

ASD Rainbows – Note of visit

9 October 2023

Committee attendees:

- Jayne Bryant MS (Chair)
- Heledd Fychan MS
- Naomi Stocks, Clerk (note taker).

1. Background

1. On 9 October Members of the Committee visited ASD Rainbows. The Committee was invited to visit ASD Rainbows, see the facilities, and speak to parents and staff.
2. We would like to thank ASD Rainbows for facilitating the visit, and to all the parents who attended and shared their experiences so openly and honestly.
3. This note provides a summary of the issues discussed.

2. ASD Rainbows

4. ASD Rainbows is based in Mountain Ash, and provides childcare and support for children on the autistic spectrum. Families from across South Wales access their provision and support. It is a non-profit charity, and is registered with the Charity Commission. It supports families with children who are diagnosed or going through assessment for autism or any other related disorders such as ADHD, Fragile X and dyspraxia.
5. It offers both pre-school and after-school provision. The pre-school provision is delivered in two separate two and a half sessions with am and pm sessions for children aged between 2



and 5. There is also a parent and child group up to school age.. The after school provision is accessible for children up to sixteen who are in full time education.

6. As part of the pre-school provision they use PECs (Picture Exchange Communication System). Staff highlighted that when children transition into school, schools often won't support the use of PECs. (As this system gives the child a voice to make their needs known, to withdraw it means taking their voice from them)

7. Staff indicated that the biggest challenge in running the charity was funding. They highlighted that they often can't access some grants because of the restrictions on what certain grants can be used for (as an example they highlighted that they can't access grants for community centre but the nursery is much more difficult to source funding for.) They currently have funding from Children in Need, Moondance Foundation and the National Lottery. At any given point they can be involved in the process for around 30 grants. They said there is a gap in available grants for services like theirs.

8. While they are registered with the Childcare Offer, they said that it doesn't "scratch the service", the Childcare Offer is £12.50 per session, whereas their costs are £63 per child per session.

9. They have four full time staff, with more part time staff. They also trying to access funding for two children who need 1:2:1 support due to complex health needs. They highlighted the importance of good quality staff, as parents have to feel confident that they will be able to support their children. They said that parents often don't want to go to mainstream settings because of concerns about how well supported their children will be.

10. In the future, they would like to provide more drop-in provision, as well provide holiday provision. At the moment, they do keep the pre-school provision open for the first three weeks of the summer holiday.

3. General issues

11. Parents spoke about how they have to fight for all elements of support. At one point throughout the session every parent we spoke to describe it as either a fight or battle and shared their own specific examples of support they had to fight for.

12. One said "everything is a battle. All we're asking for are the same opportunities for our children to succeed. Currently we're letting them fail to get what they need. Then have to work hard to undo the damage. It shouldn't be damaging our children. But our children in

mainstream education are being failed.” Another parent described the cost of having to put things right for their children in later life because of the failures in the system now. We heard that parents “need a fire in your belly” for the fight.

13. We were told that “provision always starts with the least amount.” Parents talked of the traumatising impact this is having on their children.

14. Parents also spoke that those who “shout loudest get the most.” They were concerned about those families who did not have support such as ASD Rainbows to help them in fighting to get the right type of support. A parent said that without ASD Rainbows they didn’t know how they would be coping with the mental health impacts of the constant battles. Another said they would be completely isolated without ASD Rainbows. One parent said the group of parents we were speaking to are “the pushy ones”. They said they were really concerned about those families where parents / carers are more passive because “we are really pushing and our kids are not getting anything.”

15. One parent said they wanted their child to go to Welsh medium provision but they were unable to fight for it because they had to balance “want and a need.” They said families shouldn’t have to fight to get what is right for their child. There were concerns that as a result families were getting the wrong education for their child.

16. Another parent described talking to their child’s school about potty training. The teacher told them they could not support this. The family contacted the family support charity Snap Cymru, who highlighted to the school that under the Equality Act they had to support this. The parent said the teacher did not know they had a requirement. They said that some parents in a similar situation have simply been told they will have to go in and change their child when necessary.

17. The constant battling also has a wider impact on the family, in particular on the parents / carers who find they lose their own identities. One parent said that when you embark on parenthood you don’t expect to be dealing with these issues. They said that while some people say they wouldn’t change their children, they would, if they could, “get rid of my child’s autism” because “the world is not designed for them” and that they will not always “be able to protect them.” They said their child described being autistic as being on a rollercoaster which you can’t get off which is “exhausting for them and for us.” Another parent said “slowly but surely you lose hope” and described how frustrating it was that even agreed support is not delivered.

18. Terms such as gaslighting were used in relation to local authorities and schools in their approaches to dealing with requests for support.

19. There was a call for wider awareness of autism. Parents described how some schools will do work during Autism Awareness Week, but that it will only happen in that week. They called for greater cultural training and said that unless you are directly affected by it, you don't tend to think about it. Someone said it would be helpful if policymakers had experience of autism. We were told of how autistic children will be excluded from wider social opportunities such as parties and sleepovers. Yet they are desperate to be included and accepted.

20. One parent said the system is an "absolute disaster. The current system doesn't work. The problem is everywhere in Wales." Another parent called for change "across the board", and highlighted instances of responsibility being passed between schools and healthcare services, in particular for referral to newer developmental services. They said getting referred is "a real issue" and that there is "no partnership between health and education services." While a third said the system "is not fair".

21. We were told that "it takes a team to raise an autistic child effectively". One parent said that they dread something happening to them, because although "everyone says they'll be there, but they won't." We were told that support services such as Resilient Families, will provide support but often only for short periods of time. One parent described their experiences with Resilient Families which ended before they could get to the resilient part of the programme. This was because "it took the time of the programme to build the trust with my son."

22. Concerns were raised about the information available to children, young people and their families. Often they simply don't know what they are entitled to, and parents said that local authorities did not know either.

23. The impacts of the waiting list times were also highlighted as an issue. Parents talked of the battle to get a referral, and then having to wait up to 2½ years for the appointment, in which time your child will have changed and the challenges will be different.

24. Parents felt very strongly that their children were not able to meet their full potential and that their children's rights were not being met. One parent said they are just asking for the same opportunities as other children but that their child has to take "a different route to get there."

4. Childcare provision

25. One parent described having to travel from outside the RCT area to access the ASD Rainbows provision. They have chosen to travel this distance because they "get specialist intervention here." As a result they are now not able to access an ASD Specialist in their own

local authority because they have paid for ASD Rainbows. As a result their child will have to go into mainstream school provision without support. They said it was “all about the budget”.

26. Staff highlighted that the Childcare Offer is only available if both parents are working.

5. School provision

27. Concerns were raised about the level of training for teachers in mainstream settings. We were told that these teachers are not suitably trained. One parent was concerned about knowledge and expertise for teachers in early-years provision. They said their child at the age of three was described as “manipulative” by a teacher. They said this was because the teacher didn’t know what they were dealing with and therefore couldn’t look after them safely. Another parent said that their head teacher “didn’t have a clue”

28. Parents shared their experiences of trying to secure support in schools. One parent said that provision “always starts with the least amount...” and as a result their children are being traumatised. They said that their child had been “damaged by the system”, and that having been let down previously, their child no longer trusts the school. They said their child has had no education as there is no setting that will support them. They said the only point that discussions on support only happens when their child is failing. They also said as parents they have been “purposefully given false information.”

29. We heard that in some instances “good reports” will be produced by professionals such as Educational Psychologists setting out the support that is needed. Families then believe this will be implemented, but it is not. In other instances support will be put in place and children will start to thrive, but that the support is then removed because “the schools think the job is done.” But as it is the support that is enabling the child to thrive, it needs to be maintained. One parent described how they were not told when there was a change in support, and the family started to wonder why their child was regressing, but the school hadn’t informed them. Then they had to challenge it. There were frustrations generally about support or adjustments being put in place and then just being removed by the school.

30. Concerns were raised about the limited resources available to schools and the resulting rationing of services and support. We were told that in one instance a teacher in a meeting with a family said they could not provide the support because they needed to provide support for older children. A parent said that schools are having to make decisions about where to target support, and because their child doesn’t have behavioural issues they do not get prioritised for support. They said that schools should not have to be making these types of decisions.

31. We heard that there is a struggle to get IDPs put in place because “schools don’t want to do them.” Even in instances where children have an IDP, it’s not always followed. Parents spoke of their frustrations that if the IDPs were followed their children would thrive in mainstream education. One parent said the adjustments were not “even massive, and that if they were put in place would enable their child to thrive in mainstream provision. We were told that minimal changes can make a massive difference, but they are not implemented.

32. We also heard that the waiting times to access support were “beyond a joke.” Parents said this was particularly galling, after the long time and challenges in securing a diagnosis in the first instance.

33. Safeguarding concerns were also raised when children and young people are out of school. One parent described having no contact from their school or local authority when their child was out of school for a sustained period. When their child was out of school for a nine month period, they had to ask the local authority to come and check on them. Also, when children are off for sustained periods of time, parents / carers may have to stop work altogether or reduce their hours.

34. Parents spoke of the challenges of those high functioning children who will mask issues in school, but when coming home start to “unravel”. They said it becomes infuriating as people think you are making it up, and that you become “that parent”. One parent described their head teacher saying to them “I have 450 other pupils to look after.” They said “schools are fire-fighting and our kids are collateral damage.” We also heard that it can be damaging to the parent / carer’s relationship with their child, because the child starts to lose trust in the parent / carer as safe people because they are “making them go somewhere they don’t feel safe.” We heard these children are in “fight or flight mode.” Others told us that their children said things like “I wish I didn’t exist, why are you sending me to jail?”

35. Parents talked of being constantly judged by the school, while at the same time the school does not help them. We were told that families are encouraged to go to mainstream provision, but that mainstream schools don’t want these children, because they see them as “naughty”. Families are “constantly” being given negative feedback on their children, when it’s not their children’s fault. A parent said the teachers were getting frustrated with their three year old and had no understanding of why they were behaving in a particular way, or how to help them. Others said they were “constantly” being made to feel that their child “is an impediment.” Another said staff simply said “we don’t know what to do” with them.

36. One parent said that for their child’s school “it is better for them when they are not in.” They said that for some even though home education is not their choice they feel that it is the

only option. They said that this is despite the fact that their children have a right to an education and a right to being in school.

37. We were also told that schools do not apologise when they make a mistake. Parents compared it to how children are taught to say sorry when they make a mistake. They said there is a lack of respect. One parent described how their child was accused of doing something at school, which was out of character. Their IDP stated that they would always be accompanied, but at this point they were not. As their child is non-verbal they could not give their account of what happened, it was just assumed that they had done what they were accused of. They described this as “direct discrimination” because they are non-verbal.

38. We told that children and their families don’t have a choice in terms of school provision. If you are offered a place in a specialised unit, you are not able to visit it before making a decision. This was compared to the opportunities other children and their families have in making choices about non-specialised provision.

39. Concerns were raised about access to Welsh medium provision. A parent said that they had to place their child in an English medium school, because the Welsh medium provision “was not capable of teaching my autistic child”. They said they had to choose their child’s well-being over their language. They said that there was no progress within Welsh medium provision, and that the system “has been the same for years.”

40. One parent described the challenges they have and how they impact on the rest of the family, and in particular siblings. As their child doesn’t sleep, it can affect the older siblings’ attendance, as they can’t then get them to school. The School Attendance Officer visited the family, even though the school was aware of the wider issues, and their offer of support was to provide a breakfast club place for the other children. However, this would just place additional stress as the family would then have to get the children to the same school at two different times, which would actually make life more difficult. It also caused additional stress because they were worried they could be taken to court and fined. They said there was a need for support for siblings.

41. We heard examples of how schools don’t make adjustments in terms of schoolwork and wider school activities. One parent said their child was given the same homework as those without additional needs. They said that by trying to include him, they were actually excluding him as this was all work that he could not even attempt. All that needed to happen was to give him specific homework which took account of what he can do. We also heard of a child who was struggling with a playground game, and when staff were asked to explain how the game is played staff said they didn’t have time. The headteacher said all children should have to face

humiliation. In another instance, a child was concerned about starting primary school, and the school agreed to a visit to the classroom before starting, which would have made a huge difference, but it was never organised.

42. We also heard about issues around school visits and leisure activities. Parents said that in advance of such activities schools do not get in touch, and this always has to be initiated by parents. It was suggested that “schools would prefer us to keep them at home.” Another parent said “it’s implied it’s not suitable for [them] to attend” meaning that they can’t enjoy the same experiences as their peers. One parent described their child’s experience at a sports day. They had to walk a nearby leisure centre, no transport was provided despite their child needing it. They then could not participate in the sports events because of having to walk to the venue, they had therefore walked to an event where they couldn’t participate. This was particularly challenging, as one of their child’s triggers is disappointment.

43. Parents described education as “very exclusive” and that inclusivity is only available “if you fit into a box.” But we were told it is very damaging to make children fit into particular boxes. One parent described the differences they see in how their two children are treated, with one accepted because their needs are very visible, and their other child’s needs not accepted because they mask.