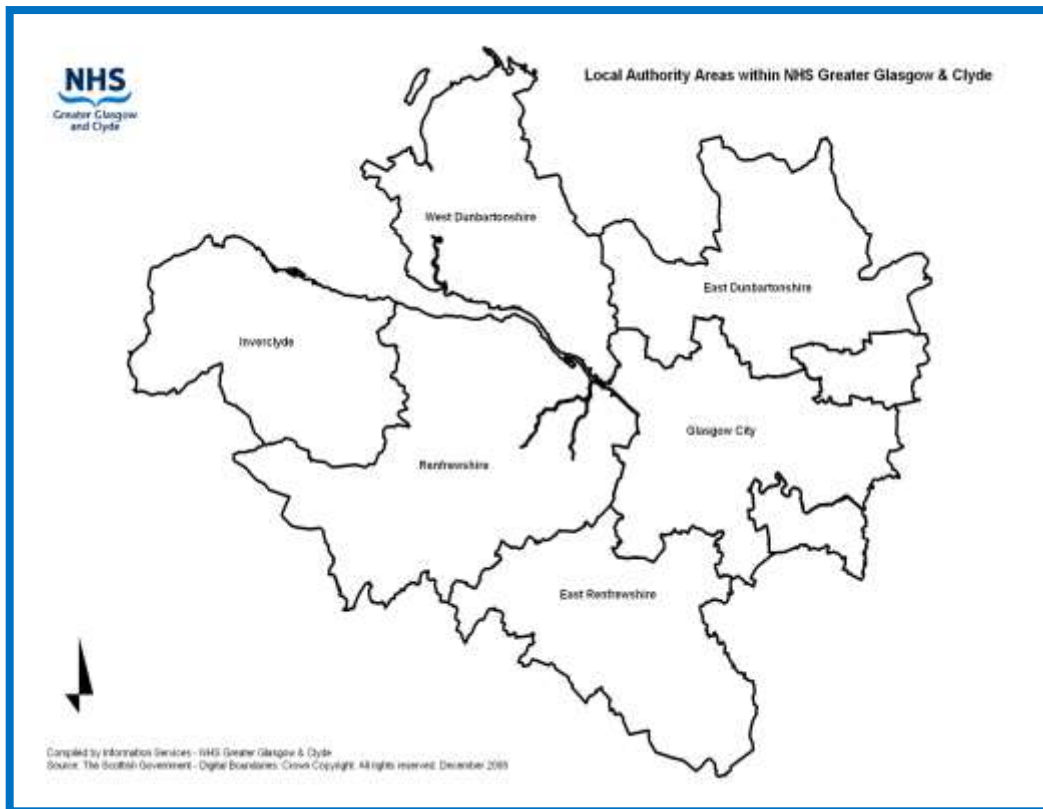


# Specialist Children's Services

## Children's Visual Impairment Services Greater Glasgow and Clyde

### Getting It Right for Children with VI

# Annual Report 2018 - 2019





[www.i-needs.org](http://www.i-needs.org)

## 1. Introduction

This annual report documents the work of the multiagency team across Greater Glasgow and Clyde NHS Board and its six local authorities working with children who have visual impairment ( VI ) and their families . These integrated services were set up in 2008 following the National Eyecare Review.

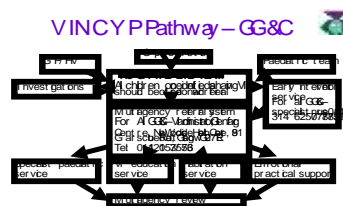
The multiagency team for children with visual impairment have continued to deliver high quality integrated services over this year with positive feedback from parents and professionals. It is clear that financial restrictions are affecting all services, but with pathways well established and multiagency cooperation, all are working to achieve the national standards of care for children with VI and endeavouring to minimise the impact on children and families. Activity is reported along with gaps in services, as feedback suggests this is of value in terms of planning services and addressing the needs of children.

This year we are very pleased to report on our joint functional vision assessment team being awarded the Greater Glasgow and Clyde NHS Board Platinum Chairman's Award for Clinical Practice. (Appendix 1). This team comprises orthoptists from Womens and Childrens and acute services, an optometrist, occupational therapist and paediatrician from specialist childrens services and teachers of VI from each of the six local authorities.

## 2. Integrated care pathways

The central referral pathway from all eye departments across GG&CNHSB is used to refer children to appropriate visual services timeously ( available via staffnet ) . This system is embedded in the practice of clinicians seeing children regularly, and reflected in each health board nationally.

Figure 1



There is a managed generic service email address [ViAdmin@ggc.scot.nhs.uk](mailto:ViAdmin@ggc.scot.nhs.uk) for use by all partners to reduce the vulnerability of the service to administrative change.

## 3. Data collection

### Data system

Our database holds information about children with visual impairment across GG&C to allow for monitoring of due dates for review meetings etc and to identify information when requested. It is particularly important in being able to quickly establish when parents / young people have provided

consent for their information to be shared between agencies. Unfortunately with administrative changes all children were not recorded on this, leaving gaps in information and inaccurate figures for planning however this is now being rectified, supported by the VI nurse. There are currently 447 children identified with a visual impairment on the database (national prevalence figures would suggest 616). 59% of these children live within Glasgow City Council area (14.5% Renfrewshire, 9.6% East Renfrewshire, 7% West Dunbartonshire, 4% Inverclyde, and 5% East Dunbartonshire). Updating and correction is not complete and this figure therefore does not yet represent a true picture of the population due to variability in recording. Work continues to improve this.

The national VINCYP datasystem is used across GG&C with an orthoptist trained in each eye department to enter data and our paediatrician entering the majority of data. Access is available to specified health staff only. The number of children notified within our Board and local authorities is increasing and the process to contact families to request that they consent to their child's data being added is progressing. As at April 2019 information for 299 children from GG&C had been entered, increasing entries by 100% from the previous year. ( Appendix 2 ) This system will allow better information for local and national planning, however the local system will require to remain in place for day to day working.

#### 4. Multiagency review

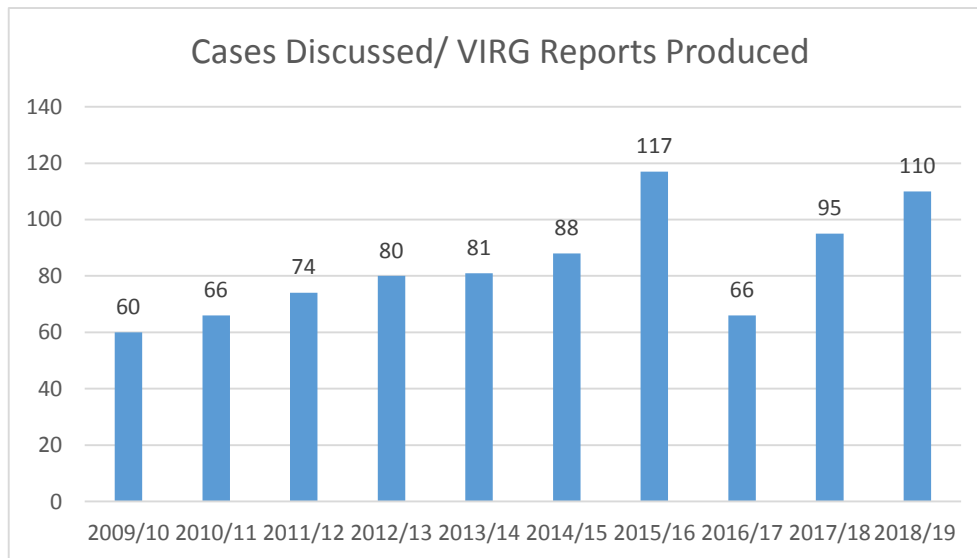
Visual Impairment Review Groups (VIRGs) continue to meet regularly in each local authority area and produce individual VI specialist advisory reports for children to support their overall care plan. The groups advise professionals on management, identify gaps and duplications in services and report them to relevant service managers in order to effect change for individuals and services. These groups are also responsible for updating service information for their area. The number of meetings scheduled is calculated according to population per local authority. This year most scheduled meetings were able to be delivered but 3 were cancelled at short notice due to the education representative being unavailable. Services remains innately vulnerable due to the small number of specialists for these children with low incidence disability (Table 1)

**Table 1. No of multiagency meetings and care plans produced in 2018/19**

	Meetings delivered 16/17	Meetings delivered 17/18	Meetings delivered 18/19	Individual Reports produced 16/17	Individual Reports produced 17/18	Individual Reports produced 18/19
<b>Glasgow</b>	9	16	15*	25	52	56
<b>East Dunbartonshire</b>	2	2	2	7	6	8
<b>West Dunbartonshire</b>	2	3	3	6	7	12
<b>East Renfrewshire</b>	3	3	3	8	10	11
<b>Renfrewshire</b>	4	5	4	13	15	16
<b>Inverclyde</b>	3	2	2	7	5	7
<b>Total</b>	23	31	29	66	95	110

\*3 cancelled due to unavailability of education representative

**Figure 2 . VIRG – No of multiagency care plans completed per year**



The value of consistent, reliable administrative support and coordination within health has been acknowledged by education and social work services since services were developed. The above demonstrates the recovery over the 2 years following administrative disruption. This has only been achieved with significant additional input from the clinicians involved, and the patience and perseverance of all staff involved. The key importance of settled knowledgeable administrative staff is recognised and the improvement plan is addressing the remaining difficulties.

### **Issues identified as gaps / difficulties within services :**

In the majority of cases the recommendations made at a VIRG can be progressed. However, as part of the role a log is kept of difficulties identified through the process. The issues are grouped below :

#### **VIRG Organisation**

Service delivery has improved since last year, with some of the difficulties related to administration being resolved. However some issues with scheduling remained particularly within Glasgow. A plan to allow better coordination of scheduling was agreed with VI teachers and this was put in place at the start of 2019. Typing delays have improved over the year but some recipients still report delays in receiving reports.

There have been significant issues with the lack of attendance of the education representative within Glasgow resulting in several meetings going ahead without their input and 3 being cancelled. There have also been numerous meetings not attended by the Glasgow social work representative, however most of these were planned and unavoidable and information was provided prior to the meeting. Two secondary schools, one in West Dunbartonshire and one in Glasgow have failed to provide information or engage with the meetings despite these being scheduled for all their pupils in one afternoon.

## **Services**

**Qualified habilitation specialists** : A shortage of habilitation services continues to be an issue reported in all local authorities except West Dunbartonshire and East Renfrewshire. Low staffing within Renfrewshire particularly has resulted in an inability to provide assessments for all children requiring these, and delays in this occurring within Glasgow. Both these services provide mobility input in the main to most children, rather than full habilitation. Within East Dunbartonshire education have in place a short-term contract with Guide Dogs to provide some service. There continues to be no habilitation provision within Inverclyde, although this has been requested through 3<sup>rd</sup> sector organisations at times for specific difficulties identified for individual children. Visibility ( third sector ) work across the area to provide additional habilitation input, mainly within the community. It is recognised that a lack of independence skills, taught by habilitation specialists, is a significant cause of unemployment and emotional ill health in young people with visual impairment

**Qualified teachers of visual impairment ( QTVI )** : Over several local authorities ( West Dunbartonshire, Renfrewshire , East Dunbartonshire and Glasgow ) pupils continue to be assessed and supported by teachers who do not hold a VI qualification. No pupils in West Dunbartonshire had input from a QTVI previously but as of June 2019 one teacher is now qualified. Glasgow continue not to provide ongoing QTVI support to pupils in schools for children with additional support needs ( including children with no vision at all ) and have no QTVI supporting pupils within their visual impairment specialist provision in Darnley Primary or Hazelwood School. In East Dunbartonshire some pupils with severe visual impairment are supported entirely by teachers not qualified in visual impairment and likewise in Renfrewshire.

The lack of QTVIs has been raised at national level and through the National Inquiry into the Attainment of Pupils with Sensory Impairment. In Scotland there is a national standard set by VINCYP that all children with VI should have as a minimum an initial assessment by a QTVI within 4 weeks of identification. Within the Education Act Scotland , teachers who teach children with VI for more than 50 % of their time require to achieve the qualification within 5 years of commencing their post.

Individual difficulties have been reported with pupils in Glasgow not receiving support when they have higher visual processing difficulties with near normal clarity of vision, and with providing input to young children and babies with severe VI. Issues across local authorities have been raised regarding the need for training particularly in relation to supporting the use of on-body signing, work with young children and their families, along with understanding and developing strategies for children with higher processing difficulties.

**Health - Hospital Eye Service** There have been delays in children being seen and in results of investigations being fed back due to staff shortages with ophthalmology. There is a national shortage of paediatric ophthalmologists and both local and national solutions are being sought.

## **Communication**

There were individual incidents with a referral being sent to, but not received by Glasgow education , and in West Dumbarton input not being given to children

within nursery as there was no communication between nursery and the education VI service, along with advice not being provided by them on one occasion. In Renfrewshire there was also one instance of a school failing to implement recommendations to support the child made by the specialist teacher

### **Equipment and Connectivity**

Lack of provision of specialist equipment was raised within Renfrewshire and East Renfrewshire in relation to accessing switches to support children's visual development and in Renfrewshire difficulties with ensuring compatibility and connectivity of various devices required in class

Service managers have been alerted to these issues through their representatives or the chairperson of the group and have been asked to address them.

## **5. Service provision**

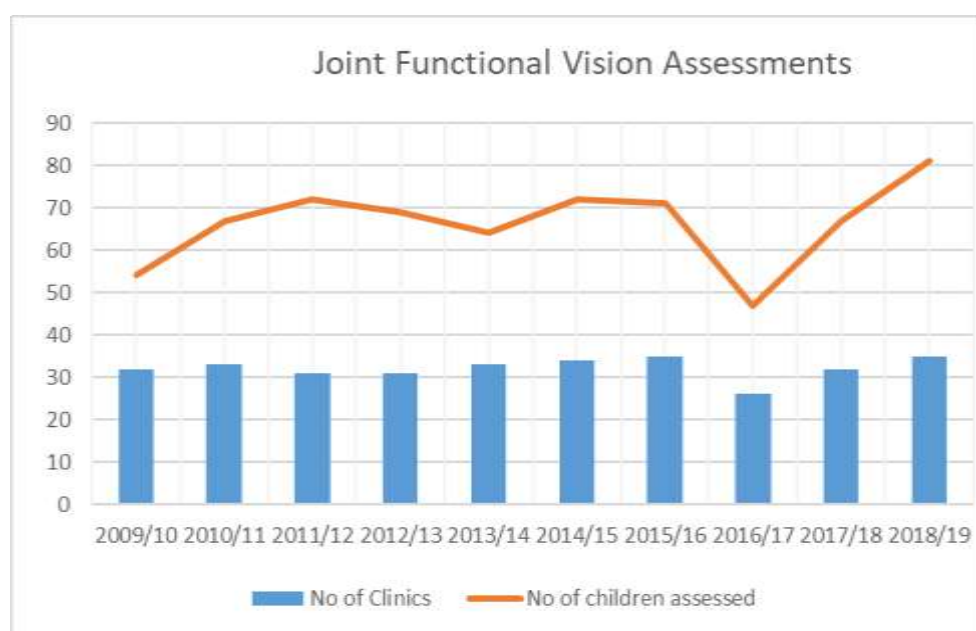
### **a) Joint Functional Vision Assessment (FVA) Clinics**

These clinics, run jointly between health and education, take place in the 6 LA areas and involve an orthoptist, optometrist, occupational therapist, VI Teacher and paediatrician. They are held outwith eye clinics in order to improve cooperation and achieve a more accurate assessment of everyday function. Three children can be seen per clinic. Feedback from parents and professionals indicates that this is beneficial. Accommodation is variable and there remain difficulties in East Dunbartonshire in finding suitable premises. Renfrewshire and West Dunbartonshire are within health premises as no other accommodation could be found. Accommodation is provided by education within Glasgow, and social work in Inverclyde. All accommodation at present allows a full number of appointments although in East Dunbarton the current accommodation remains unsuitable for some children. Once the new Woodside Health Centre opens in summer 2019 it may be possible to accommodate this clinic within the child development centre there.

**Table 2. Joint functional vision assessments**

	No of clinics delivered 2017/18	No of clinics delivered 2018/19	No of appts offered 2017/18	No of appts offered 2018/19	No of appts attended 2017/18	No of appts attended 2018/19	No of appts cancel'd 2018/19	No of appts child not brought 2018/19
Glasgow	19	19	58	58	42	43	7	8
East Dunbartonshire	2	3	5	6	4	6		
West Dunbartonshire	3	3	9	7	4	7		
East Renfrewshire	2	3	6	9	4	7	2	
Renfrewshire	4	5	12	15	9	14	1	
Inverclyde	2	2	4	5	4	4		1
<b>Total</b>	<b>32</b>	<b>35</b>	<b>94</b>	<b>100</b>	<b>67</b> <b>( 71%)</b>	<b>81</b> <b>( 81%)</b>	<b>10</b>	<b>9</b> <b>( 9%)</b>

**Figure 3 Joint Functional Vision Assessments – Number completed**



Continuing recovery of the service is demonstrated however difficulties remain in ensuring appointments are fully utilised. However, it should be recognised that many of these children have significant health needs and appointments may require to be cancelled at short notice due to illness.

There remains only one paediatrician, one optometrist and in most local authorities only one QTVI able to deliver these clinics which continues to leave services vulnerable.

At these clinics, assessment for and provision of basic independence and low vision aids continues. Over the year 15 low vision aids were issued to 11 children along with 6 independence aids to 2 children. This allows immediate access for children avoiding additional waits and clinics.

Training continues to be provided within clinics to a wide range of professionals including doctors, orthoptists, occupational therapists from GGC and other health boards, VI teachers from our and other local authorities, and habilitation specialists again from our own and other organisations.

### **b) Habilitation Training ( Child Mobility and Independent Living Skills )**

As highlighted through the VIRGs, lack of services for children continue to be of concern. Visibility continues to provide some services on an ad hoc basis in addition to local authority and contracted services from Guide Dogs. Little progress has been made as yet in addressing this national problem, but meetings have taken place led by Scottish Government to scope the extent of the shortage nationally and devise plans to address it.

The West of Scotland mobility network ,created by our group to provide professional support and CPD opportunities has ceased to meet due to a lack of leadership from within the group.



### **c) Early Intervention**

The VI specialist nurse, working part-time and covering all GG&C continues to provide early support to children and their families following diagnosis. This is a permanent post funded by Specialist Children's Services, GG&CNHS Board. She maintains close links with eye clinic clinicians within the children's hospital, provides telephone advice, home visits, ward visits, advice on play and interaction, works closely with Visibility in the provision of parent and toddler groups and links with VI teachers once they become involved. She is mainly involved with families of young children but also supports young people who suffer visual loss in childhood or the teenage years. She has supported 28 newly diagnosed children and their families throughout the year. This model of service for supporting parents and children remains recognised nationally as a good model of practice.

### **d) Low Vision Aid Service**

This service is designed to allow VI teachers to refer directly and to provide child specific clinics when they can attend with their pupils. Arrangements are in place across all areas. Clinics are now ad hoc rather than regular due to low numbers which can make linking with teachers more problematic. There is a low but steady uptake of this clinical service which remains important despite the widespread availability of electronic aids

## **6. Information / Communication [www.i-needs.org](http://www.i-needs.org)**

The i-needs website was launched in 2013 . This is sponsored by the Childrens VI Steering Group and run/ monitored on its behalf by Visibility. It has been designed with parents and a significant amount of the content is provided and directed by them. It was created to help in directing parents to the most useful information ( identified by our parents and professionals ) and give practical information on toys etc and local service information. Positive feedback has been received from families locally but also from national organisations. The web address is printed on all joint clinic reports and on business cards which professionals have been encouraged to give to families. The site information is developed and updated by Visibility's family workers, the VI specialist nurse and the children and families. Local service information is provided on VI services from all agencies, and is updated at least annually.

## **7. Monitoring and Strategic Overview**

The Children's Visual Impairment Steering Group with representation from all local authorities and the voluntary agencies meets biannually. The purpose of this group is to: maintain progress, monitor effectiveness, promote interagency working and links, develop services, promote research and act as a local expert group for local and central government.

## **8. Future Priorities**

Improvement in our services, and hence outcomes for children, continues to be planned around the guidance produced by VINCYP. We are pleased that much of our work from the GG&C service has been adopted and recommended for national use by VINCYP. A priority for all of our services continues to relate to ensuring and maintaining a skilled workforce: there is only one paediatrician, and optometrist with a specialist interest/expertise in VI ; many children do not have access to a qualified teacher of visual impairment; and habilitation services are not universally provided by qualified workers across the area. Our professionals are encouraged to attend and contribute to the provision of national training on childrens visual impairment provided by VINCYP. Our priorities centre around ensuring that our workforce is qualified and skilled.

Dr Katherine Spowart, Consultant Community Paediatrician and Clinical Lead Children's Visual Impairment Services GG&CNHSB on behalf of the GG&C Childrens VI Steering Group

## GG&CNHSB Platinum Chairman's Award 2018 for Clinical Practice

This award recognises the importance of staff innovation which helps and improves everyday practices in the workplace and/or approaches to patient care.

### Platinum Winner - Vision Assessment Team



This small team developed a vision test which could reliably indicate the smallest size of object that a child could see when a traditional vision test was not able to be used.

Young babies and children with poor vision or developmental difficulties like to look at things close up but tests of vision for this age are designed to be used at 50cm to 1 metre away and results are not easily translated into layman's language.

The test developed is a simple set of cards with an exactly measured white disc on them, randomly placed, along with a set of exactly sized plastic discs which can be used on a black background.

It has been used and piloted within the joint functional vision clinics delivered by the team and has allowed recording of vision in children where previously there was no measure. It has allowed parents and specialist teachers to know what size of objects and materials to show a child in order that they can see them.

Following use within the team, use was widened to the eye clinic within RHC and orthoptists have been using it regularly reporting it to be helpful and informative for parents.

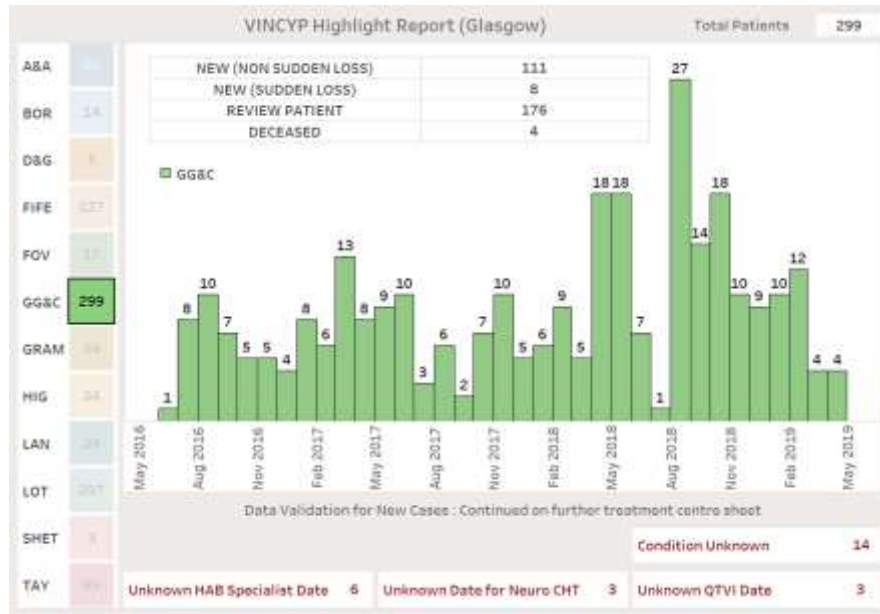
The test doesn't need special training to use, or cooperation of the child and gives the parent an understanding of what their child can see.

It has been adopted by the national MCN (VINCYP) as the test of near low vision in early development and is now used by health and specialist visual impairment education staff across the country without any challenge or question, allowing all services across Scotland to measure, record, and explain this type of low vision in the same way for the first time.



## Appendix 2 GG&C – Extract of Information from the VINCYP Clinical Audit System

At April 2019 299 children and young people living in GG&C were notified to VINCYP



Of the 299 children notified 119 had newly identified visual impairment. As part of the drive to meet national standards of service delivery data is collected on the time for children to receive services following identification and whether this meets national standards. This data is incomplete, partly due to an incomplete response to referrers from services and in the case of habilitation, often because there is no service provision within many months or at all. Data return is however improving over time.



Appendix 3

Children's Visual Impairment Steering Group

	Professional Role	Organisation Represented
Patricia Lafferty	Resource Worker	Inverclyde Council
Clare Sweeney	Children and families Worker	Visibility
Anne-Marie Fleming	Children and Families Officer	RNIB
Julie Steel	Quality Improvement Officer	Glasgow Education
Karen Keith	Headteacher	Glasgow Education
Kevin McNaught	SW Team Leader	Glasgow Social Work
Heather McColgan	VI Teacher	West Dunbartonshire Council
Sandra Metcalfe	Team Leader Social Work	Renfrewshire Council
Katherine Spowart	Consultant Paediatrician	GG&C, SCS
Hazel Leiper	VI Teacher	East Renfrewshire Council
Diana Frater	VI Teacher	East Dunbartonshire Council
Elaine McCrossan	Lead Paediatric Orthoptist	Hospital Eye Service

## **Appendix 4 – Reporting pathways**

### **Glasgow**

#### **Education**

Colin Crawford , Head of Children's Services ( Education )

#### **Health**

Jamie Redfern, General Manager of Royal Hospital for Children

Stephen McLeod, Head of SCS

Karen Lamb, service manager SCS

Jim Bretherton, Ophthalmology Service Manager , Acute Services for GGC

#### **HSCP**

Mike Burns , Assistant Chief Officer, Childrens services

### **East Dunbartonshire**

#### **Education**

Jacqueline MacDonald, Chief Education Officer

#### **Health (as Glasgow)**

#### **Social Work**

Paulo Mazzoncini, Chief Social Work Officer

### **West Dunbartonshire**

#### **Education**

Laura Mason, Chief Education Officer

#### **Health ( as Glasgow plus )**

Sheila Downie, service manager SCS

#### **HSCP**

Jonathan Hinds , Chief Social Work Officer

### **East Renfrewshire**

#### **Education**

Mhairi Shaw, Director of Education

#### **Health (as Glasgow)**

#### **HSCP**

Kate Rocks, Chief Social Work Officer

### **Renfrewshire**

#### **Education**

Steven Quinn , Chief Education Officer

#### **Health (as Glasgow plus)**

G McDaid, Service manager for SCS

#### **HSCP**

John Trainer , Head of Childcare and Criminal Justice

### **Inverclyde**

#### **Education**

Ruth Binks ,Head of Education Services

#### **Health (as Glasgow plus)**

Fiona Houlihan , Children's Service Manager

#### **HSCP**

Sharon McAlees, Childrens Services and Criminal Justice