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Communication matters: Three scoping studies about the experiences of children with learning difficulties, and their families, in Scotland

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Study 1: How professionals manage parental requests for particular therapies for children with learning difficulties

Study 2: Information needs of parents and carers of children with learning difficulties

Study 3: Positive experiences of mainstream schooling



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Summary

In 2018 Salvesen Mindroom Centre commissioned the Childhood and Youth Studies Research Group (University of Edinburgh) to conduct scoping studies on three key issues for children with learning difficulties and their families:

- How professionals manage parental requests for particular therapies for children with learning difficulties
- Information needs of parents and carers of children with learning difficulties
- Positive experiences of mainstream schooling

The three areas were explored through conversations with professionals, parents and carers and children.¹ Each area was investigated separately: there was no overlap between the people taking part in each study.

This report presents the key themes for each of the three studies and the commonalities across them. These are exploratory studies aiming to identify gaps in knowledge and key questions for future research.

Study 1: How professionals manage parental requests for particular therapies for children with learning difficulties

For this study, existing research was reviewed and ten one-on-one conversations undertaken with professionals and autism experts² about the relationships between parents and professionals.

Professionals could not easily think of examples where parents had requested a particular support for their child. Instead, professionals suggested it was more likely that parents would bring information and there would be a collaborative discussion about ways forward – the idea that a parent would bring a solution seemed to be outside professionals' expectations for parents. There was little mention of how a child's views would feature in these discussions or in decision-making generally. A key area for future research would be to observe decision-making and gather all parties' (child/parents/professional) perspectives on the interaction.

Professionals had a strong focus on 'what works', stating that evidence about what would be effective for the individual child would be the key factor in decision-making. Local resources – both cost and availability – were also likely to be part of the decision-making. Both professionals and experts suggested that parents' financial and social capital would impact on decisions, affecting both how likely a parent was to make a request and whether that request would be actioned.

Relationships among professionals arose as a key theme affecting families in all three studies. Professionals described having to be cautious not to overstep role boundaries and

¹ 'Children' or 'child' is used in the main in this report to refer to all under the age of 18, following Article 1 of the UN Convention on the Rights of the Child. 'Young people' is used for scoping study 3, due to older children generally preferring this term in the UK.

² 'Autism experts' are defined on page 25 - people who had a range of experience, specifically around autism, from fields of research, consultancy, and/or service provision.

difficulties in communication, such as professionals not understanding others' remits and not listening to others' perspectives. Families might then feel they are being passed around services, particularly on questions of resources. Positive experiences for families were underpinned by good relationships between professionals, characterised by respect for others' expertise and information sharing. Research looking at families' positive experiences may therefore be able to identify key factors that support good relationships among professionals.

Study 2: Information needs of parents and carers of children with learning difficulties

For this study, two group discussions were held with parents ('parents' here is used to include parents and carers), who talked about their access to and experience of information provision. Existing literature was reviewed.

Information seeking by parents is part of parents' emotional journey. Parents talked about feeling lost, isolated and alone – and turned to other parents both to find things out and for emotional and practical support. Current information provision did not seem to be addressing parents' emotional needs; the ways that information was provided to parents seemed to increase rather than decrease parental feelings of insecurity. In particular, parents talked about getting information by chance, of failures from professionals to tell them about things that would help their child. Parents described wanting to have someone with them because they were in this scary situation, someone who could make sure they were getting all the information that would help and direct them through the different services. An important avenue for further research would be to identify how information provision is or is not meeting parents' wider emotional needs.

Across all three studies, parents highly valued respectful, ongoing communication from professionals: being kept in touch, hearing the outcome of actions. Such communication appeared to be exceptional rather than common. Yet both parents and professionals thought it was problematic when parents did not experience respectful communication; professionals talked about parents being pushed into becoming 'warrior parents' where parents were not listened to, having to have a confrontational relationship with professionals. Future research should identify the mechanisms which position parents as warriors, to support respectful communication which benefits both parents and professionals in the long term.

Study 3: Positive experiences of mainstream schooling

For this study, 16 one-on-one conversations were held about good things about school. First, conversations took place with four young people with learning difficulties from two different schools, then a parent of each young person. During these conversations the young people and their parents were asked to identify people who were important to the young person having a generally good experience of mainstream schooling. A further eight conversations then took place with professionals who had been identified by the young people and their parents.

Positive experiences of mainstream schooling were founded on strong relationships between young people, and parents and schools. Young people both knew specialist staff and were known by them; young people talked about staff that they could have a conversation with, and staff spoke about how they respected and valued the young people. Parents talked about collaborative problem-solving with school staff. Positive experiences did not mean that everything had to be good but relationships were strong enough to move forward through difficulties. A key area for future research would be to identify the components in individual experiences which enable young people, parents and schools to move forward through challenges, to consider how these components might be more systematically provided.

Schools supported young people's positive experiences when they were flexible enough to respond to a young person's individual needs and valued the whole young person. The young people exercised agency over their support provision and learning experiences. Parents and professionals talked about the schools valuing the academic and wider achievements of each young person, seeking out and celebrating different types of success. Participants linked the schools' abilities to respond to a diverse population in general (e.g. young people from varied socio-economic background, young disabled people) to the schools' success in providing a positive experience for young people with learning difficulties in particular. This links to the concept of inclusive pedagogy; future research into positive experiences of mainstream schooling may enhance our understanding of how inclusive pedagogy is possible in practice.

1. Introduction

1.1 Salvesen Mindroom Centre

The charity Mindroom was established by Sophie and Robin Dow in 2000, in response to their experience of a lack of support as parents of a child with learning difficulties. In 2015 the charity attracted a major philanthropic donation from Alastair and Elizabeth Salvesen. This enabled a research centre at the University of Edinburgh to be established – the Salvesen Mindroom Research Centre (SMRC) – and the charity became known as (The) Salvesen Mindroom Centre.

The purpose of the charity is to support, inform and empower parents and carers, and young people, living with learning difficulties and those working with them. This is achieved by providing 1:1 advice and support, by offering training and a range of resources, and by investing in research.

1.2 Definition of learning difficulties

The Salvesen Mindroom Centre defines a learning difficulty as:

“a problem of understanding or an emotional difficulty that affects a person’s ability to learn, get along with others and follow convention.”

(The Salvesen Mindroom Centre, 2019, p.4)

However, it is recognised that there is no single interpretation or consensual definition of the term and different organisations and public bodies have adopted their own definitions.

1.3 Background to the Scoping Studies

Between 2015 and 2017 Salvesen Mindroom Centre and SMRC, together with the James Lind Alliance, conducted a priority setting exercise to identify the top ten research priorities for learning difficulties. Over 800 questions were received during this exercise. Several questions were identified as being ‘out of scope’ for the priority setting exercise itself. These questions were themed by Salvesen Mindroom Centre (www.mindroom.org) to identify three areas of further interest. The Childhood and Youth Studies Research Group, University of Edinburgh, (www.ed.ac.uk/education/childhood-and-youth-studies) was commissioned to conduct scoping studies on these three areas of:

- How professionals manage parental requests for particular therapies for children with learning difficulties
- Information needs of parents and carers of children with learning difficulties
- Positive experiences of mainstream schooling

These studies are designed to be exploratory, considering where future research might be most useful and what approaches would be most valuable.

Research Questions

Scoping Study 1: How professionals manage parental requests for particular therapies for children with learning difficulties

Aim: To explore professional attitudes to and experiences of parental requests for a specific support, such as applied behaviour analysis (ABA), for children with learning difficulties

- What aids or prevents a parental request for particular additional support being supported or progressed by relevant professionals and their services (such as education, social work and health) for children with learning difficulties?
- What are professionals' experiences when parents promote a particular form of additional support for their children? What are the processes, outcomes and associated experiences when a professional supports parents' requests or does not support the request?
- Are the answers to the above similar or different for ABA (applied behaviour analysis)?

Scoping Study 2: Information needs of parents and carers of children with learning difficulties

Aim: To explore how to most usefully provide information to parents of children with learning difficulties, in central Scotland

- What types and sources of information do parents find useful to them and why? What do they not find useful and why?
- What aids or hinders parents accessing information useful to them?
- How can and should information provision be embedded within service relationships, to be most useful for parents?
- Do the answers to the above questions differ by parental and family characteristics (such as gender, diagnosis, age of the child/ children)?

Scoping Study 3: Positive experiences of mainstream schooling

Aim: To explore the processes that support young people and their parents having a positive experience of mainstream schooling

- What do young people with learning difficulties and their parents identify as a positive experience of mainstream schooling? What are the components that make this a predominantly positive experience? What was the process leading up to and maintaining this positive experience?
- What institutionally helped support and maintain this positive experience for the young person? What relationships helped support and maintain this positive experience for the young person?

1.4 Outline of this report

This report summarises the findings from each of the three scoping studies, presenting the themes that arose in the interviews and focus groups, and linking these to existing research. The approach to the scoping studies is briefly presented in the appendix, covering the literature review, ethical considerations, approach to primary data collection and analysis.

2. Scoping Study 1: How professionals manage parental requests for particular therapies for children with learning difficulties

Key points

- Professionals could not easily think of examples where parents had requested a particular support for their child – but rather described a process of collaborative discussion.
- Professionals highlighted the importance of interactions with other professionals, with particular concerns around understanding and respecting professional role boundaries. Parental expertise, although valued, had a defined and limited function to professionals.
- Children’s views were rarely mentioned and therefore did not appear to be a key part of decision-making.
- Inequalities in parents’ financial and social capital affected children’s access to support.
- Avenues for further research include:
 - Observing decision-making and gathering all parties’ perspectives on the same interactions.
 - Exploring how professionals can productively be more open with parents about cost factors.
 - Identifying from families’ positives experiences factors that support effective relationships among professionals.

This study was motivated by particular questions raised in the priority setting exercise about responses to parental requests for applied behaviour analysis (ABA). Salvesen Mindroom Centre also had experiences of working with parents seeking particular forms of a support for a child (these would be requests for support that do not fall within specific rights that parents have, e.g. to request an assessment). Ten interviews were conducted with professionals and autism experts, asking about the scenario of parents making a request in general and specifically about ABA (see appendix for more information on the methodology). The main themes resulting from the interviews were:

- A. The relationships between parents and professionals
 - i. Professionals did not see parents as making requests
 - ii. Professionals valued parents’ expertise – as information providers
 - iii. Children’s views were absent
- B. Factors that affected decision-making
 - i. Parents’ social or financial resources
 - ii. Professionals’ focus on evidence of ‘what works’
 - iii. Financial and local factors
- C. Relationships among professionals

A. The relationships between parents and professionals

i. Professionals did not see parents as making requests

Many of the professionals could not easily think of examples where parents had requested a particular support for their child (outwith formal rights that parents have, e.g. to request an assessment). Half of the professionals had no experiences relating to applied behaviour analysis (ABA) whether through a parental request or otherwise. A small number of detailed examples were described – these appeared to be complex and contested situations, described as exceptions. The scenario of parents making requests for particular forms of support did not seem to be an everyday occurrence for professionals, not in relation to ABA nor other forms of support.

Instead, professionals described problem solving discussions, with parents bringing information about the child's behaviours or needs, and then everyone working together to look at options:

“We have a discussion about what matters to you, what matters to your child.”

(Professional 5)

Parents might not view the same conversation as a collaborative discussion; they may have intended to make a request. The literature review suggested that parents and professionals may have a different focus for decision-making (e.g. parents may focus on the child and family's lived experiences versus professionals may concentrate on evidence about what works) and different perceptions of what impacted on that decision (particular around how important financial constraints were) (e.g. Levy et al, 2016; Tissot 2011). Further research should gather both parents' and professionals' views on ongoing interactions with each other, alongside observations of these interactions, to establish any differences between those views.

ii. Professionals valued parents' expertise – as information providers

Professionals expressed empathy and understanding for families living with learning difficulties; they talked about the difference between the whole of the child's life that the family experienced and the small piece that the professional saw. Professionals described parents as the experts on their children:

“You have to trust that a parent knows the best thing for the child.” (Professional 4)

The professionals explicitly stated that they valued parental expertise and saw working together as having benefits for everyone.

The professionals viewed parental expertise as having a particular purpose. Professionals talked about parents “quite rightly” (Professional 6) coming with information that the professional did not have – such as what happens outside the school day or unexpected events like a bereavement. Professionals had limited expectations that parents would come with solutions. One professional suggested it was the role of staff to identify options before parents:

“If a parent raised that [i.e. a particular form of support] and it hadn't already been thought of I would question why. I would expect school staff to have raised it already and ask why not.” (Professional 3)

One of the autism experts talked about supporting parents to understand what was and was not advisable to say to particular professionals: for example for a parent not to suggest a

diagnosis to a consultant psychiatrist. Parental expertise was valued within the particular function of providing information. Section C below describes how professionals were cautious in general about their role boundaries and not overstepping into other's roles. Professionals may apply a similar model to parents, with boundaries around the expected areas of parental expertise.

iii. Children's views were absent

Across all the interviews little mention was made of children's views or children's participation. This may be because the research questions focused on parents' requests. Two examples were given by professionals of children's views or best interests not being in line with the parents' wishes – and how this affected the professionals' role. In one example, the professional described supporting the child to share their views with the parent, and the final decision being made in line with the child's but not the parent's views. In another example, the parents' requests for support were followed on the basis that maintaining the relationship with the parents was the priority in order to protect the child's best interests (although professionals felt that other options might otherwise be more positive for the child). Lipstein and colleagues (2016) report a lack of evidence about children's participation in shared decision-making (a terminology used in relation to healthcare); in the evidence that is available, children's participation is low. They describe 'true shared decision-making' as involving children, parents and clinicians, and suggest that this is relatively rare.

B. Factors that affected decision-making

i. Parents' social or financial resources

Across both professionals and autism experts, interviewees thought that few parents would be in a position to make a request for a particular form of support. Interviewees described the inequalities affecting this such as financial resources, social networks, education, interpersonal skills. This is consistent with previous research which describes inequalities in children's access to support, including due to differences in parents' social capital (e.g. Riddell et al, 2010).

ii. Professionals' focus on the evidence of 'what works'

Professionals described the key factor affecting decision-making as the evidence whether or not that support was appropriate for a child:

"If we did get that kind of request we'd be asking: What is the evidence base for something like that?" (Professional 1)

Some of the autism experts in this study suggested that professionals could resist parents' suggestions by focusing on evidence. Previous research has identified differences between parents' and professionals' approaches; professionals describe their role as being to help parents understand the evidence base, where parents might focus more on the child's lived experiences (e.g. Levy et al, 2016). The professionals' focus on evidence may be part of how they identify their role and position as professionals, and how they differentiate themselves from parents.

iii. Financial and local factors

Interviewees talked about overall and individual service pressures on budgets, and local availability of services. Professionals described first considering what the child needed, and then what they had locally to meet that need; however one autism expert suggested local availability could override the child's needs. Tissot (2011) similarly reported that parents perceive professionals' decisions to be overwhelmingly about resources, while professionals see this as only one factor in the decision.

Interviewees talked about communication with parents around resources. One autism expert stated that professionals were not allowed to tell parents that resources were not available, and this caused problems in the relationship between parents and professionals:

"It sets up this adversarial position between the school and the parent, but it's really about resources." (Expert 4)

In study 3, where interviewees were asked to discuss what contributed to a positive experience, resources were still an area of concern. However, they were seen as being an issue at the local authority rather than the school level. A professional in study 1 described giving information to parents about cost, and how this transparency had both helped the relationships and the outcomes for the children. A valuable further area for research would be to explore how professionals could be more open with parents about the costs of services in a way that contributes to positive relationships between parents and professionals.

C. Relationships among professionals

Professionals felt they had to be careful about their relationships with other professionals; they identified several areas of potential tension. One, a professional could suggest a support to a parent, without understanding the remit or availability of that support. Two, professionals might not truly listen to each other, taking on board their contributions. Three, resource pressures might lead to "challenging discussions" (Professional 3). Where there was tension or where professionals did not understand each other's roles, parents could feel passed around between services.

Relationships among professionals arose across all three studies. Parents in study 2 described the experience of being passed around different services confirming interviewees' concerns in study 1. Professionals in study 3 echoed the caution around professional relationships expressed in study 1. One specialist teacher emphasised this by describing how they would give advice to subject teachers:

"I wouldn't tell them, I would make suggestions." (School Staff 8)

However, interviewees in study 3 also described strong relationships between professionals, in particular where there was clear information sharing and respect for the other person; there were also examples of flexibility in professional role responsibilities where appropriate for the individual young person. With these foundations in place, professionals were able to support good relationships with young people and their families, sometimes acting as a bridge between the family and wider professionals (see study 3). Research should look further at families' positive experiences and identify from these the factors underlying strong relationships between professionals.

The challenges and the strengths described around relationships among professionals were similar to the challenges and strengths described around relationships between parents and professionals (e.g. whether people are listened to effectively). Future research should connect the insights and learning from these different and inter-related sets of relationships.

3. Scoping Study 2: Information needs of parents and carers of children with learning difficulties

Key points:

- Information seeking is part of parents' emotional journey. When parents state they are looking for information, they may be expressing a broader set of needs. Parents turn to other parents because these needs are not being met.
- Current information provision may increase rather than decrease parents' feelings of insecurity. In particular, parents described information too often being accessed by chance, instead of being identified and provided by professionals proactively.
- Parents highly value respectful, ongoing communication from professionals, including being listened to. Both parents and professionals see a negative outcome where this is missing, with parents pushed into becoming 'warrior parents'.
- Avenues for future research include:
 - Developing a clearer understanding of how and when information provision is or is not meeting parents' wider emotional needs.
 - Investigating how interactions between professionals and parents position parents as 'warrior parents', and how this can be prevented.

Two groups of parents (used here to include parents and carers) were invited to talk about information needs, including the information they wanted or received from professionals, and the types and sources of information they found useful. Ten parents took part in total, all women, with children of primary age or younger who had learning difficulties (see appendix for more information on the methodology). The main themes arising from the group discussion were:

- A. Information seeking was part of parents' emotional journey
- B. Parents' feelings of insecurity were increased by the ways information was provided
 - i. The main source of information was chance
 - ii. Professionals were not proactive in providing crucial information
 - iii. Information provided did not fit what parents needed to do with the information
- C. Communication with professionals was a key part of parents' needs

A. Information seeking was part of parents' emotional journey

Parents described receiving information but feeling lost, isolated and alone:

"Again, it's pretty much you're given the leaflets about [organisation] and then you're on your own from there on." (Group 1)

Parents described other parents, and to a lesser extent online sources, as filling gaps in the information provision and providing support and solidarity:

"So a lot of these [parents attending a group] here have like really pulled me out a hole at times." (Group 1)

These findings match previous literature that suggests parents value support groups because they provide a space to discuss real life experiences and emotions (e.g. Derguy et al, 2015).

Sometimes parents said they wanted advice, or to know what to do, but their descriptions suggested that they were looking for support around the complexity and difficulty of their and their child's life:

“When [child] is having their meltdowns and when they get aggressive and they're biting and they're kicking and they're pulling hair, and they've got you in a headlock, you want somebody you can phone after that to say 'what do I do?' Because it's how you feel. I mean, it's like, this has happened 5 times in the last 3 hours. What do I do?” (Group 1)

Previous research similarly found that parents' information seeking is part of their way of coping with their child's diagnosis and behaviours, to help the family to gain control and to manage the emotional impact (Sciberas et al, 2010).

There is a relatively large amount of previous research which recommends more or better information provision for parents, such as Brown et al (2012) which identifies the areas of information parents consider most important and the extent to which those needs are met. And yet, information provision still appeared to be an area of frustration and anxiety for parents. Azad and colleagues (2018) noted evidence of failed communications between parents and professionals, but less evidence on the causes of such failures. This study suggests that a key issue may be whether information is provided in a way that meets the wider emotional needs of parents; future research should consider how this is or is not happening in current practice.

B. Parents' feelings of insecurity were increased by the ways information was provided

i. The main source of information was chance

Parents described their access to information as happenstance rather than design:

“Because I only found out about it by chance” (Group 2)

Parents described finding out about things by being “lucky” (Group 1), through other parents or chains of people. They expressed no confidence that they had access to all the information that they needed, matching previous research's findings that there are unmet needs for parents around information (e.g. Ahmed et al, 2014).

ii. Professionals were not proactive in providing crucial information

One particular gap in information provision was from professionals; a key complaint was that professionals were not proactive. One parent described how on multiple occasions her professional was able and willing to put support in place as soon as she asked for it, but the parent was only able to ask because she knew the support was possible from another parent. She summarised her experience:

“There's never been any issues. But they're not forthcoming with the information that will make your life easier as well.” (Group 1)

This parent was generally very positive about the professional but struggled to understand why they had not told her about something basic that would help. She described feeling insecure: if it had not been for the other parent, she would never have known what was available and then would never have asked. This corresponds with previous studies which suggest a gap between where parents want to get information from – professionals, who

are trusted – and where they can in practice get information from – the internet (Sharpe et al, 2016).

iii. Information provided did not fit what parents needed to do with the information.

Information that parents did receive was not always usable in daily life. Parents reported receiving long lists of resources that might or might not help their children, without the information on how to access the resources. They also spent significant time trying to find their way around the system, being passed around different services, not being able to find out who to contact. There were also recurring gaps, in particular a lack of information or support for the whole family and specifically for siblings.

Both groups suggested needing someone to help direct them through the system:

“So it’s like, just have a central point that can connect all these... to keep you informed, because it’s a scary place to be.” (Group 1)

Parents’ idea of this central point seemed to be someone who could support them with the emotional experience of being a parent of a child with learning difficulties as well as provide them with information. As noted above, future research should understand how information provision can meet parents’ wider emotional needs.

C. Communication with professionals was a key part of parent’s needs

Parents were extremely grateful for what they described as the “human touches”, “the little things” (Group 2) – a professional who chased up a letter, who sent a text to say an action had been followed up, who filled in a home-school diary so the parent felt informed about what had happened in school that day:

“What I’ve appreciated from her is that her communication is excellent it certainly suits my needs it’s very respectful it’s very responsive she emails she texts.” (Group 2)

This matches previous research which suggests that parents appreciate ongoing contact from professionals (e.g. Starr et al, 2016).

Good communication by professionals was not universal. Parents talked about not being listened to and how difficult they found it to always have to chase for answers. This matches previous findings; for example, Tissot (2011) noted that even where parents achieved the outcome that they wanted they found the process stressful. Parents described feeling like they were forced into a position of having to fight:

“You shouldn’t have to be there fighting these people that should be put in place to support you. But they’re not. They make it even more difficult.” (Group 1)

Professionals and autism experts in study 1 shared such concerns, describing parents being turned into “warrior parents” (Expert 3) or forced into “a bit of a campaign” (Professional 1) because they did not have access to a respectful professional who listened to them. Interviewees suggested this was a negative outcome for both parents and professionals. It would be valuable for further research to investigate the mechanisms and interactions which position certain parents as warriors, to inform practice which prevents this.

4. Scoping Study 3: Positive experiences of mainstream schooling

Key points:

- In descriptions of positive experiences, young people were known as individuals and exercised agency.
- Specialist staff had strong relationships with young people, founded on knowing the young people well. These staff could act as a bridge supporting young people's relationships with the wider school to work well.
- Collaborative, problem solving relationships between staff and parents contributed to positive experiences. This helped young people, parents and staff to move forward through challenging situations.
- Schools supported young people's positive experiences when they were flexible enough to respond to a young person's individual needs and their overall ethos was positive and inclusive.
- Avenues for future research include:
 - Exploring the processes and components that enable an overall positive experience through times of challenge.
 - Identifying how positive experiences of mainstream schooling draw on an overall school ethos of responding to diversity, with the potential to enhance our understanding of inclusive pedagogy in practice.

Four young people and their parents were recruited from secondary schools, who school staff thought had had a positive experience of mainstream schooling. The young people and their parents were asked to discuss this positive experience. The young people and their parents were asked to suggest people who had contributed to their positive experience; eight interviews with school staff were conducted following their suggestions (see appendix for more information on the methodology). The main themes were:

- A. Relationships between families and schools were key to positive experiences
 - i. Staff saw young people as individuals and enabled their agency
 - ii. Specialist staff provided a bridge between young people and wider school staff
 - iii. Parents highly valued ongoing and collaborative relationships with staff
 - iv. Relationships between all parties were strong enough to move forward through difficulties
- B. A flexible school institution
- C. An overall school ethos which valued the whole individual

A. Relationships between families and schools were key to positive experiences

i. Staff saw young people as individuals and enabled their agency

Constructive relationships between young people and school staff were important for young people to have a positive experience of mainstream schooling. This came through from all the different groups of interviewees – young people, parents, school staff – though they did not necessarily characterise what was good about the relationships in the same way. The young people talked about the school staff they liked being the ones who talked to them:

“They're definitely good for a fun conversation.” (Young Person 1)

The parents talked about the staff being “caring” (Parent 2), while the staff tended to use language about trust and respect:

“I respect my students a lot, they are very much aware of that.” (School Staff 6)

While young people, parents and school staff had different ways to describe what made a positive relationship, common elements existed. In particular, staff sought to understand and know the young person as an individual:

“As long as we know the child really well, then we can support them well.” (School Staff 7)

One young person described a particularly good teacher as being “interested in everyone’s lives” (Young Person 4) and the teacher sharing information about themselves as well. A parent described how the staff really understood the young person’s likes and dislikes. The efforts by the staff to understand the young people were described as positive by the parents and the young people themselves.

Another common element was that the young people appeared to exercise agency and choice. One parent described a young person as having “ownership” (Parent 3) of his learning environment, choosing when he could be in class and when he needed to be in a quiet space. The young person also described having choice: for example about whether to participate in discussions depending on “how safe I felt” (Young Person 3). One of the staff suggested that supporting young people’s agency was an explicit intention:

“Those choices are something I create and enable them to choose.” (School Staff 6)

Other examples of young people’s choice were where a support would be offered but not imposed; in one particular example a service was offered but not put into place until the young person felt confident enough to use it. In contrast therefore to study 1, where young people were rarely visible in decision-making, the young people in study 3 were visible, known as individuals to the professionals and exercising agency over how they were supported. This matches previous research which has found that young people’s agency is supported where staff show an interest in them as individuals (Riddell, 2019).

ii. Specialist staff provided a bridge between young people and the wider school staff

Although study participants commented positively about wider school faculty (e.g. staff seeking advice from specialist teachers or giving up their own time to enable a young person to be supported), there were also difficulties in the relationships between wider school staff and young people with learning difficulties. One staff member talked about young people having a bit of space to ‘offload’ with Support for Learning staff, who might then go back and remind a subject teacher of a student’s situation (e.g. why it might be difficult for them to copy from the board). Another staff member talked about how some subject teachers might find it difficult to adapt their provision to the young person’s needs, and then the specialist staff would work with the young person to develop strategies for that particular class. The specialist staff appeared therefore to be important not only in their only direct relationships with the young people but in how they facilitated wider relationships.

iii. Parents highly valued ongoing and collaborative relationships with staff

Parents highly valued having an accessible and collaborative relationship with the school. Parents described the staff as being “approachable” (P4), as having two-way communication, where a parent could contact the school or the school might contact the

parent, both when things had gone wrong but also when things went right. Parents also described the school proactively contacting them with ideas to try to improve the support for the young person. One parent noted that communication with the school was very “efficient” (Parent 1), not only suggesting ideas but acting swiftly to make them happen. Parents described working together with the school:

“It was all spoken about, all discussed.” (Parent 2)

Part of working together with the school was that parents were listened to and their expertise recognised:

“Being able to listen to your point of view, recognise that you had some expertise in regard to your children [...] and then between us coming to some sort of plan that seemed sensible.” (Parent 3)

The descriptions of positive experiences of relationships with staff in study 3 largely matched the descriptions in study 2 of what parents wanted – but felt they were rarely receiving – in terms of communication from professionals.

In the main, the staff members recognised the effort that they put into the relationship with parents (where this was part of their role):

“I do an awful lot of informal stuff, picking up the phone and talking to parents and just letting them know things.” (School Staff 1)

However, the staff members around young person 4 did not appear to recognise the value of their activities in terms of communication with parents; they talked about being transparent with parents and listening, but also commented that there was:

“Nothing special that we do in that regard.” (School Staff 8)

In contrast, the parent of this young person saw the staff approach to communication as crucial. The parent contrasted their own experience with that of other parents, where young people had for example been excluded from activities because of professionals’ unwillingness to problem-solve with the young people and the parents. There is a risk if professionals and the institution do not recognise such communication as important, as it might not be structurally valued or supported. Professionals need time to be able to provide this ongoing communication. Further research should explore how these ways of working with parents are most effectively integrated and recognised in professionals’ roles.

iv. Relationships between all parties were strong enough to move forward through difficulties.

Although interviewees were asked to talk about positive experiences, a positive experience did not mean there would not be times of difficulty. Interviewees talked about the importance of moving forward from difficult situations. Being able to do so appeared to rest on the same key relationship factors as the overall positive experiences. Staff talked about managing problematic behaviour by a young person, of working out the next steps with the young person in a restorative way and moving forward:

“Let them know that you value them... it’s maybe obvious to say... you value them as a person, but you don’t value the behaviour”. (School Staff 2)

One parent described at times feeling quite frustrated with the school, but what moved them all forward was working together to understand the young person’s behaviour and how best to respond in the school’s environment. The parent concluded that both they and the school had learned from it. A respectful relationship with the individual young person and a collaborative, problem solving relationship between the parents and the

school appeared therefore to be key to a positive overall experience, because they were crucial to moving forward through challenging situations. Future research should consider not only what constitutes a positive experience but how an overall positive experience is maintained through times of challenge. This could consider the different processes and components in individual situations in order to develop ideas for how to embed these systematically.

B. A flexible school institution

Interviewees were not generally able to identify particular policies that contributed to positive experiences of mainstream schooling. However, one recurring aspect was flexibility of the overall school approach. This had at least four different expressions: flexibility in support that could be offered to a young person; willingness to try different things and adapt; the young person having choice around options; and flexibility around staff roles and options to tailor these to the particular young person and their needs. Staff suggested that senior management were key to this, setting the tone that the focus was on all students doing well. One staff member described how management was responsive to staff ideas for how to support students:

“If you come up and say I think things would work better this way they will listen.

They give you -- as much as resources permit -- everything you need. If it's not there at least you will understand why. They really do their best.” (School Staff 6)

There did not therefore seem to be particular policies or institutional structures that supported a positive experience. Rather it was about a flexible response to the individual young person's needs, based on an overall commitment to value each young person in the school.

C. An overall school ethos which valued the whole individual

A key element described by young people, parents and staff was the overall feel of the school:

“So this school's really helpful, any which way.” (Young Person 4)

“The atmosphere appears to be positive and encouraging and optimistic.” (Parent 1)

“The starting point is what kind of school we are [...] we think of ourselves as a learning community”. (School Staff 8)

These examples emphasise that a positive experience does not rest only on individual staff but on the experience as a whole.

One positive aspect of the overall school ethos was the ability to see the whole individual. Parents in both schools described ways in which the schools recognised achievement as including, but not being limited to, the academic:

“I do feel strongly that people who put in a lot of hard work and time, deserve recognition. And it's important that the people who are in charge of actually setting policy and practice recognise the bigger picture. That it's not all academic. There's more to life than that.” (Parent 3)

This did not mean that parents did not value the young people being pushed academically, but they appreciated other dimensions of the young person being recognised. Staff talked about finding out what the young people liked and were good at, and then giving them opportunities to work with their strengths. Again therefore schools and school staff knew

and valued the individual young person. This corresponds with research around restorative approaches in schools, which foreground the idea of the school as a community and the importance of all members of the school being respected and having positive relationships. Research suggests that restorative approaches can support inclusion in schools and that restorative approaches both rest on and shape an overall positive school ethos (McCluskey, 2018).

A positive school ethos was enhanced by having a diverse school population and a school commitment to recognising this diversity. Staff, parents and young people interviewed noted that their schools included families from socio-economically deprived areas, young people for whom English was an additional language, and young disabled people. Some of the parents and staff suggested that this led to an overall sense that being different was normal: everyone was an individual. This approach exemplified an inclusive pedagogy (e.g. Florian and Beaton, 2018), which responds to individual differences by providing all students with learning opportunities, and not marginalising some as requiring different provision. Further research on 'positive' experiences of mainstream schooling may enhance understanding of how inclusive pedagogy is possible in practice.

5. Conclusion

These three scoping studies were designed to explore certain issues around the experiences of children with learning difficulties in Scotland, opening up questions for future research. While the studies took different approaches and asked different questions, the quality of communication between parents, children and professionals was the overwhelming theme across all three studies.

Parents strongly valued what they described as the little things in communication with professionals: being treated respectfully and being kept informed. Both parents and professionals talked about collaborative decision-making, where parental expertise was recognised and listened to, and parents and professionals learned together. These 'human touches' of effective communication were not consistently happening in practice; where communication was poor, this was experienced negatively by parents and professionals. Future research should analyse interactions between parents and professionals from all perspectives. The scoping studies identify some specific areas around parent-professional interactions that may be valuable to focus on, such as how resources can be discussed positively or how parents may be positioned as 'warrior parents', pushed into confrontational relationships with professionals.

Communication with children was largely absent in studies 1 and 2. Although children's views were not explicitly asked about in these scoping studies, nevertheless it was striking that these were largely absent from professionals' and parents' accounts of their experiences. In contrast, when looking at positive experiences of mainstream secondary schooling, the young people were recognised and known as individuals to the professionals; there were also examples of the young people's agency and discussion about how professionals actively sought to support this. Future research looking at communication between parents and professionals should include consideration of how children's views inform and are incorporated into discussions and decision-making.

While none of these three studies set out to look at the relationships among professionals, the way that professionals work together can have a significant impact on families. This might be experienced by families as being passed around different professionals, particularly on issues of cost. Where professionals' relationships were strong, this could enable one professional to act as a bridge between the young person, the family, and other professionals – contributing to an overall positive experience. Future research should seek to identify the factors which underpin positive relationships among professionals, which in turn support families' positive experiences.

Overall, these three scoping studies re-emphasise that professionals' communication skills and practices make a significant difference to children's and their families' experiences. These skills, such as the ability to listen effectively, must be recognised and valued, in time and resources, as a crucial part of professionals' practice.

References

- Ahmed, R., Borst, J. M., Cheng Wei, Y., & Aslani, P. (2014). Do parents of children with attention-deficit/hyperactivity disorder (ADHD) receive adequate information about the disorder and its treatments? A qualitative investigation. *Patient Preference & Adherence*, 8, 661-669.
- Azad, G., Wolk, C. B., & Mandell, D. S. (2018). Ideal Interactions: Perspectives of Parents and Teachers of Children with Autism Spectrum Disorder. *School Community Journal*, 28(2), 63-84.
- Brown, H. K., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet Needs of Families of School-Aged Children with an Autism Spectrum Disorder. *Journal of Applied Research in Intellectual Disabilities*, 25(6), 497-508.
- Derguy, C., Michel, G., M'Bailara, K., Roux, S., & Bouvard, M. (2015). Assessing Needs in Parents of Children with Autism Spectrum Disorder: A Crucial Preliminary Step to Target Relevant Issues for Support Programs. *Journal of Intellectual & Developmental Disability*, 40(2), 156-166.
- Florian, L. & Beaton, M. (2018). 'Inclusive pedagogy in action: Getting it right for every child', *International Journal of Inclusive Education*, 22(8), 870-884.
- Levy, S. E., Frasso, R., Colantonio, S., Reed, H., Stein, G., Barg, F. K., & Fiks, A. G. (2016). Shared Decision Making and Treatment Decisions for Young Children With Autism Spectrum Disorder. *Academic Pediatrics*, 16(6), 571-578.
- Lipstein, E., Anixt, J., Britto, M., Lindly, O., & Zuckerman, K. (2016). Shared Decision Making in the Care of Children with Developmental and Behavioral Disorders. *Maternal & Child Health Journal*, 20(3), 665-673.
- McCluskey, G. (2018) Restorative approaches in schools: Current practices, future directions. In Deakin, J., Taylor, E. & Kupchik, A. (eds) *The Palgrave International Handbook of School Discipline, Surveillance and Social Control*, Basingstoke: Palgrave, 573-593.
- Riddell, S. (2019) *Autonomy, Rights and Children with Special Needs: A New Paradigm? Scottish Case Study Findings*. CREID Briefing 43.
<http://www.docs.hss.ed.ac.uk/education/creid/Briefings/Briefing43.pdf> (01.12.19)
- Riddell, S., Stead, J., Weedon, E. & Wright, K. (2010). Additional support needs reforms and social justice in Scotland. *International Studies in Sociology of Education*, 20(3), 179-199.
- The Salvesen Mindroom Centre (2019) *It takes all kinds of minds*.
[http://www.mindroom.org/media/resources/It Takes All Kinds of Minds 2017v3.pdf](http://www.mindroom.org/media/resources/It_Takes_All_Kinds_of_Minds_2017v3.pdf) (01.12.19)

The Salvesen Mindroom Centre. (2018) *Research Priorities for Learning Difficulties Final Report*. Project delivered by the University of Edinburgh. In partnership with James Lind Alliance. <http://www.jla.nihr.ac.uk/priority-setting-partnerships/learning-difficulties-scotland/downloads/Learning-Difficulties-Scotland-PSP-Final-Report.pdf> (01.12.19)

Sciberras, E., Iyer, S., Efron, D., & Green, J. (2010). Information needs of parents of children with attention-deficit/hyperactivity disorder. *Clinical Pediatrics*, 49(2), 150-157.

Seditas, Karen (2016) *Evidence Bank: Evidence Review Handbook*. Edinburgh: What Works Scotland/Centre for Research on Families and Relationships.

Sharpe, K., Pietro, N., Jacob, K., & Illes, J. (2016). A Dichotomy of Information-Seeking and Information-Trusting: Stem Cell Interventions and Children with Neurodevelopmental Disorders. *Stem Cell Reviews & Reports*, 12(4), 438-447.

Starr, E. M., Martini, T. S., & Kuo, B. C. H. (2016). Transition to Kindergarten for Children with Autism Spectrum Disorder: A Focus Group Study With Ethnically Diverse Parents, Teachers, and Early Intervention Service Providers. *Focus on Autism and Other Developmental Disabilities*, 31(2), 115-128.

Tissot, C. (2011). Working Together? Parent and Local Authority Views on the Process of Obtaining Appropriate Educational Provision for Children with Autism Spectrum Disorders. *Educational Research*, 53(1), 1-15.

Wright, K., Stead, J., Riddell, S. and Weedon, E. (2012). Parental experiences of dealing with disputes in Additional Support Needs in Scotland: why are parents not engaging with mediation? *International Journal of Inclusive Education*, 16(11), 1099-1114.

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Appendix: Approach to the Scoping Studies

The following briefly describes how the scoping studies were carried out; for further information please contact the Childhood and Youth Studies Research Group, University of Edinburgh.

Review of existing research

A literature review was carried out for studies 1 and 2 (using a shortened version of the process set out for the Evidence Bank (Seditas, 2016)). Key words were identified and searched in relevant academic databases, limited to research written in English and published in the last 10 years. Requests were sent to relevant mailing lists. 21 studies were identified and reviewed. Findings from the literature review are noted alongside the themes arising from the data. A literature review was not formally carried out for study 3 as there are existing research reviews; key recent studies are noted, as relate to the findings.

The search found more research for Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) than for Tourette syndrome, dyslexia or Developmental Coordination Disorder (DCD)/Dyspraxia. This matches the findings of the research priority setting work (The Salvesen Mindroom Centre, 2018). Because of these gaps it is unclear whether children and families affected by different conditions would have similar or different needs and experiences.

Ethical Considerations

Ethical approval was granted by the Moray House School of Education and Sport, and from the local authority areas where young people were participating in study 3. Local processes for ethical approval for interviewing professionals were followed in the relevant local areas. An extensive range of ethical issues were considered including how to ensure participants knew what they were participating in (informed consent), child protection, and data security. A particular concern throughout the work is that the small scale of the studies will make participants more easily identifiable; considerable care has been taken with the anonymisation of, for example, geographic details as well as names to prevent this.

Gathering information from children, parents and carers, professionals

Data collection was carried out separately for the three studies; there was no overlap between the participants taking part. However, the data from participants was often relevant to the issues being considered in other studies – this has been referred to in the findings.

Study 1:

Study 1 sought to speak one-on-one with front-line professionals involved in decision-making across two different job roles (educational psychologists, social workers). After the first interview, the research team decided to seek management as well as frontline perspectives on decision-making. Six interviews were conducted, prioritising reaching a range of professional roles; professionals drew on all their experiences in the interviews, e.g. also referring to frontline experiences where they were now in management or developmental roles. Four interviews were conducted with ‘autism experts’ – people who had a range of experience, specifically around autism, from fields of research, consultancy,

and/or service provision. The purpose was to hear views that were a step away from current providers. These participants are not further described because the individual nature of their expertise could make them identifiable. The interviews were started by the interviewer giving the scenario of a parent making a request for a particular form of support, and using examples from Salvesen Mindroom Centre's experiences to clarify that these were not parents making particular requests that they are entitled to in legislation (e.g. the right to request an assessment). The interviewees were asked to describe any examples they had of similar experiences or to discuss how they would respond to this scenario if they could not identify examples. Probing questions focused on the relationships between the professionals and the parents, and the processes that professionals would follow in this situation. Interviewees were asked specifically if they had any experiences around Applied Behaviour Analysis (ABA).

Study 2:

Study 2 sought to engage with two groups of parents and carers of children with learning difficulties. While diversity in participants was sought, this was not achieved. All of the participants were female; it is common in research around parents of children with additional support needs for 'parents' to mean 'mothers' (Wright et al, 2012). All of the children were primary school age, meaning these focus groups may represent a particular stage in parents' emotional journey around information needs, but not other issues such as transition away from school. Many of the children were diagnosed with Autism Spectrum Disorders (not necessarily as their sole diagnosis), because one of the groups was accessed through a specific support organisation. The relative lack of diversity in the children's diagnoses is a particular concern for this scoping study given the gaps identified in existing research around other diagnoses. The focus groups were asked to talk about what information the participants need as parents of children with learning difficulties, where and how they would get that information, and examples of what they found helpful or not helpful. The parents were asked to think about information broadly – to include information they get from other people as well as information that they might read or watch. The research invited participants' own interpretations of 'information': for example, they were not asked to distinguish between information and advice.

Study 3:

Study 3 sought to speak to four young people with a positive experience of mainstream secondary schooling, and the people around them (e.g. parents, staff) who contributed to that positive experience, creating 'pods' of data for analysis. Two schools, in different local authorities, were asked to identify young people with learning difficulties who they thought would enjoy the experience of being interviewed and who would describe their experiences of mainstream school as (at least in part) positive. Four young people and their parents agreed to be interviewed, and eight members of staff (the members of staff were often identified in relation to more than one young person). The staff identified were primarily specialist teachers or support staff. One individual in a broader role (a receptionist) was identified but not available for an interview. Time constraints around school holidays meant other young people were not interviewed, although they had been identified as contributing to the positive experience of mainstream school. The young people interviewed were all boys, of secondary school age, with single or multiple diagnoses including ASD, ADHD, dyslexia, Tourette syndrome.

The young people and their parents were asked to talk about what was good about school. Follow-on interviewees were told that they had been identified as contributing to a young person's positive experience of mainstream schooling and asked to talk about what they tried to do to create a positive experience. Probing questions to all interviewees focused on the people, relationships and aspects of the school (e.g. the atmosphere, the physical school, the school approach/policies) that supported good experiences.

Analysis

The information that was collected from speaking to individuals or to groups was first read through by the research team to become familiar with the content. An initial set of codes were developed to track recurring ideas. The information was coded individually, and then a subset compared with coding by a subject expert from Salvesen Mindroom Centre. The coding was revised, and gathered into broader themes in each study, for presentation in this report alongside information from previous research. Anonymised quotations from participants have been included to illuminate the themes; as far as possible given the small scale of these studies, quotations have been chosen to be typical of the data.

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