Swansea University
Prifysgol Abertawe

Cronfa
Setting Research Free

Cronfa - Swansea University Open Access Repository

This is an author produced version of a paper published in:
International Journal of Health Care Quality Assurance

Cronfa URL for this paper:
http://cronfa.swan.ac.uk/Record/cronfa40955

Paper:
Hurt, L., Langley, K., North, K., Southern, A., Copeland, L., Gillard, J. & Williams, S. (2019). Understanding and improving the care pathway for children with autism. *International Journal of Health Care Quality Assurance*, 00-00.
http://dx.doi.org/10.1108/IJHCQA-08-2017-0153

This item is brought to you by Swansea University. Any person downloading material is agreeing to abide by the terms of the repository licence. Copies of full text items may be used or reproduced in any format or medium, without prior permission for personal research or study, educational or non-commercial purposes only. The copyright for any work remains with the original author unless otherwise specified. The full-text must not be sold in any format or medium without the formal permission of the copyright holder.

Permission for multiple reproductions should be obtained from the original author.

Authors are personally responsible for adhering to copyright and publisher restrictions when uploading content to the repository.

http://www.swansea.ac.uk/library/researchsupport/ris-support/

Title: Understanding and improving the care pathway for children with autism

Author Details

Author 1

Name: Lisa Hurt

Qualifications: PhD

Job title: Lecturer

Department: Division of Population Medicine, School of Medicine

Institution: Cardiff University

Town/City: Cardiff

Country: UK

Telephone: 02920 687807

e-mail: Hurtl@cardiff.ac.uk

Author 2

Name: Kate Langley

Qualifications: PhD

Job Title: Senior Lecturer

Department: School of Psychology

Institution: Cardiff University

Town/City: Cardiff

Country: UK

Telephone: 02920 876259

e-mail: LangleyK@cardiff.ac.uk

Author 3

Name: Kate North

Qualifications: PhD

Job Title: Lecturer

Department: Humanities Department

Institution: Cardiff Metropolitan University

Town/City: Cardiff

Country: UK

Telephone: 02920 205839

e-mail: knorth@cardiffmet.ac.uk

Author 4

Name: Alex Southern

Qualifications: PhD

Job Title: Research Associate

Department: Faculty of Education and Communities

Institution: University of Wales Trinity Saint David

Town/City: Cardiff

Country: UK

Telephone: 02920 375055

e-mail: a.southern@uwtsd.ac.uk

Author 5

Name: Lauren Copeland

Qualifications: PhD

Job Title: Research Associate

Department: School of Medicine

Institution: Cardiff University

Town/City: Cardiff

Country: UK

Telephone: 02920 687658

e-mail: copelandlc@cardiff.ac.uk

Author 6

Name: Jonathan Gillard

Qualifications: PhD

Job Title: Senior Lecturer

Department: School of Mathematics

Institution: Cardiff University

Town/City: Cardiff

Country: UK

Telephone: 02920 870619

e-mail: gillardjw@cardiff.ac.uk

Author 7

Name: Sharon J. Williams

Qualifications: PhD

Job Title: Senior Lecturer

Department: College of Human and Health Sciences

Institution: Swansea University

Town/City: Swansea

Country: UK

Telephone: 01792 295662

e-mail: Sharon.j.williams@swansea.ac.uk

Corresponding author: Sharon Williams

Corresponding Author's E-mail: Sharon.j.williams@swansea.ac.uk

☐ *Please check this box if you do not wish your email address to be published*

Structured Abstract:
Purpose: To describe current care pathways for children with autism including enablers and barriers, as experienced by health professionals, education professionals, and families in South Wales, UK.
Design/Methodology/Approach: A mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures.
Findings: The experiences of the care pathways differed significantly across the three groups. Health professionals described the most rigidly-structured pathways, with clear entry points and outcomes. Education professionals and parents described more complex and confusing pathways, with parents assuming the responsibility of coordinating the health and education activity in a bid to link the two independent pathways. All three groups identified enablers, although these differed across the groups. The barriers were more consistent across the groups (e.g. poor communication, missing information, lack of transparency, limited post diagnosis services and access to services based on diagnosis rather than need).
Practical Implications: This research could inform the design of new services which are premised on multi-agency and multi-disciplinary working to ensure children with ASD receive joined up services and support.
Originality/value: Although this study did not represent all professional groups or all experiences of autism, we examined three different perspectives of the ASD pathway. In addition, we triangulated high-level process maps with rich pictures and creative writing exercises, which allowed us to identify specific recommendations to improve integration and reduce duplication and gaps in provision.

Key words: Autism, care pathway, education, healthcare, improvement

Article classification: Research paper

Received – 16th August 2017
Revised – 21st December 2017
Accepted –

Introduction

Globally, public service providers continue to struggle with managing increasing demands coupled with limited or shrinking resources. To provide the level and quality of care expected by service-users, providers know they must do something different (Burgess and Radnor, 2013). To date, the focus has largely been on acute services, and the need for easily-accessible, user-friendly, patient-centred healthcare delivery (Mercieca *et al*., 2014). However, with the shift in emphasis to primary care and community services, improvement activity also needs to extend to the wider healthcare system and beyond.

Improving the entire system remains a major challenge (Esain *et al*., 2008) since multiple caregivers within different contexts, often in different locations, need to be coordinated (Sorensen and Iedema, 2008). This whole-system thinking is difficult to accomplish in healthcare, which is mainly organised as independent working silos (Kim *et al.*, 2007). The improvement literature offers few system-wide examples (Kaplan and Patterson, 2008) and little is known about how the healthcare system interacts with other services such as education, social services, or housing.

Often the starting point for an improvement project will be to map an existing pathway or process. There are various maps that can be used to understand product, information, material and financial flows (see Hines and Rich, 1997). There is however limited information on how mapping activities include patients and relatives, and how to accommodate the complexity of more than one pathway.

This paper provides details of a methodology employed to map two pathways – healthcare and education – used to provide care for children with autism. For this study, we define a pathway as the patient/user (in this case a child) journey from pre-diagnosis to managing the condition post diagnosis (Williams, 2017).

Autism

Autism Spectrum Disorders (ASD) are complex life-long conditions. Early intervention is essential to help with core features, behaviours and problems commonly associated with the condition (NICE, 2013). However, delays in diagnosis are commonplace (Crane *et al.*, 2016) and specific interventions based on rigorous evidence are lacking (NICE, 2013). This causes significant hardship to individuals and families, and leads to substantial service costs across several systems (Buescher *et al.*, 2014). Children and young people with ASD frequently have adverse experiences in accessing health care and other services, and there are few improvement studies that have focused on children with autism or ASD (e.g. Pratt *et al.*, 2011). None have examined the design of care pathways or looked across different groups and stakeholders.

Care pathways

Care pathways are used to aid the delivery of effective multi-agency services and encourage patient involvement in their care (Campbell et al 1998; Goodwin 2015). Typically, when examining the (re)design of care pathways, the focus is on one pathway, usually healthcare. There is less research that spans the boundaries of healthcare providers and other related services such as education. There is an assumption (often from patients and their families) services are already fully integrated and function as one pathway (Williams, 2017).

In autism care, there is recognition that holistic, cross-agency and multidisciplinary working is essential (NICE, 2013). In Wales in the UK (where our study was conducted), the Government published a pioneering Autism Strategic Action Plan in 2008 (Welsh Government 2008), which aimed to ensure that "*individuals with ASD are supported to reach their full potential in all aspects of their lives*". However, a recent evaluation showed

accessibility and quality of care for ASD remained varied and frequently inadequate (Holtom and Lloyd-Jones, 2016). In the refreshed Autism Spectrum Disorder Strategic Action Plan, the Welsh Government commits to delivering a "*national integrated autism service*" by 2019 (Welsh Government 2016). Whilst generic, high-level care pathways were suggested within the original strategy, it is not understood how these work on the ground, nor are there clear examples of good and poor practice to inform future service planning. No revised pathway is provided within the refreshed strategy to guide the delivery of the integrated service.

The aim of our work was to pilot a new approach to understanding the current care pathway for children of primary-school age with autism, focusing on children who receive their educational provision within mainstream settings. The novel contribution of this study is examining the design of both health and education pathways to establish the level of interaction between the two, as well as involving families in the research.

The specific research objectives were to:

i) Describe and visualise the current care pathways, as experienced by health professionals, education professionals, and families;
ii) Understand the enablers and barriers when accessing or operationalising the pathways, to identify potential areas for better integration and collaboration.

Methodology

This study used a mixed-methods approach to combine information on optimal service provision with the narratives of service users and providers and produce high-level process maps of the current pathways for ASD.

Three workshops were conducted in September 2015 with:

i) health professionals working within a National Health Service (NHS) multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);
ii) staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n=8);
iii) parents of primary school children diagnosed with ASD (n=7).

The work was conducted in Wales as we were interested in understanding whether the Welsh Government's Strategic Action Plan had led to a clear understanding of the care pathway for autism; however, we felt that many of the difficulties that we would potentially identify would be consistent with and relevant for multi-agency collaborative work in other high-income settings. Participants were selected using convenience sampling, given the difficulties of recruiting busy NHS and teaching professionals to participate in research. Participants had to be over 18 years of age and able to provide written informed consent to participate. Individuals were sent information about the purpose of the sessions in advance, were given the opportunity to refuse to participate once the purpose of the study had been explained to them, and given the opportunity to leave if they were uncomfortable at any stage during the workshops; there were no refusals. Ethical approval for the work was given by the ethics committee at Cardiff University's School of Psychology.

During the workshops, we employed three methods to collect data. First, we used focus group discussions (Kitzinger, 1994), to describe their experiences of the current care pathway and identify enablers and barriers to collaborative working. The same topic guide was used for each group, and we specifically asked about pathways to diagnosis and post-diagnosis support. Parents could provide examples in both the health and education systems. Health and education professionals were mainly familiar with the design of their own pathways, although they were asked to identify areas where they worked across disciplines. Discussions lasted approximately two hours and, with consent, were audio recorded. Researchers facilitating the focus groups

were also able to capture key points of interaction within the pathway and display these using post-it notes.

Second, a graphic illustrator captured the discussions as they were taking place. Crowe *et al.*, (2017) described how rich pictures can be used in improving pathway design, by capturing the key features of a service, perceived issues and possible improvements from a whole system perspective. For participants, the rich pictures provided a visual account of the key themes discussed. For the researchers, they enabled comparisons to be drawn across the three groups.

Third, participants undertook creative writing exercises to express their experiences in narrative form. There is a developing field of "*narrative medicine*", in which the stories of patients and care-givers are used to recognise, absorb and interpret experiences, and thus inform clinical practice (Charon 2008; Greenhalgh 2016). In this part of the workshop, participants completed three writing exercises devised for the project. The aim was to enable participants to write about their professional and/or personal experience of ASD care, by expressing their lived experiences. In the final exercise, participants wrote a short story (maximum 15 words) outlining an experience of ASD care as follows: i) a beginning that set up a goal; ii) a middle stating how obstacles would be overcome; and iii) an "ideal" ending or outcome.

Thematic analysis (Braun and Clarke, 2012) was used to code the focus group data and extract the major themes from each group. The construction of the initial coding template was based upon the research topic (e.g. ASD pathway design) and the themes (e.g. enablers and inhibitors) that emerged from reading the first few transcripts. An iterative approach was used, where new codes are identified throughout the analysis (King 2004). The qualitative data were combined with the information from the post-it notes to derive three high-level process maps of the current pathways. Enablers and barriers to accessing or operationalising the pathways were also identified and converted to hotspots, which were added to each high-level pathway map. Lastly, the creative writing exercises were examined to gauge whether their messages confirmed, refuted, or added to the overall conclusions. To enhance the reliability and validity of our study the transcripts were read by all the authors and the initial identification and coding of the themes was conducted by LH and LC. In addition, we employed three types of triangulation – data, method and investigator which improved the design and validity of the study (Patton, 2014).

Results

The high-level map and the rich picture of the care pathway as described by each group are shown in Figures 1-3. The discussion of the findings below is based on the identified themes from the data and the hotspots; a visual representation of these is given in the supplementary material accompanying this paper.

Care pathways

a) Health professionals

Figure 1 shows the care pathway as described by health professionals. Their focus was on assessment and diagnosis, as this was their main role in the pathway. A child's journey through this was clearly mapped. The "Tier 2" pathway catered for relatively uncomplicated cases, with two assessment visits and one feedback visit at which a multi-disciplinary team discuss the assessments with the family and decide on whether a diagnosis is necessary. The "Tier 3" pathway catered for complicated cases, and involved more detailed assessments and discussion before the feedback session with families. Both pathways were thought to take around 2-3 months to complete. Interaction with education was limited to observations at school and an invitation to educational professionals to attend the multi-disciplinary feedback meeting.

Health professionals therefore described rigidly-structured pathways, with clear entry points and outcomes, providing diagnostic services but no post-diagnosis support.

Figure 1 here

b) Education professionals

Figure 2 shows the care pathway as described by the education professionals, a far less linear process with multiple entry points and outcomes. Some children arrived at school with a diagnosis and support in place, as outlined in a Statement of Special Educational Needs. Others had a diagnosis, but no Statement (either because an application had not been made, or an application had been made and turned down). Others may be going through a diagnosis process when they arrive, or their difficulties did not become apparent until concerns are raised by parents, teaching staff or both.

In this school, the Additional Learning Needs Coordinator (ALNCo, a teacher at the school) coordinated the support for all children with an identified need before and/or after diagnosis. They provided the link between the parents, teachers, any allied education professionals involved in the care of the child (including the process for autism diagnosis (PAD) and at times of transition between schools), and health professionals when additional support was required (for example, a primary mental health nurse was mentioned during the discussion). They also liaised with local education authority, who had teams with expertise in ASD and behavioural difficulties to provide advice. The ALNCo, class teachers and other allied staff (including a speech therapist at this school) were all involved in providing ongoing post-diagnostic support to the child and family.

This was therefore a more complex pathway than described by health professionals, and members of school staff contributed at all stages.

Figure 2 here

c) Parents

The care pathway described by the parents is shown in Figure 3. Parents made a clear distinction between the pathway to diagnosis, and post-diagnosis support pathways. The pathway to diagnosis was described as confusing. Difficulties often started with obtaining assessments. "*Battling*" to have their voices heard during that stage was a recurring theme in the discussion. Their assessment of the time to diagnosis varied widely from nine months up to a maximum of five years.

After diagnosis, parents expected to be supported by the healthcare system, but there was no clear pathway for post-diagnosis support (as clearly shown on the rich picture). They each described different post-diagnosis experiences, and a need to proactively seek support for their child. For example, several parents mentioned health services that they had only come across by chance. Obtaining formal agreement their child needed additional support at school (for example, through obtaining a Statement), and therefore an appropriate placement, was seen as difficult, with several having considered schooling their children at home.

In summary, parents found their journey to diagnosis stressful and confusing, with limited structure or direction, and a lack of consistency. After diagnosis, formal support from healthcare was felt to be limited. Obtaining agreement on the type of educational support needed was difficult, although schools with specialist units (such as the one in this study) were praised.

Figure 3 here

Enablers

a) Health professionals

The health professional group all agreed, although their work was challenging, it was also fun and worthwhile: "*I find it rewarding, particularly when it is validating parents' concerns, and giving it as feedback*"

They also felt they had created a clear and structured diagnostic pathway for families within their service, once a child had been referred, and had been able to make improvements to the referral process: "*…there's much clearer guidance as to what we expect when a referral is sent… it's working in partnership rather than saying, 'This is all yours, you need to sort it out'*"

They also believed they had introduced systems to better support families through the process, by providing structured information to allow them to track their progress through the pathway. They felt this helped families to understand their current situation and move to the future positively.

b) Education professionals

In common with the health professionals, the education professionals expressed their enjoyment and satisfaction in working with children with autism: *"It's really rewarding" "When they do have relationship with you… it's a very strong bond… it's very, very rewarding for you as a person..."*

They also identified strategies they had put into place to enable good communication with families (for example, using a staff noticeboard to share information between staff, taking time to build relationships with parents/carers, and using different communication methods such as home-school books). This school also worked closely with a speech and language therapist, which was hugely positive, as it provided links to the local education authority, and the NHS.

c) Parents

Most parents had encountered one individual, such as a specific teacher or other professional, who had made a real difference in "*pushing*" for a diagnosis or a specific form of support. The severity of the child's difficulties, and consequently, their exposure to different health and/or educational professionals was felt to enable the diagnostic and support pathways. For example, if a child had been referred to a speech therapist because of language delay, the investigative process was felt to be quicker. Several parents talked about having sought private assessments, and how these had moved the process along, especially as they were seen as being comprehensive. Parents praised the support they received from the local Portage service (a home-visiting educational service for pre-school children with additional support needs in the area), and services provided by charities such as the National Autistic Society.

Barriers

a) Health professionals

Despite attempts to improve the requirements for the referral process, they still received poor information when children were referred to them: "*some of it is two lines and some of it is four lines and that simply isn't good enough*"

They were also realistic about current problems of poor communication between agencies, stating that if these could be resolved: *"…we could have a dream service." "Unfortunately, sometimes it's a nightmare*."

They identified enhancing communication with parents would streamline the whole pathway, and empower parents to take more ownership of the process. However, the current pathway prevented this, as the information given to parents was often inconsistent: *"They get different messages from everybody… They get buffeted around a lot, they don't know where they are with it"*

The health professionals reported challenges in managing parents' expectations in relation to whether a diagnosis was necessary: *"We do often have to say we don't think the child has a diagnosis… and that's so difficult… I mean we have to be strong because if we don't feel like the child, you know, we'd be doing the child a disservice to do that…"*

This was perceived to be particularly problematic because access to services is based on diagnosis, rather than an assessment of the child and family's needs: *"Unfortunately, still everything is so diagnosis-driven, support to go back to education or whatever... Disability teams, they call up and say 'have they actually got the diagnosis?'... So, it's changing that, shifting that culture…"*

There was also an acknowledgement services post-diagnosis were limited: *"The other bit is when they've got a diagnosis, you know, then what?"*

Whilst they had organised their diagnostic services well, and could provide one-to-one advice on strategies and adaptations to help children at school if required, the group agreed links between health and education were relatively ad hoc: *"It's curious, isn't it; we don't have a very clear pathway of how to do that … it's very individual, it's extremely variable and we generally work with the people who are willing to work with us."*

One explanation for this was the organisation of the health service (managed by seven Health Boards in Wales) was different to the organisation of education services (managed by 22 local authorities), and each organisation had its own practices: *"Every local authority does things in a different way… So, we're a bit stuck because we're central and we're diverting families into something that's local that … well, we really haven't got any control over whatsoever."*

Ultimately, the responsibility for coordinating and providing care rested with families, which was felt to be appropriate, although with an acknowledgement they needed support with this (with charitable services identified as a possible source of this support):
"There genuinely is a place for families, and children and young people could be helped to be more resilient and not maybe rely on services"

b) Education professionals

Many of the barriers identified by the education professionals were like those discussed above, including the lack of formal processes for passing information between parents, schools, and other agencies.

Frustrations were expressed about both the diagnosis and support stages of the pathway. Teachers felt they had to deal with children and families whilst there were delays and a lack of transparency elsewhere in the system. They felt there were inconsistencies in how cases were dealt with. This led to variation in the time to diagnosis (timelines between 6 weeks and 2.5 years), followed by variations in the levels of support recommended. In some situations, education practitioners felt a diagnosis was necessary but had not been given: *"We do have children that we're convinced are autistic, but they won't diagnose them…"*

In common with health professionals, the education professionals expressed dissatisfaction that many of the steps in the pathway required a diagnosis, rather than an examination of the child's needs: *"…it's very difficult for the ASD team to get involved because this little girl hasn't got a diagnosis. Until she has a diagnosis, we can't access any specific help from experts"*

They acknowledged there was a need to plan service and interventions carefully, especially given limited financial and human resources. However, these decisions were felt to be based on pre-defined paper-based criteria, rather than the needs of the child, and could give examples where this had led to differential access to support for students within their school: *"I do have frustrations that people are making very life-changing decisions, and they're sat in a room, having a cup of tea. They're not sat in the classroom dealing with some of the behaviours and the issues that we are dealing with… on a day to day basis."*

The arrangements in place to transport children to school were identified as a barrier to developing good relationships with parents, and allowed situations to escalate rather than being dealt with promptly. This led to frustrations on both sides: *"Because most of them come in a taxi, you don't see the parents at the beginning of the day, so… it is keeping that relationship going, because not all parents will come forward themselves, and things do become very anxiety-provoking for them"*

c) Parents

Parents felt they had to take charge of organising both diagnostic and support processes to ensure their children received the provision they needed. They felt overwhelmed by multiple appointments with many different professionals, both in health and education. Information was frequently lost or had to be repeated during these appointments, and the care received within either system was not perceived to be well-coordinated. They also felt they needed a consistent point of contact within the system: *"It's almost like you need some kind of secretary to help you out. Somebody that is attached to your child from day one. So they are on your back, chasing these agencies for you. They are on the phone all the time sending emails and chasing to find out what's happening."*

Parents echoed the professionals' views that they could only make the system work for them once their child had a diagnosis. The required information flow to support both the education and health pathways was not well documented or accessible for parents to understand. Communication was managed separately for each pathway, allowing for duplication, delays and errors.

Several points of entry into the pathway were identified, and each seemed to result in different processes and requirements. Unlike the parents whose children had other additional needs, parents of "high functioning" children or those with atypical autistic traits described difficulties accessing the system at all: *"I think it's harder to get a diagnosis when they are gifted and they're not developmentally delayed. Because if they're developmentally delayed and they're not speaking and not communicating, something has got to be done. If they're talking and they're above their level, it's harder, isn't it?"*

After diagnosis, the support was felt to be limited and often based on out-dated information: *"They gave me a sheet that they did about ten years ago. And said, off you go. Looked them all up, they didn't exist anymore"*

Parents often felt the burden of providing their child's therapies fell to them:

"[Occupational therapy and physiotherapy] *assessed him, they said, do these exercises, log on to our website, type in this password. Which I hadn't done because... I want somebody who's trained to do it on my son, not me, a complete, you know, novice at it. I don't even know whether I'm doing the right thing, I'm just guessing, the amount of pressure to put on him. And they said, that's it, on your way, like"*

When they did receive good support, this was often when an education professional had developed a relationship with the child over time. Transitions between classes were therefore identified as hugely challenging: *"The good teachers have done lots of work and then with transition into the next year, they forget everything, nothing happens… Everything they can pass on, all of the notes myself have sent in, where have they gone, all*

of the strategies I was doing at home? All of that is gone. You've literally started at square one again." They also expressed frustration that teachers were not routinely taught about autism during their training or as a part of ongoing continuing professional development.

They appreciated there were limited resources, but were frustrated by a lack of clarity about how these resources were allocated: "*That is standard response… 'The money will follow the child.' Well, that's fine but the child's got to be in the system for the money to follow... How do you get the child to get in the system?"*

Given the length of the assessment process and the complexity of the system, parents also worried about their own fragility and vulnerability, and what would happen if they were unable to continue to "*push*": *"What happens to you if, I don't know, something goes wrong in the family, depression. What if they haven't got the energy to battle? What happens to those kids then? It's really scary, isn't it?"*

The enablers and barriers identified by the three groups are summarised in Table I. The enablers identified differed across the groups. The list of barriers was longer, but was more consistent across the groups (including, for example, poor communication, missing information, lack of transparency, limited post diagnosis services and access to services based on diagnosis rather than need).

Table I here

Creative writing exercises

Despite initial scepticism, each of the groups enjoyed the creative writing exercise, with one participant commenting "*I really liked the different ways of making us think and expressing our ideas/feelings/annoyances*" and another stating the method ensured that "*super, insightful discussion was generated*".

An example of a story written by a member of each group is presented in Table II, selected to reflect the tone and thematic focus of the other stories in each group. Despite the numerous frustrations expressed in the group discussions, the stories consistently articulate high hopes and aspirations for the children. However, there are also differences in the approach and language used by the three groups.

The first story is from the health professional group and describes the pathway as linear, with a clear and definite purpose. This group envisage themselves as supportive enablers who equip those on the pathway with the tools to help realise enjoyable and fulfilling lives. The use of the subjective 'happier' and 'productive' in the closing line demonstrates an acknowledgement of the need for individual patient support. The second story is from the education professionals. This concisely identifies their 'bridging' role in the pathway, and acknowledges the need for multiple arrangements of the pathway. The final line emphasises the need for fairness in the system. The final story comes from the parents group. The ambition of the author that the child drives 'American freight trains' shows the pathway is perceived as essential to the child's future quality of life, and identifies the need to equip the child with the tools to achieve this. However, the pathway also represents hope and potential, and the expectation of parents that it will enable a range of experiences as described in the second line.

Table II here

Conclusions and recommendations

Our findings highlight differing views of the ASD care pathway, and show the healthcare and educational systems operate independently with little crossover of activity. The expectations of the different professional groups were unclear and it was not apparent they understood their specific roles within the pathway. Parents often assumed the responsibility of coordinating the

services in a bid to link the two independent pathways. There also appeared to be a hierarchical relationship between the two systems, with education practitioners delivering interventions day-to-day but having to rely on healthcare professionals to issue diagnoses to release additional funding or support.

We employed a multi-method approach to examine a care pathway that is more complex than has previously been examined in the literature. By capturing the experiences of our three different participant groups, this provided an in-depth account and visualisation of how the cross-service care pathway is currently operationalised. This approach strengthens the popular approach of process and value stream mapping often used in improving healthcare (e.g. Dickinson *et al.,* 2009). We extend the use of high-level process mapping to provide the 'current state' of the pathway design, identifying 'hot spots' on both pathway maps that highlight the key enablers and barriers, and have incorporated different perspectives that enabled us to triangulate the data. We also showed using different methods (including focus groups, creative writing sessions, and rich pictures) allowed the participants to explore and express their experiences in diverse and compelling ways. Including different stakeholders, and listening to how they understood and work within the pathways, allowed us to identify significant overlaps in the barriers and enablers experienced by the three groups and therefore areas for improvement. These could be used to encourage improved collaborative working and design solutions, including a seamless, integrated pathway design of the two services. This, along with a shared language, will help parents and children negotiate this complex and often stressful journey.

Limitations of the study

This pilot study examined whether the method would yield useful information in relation to the design of a care pathway for children with autism. We recognise the participants of this study did not represent all professional groups or all experiences of autism (such as children who cannot access mainstream education). The insights are also confined to the localities in which we undertook our study. However, this did not prevent us from understanding the difficulties with these local versions of the pathway and identifying areas for improvement. We recognise not all pathways will be designed as presented here in this paper. However, we have outlined recommendations that can be applied to a range of settings and enable a more integrated service. Other limitations of the study have been addressed within the context of further research.

Implications of the study policy, practitioners, and educators

Radnor *et al.,* (2014), among others, have argued for public services to move away from a product-dominant logic, where production and consumption are separated as discrete processes, to a (public) services-dominant logic where the service experience is placed at the centre of public services delivery (Osborne *et al.,* 2015). Specifically, in healthcare, there have been repeated calls for better involvement of patients and the public, but progress has been patchy and slow (Ocloo and Matthews, 2016), and it is difficult to ascertain where and how users are involved in the design of services (Batalden *et al.,* 2016). Corrie and Finch (2015) highlight several ways in which patients/carers can be involved more in their health and wellbeing, such as shared decision making and improving their understanding of the health and wellbeing system. We also know that patients who engage in collaborative care and shared decision-making with their providers have improved health outcomes (Hibbard, 2003). For ASD (as well as other neurodevelopmental conditions) the reforms need to incorporate other public services such as education.

We acknowledge changes in the services have occurred since our data were collected. Specifically, in addition to plans for an integrated autism service, the Welsh Government has

established a neurodevelopment service across Wales, to integrate and standardise delivery of both diagnostic services and post-diagnosis support to individuals with autism and other neurodevelopmental conditions, with input from health and education as well as service user representation. Their work is already influencing practice, with the health team included in our work introducing new post-diagnosis interventions into their services. We hope this study can help inform this planning, as well as the planning for the new integrated autism service.

Care for children with ASD is currently described as occurring within two separate systems. Changes in existing institutional structures are needed to promote joint working and a shared language that is appropriate to all providers and users of the autism pathway. Such changes will not be driven by one provider alone, but by the input of key stakeholders (including families) and policy makers to achieve buy-in from all parties. The terminology used across the two systems needs to be streamlined to help families to better understand the pathway and their potential contribution, and clearer support structures to allow families to understand how they can also contribute to improved integration. The new Welsh Government's integrated autism service will be in operation across Wales by 2019. Research to develop an intervention to promote improved collaborative working is therefore timely and essential. The outcome of this research could feed directly into this new service, by suggesting improved mechanisms for multi-agency and multi-disciplinary working to ensure that children with ASD receive joined up services and support.

This study will also be of interest to the quality improvement community as it provides valuable insights to taking a mixed-method approach to understanding the intricacies of a pathway design that straddles two areas of public services – education and healthcare. Building on the popular approach of process mapping we have demonstrated how other methods can be used to provide a richer account of the pathway. The creation of rich pictures in real time engages participants and highlights gaps and delays in the provision of services. The inclusion of creative writing sessions enabled participants to reflect on their experiences and provided insightful narrative for the process maps. As our improvement activity expands across functional and organisational boundaries we propose there is a need to move beyond traditional approaches such as process mapping to include other methods not typically used.

Recommendations for improvement

We have identified potential areas of integration, duplication and gaps in provision. Several of the barriers identified are operational and process issues that could be improved through better information flows, especially between health and education professionals. We therefore suggest areas for improvement:

- Provide clarity and transparency in the design of the pathway, to create a resource that is accessible to all stakeholders including clarity on all stakeholders' roles and responsibilities and allows everyone to easily track a child's progress through the pathway;
- Improve communication across organisational and professional boundaries, including a common and shared language that is accessible to families and alignment of information to remove unnecessary delays, duplication, or the need to make decisions in the absence of essential information;
- Use different methods of expression (such as creative writing) to improve communication and understanding, and increase integration between different groups involved in providing care;
- When decisions are made (with regards to diagnosis or support), individuals involved in the day-to-day care of the child should be involved and any redesign activity is co-produced with input from families, education and health professionals.

- Appropriate autism awareness training provided for both health and education professionals;

Areas of further research

We have tested a mixed methods approach which includes rich pictures and creative writing exercises, two methods not typically employed in improvement work. Our research is limited to an ASD pathway in one region of the UK. Further empirical work is required to test the proposed methods with different pathways and conditions. The follow-on from this would be to identify areas of the pathway where interventions could be developed and tested to improve the care experience for families, education and health professionals.

ASD is not the only condition that requires an integrated approach. There is some debate as to whether integration offers a solution to improving health and social care services (National Audit Commission, 2017). This research illustrates some of the difficulties experienced by parents, education and healthcare professionals when trying to negotiate two independent pathways associated with one condition. Previous research indicates there are several forms of integration (Goddard and Mason, 2016). Further research is needed to explore which would be most appropriate to bring together health and education services for conditions such as ASD.

References

Batalden, M. Batalden, P. Margolis, P. Seid, M. Armstrong, G. Opipari-Arrigan, L. and Hartung, H. (2016), 'Coproduction of healthcare service', BMJ Quality and Safety, Vol. 25, pp. 509-517.

Braun, V. and Clarke, V. (2012), Thematic analysis. In Cooper, H. (Ed.), *The Handbook of Research Methods in Psychology*, American Psychological Association, Washington.

Buescher, A. Cidav, Z. Knapp, M. and Mandell, S. (2014), 'Costs of Autism Spectrum Disorders in the United Kingdom and the United States', *JAMA Pediatrics*. Vol. 168 No. 8, pp. 721-728.

Burgess, N. and Radnor, Z. (2013), 'Evaluating Lean in Healthcare', *International Journal of Health Care Quality Assurance*, Vol. 26 No. 3, pp. 220-235.

Campbell, H., Hotchkiss, R., Bradshaw, N., & Porteous, M. (1998). 'Integrated care pathways.' *BMJ: British Medical Journal*, 316(7125), pp 133-137.

Charon, R. (2008), *Narrative Medicine, Honoring the Stories of Illness*, Oxford University Press, New York.

Corrie, C. and Finch, A. (2015), *Expert Patient*, Reform, London.

Crane, L. Chester, J. Goddard, L. Henry, L. and Hill, E. (2016), 'Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom', *Autism*, Vol. 20 No. 2, pp. 153–162.

Crowe, S. Brown, K. Tregay, J. Wray, J. Knowles, R. Ridout, D. Bull, C. and Utley, M. (2017), 'Combining qualitative and quantitative operational research methods to inform quality improvement in pathways that span multiple settings', *BMJ Quality and Safety*, Vol. 26, pp. 641-652.

Dickinson, E. Singh, S. Cheung, D. Wyatt, C. and Nugent, A. (2009), 'Application of Lean Manufacturing Techniques in the Emergency Department', *The Journal of Emergency Medicine*, Vol. 37 No. 2, pp. 177-182.

Esain, A, Williams, SJ, Massey, ML. (2008), 'Combining planned and emergent change in a healthcare lean transformation', *Public Money and Management*, Vol. 28 No. 1, pp. 21-26.

Goddard, M. and Mason, A. (2016), 'Integrated Care: A Pill for All Ills?' *International Journal of Health Policy and Management*, Vol. 6 No. 1, pp. 1–3.

Goodwin, N. (2015). How should integrated care address the challenge of people with complex health and social care needs? Emerging lessons from international case studies. *International journal of integrated care*, 15(3). e037. Published online 29 September 2015.

Greenhalgh T. (2016), *Cultural contexts of health: the use of narrative research in the health sector*, WHO Regional Office for Europe, Copenhagen.

Grubnic, S. (2003), 'Care pathways: conceptualizing and developing a multi-skilling initiative', *International Journal of Healthcare Quality Assurance*, Vol. 16 No. 6, pp. 286-92.

Hibbard, J. (2003), 'Engaging health care consumers to improve the quality of care', *Medical Care*, Vol. 41 No. 1, pp.61-71.

Hines, P. and Rich, N. (1997), 'The seven value stream mapping tools', *International Journal of Operations and Production Management*, Vol. 17 No. 1, pp. 46-64.

Holtom, D. and Lloyd-Jones, S. (2016), *Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report*, Welsh Government, Cardiff.

Kitzinger J. (1994), 'The methodology of focus groups: the importance of interactions between research participants', *Sociology of Health and Illness*, Vol. 16, pp. 103-21.

King, N. (2004), Using templates in the thematic analysis of text. In C. Cassell, and G. Symon, (Eds), *Essential Guide to Qualitative Methods in Organisational Research*, Sage Publications, London.

Mercieca, C. Cassar, S. and Borg, A. (2014), 'Listening to patients: improving the outpatient service', *International Journal of Health Care Quality Assurance*, Vol 27 No. 1, pp. 44-53.

National Audit Commission (2017), *Health and social care integration*, National Audit Office, London.

National Institute for Health and Care Excellence (NICE), (2013), Autism *spectrum disorder in under 19s: support and management*, National Institute for Health and Care Excellence, London.

Ocloo, J. and Matthews, R. (2016), 'From tokenism to empowerment: progressing patient and public involvement in healthcare improvement', *BMJ Quality and Safety*, Vol. 25, pp. 626-632.

Osborne, S, Radnor, Z, Vidal, I and Kinder, T. (2015), 'The SERVICE framework: a public service-dominant approach to sustainable public services', *British Journal of Management*, Vol. 26 No. 3, pp. 424-438.

Parnaby, J. and Towill, D.R. (2008), 'Seamless healthcare delivery systems', *International Journal of Health Care Quality Assurance*, Vol. 21 No. 3, pp. 249-273.

Patton, M. (2014), *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*, Sage Publications Ltd. London.

Welsh Assembly Government, (2008), *Autistic Spectrum Disorder Strategic Action Plan for Wales*. Welsh Assembly Government, Cardiff.

Welsh Government, (2016), *Refreshed Autistic Spectrum Disorder Strategic Action Plan Wales* (consultation document), Welsh Government, Cardiff.

Williams, S.J. (2017), *Improving Healthcare Operations: The application of Lean, Agile and Leagility in care pathway design*, Palgrave Publishers, Sweden.

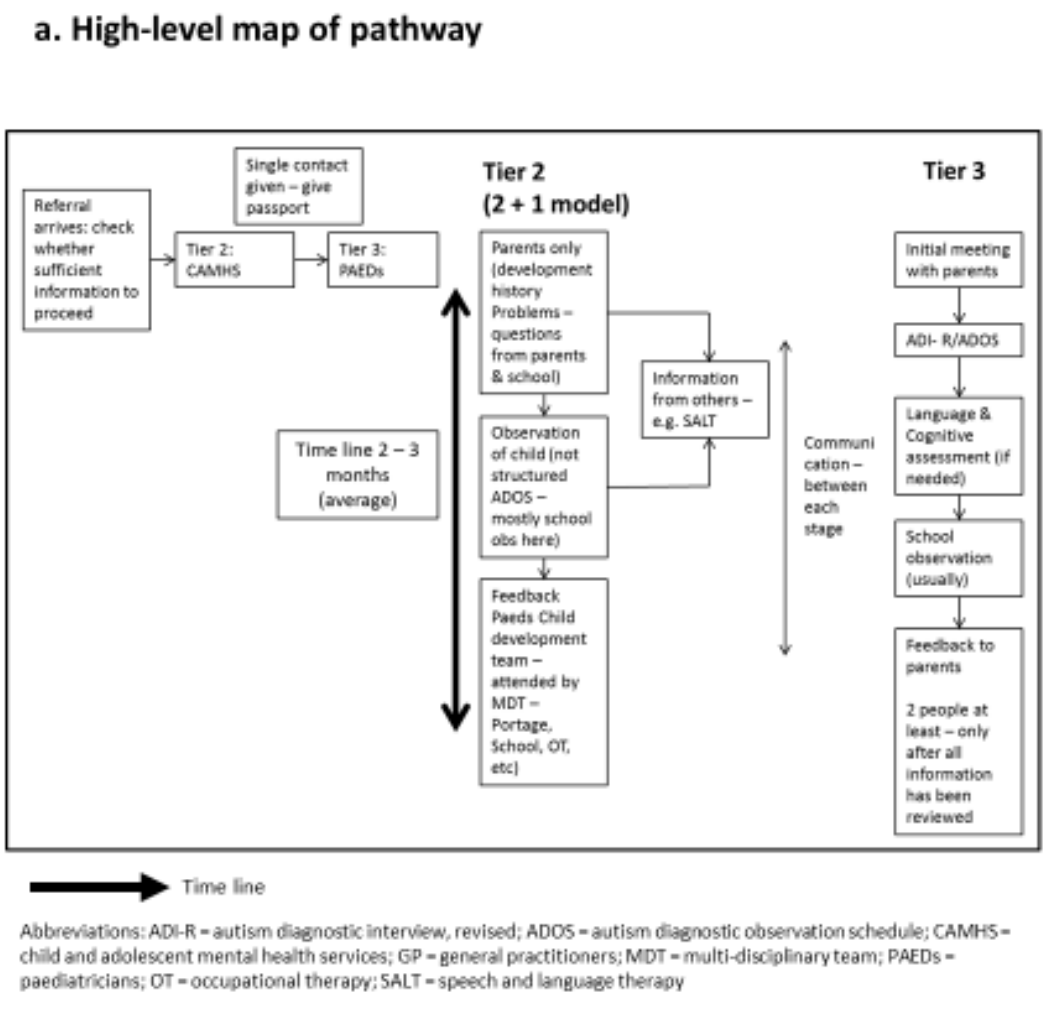
Table I: Barriers and enablers within the care pathway as identified by the three groups in the study

	Health professionals	Education professionals	Parents
Enablers			
Satisfaction and enjoyment with the work	✓	✓	
Clear guidance on the information needed	✓		
Improvements in the quality of information shared by professionals is possible	✓	✓	
Different clinical picture			✓
One individual within a service with a specific interest in autism	✓		✓
The existence of charitable organisations providing additional services and support	✓	✓	✓
Barriers			
No clear pathway linking education and health (often ad hoc)	✓	✓	
Link between education and health complicated by the different organisation of local authorities and health boards	✓		
Poor communication across the pathways	✓	✓	✓
Inadequate, inconsistent or missing information	✓	✓	✓
Lack of transparency and consistency with processes	✓	✓	✓
Burden of organisation rests with parents	✓		✓
Lack of a consistent point of contact			✓
Post-diagnosis services are limited	✓	✓	✓
Access to services based on diagnosis rather than need	✓	✓	✓
Out-dated information provided			✓
The challenge of meeting expectations in cases that are often complex and have multiple needs	✓	✓	

Table II: Examples of the stories written by the three groups

To help people understand more. By understanding and explaining. A happier, productive life. Gaps to be bridged. Bridges to be built. Built for all to achieve. Dreams of American Freight trains. Travels, watches, learns, asks questions. Grows up, drives that train.

Figure 1: Care pathway as described by health professionals



Abbreviations: ADI-R = autism diagnostic interview, revised; ADOS = autism diagnostic observation schedule; CAMHS = child and adolescent mental health services; GP = general practitioners; MDT = multi-disciplinary team; PAEDs = paediatricians; OT = occupational therapy; SALT = speech and language therapy

Images © Eleanor Beer: www.eleanorbe

Figure 2: Care pathway as described by education professionals

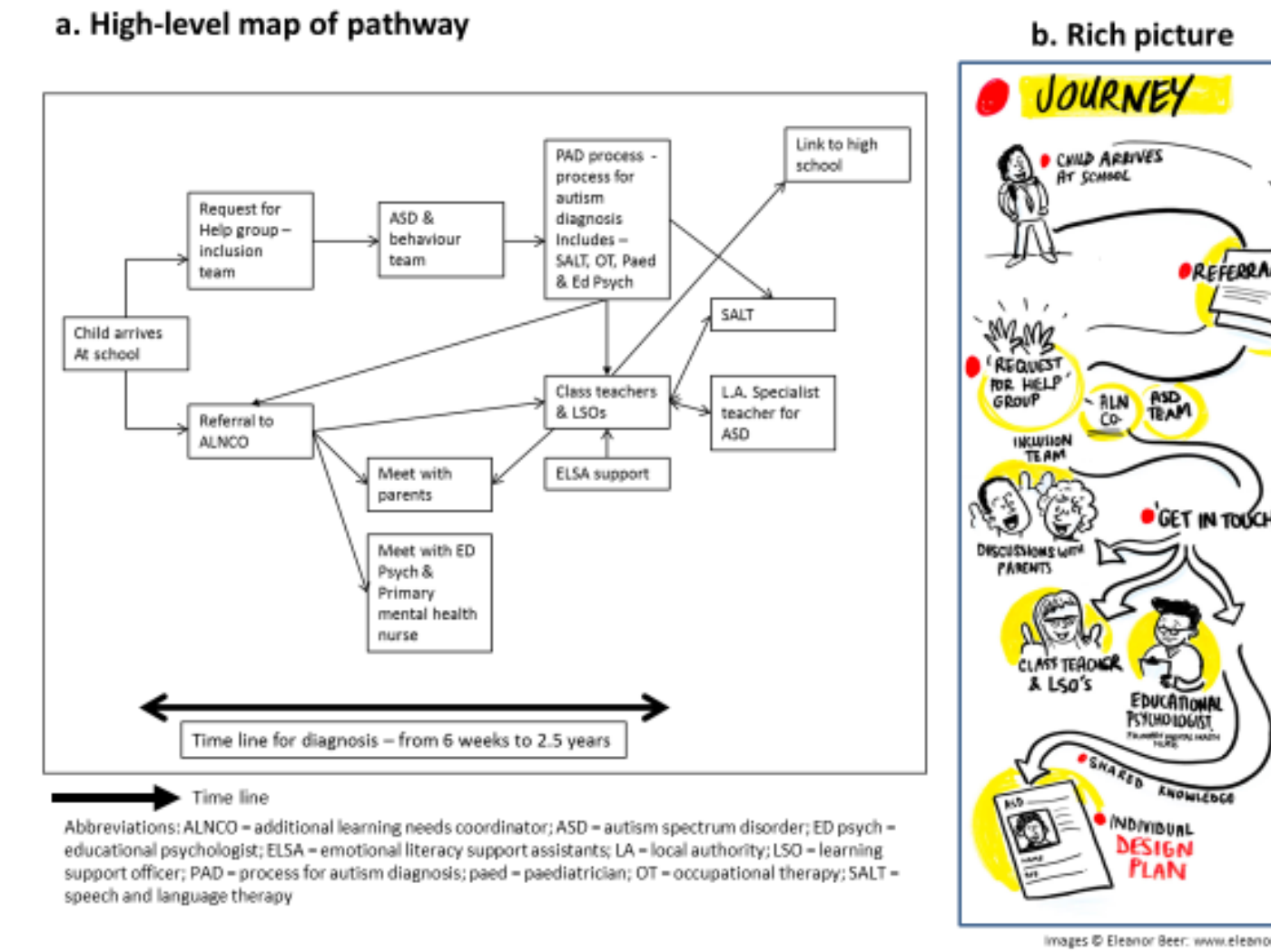
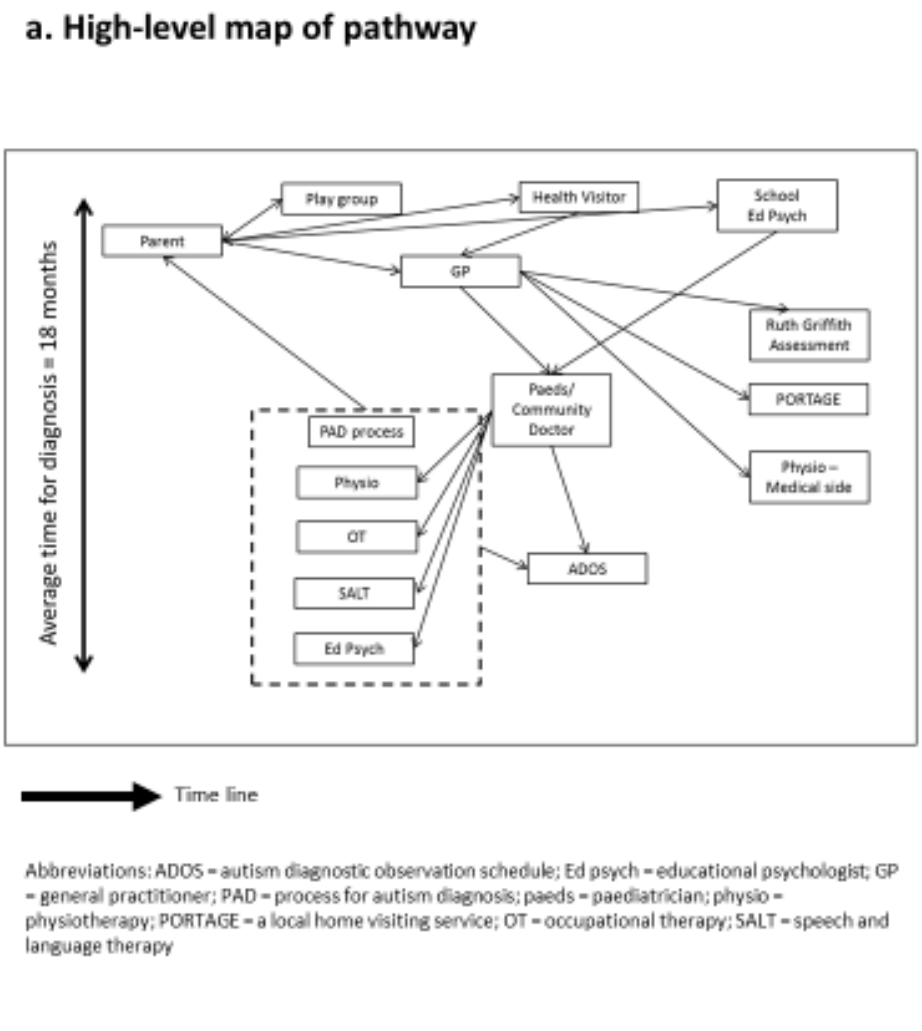


Figure 3: Care pathway as described by parents



Abbreviations: ADOS = autism diagnostic observation schedule; Ed psych = educational psychologist; GP = general practitioner; PAD = process for autism diagnosis; paeds = paediatrician; physio = physiotherapy; PORTAGE = a local home visiting service; OT = occupational therapy; SALT = speech and language therapy

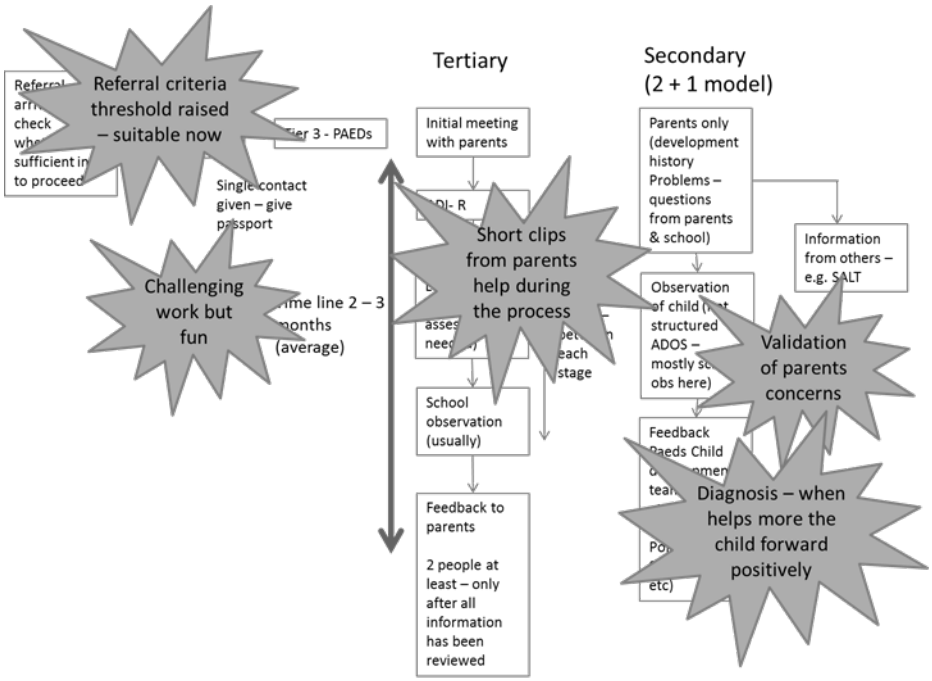
Images © Eleanor Beer: www.eleanorb

Supplementary material

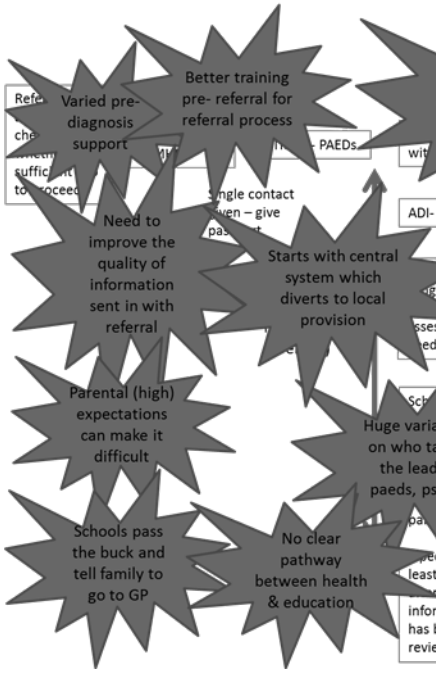
Enabler (light grey shaded) and barrier (dark grey shaded) hotspots in the care pathway for children v
health professionals, b) education professionals, and c) parents

a) Health professionals

Enablers

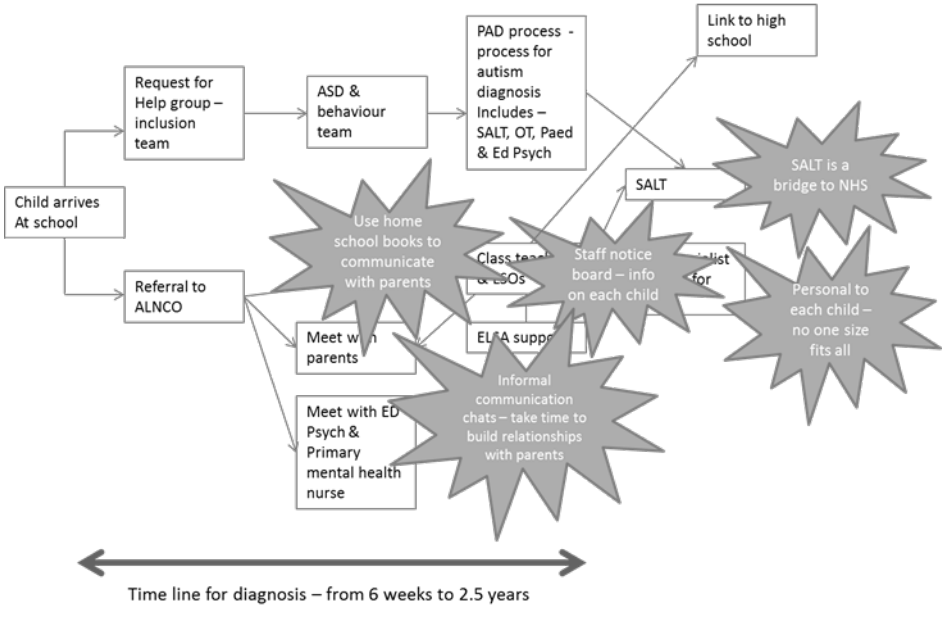


Barriers

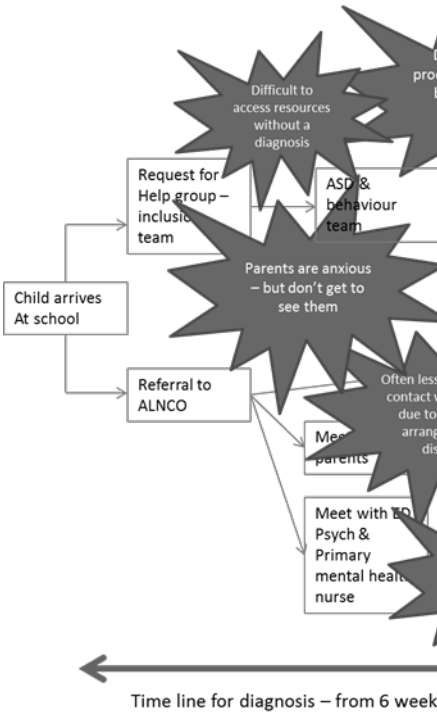


b) Education professionals

Enablers

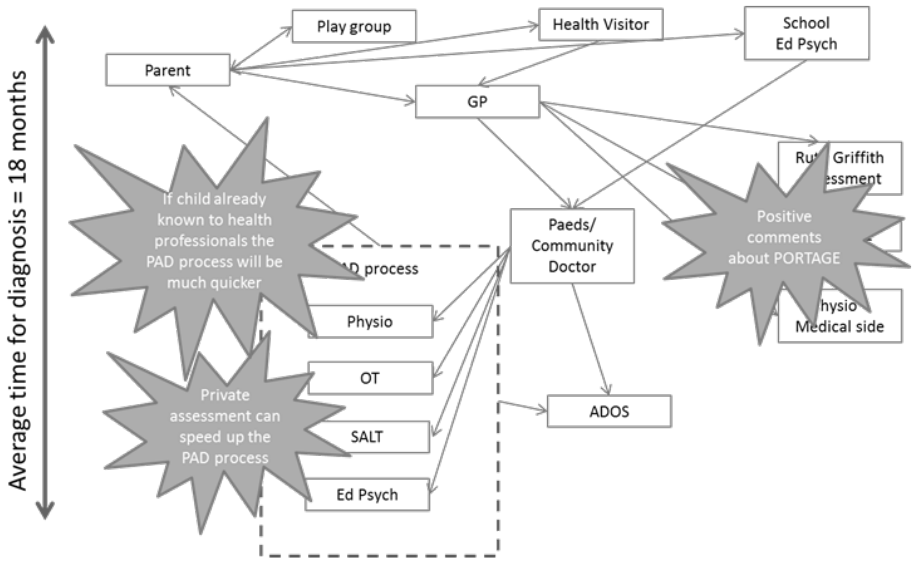
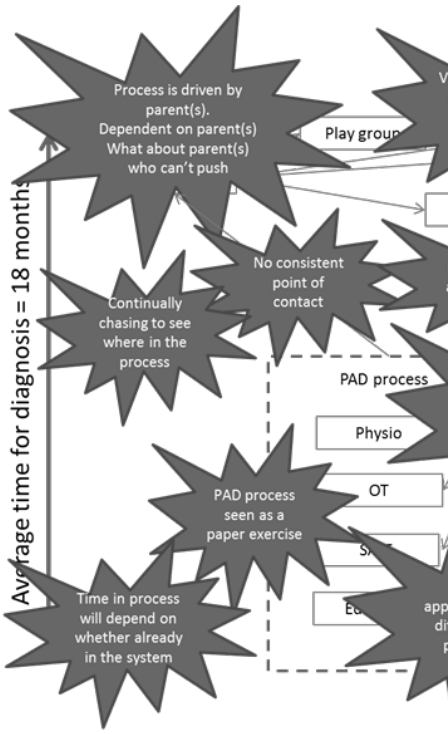


Barriers



c) Parents

Enablers



Barriers