



## 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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### Tizard Learning Disability Review

DOI:

[10.1108/TLDR-08-2023-0018](https://doi.org/10.1108/TLDR-08-2023-0018)

E-pub ahead of print: 29/04/2024

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

*Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):*

Grindle, C., Roberts-Tyler, E., Denne, L., Sapiets, S., Apanasionok, M., Hughes, C., Hastings, R., Gore, N., Baker, P., & McDowell, C. (2024). Collective effort to enhance the quality of research evidence in intellectual and developmental disabilities: a case study of an academic-practice network. *Tizard Learning Disability Review*. Advance online publication. <https://doi.org/10.1108/TLDR-08-2023-0018>

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**Collective effort to enhance the quality of research evidence  
in intellectual and developmental disabilities: A case study  
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Journal:	<i>Tizard Learning Disability Review</i>
Manuscript ID	TLDR-08-2023-0018.R1
Manuscript Type:	Service Feature
Keywords:	Evidence based practice, developmental disabilities, behavioural interventions, research and impact, intellectual disabilities, Learning disabilities

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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  
4  
5  
6 2 for other groups seeking to develop and extend their evidence base in developmental  
7  
8 3 disability research.

9  
10 4 **Keywords:** Evidence-based practice; developmental disabilities; behavioural interventions;  
11  
12 5 research and impact.

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14  
15 6 **Article Classification:** Research Feature  
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18 7

Tizard Learning Disability Review

## 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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6           2 despite the inclusion of behaviourally based intervention approaches as recommended  
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8           3 practices in several government guidelines, there was also a significant lack of high-quality  
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10           4 research recognised as providing strong evidence for those interventions. For instance, by the  
11  
12           5 end of 2015, behaviourally based intervention approaches were included as recommended  
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14           6 practices in at least eight guidelines from the National Institute for Health and Care  
15  
16           7 Excellence (NICE; n.d.): Borderline Personality Disorder (CG78), Depression (CG90),  
17  
18           8 Parent Training (TA102), Obesity (CG189), Dementia (CG42), Autism in Adults (CG142),  
19  
20           9 Autism in Children (CG170), and Challenging Behaviour (NG11). In education, many of the  
21  
22           10 strategies with the strongest evidence included in the Education Endowment Foundation  
23  
24           11 Teaching and Learning Toolkit (n.d.) and in the Hattie review (2008), were derived from  
25  
26           12 research on learning and behavioural approaches. Yet, the evidence base for behaviourally  
27  
28           13 based interventions was patchy. In particular, a lack of attention to evidence synthesis  
29  
30           14 methods such as systematic review and meta-analysis, and a lack of randomised controlled  
31  
32           15 trial (RCT) evaluations of behaviourally based interventions seen as “gold standard” within  
33  
34           16 the scientific community, meant that some behavioural interventions were not being routinely  
35  
36           17 included in evidence-based practice reviews. These limitations may have been, in turn,  
37  
38           18 contributing to a lack of understanding of behaviourally based interventions and potentially  
39  
40           19 limiting the dissemination of interventions to the populations of children and adults with  
41  
42           20 developmental disabilities and their families who were most likely to benefit from them.

43  
44  
45           21           The SF-DDARIN aims to increase the quality of evidence for behaviourally based  
46  
47           22 interventions and contribute to understanding and dissemination of these interventions  
48  
49           23 through four inter-linked areas of work: (1) conducting high-quality research; (2) conducting  
50  
51           24 special projects with a focus on impact, (3) informing professionals, and (4) dissemination  
52  
53           25 through using mainstream social media.  
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## 1 2 3 **Organisation of the SF-DDARIN**

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5  
6 2 Working with academics and practitioners in the UK, SF-DDARIN focuses on two  
7  
8 3 areas of behaviourally-based developmental disability research:

- 9  
10 4 • Teaching skills to children, young people, and adults.
- 11  
12 5 • Positive Behavioural Support (PBS) across the lifespan.

13  
14  
15 6 Each workstream is co-chaired by two network members and supported by one of the  
16  
17 7 post-doc researchers, with additional research assistant time available for cross-workstream  
18  
19 8 activities. As noted above, these resources are a key factor in successfully delivering projects  
20  
21 9 that are not otherwise externally funded. Workstreams meet monthly and are expected to  
22  
23 10 submit project proposals that will result in various outputs, including research projects,  
24  
25 11 practice or academic articles and grant applications. Members can contribute to either  
26  
27 12 workstream, sponsor their projects, and request support (research, mentorship, resources,  
28  
29 13 funding, research officer time) from the network.  
30  
31  
32

## 33 **Conducting high-quality research**

34  
35 15 To address the identified gaps in the evidence base around behavioural interventions  
36  
37 16 that support people with developmental disabilities, the network has outlined a number of  
38  
39 17 progressive research steps that need to take place based on frameworks for the development  
40  
41 18 of complex interventions (e.g., Medical Research Council; Skivington *et al.*, 2021): defining  
42  
43 19 a problem, initial testing and evaluation of interventions; developing a description/model or  
44  
45 20 manual for an intervention so that it can be delivered in applied settings, more robust pilot  
46  
47 21 studies and research including small RCTs, systematic reviews and meta-analyses (see figure  
48  
49 22 1). With the evidence gathered from these early studies, major funding applications can be  
50  
51 23 put together to deliver large scale RCTs.  
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----FIGURE ONE ABOUT HERE---

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3 1 Within the two workstreams, SF-DDARIN activities are organised across three tiers  
4  
5 2 designed to progressively and systematically develop an evidence base as well as maximise  
6  
7 3 research opportunities by facilitating network members working together.  
8  
9

10  
11 4 Tier 1 focuses on broad collaboration across small-scale projects from an often-under-  
12  
13 5 utilised resource of Masters and PhD projects. Often, these studies exist but are dispersed  
14  
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  
18  
19 8 projects for students and those with projects in mind to find students. It is largely driven by  
20  
21 9 universities but with all network members contributing.  
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23  
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25  
26 10 Tier 2 is a focused collaboration on small to medium projects proposed by the two  
27  
28 11 workstreams, which can be resourced from within the network and do not require external  
29  
30 12 funding. The focus is on pivotal projects that are either a necessary step in taking forward a  
31  
32 13 proposal to Tier 3 (for example, developing a manual to describe proposed interventions), the  
33  
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  
37  
38 16 example a survey that helps shape a subsequent proposal).  
39  
40

41  
42 17 Tier 3 includes larger-scale projects, including RCTs and special projects focusing on  
43  
44 18 impact. Often, small working groups are established from the workstreams to take forward  
45  
46 19 the work needed for a larger-scale RCT (e.g., developing a grant proposal).  
47

48  
49 20 Denne *et al.* (2024; this issue) illustrate how activities across these tiers are organised  
50  
51 21 and the progressive research/evidence steps achieved by network members in developing an  
52  
53 22 evidence base for teaching people with developmental disabilities to read using an online  
54  
55 23 reading programme, Headsprout®.  
56  
57

#### 58 24 **Special projects with a focus on impact**

59  
60



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

1  
2  
3 1 early intervention (Cerebra, 2022), which included a case study on Early Positive Approaches  
4  
5 2 to Support (E-PAtS), an early support programme for families of young children with  
6  
7 3 suspected or diagnosed developmental disabilities. Other examples include resources  
8  
9 4 developed under the PBS Academy umbrella targeted at different professional groups  
10  
11 5 (commissioners and care managers, service providers, and support workers) to help embed  
12  
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  
16  
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  
20  
21 10 providers, and individual practitioners (see [www.pbsacademy.org.uk](http://www.pbsacademy.org.uk)). More recently, a PBS  
22  
23 11 State of the Nation report (Gore *et al.*, 2022) was published open access, which included a  
24  
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  
28  
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  
17  
18 17 media outlets to generate as much positive press for behaviourally-based interventions and  
19  
20 18 developmental disabilities research as possible. We also disseminate various stories, news  
21  
22 19 articles, research papers, upcoming events and guidance documents tailored for individuals  
23  
24 20 interested in behavioural science and its applications. For example, several press releases  
25  
26 21 have featured details of SF-DDARIN work, such as the use and impact of restrictive  
27  
28 22 interventions in schools (Challenging Behaviour Foundation [CBF], 2019), funding to  
29  
30 23 evaluate an online reading intervention (University of Warwick, 2019), and recent work with  
31  
32 24 the CQC (University of Warwick, 2023). The network uses Twitter (now called X) to share  
33  
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  
4  
5 2 feedback on their presentation, and one of our network members, a journal editor, delivered  
6  
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  
11  
12 5 other stakeholders, including (a) people with developmental disabilities, (b) their family  
13  
14 6 carers, (c) family members and friends, (d) front-line staff delivering services, (e)  
15  
16 7 professionals working with people with developmental disabilities, (f) provider organisations  
17  
18 8 such as education/school providers; and (g) policymakers and charities. An effective way to  
19  
20 9 build such partnerships is to support internships working on different projects. Since 2016,  
21  
22 10 the network has supported internship positions with a key strategic partner, the Challenging  
23  
24 11 Behaviour Foundation. Hosted in collaboration with the PBS across the lifespan workstream,  
25  
26 12 the interns have worked on several different projects, for example, helping to facilitate the  
27  
28 13 research agenda of the Challenging Behaviour National Strategy Group, evaluating the  
29  
30 14 impact of the PBS Academy, seeking the views of people with learning disabilities and  
31  
32 15 complex communication challenges, exploring the impact of the Covid-19 pandemic,  
33  
34 16 facilitating advisory groups with family carers and other stakeholders, and responding to  
35  
36 17 government consultations. In addition to facilitating partnerships, interns have contributed to  
37  
38 18 a range of outputs, including academic papers (Scott *et al.*, 2018a, 2018b), articles (Bradshaw  
39  
40 19 and Humphries, 2021), reports (CBF, 2021), and resources (CBF and Mencap, 2017). SF-  
41  
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  
6  
7 3 diversity within the developmental disabilities field. We are striving to empower women  
8  
9 4 researchers and highlight their contributions. We are aware that relatively little research  
10  
11 5 focuses on issues that are gender specific. We are also conscious that, to date, the experiences  
12  
13 6 and views of neurodivergent people have been relatively underrepresented in both research  
14  
15 7 and practice. We are seeking to address this by listening to and engaging with the  
16  
17 8 neurodivergent community, by providing training on neurodiversity and research to network  
18  
19 9 members, and by inviting experts in neurodiversity (primarily through those with lived  
20  
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  
27  
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  
31  
32 14 accessible projects. We aim to embed an understanding of neurodiversity across all network  
33  
34 15 activities and that this understanding translates into empathetic and appropriate research and  
35  
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  
45  
46 20 schools contribute to projects and studies, and have recruited over 500 participants to studies  
47  
48 21 and projects. SF-DDARIN has supported 12 PhD students and 13 master's students. Network  
49  
50 22 members have collaborated on 67 published articles in peer-reviewed journals (with 11 under  
51  
52 23 review), delivered 47 research presentations based on SF-DDARIN work, and have delivered  
53  
54 24 25 training workshops to family carers and other stakeholders (e.g., on improving staff  
55  
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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3  
4  
5 1 investment, securing a seven-fold return from additional research and impact grants, PhD  
6 2  
7 3 studentships or contributing resources to the value of over £6 million. Examples of large-  
8 4  
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  
22 18  
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  
32 13  
33 14 in SF-DDARIN to improve the evidence base for practitioners working in services for people  
34 15  
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  
38 19  
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  
46 27  
47 28 intervention, the Headsprout® Early Reading programme, which uses behavioural principles  
48 29  
49 30 to promote learning to read.  
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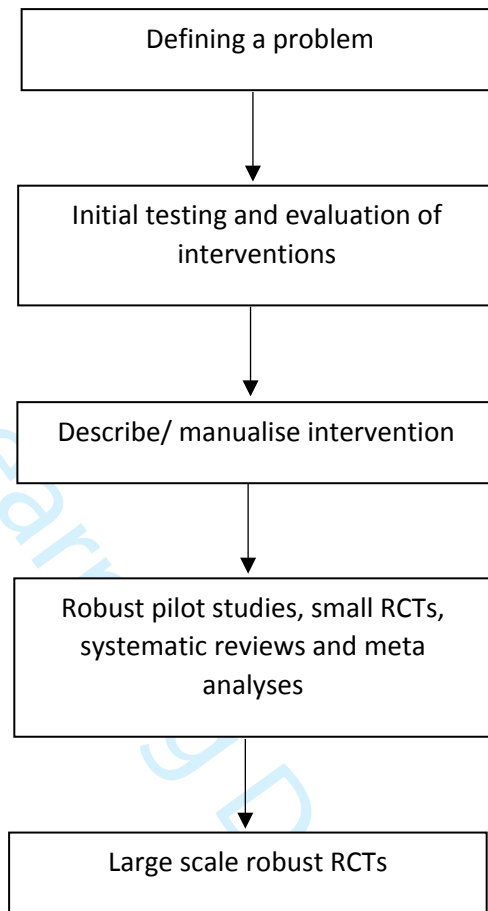


Figure 1: Progressive Research Steps