



Alder Hey Children's

NHS Foundation Trust

Alder Hey

Eaton Road

Liverpool

L12 2AP

www.alderhey.nhs.uk

Tel: DPA

Our Ref: KP/EW DPA

Date of Clinic: 10/05/2019

Date Dictd: 10/05/2019

Date Typed: 16/05/2019

Urology Nurse Specialists

Alder Hey Children's NHS Foundation Trust

PCO Brenda Murray DPA

Department of Urology

Miss H Corbett

Consultant in Paediatric Urology

Dear Colleagues

REFERRAL

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

History/Current Symptoms

I would be grateful if you could meet Axel in your clinic and offer biofeedback to him. He is a 12 year old boy who has been troubled with dysuria for the past 2 months. **DPA**

DPA

Of note, Axel is a very anxious young man and he is on the waiting list for parenting 2000 to discuss his anxieties. These mainly concern his perception but he has increased saliva production and he gets very nervous when this happens as he feels that everyone is looking at him and commenting.

Examination

DPA

Investigations, Procedures and Results

I therefore asked him to carry out a flow study to see if he maybe obstructed. **DPA**

DPA

Management Plan

I reassured Axel that there is no evidence of meatal stenosis and obstruction to justify his symptoms. I wondered whether he has posterior urethritis. I explained that this is very common in adolescents, and obviously can be exacerbating in children with anxiety.

I would be grateful if you could meet with him and offer some biofeedback. Hopefully, this will help him relax his pelvic muscles when he is voiding and his symptoms improve. I also advised him to take painkillers as required when he has exacerbations of the dysuria. I have request an ultrasound scan of his urinary tract to make sure there is no pathological finding.

Follow Up Arrangements

I will see him in clinic in a couple of months.

Kind regards,

Yours sincerely

Electronically checked and authorised by Miss Katerina Prodromou

Miss Katerina Prodromou
Fellow in Paediatric Urology

Copy to:

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB



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Alder Hey

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Liverpool

L12 2AP

www.alderhey.nhs.uk

Tel: DPA

Our Ref: KP/mb, DPA

Date of Clinic: 08/07/2019

Date Dictd: 08/07/2019

Date Typed: 11/07/2019

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

PCO Brenda Murray DPA

Department of Urology

Miss H Corbett

Consultant in Paediatric Urology

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006

Hospital No. DPA

NHS No. DPA

Diagnosis

Dysuria
Interrupted stream
Terminal haematuria
? Posterior urethritis
Anxiety

Acute / Suspected Problems:

No Acute / Suspected problems reported.

Chronic Problems:

No Chronic problems reported.

Past Problems:

No Past problems reported.

During transition from paper to full electronic records, the past problem table may not reflect all past patient problems

Known Allergies and Adverse Reactions

Allergy/Adverse Reaction	Type	Severity	Reaction	Status	Date/Time
NO KNOWN ALLERGIES	Allergy			Verified	10/05/19 13:10

History/Current Symptoms

It was lovely to meet Axel and his dad. Unfortunately he has not had his ultrasound scan yet and I apologised for this. I will try to arrange it for the 22nd July when he will come to the hospital for his first biofeedback session.

He tells me that he has been a little better since we last met. He drinks more and he tries to void more regularly although dad thinks that Axel tends to hold his urine for too long. DPA

DPA

I will see Axel in 3 months and hopefully with biofeedback his symptoms will improve.

Investigations, Procedures and Results

No Laboratory Orders or Results recorded within this period:

Follow Up Arrangements

18 Week Outcome for this visit: Watchful Wait/Monitoring

Future Follow Up: Same Clinic

Follow Up Time Frame: 3 Months

Yours sincerely

Electronically checked and authorised by Miss Katerina Prodromou

Miss Katerina Prodromou
Fellow in Paediatric Urology

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Urology Nurse Specialists
Alder Hey Children's NHS Foundation Trust



Alder Hey Children's

NHS Foundation Trust

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Tel: 0151 2284811

Our Ref: ED/bm **DPA**

Date Dictd: 23/07/2019

Date Typed: 26/07/2019

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

Secretary: Urology Nurses PCO
Urology Nurse Appointments Clerk

Fax:

DPA

DPA

DPA

Department of Urology
Urology Nurses

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006

Hospital No.

DPA

NHS No.

DPA

Diagnosis Dysuria
Interrupted stream
Terminal haematuria ? posterior urethritis
Anxiety

History and current symptoms

Axel attended with his dad today for a short appointment. He had missed some of his appointment yesterday with my colleague Kate Thompson and therefore was unable to complete the biofeedback session. He was therefore booked for a biofeedback session into my clinic today.

DPA

Future management

I will request two more appointments for Axel to attend our clinic. I will of course keep you updated with all of Axel's progress.

Yours sincerely

Electronically checked and authorised by Emily Dobson

Emily Dobson

Urology Nurse

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB



Alder Hey Children's

NHS Foundation Trust

Alder Hey

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www.alderhey.nhs.uk

Tel: DPA

Our Ref: KT/tm DPA

Date Dictd: 23/08/2019

Date Typed: 27/08/2019

**Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN**

**Secretary: Urology Nurses PCO - DPA
Urology Nurse Appointments Clerk - DPA
Fax: DPA**

**Department of Urology
Urology Nurses**

Dear Dr Arnold

**Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB**

D.O.B. 07/08/2006

Hospital No. DPA

NHS No. DPA

Diagnosis

**Dysuria
Interrupted stream
Terminal haematuria
Posterior urethritis
? anxiety**

History/current symptoms

Axel attended the urology nurse led clinic today with Dad. He was slightly late to today's appointment once again and he was able to carry out his biofeedback for 10 minutes. DPA

DPA
DPA Unfortunately he reports no real change in his symptoms however Dad has noticed that he has been able to notice a difference. **DPA**
DPA

DPA

DPA He has a new appointment in the near future where a full assessment will be carried out and future treatment will be decided.

I look forward to seeing Axel in the near future and will of course keep you updated with all of his progress.

Yours sincerely

Electronically checked and authorised by Kate Thompson

Kate Thompson

Urology Nurse

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB



Alder Hey Children's

NHS Foundation Trust

Alder Hey

Eaton Road

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www.alderhey.nhs.uk

Tel: DPA

Our Ref: ZK/trm DPA

Date Dictd: 05/09/2019

Date Typed: 10/09/2019

Miss K Prodromou
Fellow in Paediatric Urology
Alder Hey Children's NHS Foundation Trust

Secretary: Urology Nurses PCO - DPA
Urology Nurse Appointments Clerk - DPA
Fax: DPA

Department of Urology
Urology Nurses

Dear Miss Prodromou

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

Diagnosis:

Dysuria.

Interrupted stream.

Terminal haematuria.

Posterior urethritis.

Anxiety.

Medication:

None taken.

Axel attended the nurse-led urology clinic on 5 September 2019 accompanied by dad.

Axel has attended today for a further session of biofeedback. Axel has admitted to not carrying the exercises out on a regular basis at home.

DPA

Axel has done well to improve his oral intake and is now taking around 1 litre of clear fluid each day.

DPA

I believe that you are due to review Axel again around October with a repeat ultrasound scan.

I have encouraged Axel to continue to improve his oral intake and practice his biofeedback at home.

I have not booked any further nurse-led follow up.

Yours sincerely

Electronically checked and authorised by Zoe Kavanagh

Zoe Kavanagh
Urology Nurse



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NHS Foundation Trust

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Tel: DPA

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Fax: DPA

Department of Urology

Our Ref: KP/bm: DPA

Date of Clinic: 07/10/2019

Date Dictd: 07/10/2019

Date Typed: 09/10/2019

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

Diagnosis

Dysuria
Interrupted stream
Terminal haematuria
? Posterior urethritis
Anxiety

It was lovely to meet Axel and his dad in clinic. I am happy to report that after his biofeedback sessions: DPA

DPA

His ultrasound scan showed normal kidneys, a normal bladder with a volume of 470ml and good emptying.

Once again I explained that posterior urethritis usually self-resolves with time: DPA

DPA

I have offered him one last appointment in 6 months and if he remains well I will discharge him back to your care.

Yours sincerely

Electronically checked and authorised by Miss Katerina Prodromou

Miss Katerina Prodromou
Fellow in Paediatric Urology

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Urology Nurse Specialists
Alder Hey Children's NHS Foundation Trust



Alder Hey Children's

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Our Ref: JA/gb DPA

Date Dictd: 02/07/2020

Date Typed: 03/07/2020

<https://alderhey.nhs.uk/parents-and-patients/services/developmental-paediatrics>

Tel: DPA

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

Secretary: DPA

PCO: Diane Powell

Repeat Prescriptions: DPA

Fax: DPA

Department of Developmental Paediatrics
Southport

Dear Dr Arnold

TELEPHONE CONSULTATION

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

This letter is following my telephone consultation with Axel's dad in replacement of a face-to-face consultation due to COVID-19 pandemic.

History/Current Symptoms

Axel was referred by his GP because there was concern about whether he has ADHD or ASD.

Family Background

He lives with his mum Letitia and dad, Alphonse. Mum: DPA
DPA is in Preston and dad is self-employed. They both are well and Axel's brother Dion who is 16 now DPA, is wheelchair bound DPA
DPA

Birth History

There are no major concerns about birth or pregnancy.

Concerns

They are concerned about his social interaction, communication difficulties while he was in nursery.

I gather from information from father that from a physical health point of view Axel is fine. He is not allergic to anything and he is not taking any medication. He is fully vaccinated. His hearing and vision are fine.

This patient interaction took place during the Covid-19 pandemic.

His toileting is fine as well as his sleeping but eating can be difficult. He eats only burger and chips and very unhealthy food and is very rigid eating the same foods all the time.

Social Interaction

Dad tells me that Axel does not always show good eye contact and he will speak to people with his head down, has only a few friends and he finds it difficult to make long term friendships.

Social Communication

He doesn't always understand what is going on around his surroundings although he has good language. He finds it very difficult to communicate and express himself and he doesn't always understand circumstances.

Rigidity

He is very rigid and inflexible in his thinking. He mainly plays with computer games and he collects games.

He also has other sensory issues.

School

School are concerned about these issues as well. He attends Acorn School but these issues are more obvious now he has gone to high school. In nursery there were some concerns but he is more rigid, inflexible and has social interaction and communication difficulties which are more obvious now.

Summary

In summary Axel [DPA] is presenting with social interaction, social communication and some rigidity in thinking.

Management Plan

I have agreed with the parents that we need to do a further assessment. I promised father that I will put Axel on the ASD Pathway and the ASD team will get in touch with them.

Yours sincerely

Electronically checked and authorised by Dr Jamuna Acharya

Dr Jamuna Acharya
Locum Consultant in Community Paediatrics

This patient interaction took place during the Covid-19 pandemic.

Copy to:

The Parent/Guardian of
Mr Axel Muganwa Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

ASD Pathway
Alder Hey Children's NHS Foundation Trust

This patient interaction took place during the Covid-19 pandemic.

Our Ref: KP/mb DPA

Date of Clinic: 07/09/2020

Date Dictd: 07/09/2020

Date Typed: 08/09/2020

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

Alder Hey Children's

NHS Foundation Trust

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www.alderhey.nhs.uk

Tel: DPA

Secretary: PCO: Brenda Murray: DPA

Fax: DPA

Department of Urology

Miss H Corbett

Consultant Paediatric Urologist

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006

Hospital No. DPA

NHS No. DPA

Diagnosis

Dysuria

Interrupted stream

Terminal haematuria

Likely Posterior urethritis **now resolved after biofeedback training**

Anxiety, behavioural issues, now on ASD pathway

Known Allergies and Adverse Reactions

Allergy/Adverse Reaction	Type	Severity	Reaction	Status	Date/Time
NO KNOWN ALLERGIES	Allergy			Verified	10/05/19 13:10

I had a telephone consultation with Axel's mum today in view of the covid 19 pandemic. Axel has been well from a urological point of view. He has not had any further symptoms or signs of posterior urethritis.

DPA

DPA

Lately he has been assessed and placed on the ASD pathway. I explained that children with ASD usually have difficulties with toileting and this could explain the mentioned behaviour. I however have no urological concerns. I would be grateful if you could keep an eye on things and re-refer Axel to us if his symptoms recur.

Plan

I have now discharged him back to your care.

Investigations, Procedures and Results

No Laboratory Orders or Results recorded within this period:

Follow Up Arrangements***This patient interaction took place during the Covid-19 pandemic.***

18 Week Outcome for this visit: Discharge

Yours sincerely

Electronically checked and authorised by Miss Katerina Prodromou

Miss Katerina Prodromou
Fellow in Paediatric Urology

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Miss H Corbett
Consultant Urologist
Alder Hey Children's NHS Foundation Trust

Urology Nurse Specialists
Alder Hey Children's NHS Foundation Trust

This patient interaction took place during the Covid-19 pandemic.

Our Ref: ASDT/dh **DPA**

Date Dictd: 27/10/2020

Date Typed: 27/10/2020

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Department of Developmental Paediatrics

ASD Team

ASD PATHWAY SPEECH AND LANGUAGE THERAPY REPORT

DIGITAL CONSULTATION

(Private & Confidential)

Date of Video Consultation: 28.08.2020

DPA

NAME: Axel Rudakubana	D.O.B: 07/08/2006	ADDRESS: 10 Old School Close, Banks, Southport, PR98SB	SETTING: Acorns School Ormskirk
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BACKGROUND INFORMATION

Axel was referred to the Autism Spectrum Disorder (ASD) Pathway and was seen for an initial speech and language assessment as part of the ASD Pathway process on 28/08/20. A video assessment with Axel and discussion with Mum took place via NHS Attend Anywhere.

Axel was aware that the assessment was in relation to Autism. Axel does not think that he has Autism.

Mum reported that her main concerns are around the incident late last year, but Mum feels that Axel has improved since he has been at home.

In school Axel is 1:1 with his teacher.

SOCIAL COMMUNICATION & INTERACTION SKILLS

Conversation:

- Axel did not greet or say goodbye to the assessor during the assessment. On one occasion Axel stood up saying "wait a minute" and disappeared, when he returned he gave no explanation why he had got up until he was directly asked.
- Axel would answer direct questions, and was reluctant to give additional information.
- Axel reported that he likes YouTube and TV, he likes to watch history videos and videos which are factual or "informative".
- Axel demonstrated inconsistent understanding of others emotions when looking at pictures, for example he could recognise that people were "sad" in a funeral scene, but when shown two boys fighting over a game Axel stated "they're playing...they're having fun", the assessor then suggested the boys were fighting and Axel said "well, why are they smiling?". When looking at a picture of a girl who looks worried, Axel was asked how the girl was feeling and said "traumatized... actually I didn't see her other hand, I think just out of breath".

- Axel found it difficult to think of anything that would make him feel happy or excited. Axel feels "worried" about "going outside" he explained, "I don't like being near other people" because "I feel like other people are judging me". Axel stated that he didn't have specific worries about what others thought of him, but felt it was "generally bad things", Axel thinks that most people will think these things except "close friends".
- It was very difficult to engage Axel in two-way conversation, though this was impacted by the signal during the video assessment, however a conversation was had with Mum following the assessment via the same platform indicated that in part this issue was due to Axel's difficulties with social communication.
- Mum reported that Axel struggles with talking to people, because he always wants to "win the debate" and if the conversation does not go his way, he will start arguing.
- Mum reported that Axel will invite her to watch television with him. Axel will enjoy discussing with the other person the topic of the shows he is watching.
- During the assessment Axel was observed to put his head down on the desk while the assessor was speaking because he wanted to change topic.
- Mum stated that if she was talking about something Axel is not interested in then he will ask her to stop. Axel will listen to information about other people, for example about their day.

Non-verbal communication:

- Axel had a neutral facial expression throughout the assessment.
- Mum reported that when Axel looks at someone he just looks at "one point", and will avoid looking at the person.
- During the assessment Axel appeared to be looking round the room at times, or to the side of the computer.
- Axel was not observed to use gesture during the assessment.

Friendships and relationships:

- Axel reported that he doesn't have any friends in his school.
- Axel stated that he had friends in his old school. When asked if he had any best friends he said "I don't really know, I don't think so". Axel reported that a best friend is someone you are "always with" and "always talking" to. Axel stated that he wouldn't be allowed to see his friends outside of school, but that he wasn't "really bothered" either way.
- Axel stated that he has not kept in contact with his friends from previous schools, he is unsure why. Axel stated that he doesn't miss these friends.
- Axel reported that a good friend is being "friends with them" and "you speak to them a lot".
- Axel stated that his brother is "annoying" because "he just likes to argue". Mum stated that Axel will not tolerate other people "winning" a discussion or argument.
- Mum reported that Axel will often refuse to go out.
- Mum stated that when Axel was in primary school he was very popular, and was good with friends. Mum reported that since going to high school Axel did not show much of an interest in others.
- Axel stated that he is "bullied" by his Dad, because his Dad will say things that are "annoying" on purpose. Axel was asked what kind of thing he finds annoying, but was unable to say what annoys him. The assessor then asked if Axel thought his Dad would know what is "annoying" for Axel, but Axel was unsure. Mum reported that Axel's Dad has been on communication courses because he was finding it difficult to communicate with Axel in a way which wasn't perceived as arguing or bullying.

RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOUR, INTERESTS OR ACTIVITIES

- Mum reported that Axel can often take what has been said as an offence, and struggle to interpret it in a different way.
- Mum reported that Axel is literal.
- Mum stated that Axel will refuse to engage in something that he is not very interested in. This can have an impact on Axel in school, for example Axel can find it very difficult or impossible

to engage in an activity or piece of work that he is not actively interested in. Mum is concerned that this will impact Axel academically.

- Mum reported that when Axel was in primary school and the beginning of high school, he would play tennis with other children, enjoyed swimming, gymnastics and other activities. Axel then began quitting everything and stated he didn't like it anymore. Axel preferred to play computer games which were his main interest at the time. Axel has since stopped playing games, and now only tends to watch YouTube and shows on television about History, animals, and shows rooted in fact.

SUMMARY & RECOMMENDATIONS

It was a pleasure to meet Axel who presented with appropriate speech and language skills but difficulties in the areas of social communication, social interaction and flexibility of thought. This report will now be discussed at a multi-agency meeting in order for these findings to be viewed in the context of assessments and observations from other agencies.

Recommendations:

- It may be useful to maintain communication between home and school, as Axel may not always update his parents on what is taking place in school, and consistent strategies can be shared.
- Support with social communication through access to social communication group may be useful for Axel to help to develop his social communication skills, in particular his understanding and awareness of emotions, friendships and turn taking within conversation.
- It may also be useful for Axel to have a named member of staff within school to discuss when he feels he is being bullied. This can help to identify how Axel is interpreting the behaviour of others as at times he may misinterpret others disagreeing with him as bullying.
- As part of Axel's routine or structure it may be helpful to have a specific time identified for when Axel can raise his concerns, or for him to use a diary so that he can communicate in some way when he feels that bullying is taking place and be supported to consider how he can respond to this or seek support of adults if necessary.

If you have any questions or require any further advice, please do not hesitate to contact me on the e-mail address above.

This patient interaction took place during the Covid-19 pandemic

Yours sincerely

Katherine O'Dempsey
Highly Specialist Speech & Language Therapist
ASD TEAM
NEURODEVELOPMENTAL PATHWAY

Copy to:

Dr EE Arnold
 Roe Lane Surgery
 172 Roe Lane
 Southport
 Merseyside
 PR9 7PN

SENCO SENCO
The Acorns School
43 Ruff Lane
Ormskirk
Merseyside
L39 4QX

CAMHS
2nd Floor Burlington House
Crosby Road North
Liverpool
Merseyside
L22 0PJ



Alder Hey Children's

NHS Foundation Trust

Alder Hey

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L12 2AP

developmental-

paediatrics

Tel: DPA

Secretary: DPA

PCO: Danielle Kelly & Emma Carey

PCO: Janet Riddell

Department of Developmental Paediatrics

ASD Clinic

Our Ref: KM/jh/ DPA

Date Dictd: 17/11/2020

Date Typed: 19/11/2020

<https://alderhey.nhs.uk/parents-and-patients/services/developmental-paediatrics>

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

Due to the new clinical working conditions implemented as a result of Covid-19, it was not possible to complete a face-to-face appointment with Axel's parent / carer. The appointment was therefore completed over the phone with parent / carer's agreement.

The purpose of this appointment was to complete a neurodevelopmental assessment as part of the ASD pathway process. The information was obtained from Dad on 17/11/2020 and additional information added from Dad on the 18/11/2020

Future/Action Plan

The information gathered today has been recorded and documented on the Alder Hey electronic records; this along with any other information available will be discussed by the ASD team. It will be decided which further assessment is required before a decision can be made on whether Axel meets the criteria for an ASD diagnosis.

Currently the Community Paediatrics / ASD service are receiving an extremely high volume of calls. We understand the frustration this is causing to families trying to contact us and are working on a solution to remedy this. If you need to contact the service please email comm paed queries@alderhey.nhs.uk. We are aiming to respond to all emails within 2 working days of receipt.

Yours sincerely

Electronically checked and authorised by Kate Murphy

Kate Murphy
Community Nurse Practitioner

This patient interaction took place during the Covid-19 pandemic.

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

This patient interaction took place during the Covid-19 pandemic.



Alder Hey Children's

NHS Foundation Trust

Alder Hey

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Department of Developmental Paediatrics

Tel: DPA

Repeat Prescriptions: DPA

Fax: DPA

Department of Developmental Paediatrics

Knowsley Contact: DPA

Liverpool Contacts: DPA / DPA

Our Ref: ASDT/kt **DPA**

Date Dictd: 12/02/2021

Date Typed: 12/02/2021

<https://alderhey.nhs.parents-and-patients/services/developmental-paediatrics>

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Alder Hey Autism Spectrum Disorder Assessment Pathway

Name: Axel Rudakana

Address: 10 Old School Close, Banks, Southport, PR9 8SB

DOB: 7.8.06

DPA

Chronological Age: 14

Setting: The Acorns School, 43 Ruff Lane, Ormskirk

Date of MDT Meeting: 30.12.20

Axel was referred to the Alder Hey Autism Spectrum Disorder (ASD) Pathway for a more detailed assessment of his social and communication development following concerns that he was displaying features of an Autism Spectrum Disorder.

Autism Spectrum Disorder is a lifelong developmental disability. People affected by an Autism Spectrum Disorder are likely to have broad areas of impairment with:

- Persistent difficulties in social communication and interaction
- Restricted, repetitive patterns of behaviour, interest or activities

These impairments are present from early development of the child, affecting how a person communicates with and relates to other people and how they experience the world around them. These difficulties would cause clinically significant impairment in social/educational settings and other areas of current functioning.

Axel was discussed at the ASD Multidisciplinary Team Meeting (MDT) on: 30.12.20

The MDT team consists of practitioners with expertise in Autism Spectrum Disorders. This may include: Consultant Community Paediatrician or Consultant Child & Adolescent

Psychiatrist, Speech and Language Therapist and a Clinical Psychologist. The team meets to consider all the information available about a child or young person to assess if they meet the criteria for an Autism Spectrum Disorder.

If the MDT team has sufficient information, it will aim to reach a conclusion regarding the question of Autism Spectrum Disorder. The aim of this process is to avoid duplication through re-assessment and to avoid long waiting times for families.

Professionals Involved in MDT:

- Consultant Community Paediatrician – Dr. Sultan
- Advanced Speech & Language Therapist – Ruth Mitchell
- Physician Associate – Dawn Devine

Reports Available at MDT:

- Developmental history
- Assessment by a Speech and Language Therapist
- Information from school professionals
- Educational Psychology report

Summary:

Having reviewed all of the information available, the assessment team agree there is sufficient evidence that Axel does meet the criteria for an Autism Spectrum Disorder (ASD).

Recommendations:

- A referral will be made, by way of this letter to the Sefton ADHD/ASD Children's Service. Please use the following telephone number to contact the team for any advice on **DPA**
- ASD information pack to be sent to parents.
- Follow up appointment from Community Paediatrician
- Axel's social communication needs and behaviour should be considered within the context of their ASD diagnosis and supported as appropriate by relevant strategies which may be identified by the various professionals working with them. It is advised that parents and school should stay in regular contact to ensure that any support is consistent across both the home and school environments.

- Visual support should be implemented consistently as an integral part of the whole day both at home and school. Visuals would support a) active listening skills b) attention to task and c) independent learning skills. Visuals don't have to be picture based. Pictures do help but for older children, who have good reading skills, a well-placed written visual timetable will also work well. It is sometimes presumed that verbal children 'don't need' or 'grow out' of a visual timetable. However, many children with ASD can be anxious about 'what will happen next', but don't always express this anxiety. A timetable would serve to support this type of potential hidden anxiety. School should also actively provide support if there are any unplanned changes or at other times where normal routine is altered (e.g. exams / school events / trips, changes between year groups and changes of teachers). Transition strategies could include resources such as photo transition books, Social Stories, staggered starts and practice / preparation visits.
- In certain situations, either at home or at school, it may be helpful to explicitly teach a specific social skill or strategy. Social situations may need to be explained more clearly. Writing down information in a Social Story or Comic Strip Conversation format rather than explaining things verbally is sometimes recommended for these situations. Advice on Social Stories and Comic Strip Conversations can be found on the National Autistic Society Website www.autism.org.uk and www.carolgraysocialstories.com.
- Families may wish to seek advice and guidance from the Social Communication Team via e-mail socialcom@sefton.gov.uk or via the Local Offer <https://www.seftondirectory.com/>
- ADDvanced Solutions is a service that provides support and information to families. They run training courses for parents and groups for young people. They can be contacted on: **DPA**
- Families can self-refer to organisations such as Parenting 2000 <https://parenting2000.org.uk/> for talking therapies to support emotional well-being and mental health.
- For support and advice around mental health, parents and young people can self-refer to FRESH CAMHS via the Single Point of Access in the first instance. Please call **DPA** to discuss. Additionally, **the CAMHS Crisis Team offer a dedicated crisis telephone line 24 hours a day**, which aims to help children, young people, families and carers who are very worried about the mental health of anyone with a GP in Liverpool or Sefton up to their 18th Birthday. For support regarding presenting risks, children, families and professionals can contact the CAMHS Crisis Line to speak directly to a mental health practitioner. Their contact number for the service is (free phone) [0808 196 3550](tel:08081963550) or [0151 293 3577](tel:01512933577)
- Should you or your child require information or support regarding their education and related health and social care issues advice can be sought from: Special Education needs & Disability Information Advice & Support Service (SENDIASS). This was formally known as 'Parent Partnership'. Telephone: **DPA** E-mail: seftonsendiass@sefton.gov.uk
- Applying for Disability Living Allowance (DLA) may help to support daily living needs such as mobility and care costs.

- Our social communication skills change all the time. Choosing how best to help and support your child with this will take time and there may be elements of trial and error.

The content of this report has been agreed between the professionals involved in this team.

ASD TEAM
NEURODEVELOPMENTAL PATHWAY

Copy to:

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Sefton ADHD/ASD
Children's Service: Formby Health Centre, Phillips Lane, Formby, Liverpool,
L37 4AY

Alder Hey Children's

NHS Foundation Trust

Alder Hey

Eaton Road

Liverpool

L12 2AP

www.alderhey.nhs.uk

Tel: DPA

Our Ref: ASDT/ko DPA

Date Dictd: 16/02/2021

Date Typed: 16/02/2021

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Secretary: DPA

PAULINE BLOXSOME

Email: janice.wilson@alderhey.nhs.uk

Department of Developmental Paediatrics

JAN WILSON

Alder Hey Autism Spectrum Disorder Assessment Pathway

Dear Parent/Guardian of Axel Rudakubana

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B.	07/08/2006
Hospital No.	DPA
NHS No.	DPA

Setting: The Acorns School, 43 Ruff Lane, Ormskirk

Date of MDT Meeting: 30.12.20

Axel was referred to the Alder Hey Autism Spectrum Disorder (ASD) Pathway for a more detailed assessment of his social and communication development following concerns that he was displaying features of an Autism Spectrum Disorder.

Autism Spectrum Disorder is a lifelong developmental disability. People affected by an Autism Spectrum Disorder are likely to have broad areas of impairment with:

- Persistent difficulties in social communication and interaction
- Restricted, repetitive patterns of behaviour, interest or activities

These impairments are present from early development of the child, affecting how a person communicates with and relates to other people and how they experience the world around them. These difficulties would cause clinically significant impairment in social/educational settings and other areas of current functioning.

Axel was discussed at the ASD Multidisciplinary Team Meeting (MDT) on: 30.12.20

The MDT team consists of practitioners with expertise in Autism Spectrum Disorders. This may include: Consultant Community Paediatrician or Consultant Child & Adolescent

Psychiatrist, Speech and Language Therapist and a Clinical Psychologist. The team meets to consider all the information available about a child or young person to assess if they meet the criteria for an Autism Spectrum Disorder.

If the MDT team has sufficient information, it will aim to reach a conclusion regarding the question of Autism Spectrum Disorder. The aim of this process is to avoid duplication through re-assessment and to avoid long waiting times for families.

Professionals Involved in MDT:

- Consultant Community Paediatrician – Dr. Sultan
- Advanced Speech & Language Therapist – Ruth Mitchell
- Physician Associate – Dawn Devine

Reports Available at MDT:

- Developmental history
- Assessment by a Speech and Language Therapist
- Information from school professionals
- Educational Psychology report

Summary:

Having reviewed all of the information available, the assessment team agree there is sufficient evidence that Axel does meet the criteria for an Autism Spectrum Disorder (ASD).

Recommendations:

- A referral will be made, by way of this letter to the Sefton ADHD/ASD Children's Service. Please use the following telephone number to contact the team for any advice on: **DPA**
- ASD information pack to be sent to parents.
- Follow up appointment from Community Paediatrician
- Axel's social communication needs and behaviour should be considered within the context of their ASD diagnosis and supported as appropriate by relevant strategies which may be identified by the various professionals working with them. It is advised that parents and school should stay in regular contact to ensure that any support is consistent across both the home and school environments.

- Visual support should be implemented consistently as an integral part of the whole day both at home and school. Visuals would support a) active listening skills b) attention to task and c) independent learning skills. Visuals don't have to be picture based. Pictures do help but for older children, who have good reading skills, a well-placed written visual timetable will also work well. It is sometimes presumed that verbal children 'don't need' or 'grow out' of a visual timetable. However, many children with ASD can be anxious about 'what will happen next', but don't always express this anxiety. A timetable would serve to support this type of potential hidden anxiety. School should also actively provide support if there are any unplanned changes or at other times where normal routine is altered (e.g. exams / school events / trips, changes between year groups and changes of teachers). Transition strategies could include resources such as photo transition books, Social Stories, staggered starts and practice / preparation visits.
- In certain situations, either at home or at school, it may be helpful to explicitly teach a specific social skill or strategy. Social situations may need to be explained more clearly. Writing down information in a Social Story or Comic Strip Conversation format rather than explaining things verbally is sometimes recommended for these situations. Advice on Social Stories and Comic Strip Conversations can be found on the National Autistic Society Website www.autism.org.uk and www.carolgraysocialstories.com.
- Families may wish to seek advice and guidance from the Social Communication Team via e-mail socialcom@sefton.gov.uk or via the Local Offer <https://www.seftondirectory.com/>
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- Should you or your child require information or support regarding their education and related health and social care issues advice can be sought from: Special Education needs & Disability Information Advice & Support Service (SENDIASS). This was formally known as 'Parent Partnership'. Telephone: **DPA** E-mail: seftonsendiass@sefton.gov.uk
- Applying for Disability Living Allowance (DLA) may help to support daily living needs such as mobility and care costs.

- Our social communication skills change all the time. Choosing how best to help and support your child with this will take time and there may be elements of trial and error.
- School to complete referral to ADHD pathway.

The content of this report has been agreed between the professionals involved in this team.

Yours sincerely

ASD TEAM
NEURODEVELOPMENTAL PATHWAY

Copy to:

Dr EE Arnold
Roe Lane Surgery
172 Roe Lane
Southport
Merseyside
PR9 7PN

Alder Hey Children's

NHS Foundation Trust

Alder Hey

Eaton Road

Liverpool

L12 2AP

Tel: DPA

Sonya Brumskill - PCO DPA

<http://www.alderhey.nhs.uk/repeat-prescriptions>

Department of Developmental Paediatrics

Southport

Our Ref: ZS/ha DPA

Date of Clinic: 07/07/2021

Date Dictd: 07/07/2021

Date Typed: 10/07/2021

Dr EE Arnold
Christiana Hartley M/prac
5 Curzon Road
Southport
Merseyside
PR8 6PL

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006

Hospital No. DPA

NHS No. DPA

Problems:

Autistic spectrum disorder (diagnosed 16/02/2021)

Anxiety disorder with avoidance behaviour

School: The Acorns school

I had a video consultation with Axel today. His father Alphonso was also present. They did not switch on the video as Axel does not like to be on the video. I was talking to them through the audio only.

Axel was started on propranolol 10mg twice daily by the CAMHS team on the 02/07/2021. Axel said that he is not taking these medications because he has read on the NHS website, and he does not have any physical symptoms.

His general health has remained well. His appetite is okay. He usually sleeps anytime from 2am to 11am. He is usually watching Youtube till he goes to sleep.

Plan:

1. I have suggested arranging an appointment with the CAMHS team to discuss about the medications.
2. I have explained to him and to Alphonso that supports for the Autism come from the support organisations and the education departments. As a Community Paediatrician we have no role in it. Therefore, I am discharging him from the Community Paediatrics. They agreed.

Currently the Community Paediatrics / ASD / ADHD service are receiving an extremely high volume of calls. We understand the frustration this is causing to families trying to contact us and are working on a solution to remedy this. If you need to contact the

This patient interaction took place during the Covid-19 pandemic.

service please email commpaedsqueries@alderhey.nhs.uk. We are aiming to respond to all emails within 2 working days of receipt.

Yours sincerely

Electronically checked and authorised by Dr. Zaffar Sultan

Dr. Zaffar Sultan
Consultant Community Paediatrics

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

This patient interaction took place during the Covid-19 pandemic.

Alder Hey Children's

NHS Foundation Trust

Alder Hey

Eaton Road

Liverpool

L12 2AP

www.alderhey.nhs.uk

Tel: DPA

Secretary: DPA Ext: DPA

Fax: DPA

Email: ciara.o'shea@alderhey.nhs.uk

Department of Paediatrics

Dr E Weir - Consultant Paediatrician

PCO: Ciara O'Shea

Our Ref: EW/sw DPA

Date of Clinic: 08/09/2022

Date Dictd: 09/09/2022

Date Typed: 13/09/2022

Dr L Ramasubramanian
Consultant Child & Adolescent Psychiatrist
Alder Hey Children's NHS Foundation Trust

Dear Dr Ramasubramanian

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

Diagnoses:

1. ASD.
2. Anxiety.
3. Avoidant behaviours.
4. Previous school refusal.
5. Previously reduced food intake.

Medication:

Fluoxetine 3 mg once daily.

Allergies:

None known.

History:

It was lovely to meet Axel in clinic along with his dad. He had been referred as he had reduced the amount of food he was taking and his weight had reduced. After meeting with his Psychiatrist and with the Dietitian, Axel has now increased the amount that he is eating. He is tending to have McDonald's and ready meals at home. He will also eat things like pasta, spaghetti Bolognese and egg on toast and will also drink some smoothies. He told me that yesterday he had two pies in the morning, a pasta meal from the Co-op and some muffins and in addition tries to drink plenty of water.

He tells me that around six months ago he was not eating very much at all and only eating small amounts when he was very hungry. Currently, he is aiming to have around 3000 calories per day and does want to gain weight. Axel himself feels he can continue to do this. I note when talking to Axel that he does not have much dairy in his diet and have suggested that he add in at least a glass of milk per day, which he thinks he would be able to do.

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Previously, he tells me he was experiencing dizzy episodes but these have now settled and he is not experiencing any physical symptoms. Axel is generally otherwise fit and well from a physical health perspective, he currently is on 3 mg of Fluoxetine per day, has no known drug allergies and his immunisations are up to date.

His dad tells me he was born at 8 months' gestation but weighed a reasonable weight and was with mum the whole time. He was fit and well in the newborn period. He lives at home with his parents and 18 year old brother **DPA** and is wheelchair dependent.

Axel's dad tells me he has not been in school since 2019, although has previously tried education in referral units and special schools and they did not suit him. Currently, he tends to spend his day watching TV and YouTube videos.

Examination:

Height 172.3 cm, weight 50.5 kg increase of 5 kg since last recorded weight, blood pressure 121/83 mmHg, pulse 86, percentage median BMI 85.3 kg/m²

On examination today, Axel appeared alert and well with no evidence of any jaundice, anaemia, clubbing or lymphadenopathy. Examination of his heart, chest and abdomen were all normal.

Investigations:

Blood tests requested for full blood count, ferritin, iron studies, liver function tests, lipid profile, selenium, thyroid function tests, renal profile, bone profile, vitamin A&E, vitamin D and zinc. Bloods as yet not received.

Management:

Axel has made great improvements to his dietary intake, which is resulting in a good weight gain, I would suggest that he has a multivitamin, Axel did not like the Forceval tablets and I have suggested that he have a look around the supermarket and take any multivitamin, which he feels he could tolerate.

I will also send a copy of our calcium dietary fact sheet so he and his parents can look together to see how to maximise the amount of calcium in his diet. I will arrange further follow-up in around four months in my telephone clinic but will have arrangements made for him to be weighed before this appointment.

Yours sincerely

Electronically checked and authorised by Dr Elaine Weir

Dr Elaine Weir
Consultant Paediatrician

Copy to:

This patient interaction took place during the Covid-19 pandemic.

Dr EE Arnold
Christiana Hartley M/prac
5 Curzon Road
Southport
Merseyside
PR8 6PL

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

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Calcium : Fact Sheet

Calcium is important at all ages for having strong bones and teeth. This information sheet lists the recommended amounts of calcium for different groups of people and the foods and drinks that are high in calcium. Be sure to choose a wide variety of foods to get all the nutrients your body needs.

Table of Calcium Requirements:

Group	Age	Calcium (mg)	No. of 50g portions/day
Children	7-10	550	11
Adolescents	11-18	1000	20

The following tables list foods in groups from highest to lowest calcium content.

Foods providing 6 portions of calcium/day:

Food	Amount	How many did you have today?
Edam, Gouda or Feta cheese	2 miniature cheeses	
Paneer or parmesan cheese	About the size of 2 thumbs	
Cheese omelette	1 serving	
Quiche (with cheese & egg)	1 serving	
Macaroni cheese/Lasagna/Moussaka	1 serving	
Total times 6:		

Foods providing 4 portions of calcium/day:

Food	Amount	How many did you have today?
Milk/milk drink (e.g. hot chocolate) - with any type of cow's milk	1 glass/mug	
Calcium fortified soy milk	1 glass/mug	
Cheddar cheese	Matchbox size	
Yoghurt (dairy or fortified soya)	1 pot /3 large tbps	
Porridge (made with milk)	1 bowl	
Halloumi cheese	2 slices	
Cauliflower cheese	1 serving	
Pizza (including a cheese topping)	¼ of a large pizza	
Tofu	½ a block	
Canned sardines	1 can	
Rice Pudding	1 pot/3 large tbps	

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Total times 4:

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Foods providing 2 portions of calcium/day:

Food	Amount	How many did you have today?
Cottage cheese	3 tbps	
White pitta bread	1 (large)	
Naan bread	1/3 (large)	
Baked beans	1 can (small)	
Sausages (meat or vegetarian)	2	
Canned salmon	1 can	
Custard Pot	1 pot	
Fortified breakfast cereals	6 tbsp/lg bowl	
Mars Bar	1 (standard size)	
Ice Cream	2 scoops	
Total times 2:		

Foods providing 1 portion of calcium/day:

Food	Amount	How many did you have today?
Fortified Fromage frais	1 mini pot	
Muesli	1 serving (50g)	
White bread	1 medium slice	
Wholemeal bread	1 thick slice	
Boiled pasta	10 tbsp	
Boiled rice	10 tbsp	
Veggie Burger	1	
Canned tomatoes	1 can	
Broccoli/ green beans	3 large tbsp	
Dried apricots	8	
Oranges	1 whole/1 glass of juice	
Almonds	10/ small handful	
Cheese triangle	1	
Milk chocolate	3 squares	
Total:		

Sum of all totals: _____

If you are not meeting the daily requirement for calcium on most days of the weeks you may need a calcium supplement.

References:

- Royal Osteoporosis Society website
- British Dietetic Association website
- Nutrition.org website

This patient interaction took place during the Covid-19 pandemic.

This patient interaction took place during the Covid-19 pandemic.



Alder Hey Children's

NHS Foundation Trust

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Fax: DPA

Email: ciara.oshea@nhs.net

Department of Paediatrics
Dr E Weir - Consultant Paediatrician
PCO: Ciara O'Shea

Our Ref: EW/je/ DPA

Date of Clinic: 31/01/2023

Date Dictd: 31/01/2023

Date Typed: 31/01/2023

Dr EE Arnold
Christiana Hartley M/prac
5 Curzon Road
Southport
Merseyside
PR8 6PL

Dear Dr Arnold

Axel RUDAKUBANA
10 Old School Close
Banks, Southport PR9 8SB

D.O.B. 07/08/2006
Hospital No. DPA
NHS No. DPA

Diagnosis:

1. ASD
2. Anxiety
3. Previously reduced food intake – now improved

Medication:

Sertraline liquid 25mg on an increasing dose

History:

It was lovely to speak Axel's dad on the telephone today as part of a virtual clinic. I understand that Axel had gone to bed late last night so was not available for today's consultation. His dad tells me his eating has much improved, both in quantity and that he is now trying new things. He has recently been seen by the dietitian around a month ago and weighed 60.4kg at that time and is due to see them again. His dad is happy that he has continued to put on weight although notices that his appetite has possibly slightly decreased since starting sertraline. He is aiming for 64kg and is currently having 3 meals during the day mostly plus snacks.

His dad did mention that they are concerned regarding Axel's attention span and would like to be considered for an ADHD assessment, I wonder whether this could be reviewed by his CAMHS team or his GP?

Management:

As Axel is doing well with his eating and is gaining weight and remains under the care of the dietitian, I am happy to discharge him from my clinic today.

Yours sincerely

Electronically checked and authorised by Dr Elaine Weir

Dr Elaine Weir
Consultant Paediatrician

Copy to:

The Parent/Guardian of
Mr Axel Rudakubana
10 Old School Close
Banks
Southport
Lancashire
PR9 8SB

Dr A Molyneux
Consultant Child and Adolescent Psychiatrist
Alder Hey Children's NHS Foundation Trust