The Validity of Autism Spectrum Diagnoses after the Age of 7 – Experience in a Community Child Development Centre

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Clalit Community Child Development Centre in Netanya, Israel

Netanya – a City of Immigration

- East Europe(1950)
- North Africa (1960)
- USSR (1970)
- Ethiopia (1980)
- Russia and Caucasian Mountains (1990)
- France (North Africa) (2000)

- 18% of children in Netanya – at risk

Clalit Child Development Centre

- Since 1997
- 30,000 children in area
- ~1500 new referrals each year
- 25 new ASD's diagnoses each year

Background

- Reliably diagnosed at 2-3 years of age
- Stability of the diagnosis until and in school age (Lord et al., 2006)
- Still in USA average age of ASD diagnosis : 5.7 (Shattuck et al., JAACAP 2009)
- With earlier age reported by others (Mandell, et al, Pediatrics 2005)

- More severe cases are diagnosed at an earlier age
  (Wiggins et al. 2006)

- Even qualified professionals can hesitate and diagnose as late as 13 month after first assessment
  (Wiggins et al., 2006)

Iceland : Cohort of 99 ASD Children

- Children diagnosed early were
  - more severely affected
  - IQ 20 points lower
- **Co-morbid** developmental disorders caused a delay in diagnosis
- Parents, felt the difficulties earlier than 3

- Jonsdottir S. L, et al. Children diagnosed with autism spectrum disorder before or after the age of 6 years. Research in Autism Spectrum Disorders (2010)

Why Early

- Early intervention will enable children to receive therapy, even to be “cured” sometimes (Helt et al., 2008)

- Risk of lowering chances of improvement with late diagnosis
- Risk of withholding correct genetic counseling

What Is The Problem

S p e c tr u m

Is there a Problem with Too Early?

If we "over-diagnose":

- Parental unnecessary stress and grief
- Ignoring other developmental Dx

- Other DC 0-3 Dx such as MSDD, attachment disorders?

- **Excessive public financial recourses**

Social Resources

- Social Security Certificate of Disability
- Special Welfare Committee
- Special Education Committee
- Remedial education, Monthly allowance, a personal assistant, extended health “basket” etc.

Tools

- Not standardized in Israel

- ADOS for < 18 months?
- ADI for younger children?
- SCQ for younger children?
- CARS > 2 y/o
- GARS > 3 y/o very elegant, not sensitive
- CHAT >18 m/o is now being validated
- DSM-IV criteria are mandatory in Israel at any age

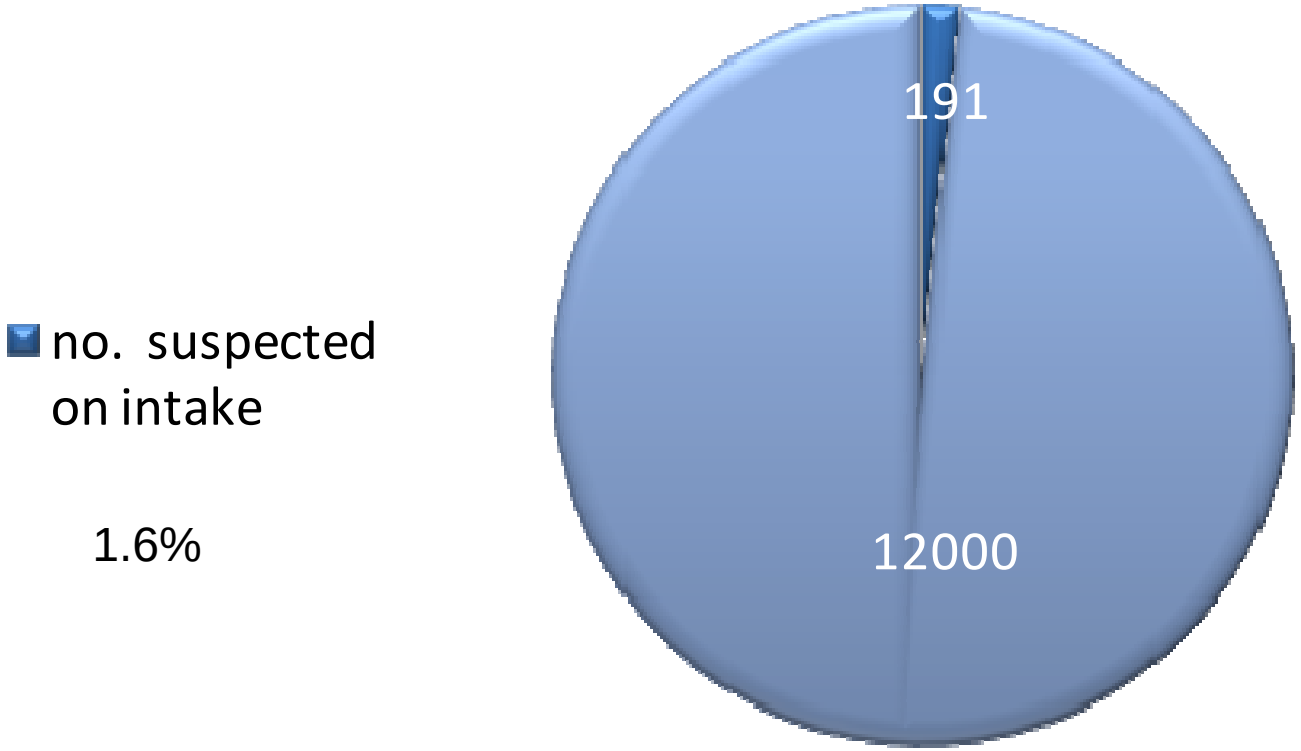
OUR QUESTIONS

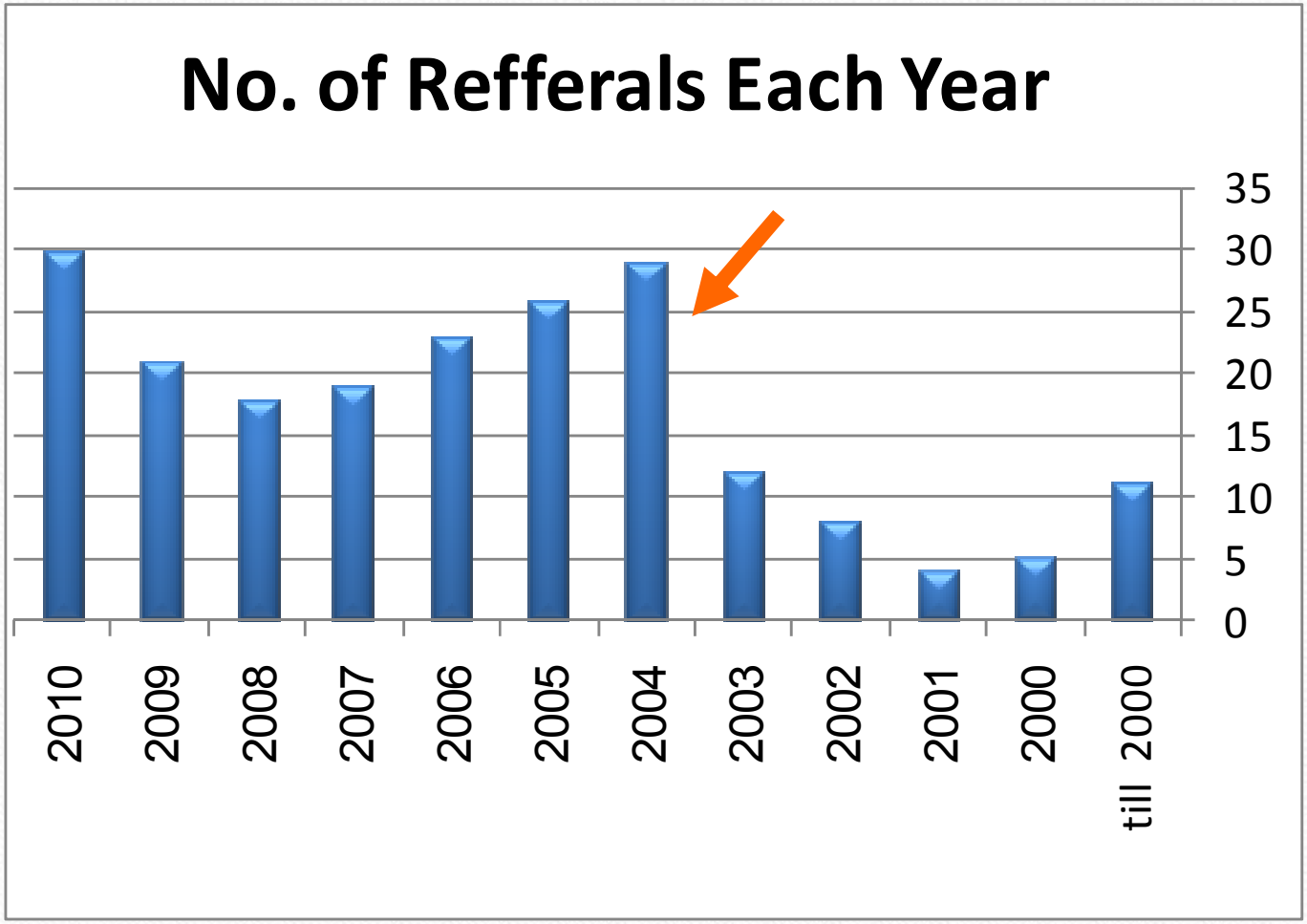
- Were we too hasty to diagnose our patients? (outcome after their 7th birthday)
- Were we sometimes too slow?
- Did the tools we used matter?

Population

- 191 children were evaluated for suspected ASD'S since 1998
- 166 were given ASD's diagnoses
- 78 have passed the age of 7 y/o
- 4 non relevant (Diagnosed elsewhere)
- 74 remaining for analysis

1999-2010 Netanya Clalit Child Dev Center




No. of Refferals Each Year
35
30
25
20
15
10
5
0
2010
2009
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2005
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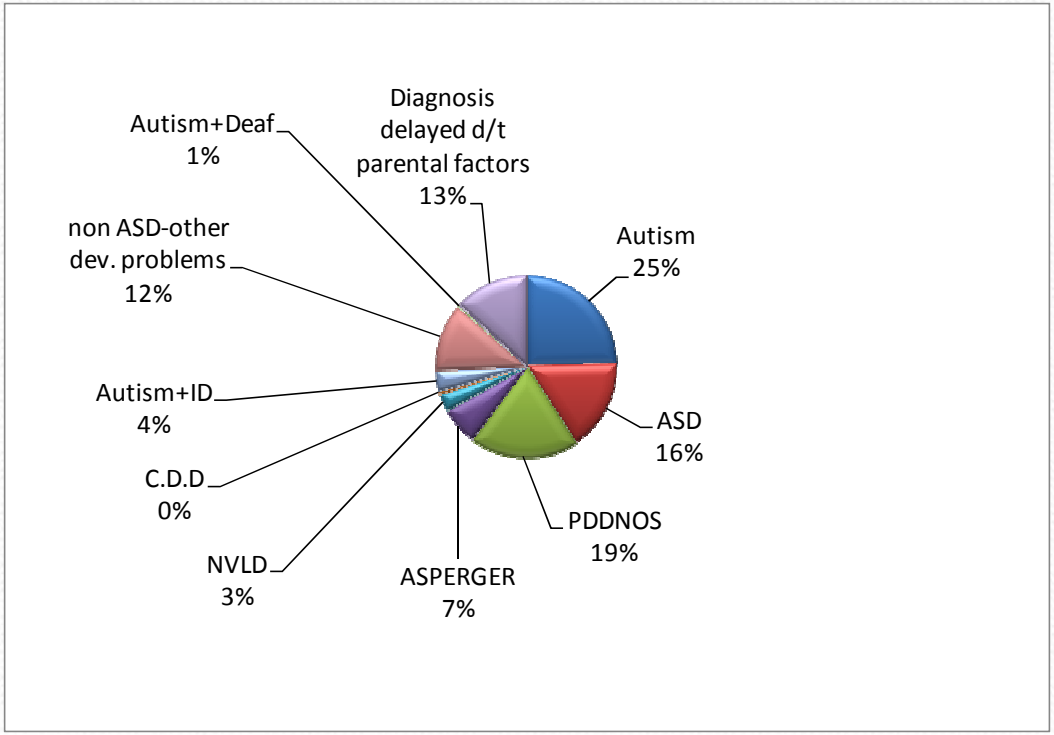
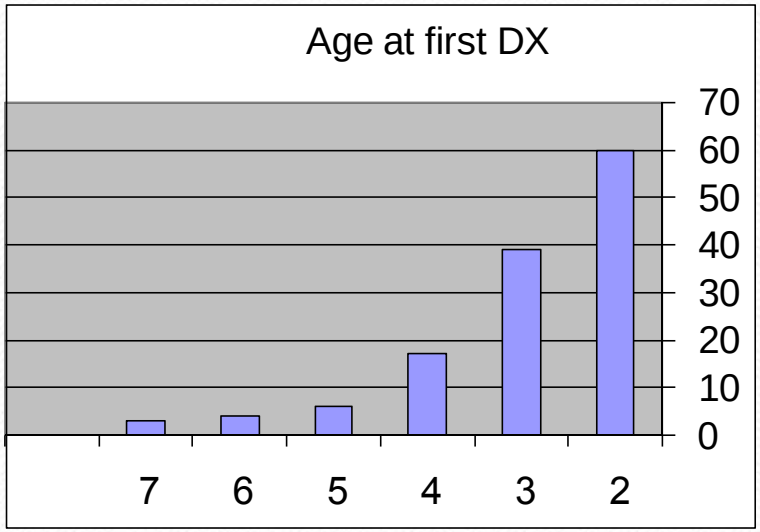
2001
2000
till 2000

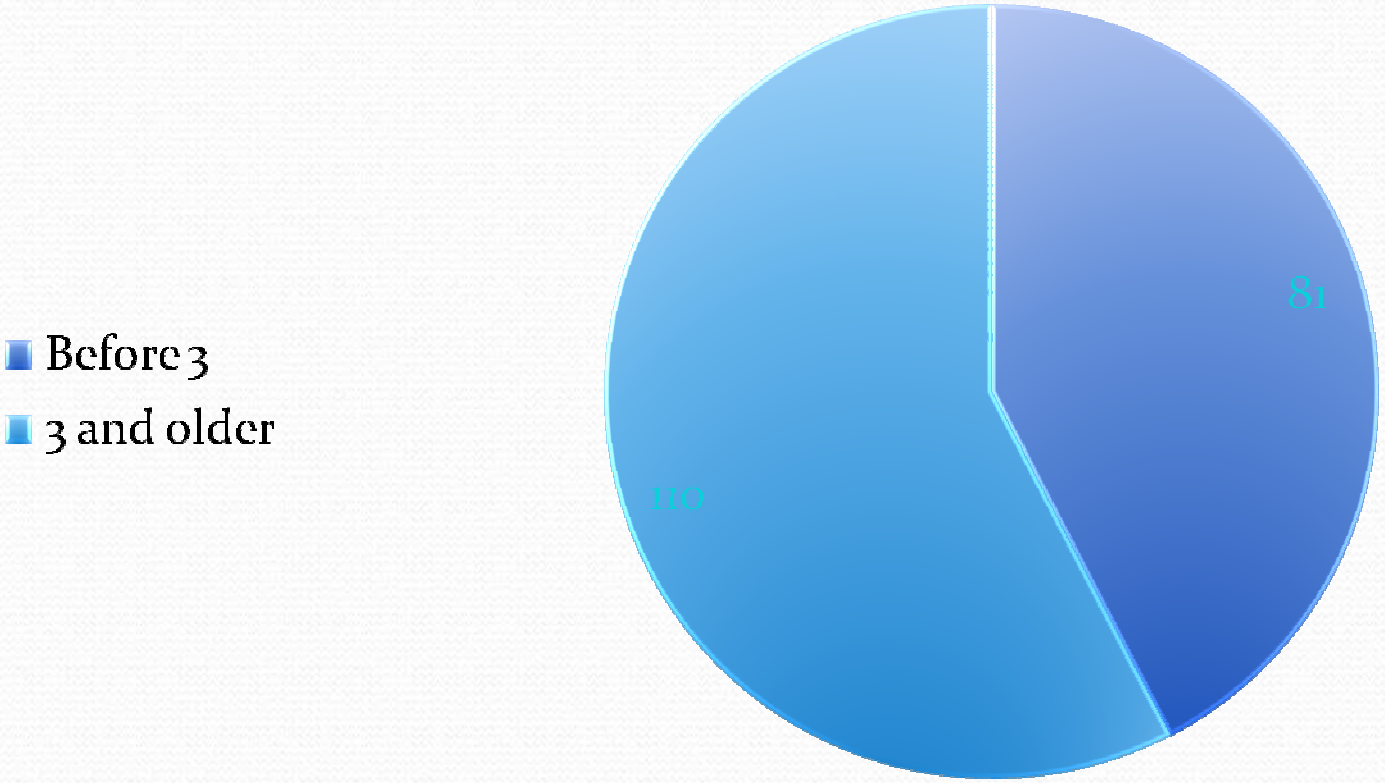
191 suspected children



191 Children



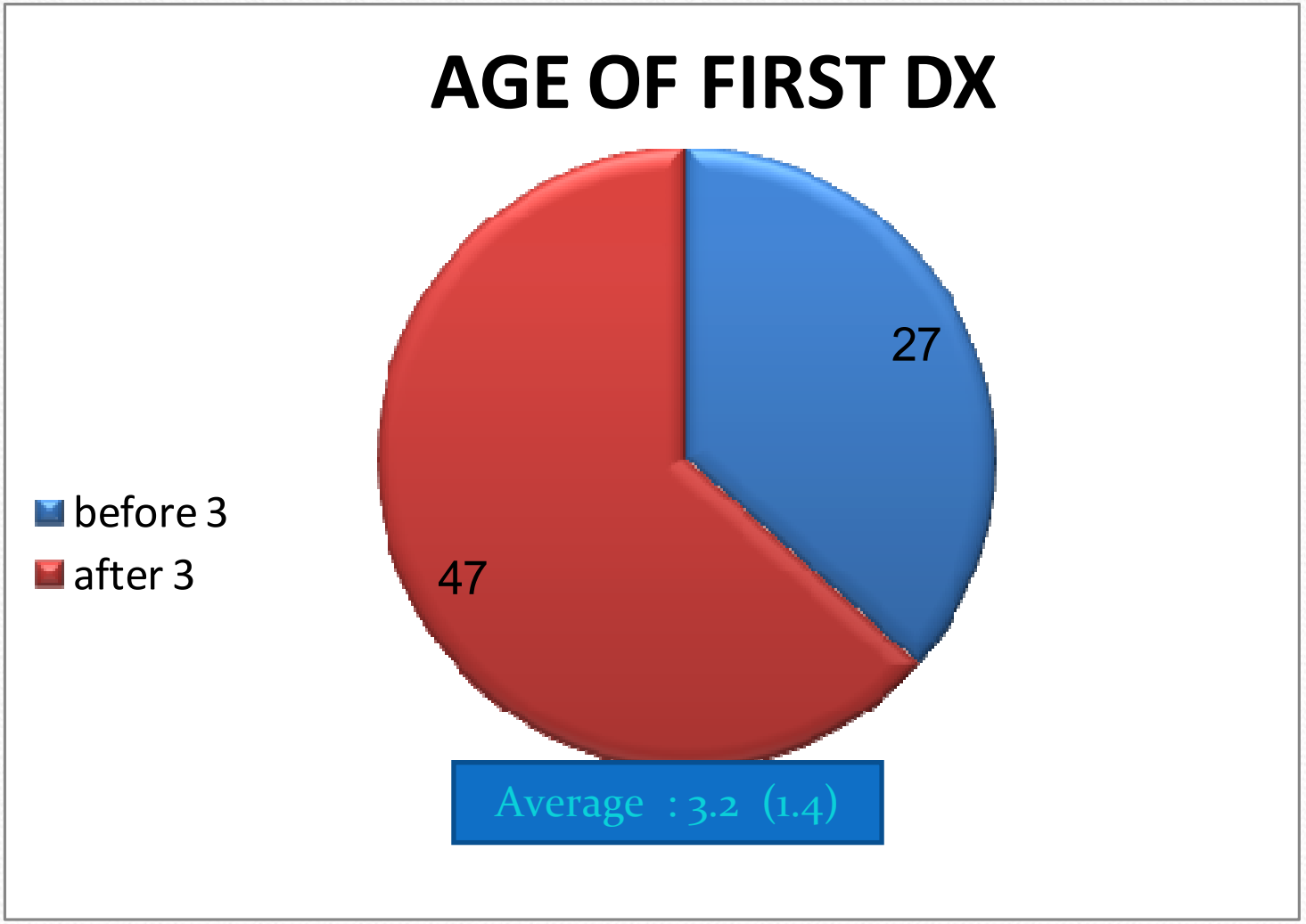
191 Children: Age at Diagnosis



Average age of Diagnosis: 3.08 (1.45) years

The Children Over 7 Y/O

OLDER THAN 7



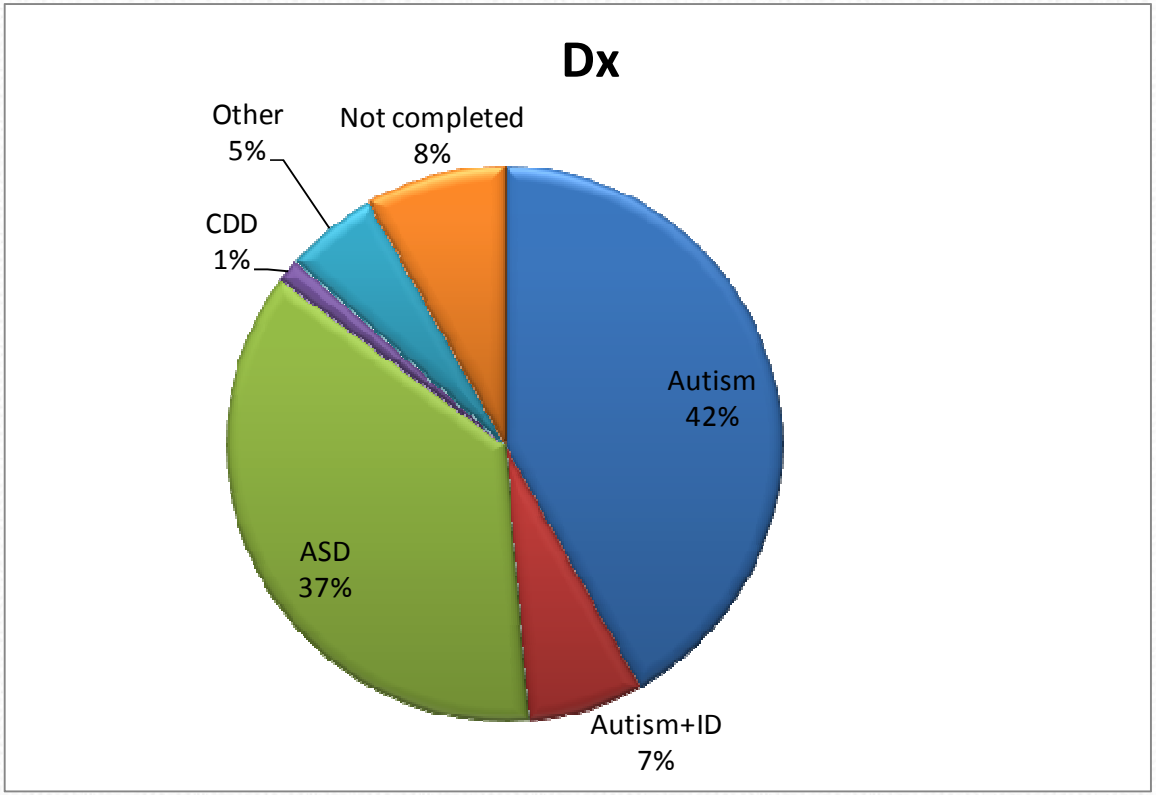
OLDER THAN 7

	FEMALE	MALE
Autism	3	28
Autism+ID	0	5
ASD	1	26
	4	59

P= NS

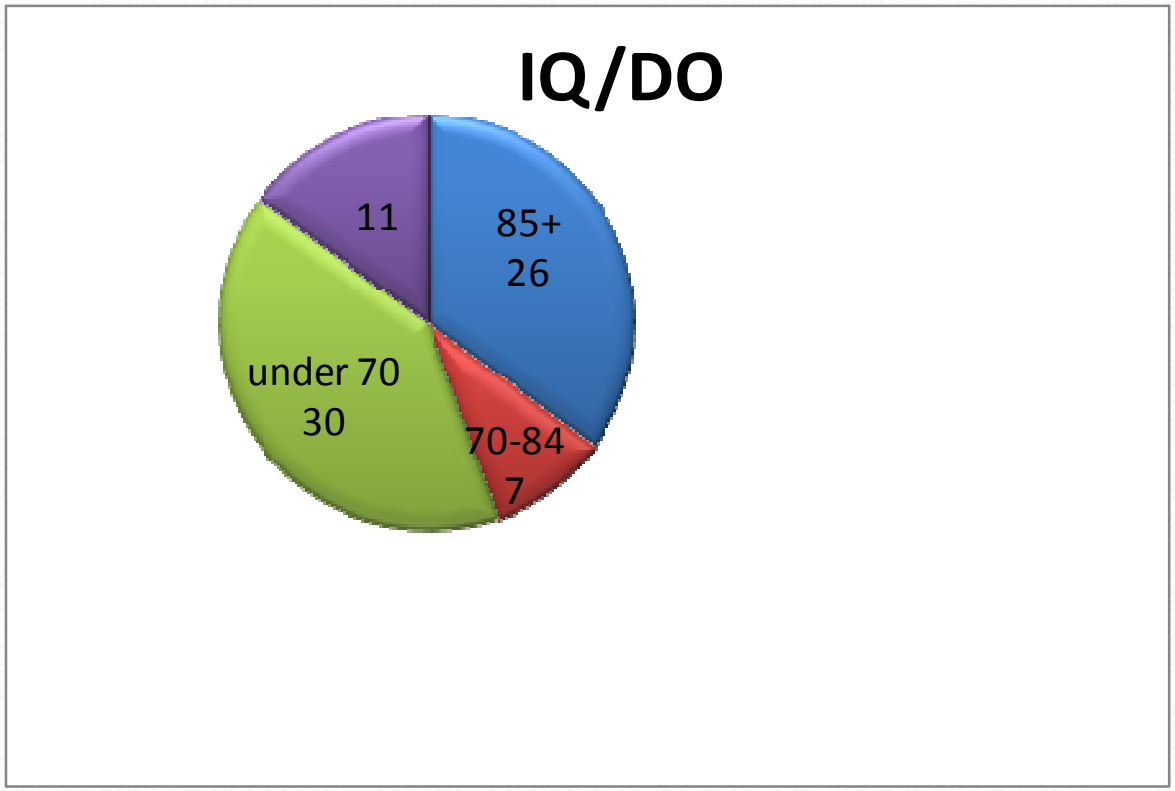
Total: 63

OLDER THAN 7



AUTISM	31
AUTISM+ID	5
ASD	27
CDD	1
OTHER	4
NOT COMPLETED	6
	74

OLDER THAN 7



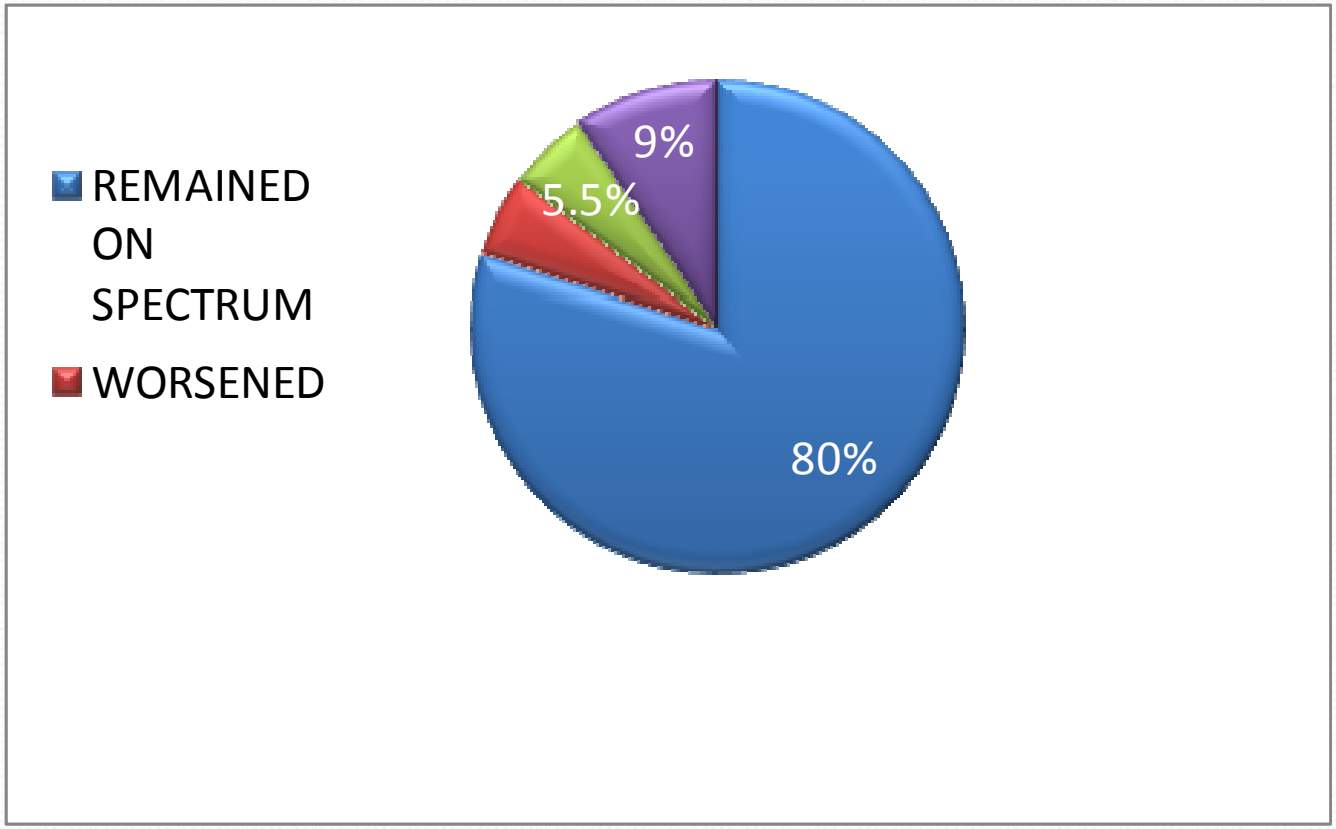
IQ/DQ	N
85+	26
70-84	7
UNDER 70	30
N/A	11

74

OUTCOME - OLDER THAN 7

Outcome	No
Remained in the spectrum	(50) 59
Worsened (from Global Dev. Delay)	(6) 4 (2 from PDD to A)
Dx Removed	(2) 4
Dx process not complete/ lost contact	(16) 7** (2 recovered, 7 remained)
TOTAL	(74) 74

Outcome at 7 years



Age at Diagnosis

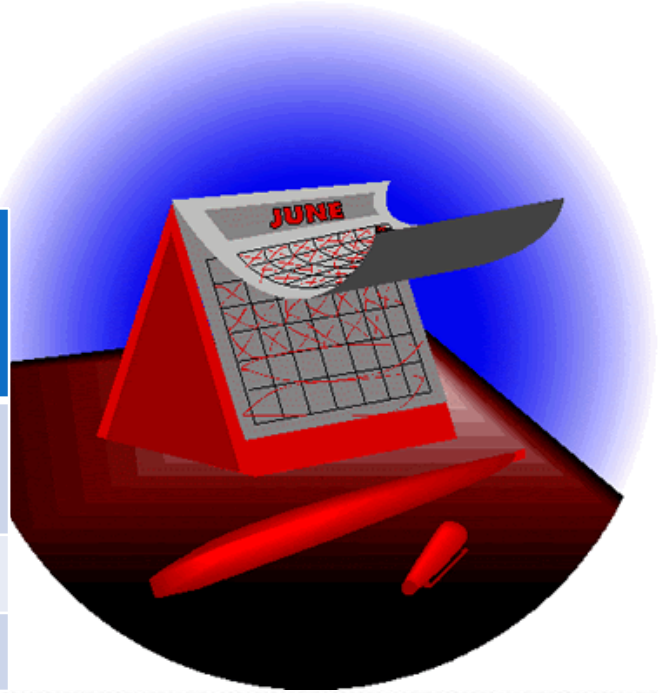
	Age at Diagnosis	(No)
Remained on the spectrum or worsened	3.2 (1.4)	63
Diagnosis was removed	2.6 (0.5)	4
(ANOVA) P		NS

What about us, the professionals?

Year of Diagnosis

	N	Age
Before 2004	24	3 (1.53)
After 2004	50	3.38 (1.31)
P (ANOVA)		NS

	Remained on Spectrum or worse	Dx Removed
Before 2004	21	1 (3.8%)
After 2004	49	3 (5.7%)
P		NS

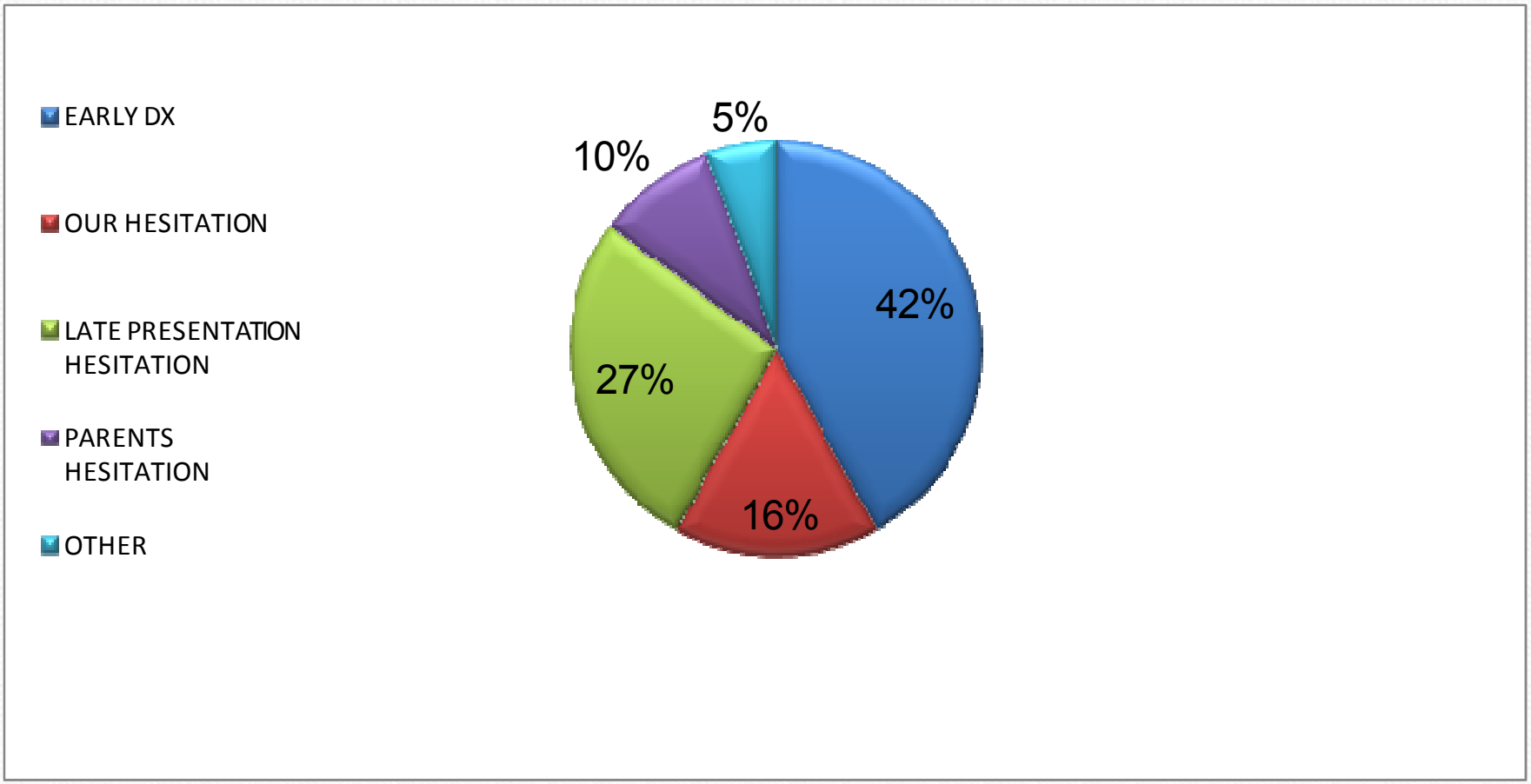


(65)	ADOS	Other measures
Dx Removed	1 (5%)	3 (6.7%)
Remained on spectrum or worse	19	42
p		NS

	ADOS	Other measures
Age at Dx	2.75 (0.9)	3.44 (1.5)
N	23	52
p		0.047

12
1
2
3
4
5
6
7
8
9
10
11
http://www.coloring-book.info

Why were the Dx Delayed (After Age 3) ?



ETHNICITY / AGE OF Dx

ETHNICITY	AGE OF Dx BEFORE/AFTER 3
ASHKENAZI	10 /21
USSR	3 /4
SEPHARADI	9 /9
ETHIOPIAN	**0 / 4**
MIX	5 / 8
TOTAL	74

P = NS

No arab children were diagnosed before 2007

Titian, the three ages of man

Dx / AGE OF Dx

Dx	BEFORE 3	AFTER 3
AUTISM	**18**	13
AUTISM+ID	2	3
SPECTRUM	7	19

P=0.0061

Total: 62

REASON OF DELAYED Dx / Dx

	OUR HESITATION
AUTISM	**3***
AUTISM+ID	**2***
SPECTRUM	**7****
(N)	**12**

אלברט אינשטין
ALBERT EINSTEIN
ISRAEL
$E=mc^2$
ישראל
350
תרל"ט-תשט"ו
1879-1955

Dx / Psychometrics

לבדוק

	Autism	Autism+ID	Spectrum
85+	5	0	**16**
70-84	1	0	3
Under 70	**18**	5	5

Total: 53

P= 0.001

DELAYED Dx / Psychometrics

	Early Dx	Our hesitation	Late referral	Parental hesitation	
85+	8	4	**10**	4	26
70-84	1	2	1	3	7
Under 70	**17**	6	6	1	30
total	26	12	17	6	63

P=0.034

Psychometrics / Outcome

	Remained in spectrum	Worsened **to** spectrum	Dx. relieved	Dx deferred	n/a
85+	20	1	2	1	1
70-84	4	1	0	0	1
Under 70	**26**	2	1	0	1

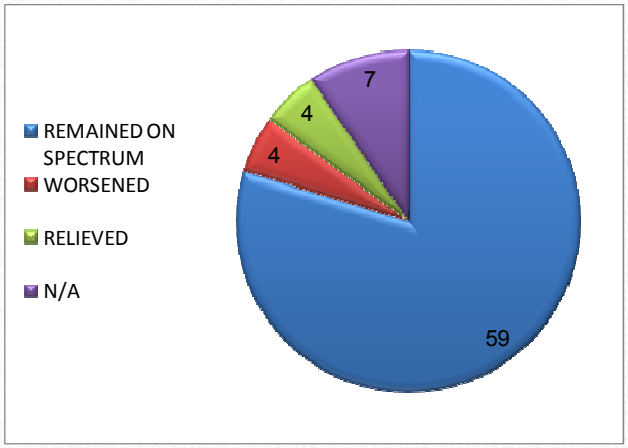
Total: 61

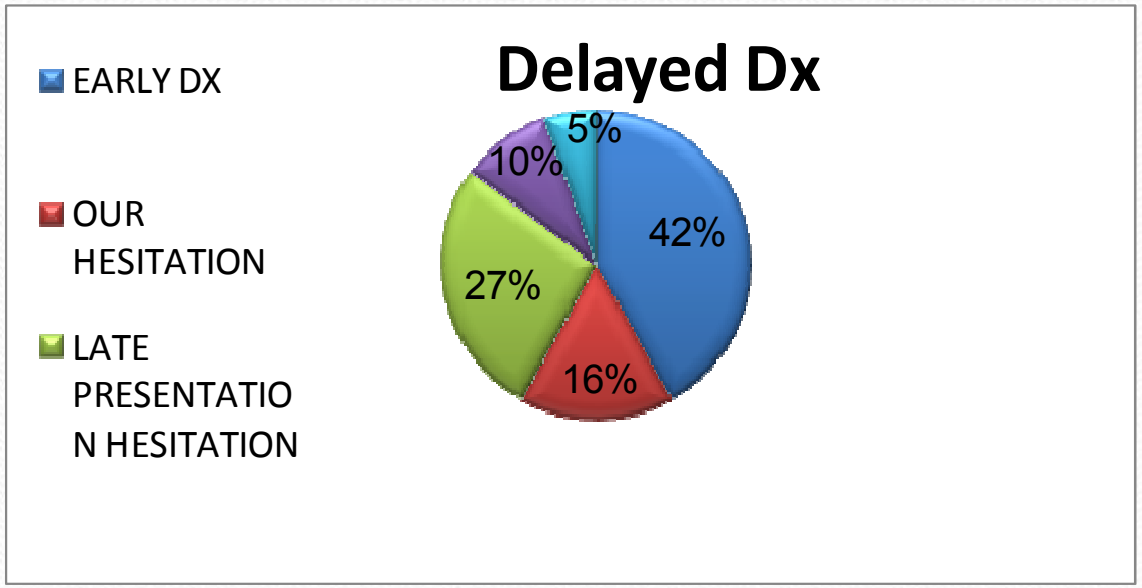
P = NS

Summary

- 27% of the late diagnoses were d/t late referrals
- 16% were d/t our hesitations
- A few cases were misleading
- 4 children “outgrew” gradually their problems and function well now. In 1 it was definitely a wrong Dx.
- Looking at the tools - Earlier Dx with ADOS but not more accurate

- We had 5% over – diagnoses of ASD
- And we diagnosed too late 16% (a third of the "late diagnoses")





Conclusions:

- MANY referrals were not early enough
- We should refine our attitude to parents

Early Dx has practical importance:

1. National Security……

2

3

……special education

- There is no real fear of too early and too hasty diagnosis or of abuse of public resources

- On the contrary, efforts should be made to increase awareness and early referrals

Thank You . . .