)	
SIGN (2016)	Psychosocial: "SIGN 145 • Assessment, diagnosis and interventions for autism spectrum disorders"	Not stated	NICE Levels of evidence	Russell et al. (2013) (Low risk of bias)	1
Spain & Blainey (2015)	Psychosocial: "Group social skills interventions for adults with high-functioning autism spectrum disorders: A systematic review"	5		Howlin & Yates (1999)	1
Tobin et al. (2014)	Psychosocial: "A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life"	13	What Works Clearinghouse Single Case Design evidence standards (Kratochwill et al. 2010)	Howlin & Yates (1999) (Poor)	1
Wilson et al. (2019)	Psychosocial: "Interventions Targeting Expressive Communication in Adults With Autism Spectrum Disorders: A Systematic Review"	22	What Works Clearinghouse Single Case Design evidence standards (Kratochwill et al. 2010)		

Appendix 3: Qualitative Synthesis of Service Pathway Data

Stage of Pathway	**Facilitating Mechanisms**	**Example Supporting Quotes**	**Barriers**	**Example Supporting Quotes**
Enrolment	Identification of needs	*"The Liverpool Asperger Syndrome service was set up in 2003 so that people with Asperger Syndrome who were not eligible for either Learning Disability or Mental Health services would have specialised support and a direct route into multi-disciplinary services."* (National Audit Office, 2009, p.37) *"Andrew's family contacted the support team directly to request support"* (Macleod & Green, 2009, p.635). *"An age range of 18 to 24 years was identified for mentees but the upper age limit was dropped because the team received enquiries from autistic people of 25 and over"* (Milton et al., 2017)	Lack of ability to identify needs in time	*"In both of the illustrations given here, students had initially not accessed the support they needed. […] Although they did declare their disabilities, both were initially confident that they had no additional support needs"* (Macleod & Green, 2009, p.639). *"Participants tended to deny their difficulties: this was especially noticeable in Participant 4."* (Newey, 2002, p.143) *"There was clear indication that intervention at an earlier stage with young people would be more cost-effective in the long-term"* (Ridout et al., 2011, p.9)
	Managing expectations	*"Individuals that met with the researcher for the initial meeting to discuss what participation would involve, were more likely to continue with the study"* (Gracey, 2011, p.106). *"Prior to the group, we offered each patient an individual 30 min meeting with one or all of the group facilitators to confirm presenting difficulties and risk issues, and also, to allay potential anticipatory anxiety*	Unrealistic expectations of service users or partner organisations	*"Other line managers suggested (somewhat unrealistically given the technical nature of many of the jobs) that the support worker should learn more about the specific job requirements; others wanted support sessions to be held outside working hours"* (Howlin et al., 2005, p.543). *"Another difficulty involved clients' employment goals. Nine support workers noted that 'job preferences were not*

		about joining or participating in a group." (Spain et al., 2017, p.24)		*always realistic'"* (Howlin et al., 2005, p.545).
Engagement	Collaboration	*"The collaborative nature of the model has been critical in this respect. As a specialist organisation, the support team was well placed to predict changing needs, and their infrastructure was designed to offer a flexible model of support, to an extent that the Disability Team could not have done."* (McLeod & Green, 2009, p.639) *"The benefit of having training designed and delivered with significant input from autistic people was consistently highlighted and has been adopted as an underpinning principle for all future training"* (Milton et al., 2017)	Collaboration barriers	*"Both teams were extremely committed, yet encountered considerable difficulties as colleagues in other key services are not sufficiently trained in autism awareness."* (Ridout et al., 2011)
	Opportunities for social interaction	*"'I am usually uncomfortable in group situations. […] But this was different. There was something reassuringly familiar about these people'."* (MacLeod & Johnston, 2007, p.85) *"The group discussion sections were helpful because they make me realise that I am not the only one like me"* (Lambe, 2015, p.51). *"Results suggest that attendance at the group led to a reduction in anxiety about, and avoidance of, social situations"* (Spain et al., 2017, p.26)	Challenges of social interaction	*"Two participants dropped out after one session because they found the group environment overwhelming and felt too anxious to continue"* (Spain et al., 2017, p.25). *"One person said that he had not enjoyed mixing with the other group members"* (Howlin & Yates, 1999, p.302)
	Accessibility	*"Various mentoring arrangements were implemented, including face-to-face and email based interactions depending on the*	Accessibility issues	*"Potential participants were not obliged to say why they declined to attend, but we noted that this was largely due to difficulties travelling to the hospital,*

		preferences of the mentees." (Milton et al., 2017)		*conflicts with other commitments, or a preference not to engage in a group."* (Spain, 2017) *"Participants failed to think of calling the researcher to explain that they were unable to attend."* (Newey, 2002, p.164)
			Low acceptability or engagement	*"All of them related dropping out/not completing their work to being too busy and not getting to do the required amount of work."* (Golan & Baron-Cohen, 2006, p.597) *"All of the participants who responded felt that the PDA interfered with their daily lives to some degree and more than half reported the PDA increased their anxiety. Only one participant reported finding the strategies helpful"* (Gracey, 2011, p.92).
Adherence	Staff skills	*"The lack of prominence of the co-ordinators [....] is worthy of consideration. This is not to suggest that the co-ordinators were unnecessary, it may in fact highlight the success of the co-ordinators in providing a consistent but unobtrusive framework and ensuring a balance of contributions."* (MacLeod & Johnston, 2007, p.87) *"Supervision by the project team was valued by mentors and thought to be crucial to the success of the project."* (Milton et al., 2017) *"Both of the qualified staff had experience of developing and running therapy groups with young people and adults with and without ASD."* (Spain et al., 2017, p.25)	Lack of training	*"None of the student ambassadors had any health or social care training or specialist expertise in working with people with ASD. […] 'Sometimes seemed ambassadors didn't know what to do' ([Participant 2])"* (Lambe, 2015, pp.46-51) *"There is […] no precedent for this unusual partnership and no formal protocol to follow."* (Macleod, 2009, p.642) *"During the mentoring program it was found that, disappointingly, the reliability of mentors was variable. Whilst the vast majority were reliable, when mentors were unreliable this clearly impacted negatively*

				on the quality of the mentoring relationship.” (Milton et al., 2017)
	Reinforcement	*“Paula’s description does not reflect a traditional teacher– learner intervention. It is apparent that she learnt about herself by observing other participants.”* (MacLeod & Johnston, 2007, p.87). *“Provision of written information and visual materials may help to overcome possible impairments in memory or attention”* (Spain, 2017, p.28) “*This suggests that longer use of the software leads to improved generalization”* (Golan & Baron-Cohen, 2006, p.612)	Lack of reinforcement opportunities	*“The brevity of the interventions in the current study may have played a role in the lack of meaningful change in the progress measures.”* (Newey, 2002, p.151)
	Resources	*“Acting as a central point of access from assessment and diagnosis, the team provides its clients with ongoing care management and co-ordinates a range of other services, including employment support, education, service-user and carer groups, mental health, criminal justice liaison and alcohol/substance misuse services.”* (National Audit Office, 2009, p.37) *“Participants […] were asked to use the software (provided free of charge) at home”* (Golan & Baron-Cohen, 2006, p.597)	Lack of resources	*“There was a general feeling of ‘running against the tide’ in terms of never having enough time, money, or other necessary resources in order fully to meet the needs of their clients. The financial costs of running the programme also remain high.”* (Howlin et al., 2005, p.547). *“The ability to be responsive when needed can be subject to practical restrictions […] Often, we do not know if the student will definitely be taking up a place until a few weeks beforehand, and, until that time, funding remains uncertain. There may be a waiting list for support from the voluntary sector team, who are tied by their own resource limitations”* (MacLeod & Green, 2009, p.642)

	Tailoring	*"A great deal of time was spent collecting information on both clients and potential jobs so that these could be carefully matched, and individuals' strengths, interests, weaknesses and previous experience taken into account."* (Mawhood & Howlin, 1999, p.248) *"In the first meeting the agenda for the year as a whole was agreed, taking major issues that were raised by the group members themselves."* (Howlin & Yates, 1999, p.300) *"Session duration was negotiable in line with student participants' preference, tolerance and concentration span"* (Holgate, 2012, p.95)	Problems outside intervention remit	*"Freddie: …the CBT sessions themselves, they were alright, because we simply tried to save the situation: it didn't work because of circumstances, not the therapy."* (Holgate, 2012, p.142) *"There was some indication that family factors (family accommodation) were associated with treatment outcome"* (Russell et al., 2013, p.706)
All stages	Individual differences	*"It is possible that those who have higher verbal IQ coped better with the tasks, as they were less distracted and stressed by the need to use the handouts"*(Golan & Baron-Cohen, 2006, p.612) *"The other individual, who had seemed to be coping well and enjoying his work, left suddenly without warning […] It appeared he and his family found it difficult (probably for cultural reasons) to accept help from an outside agency."* (Mawhood & Howlin, 1999, p.246). *"Ben was able and prepared to take risks in terms of social activities […] Not all students with Asperger syndrome can do this, even with support"* (Macleod & Green, 2009, p. 638)		