



Collective effort to enhance the quality of research evidence in intellectual and developmental disabilities: a case study of an academic-practice network

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**Collective effort to enhance the quality of research evidence
in intellectual and developmental disabilities: A case study
of an academic-practice network.**

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Structured Abstract

3 **Purpose:** With a historic lack of attention to synthesis methods such as systematic review
4 and meta-analysis and a lack of randomised controlled trials (RCTs), the evidence base for
5 behavioural interventions for children and adults who are autistic or are diagnosed with
6 developmental disabilities is patchy. The Sharland Foundation Developmental Disabilities
7 Applied Behavioural Research and Impact Network (SF-DDARIN), a network of like-
8 minded researchers and practitioners across the UK, aims to address this. The purpose of this
9 article is to describe the network's work and provide the context for the remaining articles in
10 the special issue that exemplify network projects.

11 **Approach:** In this case study paper, we describe how the SF-DDARIN works and is
12 resourced, detailing the process used to maximise research opportunities by facilitating
13 network members working together. We outline the progressive research steps that the SF-
14 DDARIN has identified are needed to develop and improve the evidence base for behavioural
15 interventions systematically and, with examples, describe how the network delivers these
16 steps.

17 **Findings:** Since its establishment in 2016, the SF-DDARIN network members have
18 collectively worked on more than 53 projects involving over 50 researchers, had over 120
19 special schools contribute to projects, and have recruited over 500 participants. This has been
20 achieved via funding from the Sharland Foundation, primarily to cover the staffing costs of a
21 small support team and internship partnerships with external organisations. Some projects
22 have attracted external funding.

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3 1 **Originality:** SF-DDARIN may provide an innovative, effective, and resource-efficient model
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5 2 for other groups seeking to develop and extend their evidence base in developmental
6
7 3 disability research.

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10 4 **Keywords:** Evidence-based practice; developmental disabilities; behavioural interventions;
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12 5 research and impact.

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15 6 **Article Classification:** Research Feature
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Background

The Sharland Foundation Developmental Disabilities Applied Behavioural Research and Impact Network (SF-DDARIN) is a network of like-minded researchers and practitioners. Its overarching purpose is to increase the reach and impact of evidence-based behavioural interventions for children and adults with developmental disabilities (including learning disabilities and/or autism) to support their independence and increased quality of life. Established in the UK in 2016, with funding from the Sharland Foundation, it is a collaboration between the Centre for Research in Intellectual and Developmental Disabilities (CIDD) at the University of Warwick; Bangor University; Ulster University; and the Tizard Centre, University of Kent. Now into its fourth round of funding, the network has 39 active members, comprising 23 academics (some of whom are researcher-practitioners) from 10 universities and 16 practitioners working across 11 applied settings in the UK. Members from applied settings include those working in schools, colleges, or community service settings for individuals with developmental disabilities. Membership is by invitation, and apart from the roles outlined below, individual member contributions are not funded. SF-DDARIN members contribute to network activities in their own time while gaining access to the network's resources (e.g., databases developed, access to Masters & PhD projects). The network is directed and managed by a core management team which oversees and prioritises projects and resource allocation. The management team includes seven members drawn from each of the collaborating universities. A critical factor in sustaining projects for which there is otherwise no external funding is the availability of project management and research assistant resources. The management team is supported by a network manager (currently 0.2 FTE), two post-doc researchers (0.6 FTE each, based at CIDD and the Tizard Centre) and a PhD student.

1 The rationale behind the network’s establishment was a recognition, at the time, that
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1 The rationale behind the network’s establishment was a recognition, at the time, that
2 despite the inclusion of behaviourally based intervention approaches as recommended
3 practices in several government guidelines, there was also a significant lack of high-quality
4 research recognised as providing strong evidence for those interventions. For instance, by the
5 end of 2015, behaviourally based intervention approaches were included as recommended
6 practices in at least eight guidelines from the National Institute for Health and Care
7 Excellence (NICE; n.d.): Borderline Personality Disorder (CG78), Depression (CG90),
8 Parent Training (TA102), Obesity (CG189), Dementia (CG42), Autism in Adults (CG142),
9 Autism in Children (CG170), and Challenging Behaviour (NG11). In education, many of the
10 strategies with the strongest evidence included in the Education Endowment Foundation
11 Teaching and Learning Toolkit (n.d.) and in the Hattie review (2008), were derived from
12 research on learning and behavioural approaches. Yet, the evidence base for behaviourally
13 based interventions was patchy. In particular, a lack of attention to evidence synthesis
14 methods such as systematic review and meta-analysis, and a lack of randomised controlled
15 trial (RCT) evaluations of behaviourally based interventions seen as “gold standard” within
16 the scientific community, meant that some behavioural interventions were not being routinely
17 included in evidence-based practice reviews. These limitations may have been, in turn,
18 contributing to a lack of understanding of behaviourally based interventions and potentially
19 limiting the dissemination of interventions to the populations of children and adults with
20 developmental disabilities and their families who were most likely to benefit from them.

21 The SF-DDARIN aims to increase the quality of evidence for behaviourally based
22 interventions and contribute to understanding and dissemination of these interventions
23 through four inter-linked areas of work: (1) conducting high-quality research; (2) conducting
24 special projects with a focus on impact, (3) informing professionals, and (4) dissemination
25 through using mainstream social media.

Organisation of the SF-DDARIN

Working with academics and practitioners in the UK, SF-DDARIN focuses on two areas of behaviourally-based developmental disability research:

- Teaching skills to children, young people, and adults.
- Positive Behavioural Support (PBS) across the lifespan.

Each workstream is co-chaired by two network members and supported by one of the post-doc researchers, with additional research assistant time available for cross-workstream activities. As noted above, these resources are a key factor in successfully delivering projects that are not otherwise externally funded. Workstreams meet monthly and are expected to submit project proposals that will result in various outputs, including research projects, practice or academic articles and grant applications. Members can contribute to either workstream, sponsor their projects, and request support (research, mentorship, resources, funding, research officer time) from the network.

Conducting high-quality research

To address the identified gaps in the evidence base around behavioural interventions that support people with developmental disabilities, the network has outlined a number of progressive research steps that need to take place based on frameworks for the development of complex interventions (e.g., Medical Research Council; Skivington *et al.*, 2021): defining a problem, initial testing and evaluation of interventions; developing a description/model or manual for an intervention so that it can be delivered in applied settings, more robust pilot studies and research including small RCTs, systematic reviews and meta-analyses (see figure 1). With the evidence gathered from these early studies, major funding applications can be put together to deliver large scale RCTs.

----FIGURE ONE ABOUT HERE---

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3 1 Within the two workstreams, SF-DDARIN activities are organised across three tiers
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5 2 designed to progressively and systematically develop an evidence base as well as maximise
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7 3 research opportunities by facilitating network members working together.
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11 4 Tier 1 focuses on broad collaboration across small-scale projects from an often-under-
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13 5 utilised resource of Masters and PhD projects. Often, these studies exist but are dispersed
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15 6 across organisations and Universities and lack the mechanism for collaboration that the
16
17 7 network affords. This is a two-way process for network members looking for research
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19 8 projects for students and those with projects in mind to find students. It is largely driven by
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21 9 universities but with all network members contributing.
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26 10 Tier 2 is a focused collaboration on small to medium projects proposed by the two
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28 11 workstreams, which can be resourced from within the network and do not require external
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30 12 funding. The focus is on pivotal projects that are either a necessary step in taking forward a
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32 13 proposal to Tier 3 (for example, developing a manual to describe proposed interventions), the
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34 14 development of resources to help translate knowledge into practice (for example, tools to
35
36 15 assess the quality of services), or basic research to identify or support a research need (for
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38 16 example a survey that helps shape a subsequent proposal).
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42 17 Tier 3 includes larger-scale projects, including RCTs and special projects focusing on
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44 18 impact. Often, small working groups are established from the workstreams to take forward
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46 19 the work needed for a larger-scale RCT (e.g., developing a grant proposal).
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49 20 Denne *et al.* (2024; this issue) illustrate how activities across these tiers are organised
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51 21 and the progressive research/evidence steps achieved by network members in developing an
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53 22 evidence base for teaching people with developmental disabilities to read using an online
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55 23 reading programme, Headsprout®.
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58 24 **Special projects with a focus on impact**

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1 “Special projects” are where network members actively engage with collaborators to
2 facilitate and/or lead projects of national significance designed to improve access for people
3 with developmental disabilities to evidence-based behaviourally based interventions and/or to
4 skilled behavioural practitioners. An example of a special project is the work of the PBS
5 Academy: An informal collection of individuals from PBS training organisations, service
6 provider organisations, the third sector, and academics interested in the development of PBS
7 and the establishment of best practices. Under the SF-DDARIN umbrella, the PBS Academy
8 works collaboratively to translate knowledge from research into best-practice service delivery
9 by raising standards of practice by developing freely available practical resources for all
10 stakeholders. Evidence of the impact of the activities of the PBS Academy, particularly at a
11 national policy level, was published in two articles (Scott *et al.*, 2018a, 2018b), which
12 showed that the resources produced have been used to inform key initiatives such as the
13 Learning Disabilities Core Skills Education and Training Framework commissioned and
14 funded by the Department of Health, in 2016, and developed in collaboration by Skills for
15 Health, Skills for Care and Health Education England.

16 More recently, the PBS Academy has been working with the Care Quality Commission to
17 help with inspections of services that support people with developmental disabilities. The
18 project was a collaboration/co-production between CQC and the PBS Academy involving
19 academic input, a mix of inspectors, experts by experience and bringing in insights from
20 CQC’s “closed cultures” project, which aims to improve the regulation of services identified
21 as being at a higher risk of poor care and abusive cultures (Care Quality Commission [CQC],
22 2022). The project produced two outputs: a quality-of-life framework and a quality-of-life
23 tool.

24 The Quality-of-Life draft framework (CQC, 2022b) provides a structured and logical set
25 of questions CQC inspectors might ask and that providers should be asking themselves. They

1 help CQC understand whether the service meets the needs and aspirations of the people it
2 supports. It points to potential sources of evidence with guidance about how to find the
3 answers. Although the draft framework was never formally tested by CQC in day-to-day
4 work, it laid the important groundwork needed for developing the Quality-of-Life tool, which
5 reflects much of its content.

6 The Quality-of-Life tool (CQC, 2023) aims to improve CQC's ability to consistently
7 identify and take appropriate regulatory action in services that fail or are failing to meet the
8 needs, aspirations, and skills development of people with an intellectual disability and/or
9 autistic people. The tool, used by inspectors on on-site visits, looks at how well people's care
10 plans are delivered in practice, focusing on people's experience rather than how providers
11 describe the support.

12 Both resources prompt a shift in thinking away from a service delivery perspective to one
13 that is wholly person-centred: Who are the people the service is delivering support to? What
14 are their needs and aspirations? Does the service meet those needs and aspirations? They
15 emphasise the importance of spending time with people who are using services so that
16 inspectors can get to know them and describe who they are and what they need, as well as the
17 need to corroborate evidence from different sources: what inspectors see in situ, hear from
18 others, and read in the documentation. The Quality-of-Life tool is currently embedded in the
19 CQC inspection process for all settings supporting people with intellectual disabilities.

20 **Informing professionals**

21 SF-DDARIN aims to inform professionals by publishing case studies, clinical
22 examples, intervention manuals and protocols, and programme descriptions that can address
23 common problems when working with children or adults with developmental disabilities. For
24 example, SF-DDARIN contributed to a report highlighting the importance of investing in

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3 1 early intervention (Cerebra, 2022), which included a case study on Early Positive Approaches
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5 2 to Support (E-PAtS), an early support programme for families of young children with
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7 3 suspected or diagnosed developmental disabilities. Other examples include resources
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9 4 developed under the PBS Academy umbrella targeted at different professional groups
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11 5 (commissioners and care managers, service providers, and support workers) to help embed
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13 6 the PBS Competence Framework (Positive Behavioural Support Coalition UK, 2015)
14
15 7 developed the year before the establishment of the network into practice. Subsequent
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17 8 resources include an observational checklist to check the quality of PBS services and three
18
19 9 sets of standards to improve the quality of PBS for service providers and teams, training
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21 10 providers, and individual practitioners (see www.pbsacademy.org.uk). More recently, a PBS
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23 11 State of the Nation report (Gore *et al.*, 2022) was published open access, which included a
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25 12 refined definition of PBS, an overview of the evidence base for PBS, and a proposed logic
26
27 13 model for PBS to guide future practice and research in the UK. This work has been shared
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29 14 with various professionals at conferences and community of practice events across the UK.

15 **Mainstream and social media**

16 Network outputs and projects are regularly disseminated into mainstream and social
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18 17 media outlets to generate as much positive press for behaviourally-based interventions and
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20 18 developmental disabilities research as possible. We also disseminate various stories, news
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22 19 articles, research papers, upcoming events and guidance documents tailored for individuals
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24 20 interested in behavioural science and its applications. For example, several press releases
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26 21 have featured details of SF-DDARIN work, such as the use and impact of restrictive
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28 22 interventions in schools (Challenging Behaviour Foundation [CBF], 2019), funding to
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30 23 evaluate an online reading intervention (University of Warwick, 2019), and recent work with
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32 24 the CQC (University of Warwick, 2023). The network uses Twitter (now called X) to share
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34 25 SF-DDARIN work and related content. Several of the network's tweets have been viewed

1 over 1,000 times on Twitter, including one to promote an SF-DDARIN early career
2 researcher event, which was viewed 2,568 times. In 2022, the Network's tweets had been
3 viewed 3,291 times, the Twitter profile was viewed 4,999 times, the account was mentioned
4 in 14 tweets by other profiles, and the account had 85 new followers.

5 Our dissemination serves several purposes: we can share our SF-DDARIN research
6 and activities more widely, we can share accurate and positive information regarding
7 different service delivery models for behavioural interventions, we can share up-to-date and
8 interesting applied behavioural research, and we can disseminate updates in guidance and
9 policy that may be of interest to our followers.

10 **Cross-cutting priorities**

11 The four inter-linked areas of work described above also support cross-cutting
12 priorities: developing early career researchers, building on partnerships with behavioural
13 practice organisations and other stakeholders, and encouraging diversity and inclusivity in the
14 network, including its composition, its research agenda, and adopting a co-production
15 approach to research whenever possible.

16 As mentioned previously, early career staff employed by SF-DDARIN are two post-
17 doctoral research fellows chosen specifically for the role due to their known skills and
18 expertise in the field. They receive ongoing supervision and support from the SF-DDARIN
19 project manager (first author) and the chairs of the workstream groups, who are
20 internationally renowned experts in behavioural research. One PhD student who provides
21 administrative support to the network has also been recruited while receiving direct
22 experience and supervision working on network activities. The SF-DDARIN provides
23 additional support to early career researchers both within and outside of the network by
24 hosting one or two early career research events a year. For example, we have held events

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3 1 where early career researchers have had an opportunity to present their research and receive
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5 2 feedback on their presentation, and one of our network members, a journal editor, delivered
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7 3 two workshops on the peer-reviewing process.
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10 4 We also build on partnerships with behaviourally based practice organisations and
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12 5 other stakeholders, including (a) people with developmental disabilities, (b) their family
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14 6 carers, (c) family members and friends, (d) front-line staff delivering services, (e)
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16 7 professionals working with people with developmental disabilities, (f) provider organisations
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18 8 such as education/school providers; and (g) policymakers and charities. An effective way to
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20 9 build such partnerships is to support internships working on different projects. Since 2016,
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22 10 the network has supported internship positions with a key strategic partner, the Challenging
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24 11 Behaviour Foundation. Hosted in collaboration with the PBS across the lifespan workstream,
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26 12 the interns have worked on several different projects, for example, helping to facilitate the
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28 13 research agenda of the Challenging Behaviour National Strategy Group, evaluating the
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30 14 impact of the PBS Academy, seeking the views of people with learning disabilities and
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32 15 complex communication challenges, exploring the impact of the Covid-19 pandemic,
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34 16 facilitating advisory groups with family carers and other stakeholders, and responding to
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36 17 government consultations. In addition to facilitating partnerships, interns have contributed to
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38 18 a range of outputs, including academic papers (Scott *et al.*, 2018a, 2018b), articles (Bradshaw
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40 19 and Humphries, 2021), reports (CBF, 2021), and resources (CBF and Mencap, 2017). SF-
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42 20 DDARIN has supported interns in developing their skills and profile as early career
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44 21 researchers through regular research supervision, encouraging attendance at research
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46 22 seminars, and providing opportunities (and support) to present research. Interns have
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48 23 progressed to post-graduate courses (MSc, PhD) and research-related roles (Research
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50 24 Assistant, Statistician).
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3 1 Finally, we are committed to promoting diversity and inclusivity within the network
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5 2 and its research activities. This includes addressing the importance of gender equality and
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7 3 diversity within the developmental disabilities field. We are striving to empower women
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9 4 researchers and highlight their contributions. We are aware that relatively little research
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11 5 focuses on issues that are gender specific. We are also conscious that, to date, the experiences
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13 6 and views of neurodivergent people have been relatively underrepresented in both research
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15 7 and practice. We are seeking to address this by listening to and engaging with the
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17 8 neurodivergent community, by providing training on neurodiversity and research to network
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19 9 members, and by inviting experts in neurodiversity (primarily through those with lived
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21 10 experience) to present to the network.
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26 11 Critically, we are increasingly adopting a co-production model across research
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28 12 activities – engaging with people with developmental disabilities and their families at the
29
30 13 outset to focus on issues and potential outcomes that are important to them and to design
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32 14 accessible projects. We aim to embed an understanding of neurodiversity across all network
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34 15 activities and that this understanding translates into empathetic and appropriate research and
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36 16 practice in behaviour analysis.
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40 17 **Measures of impact**

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42 18 Since its establishment at the beginning of 2016, the SF-DDARIN network members
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44 19 have worked on more than 53 projects involving over 50 researchers, had over 120 special
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46 20 schools contribute to projects and studies, and have recruited over 500 participants to studies
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48 21 and projects. SF-DDARIN has supported 12 PhD students and 13 master's students. Network
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50 22 members have collaborated on 67 published articles in peer-reviewed journals (with 11 under
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52 23 review), delivered 47 research presentations based on SF-DDARIN work, and have delivered
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54 24 25 training workshops to family carers and other stakeholders (e.g., on improving staff
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56 25 wellbeing and resilience, improving positive behaviour support plans).
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1 Activity to date represents a substantial return on the SF-DDARIN funding
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5 1 investment, securing a seven-fold return from additional research and impact grants, PhD
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7 3 studentships or contributing resources to the value of over £6 million. Examples of large-
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9 5 scale RCTs that have been externally funded include Early Positive Approaches to Support
10 6
11 7 (E-PAtS) for families of young children with intellectual disability: Feasibility study funded
12 8
13 9 by the National Institute for Health Research (NIHR) Public Health Research Programme
14 10
15 11 (£643,718); Mapping and Evaluating Services for Children with Learning Disabilities and
16 12
17 13 Behaviours that Challenge (MELD) funded by the NIHR (Health Services and Delivery
18 14
19 15 Research) (£1,245,271) and Headsprout Early Reading® in Special Schools (HERiSS) – A
20 16
21 17 randomised control trial funded by the EEF (£400,152). It is important to note that these
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23 19 outcomes have been achieved with a very small part-time staff support structure.
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30 Introduction to the special issue

31 This special issue aims to showcase how researchers and practitioners work together
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33 14 in SF-DDARIN to improve the evidence base for practitioners working in services for people
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35 16 with developmental disabilities. The following papers showcase the work of the Teaching
36 17
37 18 Skills to children, young people and adults workstream. They exemplify two tier-1 projects
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39 20 conducted by master's students (Goyen *et al.*, 2024; Reardon *et al.*, 2024; this issue) and a
40 21
41 22 case study describing a series of discrete projects organised across the three tiers (Denne *et*
42 23
43 24 *al.*, 2024; this issue). Targeting gaps in the evidence base, this series of projects was designed
44 25
45 26 to develop the evidence base progressively and systematically for an online reading
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47 28 intervention, the Headsprout® Early Reading programme, which uses behavioural principles
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49 30 to promote learning to read.
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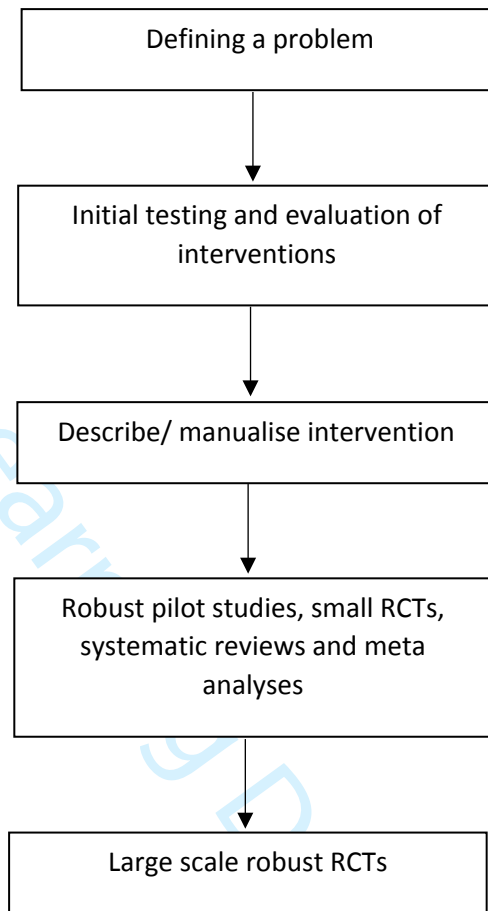


Figure 1: Progressive Research Steps